

# **The Autism Framework for the Bailiwick of Guernsey 2016**

## **Building Foundations**

**Approved by the Committee for Health and Social Care  
26<sup>th</sup> October 2016**

## Background to the Autism Framework

The key driver for the development of this document was the passing of the Disability & Inclusion Strategy<sup>1</sup> which included a mandate from the States of Guernsey for the former HSSD (now **HSC**) to lead on the development of the underpinning frameworks for the Strategy, of which this is one.

The Strategy is based on the following key principles:

- Respect
- Non-discrimination
- Participation and inclusion
- Acceptance
- Equality of opportunity
- Accessibility
- Gender equality
- Respect for Children

These key principles for the Bailiwick of Guernsey are based on the General Principles under Article 3 of the United Nations Convention on the Rights of Persons with Disabilities.<sup>3</sup>

Strong leadership is needed to translate these aspirations into reality, which is why the Autism Spectrum Condition (ASC) Steering Group was convened to provide a clear focus and leadership in developing this Framework. This Group consists of carers, third sector representatives and statutory services and has been chaired by the Director for Communities, within H & SC. It has made a commitment to continue to collaborate to provide oversight of the delivery of effective care and support for those who require it.

Additionally in order to develop the framework, an off-island consultant, Richard Mills (Research Autism), who provided similar support to develop autism services in Jersey, was appointed and tri-funded by Autism Guernsey, the NAS, and H & SC. This included 15 days of his time over 18 months and comes to an end in November, 2016.

So far the steering group has undertaken a number of tasks. Terms of reference were agreed for the group, workshops were organised in September 2015, and June 2016, with key stakeholders to consider proposals on how to develop services and supports for people with Autism. Feedback from these workshops has informed development of this document.

The steering group has met monthly and has considered a number of Autism strategies from other jurisdictions, specifically Jersey and Scotland. It has

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<sup>1</sup> Disability and Inclusion Strategy, policy Council, states of Guernsey, passed 2013  
<https://www.gov.gg/CHttpHandler.ashx?id=101980&p=0>

<sup>3</sup>United Nations Convention on the Rights of Persons with Disabilities.  
<http://www.un.org/disabilities/convention/conventionfull.shtml>

adopted the autism specific values from the Scottish Strategy for Autism <sup>4</sup>, which were agreed at the most recent cross-agency workshop in June 2016, and are in alignment with the key principles of the disability and inclusion strategy, as follows:

## Our values

Underpinning values will be:

**Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;

**Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens;

**Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;

**Safety:** people should be supported to feel safe and secure without being over-protected;

**Realising potential:** people should have the opportunity to achieve all they can;

**Equality and diversity:** people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination.

People with AUTISM should expect to have the support of professionals working in their best interests to make these values a reality.

## What is autism?

There are various terms used to describe Autism, the most recent iteration of the diagnostic manual DSM-V<sup>5</sup> uses the term 'Autism Spectrum Disorder' and recognises Autism as a neurodevelopmental and lifelong condition. Recently the term 'condition' has been favoured over disorder<sup>6</sup>, as it recognises both the strengths and difficulties that may be faced, by people who may be neurologically different, but don't necessarily consider themselves 'disordered' or disabled. We have used the term 'Autism' throughout this document to recognise that Autism affects people very differently, with some individuals

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<sup>4</sup> <http://www.autismstrategyscotland.org.uk/strategy/linking-goals-aims-and-recommendations.html>

<sup>5</sup> <https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5%28ASD.Guidelines%29Feb2013.pdf>

<sup>6</sup> <http://bestpracticeautism.blogspot.com/2011/07/normal-0-microsoftinternetexplorer4.html>

being able to live independently with little or no support, and others will need very specialist and intensive support.

Each individual will have different and specific challenges, but there are a number of areas in which many people with Autism are likely to have some degree of difficulty, these include:

- Social communication
- Social interaction
- Social imagination (i.e. 'putting yourself in someone else's shoes')
- Sensory difficulties

## 4 What is the Autism Framework for?

Autism has been the subject of a number of initiatives over the past decade in The Bailiwick of Guernsey. Considerable efforts have been made to improve diagnosis and assessment, to create consistent service standards, to match resources to need and to underpin this with appropriate research and training opportunities. These significant contributions now need to be harnessed into the development of a national 10 year Autism strategy that addresses the entire Autism spectrum and the whole lifespan for people with this condition in The Bailiwick of Guernsey.

Previous efforts to progress a strategy for autism have failed (Hinshaw Report, 2009), and subsequently, services and opportunities for people with Autism and their families and carers has not improved. Additionally, some positive initiatives have not been sustained in the absence of a co-ordinated framework or strategy.

There is significant research evidence that demonstrates that people with autism are at risk of poorer outcomes in terms of quality of life<sup>7 8</sup> and that many risks continue throughout life<sup>9 10</sup>. There is also anecdotal local evidence that we are not getting it right for some people with autism, but that when people are identified and their needs recognised and supported, they and their families outcomes improve (Case study 1, Case study 2, Case Study 3: Young man with Autism in transition.).

In The Bailiwick of Guernsey there remain gaps in service provision, in terms of diagnostic pathways, support for people with autism with no learning disability, transition, and employment (See Appendix 3).

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<sup>7</sup>Howlin, P., & Moss, P. (n.d.). Adults with Autism Spectrum Disorders. *57*(5), 275-283.

<sup>8</sup> Billstedt, Eva, Gillberg, I Carina, & Gillberg, Christopher. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism : The International Journal of Research and Practice*, *15*(1), 7-20.

<sup>9</sup> Mukaetova-Ladinska, E., Perry, E., Baron, M., & Povey, C. (2012). Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry*, *27*(2), 109-118.

<sup>10</sup> Happé, F., & Charlton, R. (2012). Mini Review: Aging in Autism Spectrum Disorders.

## 5 Who is the Framework for?

Research indicates that we should expect approximately 1 in 100 people to have Autism<sup>1112</sup>. This would give an estimated figure of around 650 people in the Bailiwick .

Although this is a relatively small number, the problems for these individuals if not supported appropriately can be big in terms of impact on them and their families, and in terms of the financial demands on the States (there are 12 people in off-island placements with Autism and 2 with suspected but undiagnosed autism) and corporate and clinical risk. These individuals will access services, e.g employment, mental health, the criminal justice system, child protection, but unless they are identified as having autism, and their needs met appropriately, outcomes from accessing these services may remain poor.

*'Autistic parents, if they get the help, can learn with the routines and they can become good parents and do a really, really good job.'* (Father with Aspergers.)

This framework aims not to repeat an examination of the issues faced by this population and the various services supporting them, as this work has been done before. Instead, it aims to make some practical recommendations about how improvements might start, and be achieved and maintained. The

*'I felt unable to continue with what had become a stressful and frustrating process, and was discharged from mental health services.'* (Woman with Aspergers, on lack of diagnosis)

document follows a logical order. It begins with a vision which describes where we want to get to. This is underpinned by the values described, that need to be at the heart of the Autism Framework as a whole and at the heart of the behaviour of all those who are responsible for implementing it. To be

achievable and sustainable, the recommendations also link into the broader transformation work taking place across the Sates of Guernsey, and specifically being developed across children and adult services in HSC and Education, Culture and Leisure.

*'That single contact with the UK Diagnostician was life-changing'*

## 6 Our vision

Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.

<sup>11</sup> Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum, & Charman. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531), 210-215.

<sup>12</sup> Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, 68(5), 459-465.

## 7 Goals

The goals are what this framework aims to deliver., and they are divided into three parts – Foundations (by 2 years), Whole-life journey (by 5 years) and Holistic-personalised approaches (by 10 years). Some goals will principally be for one agency to deliver, and others will require joined up and co-ordinated efforts across agencies. These goals are to ensure the development of comprehensive services that meet the needs of children, adults and older people with Autism, and a method for which service providers can evaluate their processes. The Scottish Strategy for Autism proposes ten indicators for current best practice in the provision of effective Autism services and these are set out in Appendix 2. It is envisaged that these be used to identify outcomes that may be achieved over the two, five and ten year timeline of the autism framework. Clearly, each outcome indicator has a number of related tasks and processes and we have made recommendations as to how these outcomes might be realised.

### How can this be accomplished?

To achieve these goals, there are 11 key recommendations (see Appendix 1: Recommendations). It is proposed that the Autism steering group continues in the long term, and it is envisioned that a number of smaller working groups should be convened around specific topics, such as gathering statistics, diagnosis, training, and transition, and that these subgroups should report to the steering group. To do this work, both the membership and voices of people with autism and their carers will need to be strengthened. For this plan to be successful, there will need to be strong leadership of the steering group and subgroups, and it is suggested that this may realised through the appointment of an Autism lead within H & SC.

### Opportunities:

There are a number of current opportunities and developments which should be capitalised upon, to build strong foundations in the next 2 years and to gain the most benefit for people with Autism and their families:

- **Development of a single point of access to adult services):** This is a core element of the transformation programme in HSC and will provide a structure under which individual needs for adults with Autism can be considered, and a referral route agreed for them to access services.
- **Guernsey Autism Partnership (GAP) (funded by co-op helping hands grant):** Autism Guernsey and the NAS have established this, as recommended by Richard Mills (See appendix 3), to provide information, advice, signposting and support to people with autism on an informal, drop in basis. Commitment through the release of

personnel to support joint running, from H & SC, would enhance both the scope and quality of the support available.

- **Development of autism lead and transition posts:** These posts would play a crucial role in development and implementation of this framework overall, and would enable strong foundations to be laid within existing services in HSC.

**Review of access to services:** HSC is proposing to implement a new care assessment and management process, whereby services are provided to address the impact of a person's needs on their ability to achieve independent and healthy lives. This will also remove the learning disability register as a means of accessing services. This should be considered as being potentially more inclusive for those with a diagnosis of autism, as many people with autism do not have an intellectual disability but do have other support needs. This should be carefully considered as part of the new criteria to ensure that people with autism are not disadvantaged

- **Children's disability review:** This review, carried out by Sue Allen, makes recommendations relevant to children with autism. Therefore development of the framework should reflect these recommendations, and aim to use the momentum from the review, to achieve the relevant goals for children and young people with Autism.
- **Signpost website:** The development of this website, as a single point of information on services and support for people with disability can be used to provide much of the information needs identified in the 2 year goals of the framework.
- **Autism build:** Given the significant investment in this proposed development, it is essential that this project and the framework are aligned. The lead for Autism and the steering group should closely influence the design of services using this building, to ensure it results in enhancement of quality of life for people with autism, through realising both the short and longer term goals of the framework and the aims of disability and inclusion strategy as a whole.

## Goals to build foundations – within 2 years

### To do this we need to develop:

- Access to mainstream and specialist services where these are appropriate to meet individual needs.
- Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.
- Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).
- Access to effective transition planning across the lifespan.
- Consistent adoption of good practice guidance in key areas e.g. education, health and social care.
- Meaningful partnership between the States of Guernsey, independent sector (3<sup>rd</sup> sector) people with ASC, their families and carers.

*'The diagnosis has underlined that "belonging" and is helping me to make sense of the various difficulties I experience.'*

*It felt like 'okay, you've got your diagnosis, so get on with it'*

## Goals to provide for the whole life journey - within 5 years

- Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism.
- Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism
- Access to services which understand and are able to meet the needs of people specifically related to their autism.
- Creative and collaborative use of service budgets to meet individual support and needs across lifespan. (Irrespective of what the entry route to the system is).
- Access to appropriate assessment and review of needs throughout life.

## Goals to Access to Holistic-personalised approaches - within 10 years

- To develop comprehensive self-evaluation frameworks to ensure best practise implementation and monitoring.



## Implications of not developing services

The States of Guernsey and H&SC are trying to provide services and supports for the people of the Bailiwick of Guernsey in a period of significant financial constraints. In such a climate, developing services for this small population within the overall community may be difficult to prioritise. However, there are risks associated with not developing services which include:

- HSC failing to meet its responsibilities in terms of the disability and inclusion strategy.
- Over-utilisation of some agencies, such as adult mental health and the criminal justice system, and the ongoing financial impact on these agencies, linked to poorer population and individual outcomes.
- Failure to deliver value for money, by continuing to provide uncoordinated piecemeal services that are not cost effective.
- Potential for continued and unnecessary off island placements, with associated expenditure and social consequences (e.g., removal from family and community support networks) and risks of abuse, and difficulty of repatriating.
- Continued lack of awareness about the size and population demographics in Guernsey, and therefore unknown risks in the future
- Continued lack of awareness about the long-term needs of this population with the associated impact on the States financial model.
- Potential complaints and litigation from families, if HSC and the States of Guernsey are seen to be failing to meet core needs of the most vulnerable in the community.

Alternatively, proactive development and co-ordination of services and strong partnership with the third sector and with people with autism themselves, can reduce unnecessary costs, enable people with autism to help themselves, and make the most of the positives of autism.

For example, the work of Knapp<sup>13</sup> recognises the importance of an 'invest to save' strategy and approach for people with Aspergers, and asserts that if those with Aspergers were given appropriate support to access employment, this would lessen the financial burden overall, enable them to contribute to the economy, and improve their outcomes.

Partnerships between services and third sector agencies, could look to creative solutions to resolve the gap in employment opportunities, recognising that there are people with autism who require more long term support to be able to access paid employment<sup>14</sup>, given the evidence that supported employment services have been shown to

*'He has the chance of bringing significant benefit to the Guernsey community but he needs to have support for that to be possible.'* (Father of a young man in transition)

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<sup>13</sup> Knapp, Martin R J., Romeo, Renee, & Beecham, Jennifer. (2007). *The Economic Consequences of Autism in the UK*.

be cost effective when compared with traditional day service provision for this population <sup>15</sup>.

Investment in co-ordination and provision of services is a potential spend to save or cost neutral exercise, which may result in improvements in quality of life and outcomes for the whole population of people with autism. For

*'He is good though because he can use some of these patterns to get up in the mornings and look after our daughter and tidy the home. This is a good way to use his routines.'* (Woman talking about her partner with autism).

example, by developing infrastructure, like housing, support staff and therapy services to enable repatriation of off-island service users with autism, outside costs of placements are reduced, and those people living locally will also be able to benefit from the improved services.

The foundation goals for the first 2 years therefore emphasise co-ordination and partnership, and capitalising on the existing opportunities to improve services, using existing pockets of good work already going on to provide the building blocks for more sustainable change. By improving integration and communication of what is provided, duplication can be avoided, and access to things like training, can be improved without additional spending.

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<sup>14</sup> Gerhardt, P. F., & Holmes, D. L. (1997). Employment: Options and issues for adolescents and adults with autism spectrum disorders. *Handbook of Autism and Pervasive Developmental Disorders, Volume 2, Third Edition*, 1087-1101.

<sup>15</sup> Mavranzouli, I., Megnin-Viggars, O., Cheema, N., Howlin, P., Baron-Cohen, S., & Pilling, S. (2014). The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism, 18*(8), 975-984.

## Appendix 1: Recommendations

These recommendations reflect the ‘: Ten indicators for current best practice in the provision of effective Autism services’ in Appendix 2 and should be read in conjunction with the previous section ‘.

### RECOMMENDATION 1

It is recommended that the Autism Steering Group is convened on a long term basis and reports to the Disability and Inclusion Board and be included in HSC Business Plan for reporting to the Committee *for* Health and Social Care as part of that Plan

### RECOMMENDATION 2

It is recommended that a dedicated lead for autism be appointed within HSC, to chair the Steering Group, and have responsibility for the development and delivery of the framework, as is recommended in the NICE guidelines.<sup>16</sup>

### RECOMMENDATION 3

It is recommended that the Autism Steering Group works collaboratively, continuing to include stakeholders from across other departments, organisations and the third sector, and strengthens the voice of service users and families within this forum via recommendation 4. It is recommended that representation of the steering group should be reviewed to ensure it reflects this and includes missing key agencies, as identified in Nice guidance e.g. employment .

### RECOMMENDATION 4

It is recommended that the lead for Autism within HSC works alongside Autism Guernsey and the NAS, to establish a forum for people with Autism and their family’s opinions to be sought and views be collated on the ongoing work of the Steering Group. This should not replace the representation on the Steering Group, but aim to strengthen the voice of these key groups in planning and development of services.

### RECOMMENDATION 5

The Autism Steering Group should collaboratively identify the key determinants of service provision that result in improved quality of life for people with Autism, locally and across the lifespan to inform the development of and implementation of 2, 5 and 10 year goals.

### RECOMMENDATION 6

The Steering Group should undertake to determine more valid statistics on the identified population of children and adults with Autism in the Bailiwick of Guernsey. This data should be maintained to enable strategic planning and further scoping of unmet need. This should also be linked to developing service pathways, for example, the single pint of access and their data collection.

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<sup>16</sup> <https://www.nice.org.uk/guidance/cg142/chapter/1-Guidance>

### **RECOMMENDATION 7**

It is recommended that pathways and information as to how and where people can get a diagnostic service, and who diagnoses on island should be developed. Services should aim to standardise practise in relation to relevant NICE guidance, and review current diagnostic practise on island, make recommendations on needs in terms of professional training, and resourcing to enable more efficient diagnostic services to be delivered, both in adult and paediatric populations.

### **RECOMMENDATION 8**

The states website (Signpost) should make available information about what is available in the Bailiwick of Guernsey (Building on the work of Caroline Mullins attached in Appendix 3 Autism Pathway in the Bailiwick of Guernsey) including for example, diagnostic services, interventions, advice and training, for children, young people and adults with Autism and their families. This information should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions, and include both statutory and third sector information.

### **RECOMMENDATION 9**

It is recommended that the steering group should ensure that training is properly co-ordinated and evaluated as part of the framework implementation, as well as identifying opportunities for improvement. (e.g. agencies sharing training to make it available to more people, avoiding duplication, and implementing new training programmes and initiatives. )

### **RECOMMENDATION 10**

It is recommended that the planned new transition post in adult services should consider all young people with Autism who may require adult services Transition processes and pathways should be developed and made available via signpost, based on best practice, to support those in transition from paediatric services, but also recognising the lifelong challenges posed by transition for people with Autism. Gaps in statutory and third sector provision in adulthood should be clearly identified.

### **RECOMMENDATION 11**

Specific consideration of the needs and supports of more able individuals with Autism should be considered within all of the above recommendations, as a group with particular unmet needs, especially in adulthood. This will include a range of issues including work, accommodation, and other elements of well-being, as well as reviewing criteria which often excludes them from services, irrespective of need.

## **Appendix 2 : Ten indicators for current best practice in the provision of effective Autism services**

1. A local Autism Strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with Autism and carers are reflected and incorporated within local policies and plans.
2. Access to training and development to inform staff and improve the understanding amongst professionals about Autism.
3. A process for ensuring a means of easy access to useful and practical information about Autism, and local action, for stakeholders to improve communication.
4. An Autism Training Plan to improve the knowledge and skills of those who work with people who have AUTISM, to ensure that people with AUTISM are properly supported by trained staff.
5. A process for data collection which improves the reporting of how many people with Autism are receiving services and informs the planning of these services.
6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with Autism and remove barriers.
7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
8. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with Autism.
9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
10. A self-evaluation framework to ensure best practice implementation and monitoring

## **Appendix 3 Autism Pathway in the Bailiwick of Guernsey**

### **Introduction**

Understanding Autism in Guernsey has since 2008 generated a variety of stakeholder events, focus groups and consultations. In addition there have been a number of papers written and some reflection on the UK Autism Strategy 2010 and the change in service provision to meet these needs.

The Autism Steering Group was established to “design and provide a framework to better meet the needs of people with Autism as part of the States of Guernsey Disability and Inclusion Strategy”.

In relation to the Autism Pathway the group agreed to:

- Consider and evaluate the current and proposed support pathway from birth to the end of life care for people with Autism
- Identify and propose solutions for any gaps in service provision

### **Overview of current provision and gaps in service**

This paper provides the current pathway for individuals with Autism and support available for carers. The information gathered has been informed by discussions with Autism Guernsey, the National Autistic Society and Adult Disability Services.

The document also includes comments made by parents, carers, professionals and charity groups who attended a workshop in September 2015 at Beau Sejour facilitated by Richard Mills (consultant).

Following a review of the workshop Richard Mills made some suggestions based on similar initiatives elsewhere and these suggestions have been included below.

Whilst gathering information for the pathway a number of as yet unanswered questions were raised and these have been noted in ‘areas requiring further consideration’.

As mentioned earlier in the report a number of papers about Autism services have been written. Reading through the report from September 2014 ‘Establishing a Care Pathway for Autistic Spectrum Disorder (Autism)’ much of the information and recommendations are still relevant in 2016 and should be taken in to account when developing service provision. (See Appendix 1).

## Guernsey's Current Autism Pathway

KEY: Areas requiring further information in **red**

Gaps in service in **blue**

Where do I learn about autism?	<ul style="list-style-type: none"> <li>• Friends</li> <li>• Support groups</li> <li>• Websites</li> <li>• Autism Guernsey</li> <li>• One stop shop still to be defined (gap in service)</li> <li>• Signpost.gg (needs defining)</li> <li>• Advocacy Service (gap in service)</li> </ul>
Who do I talk to?	<ul style="list-style-type: none"> <li>• GP</li> <li>• Health Visitor (under 5 years)</li> <li>• School Nurse (over 5 years)</li> <li>• School teacher (Communication and Autism Support Service (CASS) if known to service)</li> <li>• Autism Guernsey</li> <li>• National Autistic Society</li> <li>• One stop shop (gap in service)</li> <li>• Learning Disability Team (if co-morbid LD)</li> </ul>

	CHILD	ADULT
How do I get a diagnosis?	<p>Under 5years GP, HV may refer to Child Development Centre (CDC) – referral is to Developmental Concerns.</p> <p>CDC initial assessment by multi-agency panel</p> <p>Over 5 year's referral to ASDAT</p> <p>Over age 11 years assessment by CAHMS</p>	<p>Dual diagnosis with Learning disability</p> <ul style="list-style-type: none"> <li>• Referral to Adult Learning Disability Services for assessment</li> </ul> <p>If autism only: no diagnostic route (gap in service. Adult Disability Team have the expertise but not the resources for diagnostics)</p> <p>GP rings Autism Guernsey to ask where to refer</p> <p>No LD client passed in a circle of GP-MH-LD-NAS-AG etc. (gap in service)</p> <p>AG funding specialist UK?</p> <p>AG have expertise in Chief Operating Officer (<b>not team approach</b>) ADOS (tool for diagnosis)</p> <p>If over 11 years assessment by CAMHS (this is only a temporary arrangement which was agreed in order to assist the waiting time for the ASDAT team(now over a</p>

	CHILD	ADULT
How do I get a diagnosis?		<p>year) and was only meant to be for those presenting with co-morbid diagnoses e.g. anxiety/depression).</p> <p>There used to be a shared psychology post which incorporated 2 sessions for assessment /intervention for ASD within CAMHS –the other 8 sessions being for Children’s learning disabilities.</p> <p>These 2 sessions played an important part in providing a service for ASD children (in particular those in secondary school) and in providing dedicated time for assessment for the ASDAT team (the post was changed without discussions with clinicians).</p> <p>Waiting times for assessment are significant and there are no performance indicators by which to be measured.</p>
Post diagnosis	<p>Informed about AG and NAS</p> <p>In education referred to communications team. Not all diagnosed children are referred to CASS – only if a concern in school.</p> <p>Referred to autism service if in mainstream school.</p> <p>CASS offer private schools free access to all training and provide generic advice if invited by private school.</p> <p>Support for special schools is internal. Special schools able to access CASS training. CASS/Special Schools work together on</p>	<p>If autism and LD then referred to Adult Disability Service and AG</p> <p>If autism only diagnosis referred to AG and/or NAS</p> <p>Substance misuse/mental health condition with autism referred to mental health services and AG <b>(determine support)</b>.</p> <p>Individuals need to have significant MH disorders to be eligible for MH Services</p> <p>Gap in service as no clinical support (e.g. multidisciplinary access for disciplines such as psychology, SLT, OT etc.) available if autism only</p>



	<b>CHILD</b>	<b>ADULT</b>
	<p>transitions between settings.</p> <p>Substance misuse/mental health with autism should be remit of Child and Adult Mental Health Services (CAHMS) (clarification of service required)</p> <p>Preschool parents offered EarlyBird</p>	<p>diagnosis</p>
<b>Benefits</b>	<p>Severe Disability Benefit (determine severity)</p> <p>Carers allowance for carer</p> <p>Supplementary benefit if low/no income (16-18 year olds can be means tested in own right)</p> <p>Equipment – SSD (means tested or loan available on application)</p>	<p>Severe Disability Benefit (determine severity)</p> <p>Carers allowance for carer</p> <p>Supplementary benefit if low/no income</p> <p>Equipment – SSD (means tested or loan available on application)</p>
<b>Education</b>	<p>Special schools: Le Rondin and Le Murier</p> <p>Community and autism service. CASS offer advice/training to mainstream schools on ASD. By September 2016 all primary teachers will have Autism Education Trust training – 325 teachers. CASS Learning Support Assistants model good practice.</p> <p>The Base. CASS has Primary and Secondary Communication Bases, 12 places in each. Specialist Teacher in each with specialist LSA support to help diagnosed/determination learners access curriculum and develop life skills. LMDC rebuild proposal will have 18 places in each. Determination of need. Formal Education Process recognising learner has</p>	<p>College of Further Education (define service)</p> <p>Gap in service as no other providers</p>

	<b>CHILD</b>	<b>ADULT</b>
	<p>special educational needs.</p> <p>College of Further Education: Access Course. CASS offer training/advice to CFE/Sixth Form.</p> <p>Private education (gap in service)</p> <p>Transition planning from 14 years. Detailed and enhanced transitions from Base to CFE/Sixth Form. May involve CASS staff working in CFE for period of time.</p>	
<b>Employment</b>	<p>Preparation in school. Base students have enhanced additional support on work experience. Offer of AET training to be made to employers from September 2016.</p> <p>CASS support one ASD learner from CFE on extended work experience two days per week at Tax Office.</p>	<p>Guernsey Employment Trust (gap in service as does not provide on-going support at work) Work ready not pre work skills</p> <p>GO GROW Careers SSD job seekers University access (gap in service)</p>
<b>Short breaks</b>	<p>Residential: The Croft if autism and LD</p> <p>Outreach: The Croft if autism and LD</p> <p>Gap in service as no provision if autism diagnosis only</p>	<p>Residential, outreach and support in own home if autism and LD</p> <p>Gap in statutory service as no provision if autism only diagnosis AG (limited resources)</p>
<b>Support Groups</b>	<p>Autism Guernsey</p> <p>National Autistic Society</p> <p>Wigwam The HUB</p>	<p>Autism Guernsey</p> <p>National Autistic Society</p>
<b>Independent living accommodation</b>	<p>Gap in service as no life skills training</p> <p>No apparent support for 'high functioning' ASD's who are likely to have specific learning disability.</p>	<p>Life skills training if autistic with LD through Adult Disability Service</p> <p>Action for Children (define service)</p> <p>Gap in service as no skills training if autistic only diagnosis</p>

	<b>CHILD</b>	<b>ADULT</b>
<b>Residential accommodation</b>	<p>Gap in service as no provision</p> <p>No apparent support for 'high functioning' ASD's who are not likely to have specific learning disability.</p>	<p>Autism with LD accommodation available through Adult Disability Service (although currently full)</p> <p>Autism build (define who this service is for)</p> <p>Gap in service as no provision if autism only diagnosis</p>
<b>Supported accommodation</b>	<p>N/A</p> <p>No apparent support for 'high functioning' ASD's who are likely to have no specific learning disability.</p>	<p>Le Grand Courtil Nouvelle Maritaine Adult Disability Service have a team to support individuals with autism and LD</p> <p>Gap in service if autism only diagnosis and don't want/not appropriate to live in extra care</p>
<b>Carers support</b>	<p>National Autistic Society The HUB Wigwam (parent and sibling support) AG</p>	<p>National Autistic Society Carers Coming Together Parent Carers Council AG</p>
<b>Befriending</b>	<p>The HUB (?)Mentoring</p>	<p>Autism Guernsey 18+ partnership with MENCAP</p>
<b>Activities/groups</b>	<p>D le P NAS /AG</p>	<p>AG</p>
<b>Parenting assessment and support</b>	<p>Close working relationship/support between CASS Base and parents but post 16 little support for parents.</p>	<p>Might get some help through family partnership, but if no LD, no clinical support to access parenting etc. or provide specialist support</p>
<b>Criminal justice system (forensic)</b>		<p>Possible gap in service</p>
<b>Services for older adults with autism</b>		<p>No services/training or clinical support directed at this group, who are less likely to have a diagnosis, and will be difficult to identify and diagnose. Older people's services may not be equipped for people with autism e.g. care homes/nursing homes and learning disability services and the autism build may not be equipped to deal with issues around aging.</p>

### **Areas requiring further consideration**

- Lack of data (AG collating some data)
- Need to consider impact of accessing all services through a GP (cost)
- Access to services at the weekend
- Access to services out of hours
- Raising awareness of autism in services, activities and at work
- Training available through NAS possible resource implications
- Clarity about transition from child to adult services for all service areas
- Challenging behaviour support available only for individuals with LD
- Advocacy services: currently not commissioned
- No planning between services
- Annual reviews seen as education's remit
- Autism only diagnosis then no services post 18 years, all referrals back to the GP (cost)
- Require clarity of planning, reviewing, recording and lead professional pathways
- Risk with no diagnosis, no service and therefore unmet need which can lead to additional problems
- Individual may meet some of the criteria for ASD but not have a diagnosis however they may still have unmet needs. Can they access part of a pathway to meet needs?

### **Comments from parents/professionals at the workshop September 2015**

- Charities doing a lot of good things but not joined up
- Uneven response from services: one size design to fit all, no account for severity
- Training for parents on the basics for supporting children (practical advice)
- A centre offering a café and a workshop to provide meaningful occupation/sheltered work
- Feeling vulnerable and not able to challenge professionals
- Big public meetings counter productive
- Nothing in the evenings
- More training for Health Visitors to spot the early signs
- Mental health problems in young adults; how to prevent, supportive resources
- Having to tell and re tell your story
- Services targeted at early intervention
- Many children have sensory and motor co-ordination issues – gap in services

### **Following Septembers workshop Richard Mills made some suggestions based on similar successful initiatives elsewhere.**

Concept of a 'one stop shop' or 'first base' be pursued as a mechanism for delivery of the strategy and the framework – not a service as such but a physical location that would be seen as a place where people could go to be heard and helped or sign-posted. This would include individuals on the autism

spectrum, families and carers and of course professionals. Care would need to be given as to how this was described. It is important that the label should not exclude people who might need support. It would be pivotal in defining the work to be done and the provision of low profile support and guidance. Richard Mills suggested the following based on similar successful initiatives elsewhere that the facility should, as a starter meet these basic criteria:

- Accessible during weekdays and other times by agreement
- Located where people could drop in or be seen by appointment
- 'Autism-friendly' taking account of the need for a clutter-free well-lit environment sensitive to the needs of individuals with sensory processing issues
- A place to meet (meeting room (s))
- Develop and host a directory of resources (not provide them) of what is available in Guernsey –health- social services –education- leisure- transport- social security – recreation- vocation- etc.
- Develop expertise and knowledge on signposting and liaison
- Develop and host a library and on-line resources
- Be the administrative hub for information and coordination of autism related activity
- Consultation with the Guernsey community
- Serve as a base for Autism Guernsey, the NAS and States

## **Conclusion**

The Autism Pathway shown above is the first step in providing disabled people and carers in Guernsey with the information they require on the current provision of services and support.

It provides a baseline of services which will inform the steering group so that they can identify and propose solutions for any gaps in service provision against the framework.

## Appendix 4

Case study 1 (written by a person with Autism themselves, a woman with a late diagnosis of Aspergers)

### **Experience of the Local ASD Assessment Process**

#### **Initial Difficulties/Obstacles**

- No local diagnostician
- UK assessment cost prohibitive, also personal challenges around travel
- No formal referral process or pathway, and no means of instigating self-referral locally
- Difficulties in getting a response from Adult Mental Health Services to telephone enquiries and letters (both with regards my own correspondence and that of my GP)
- Ended up being passed from one Department to another, but no-one seemed to know what to do with an adult seeking a diagnosis or how to go about arranging a formal assessment.
- Child Health and Education records had been destroyed many years ago, in accordance with States Retention and Destruction policies. This meant I would not be able to provide any childhood documents that might support the possibility of an ASD.

Felt there was little chance of ever having a formal assessment unless it was self-funded. (Financial implications) Felt I had no choice but to give up and accept that I would probably never have a formal diagnosis. I informed my Psychotherapist that I felt unable to continue with what had become a stressful and frustrating process, and was discharged from MH services.

Autism Guernsey – I had several meetings and quite a lot of email exchanges with. They fully supported my pursuit of an ASD assessment, but were also well aware of the challenges AG did intervene on my behalf and liaise with Health Services, but had similar difficulties. I was aware that the Autism Framework was in the early stages of discussion, but felt that any local arrangements for adult assessment could well come too late for me to it make any real difference.

#### **Assessment and Diagnosis**

A few months after I was referred back to Statutory Services due to depression and work related stress.

Once that happened, things progressed very quickly and just a few weeks later a diagnostician came to Guernsey and carried out my ASD assessment. He told me at the end of the assessment that he was in no doubt that I had Aspergers Syndrome.

## Post-Diagnosis

Although the report contained a few basic recommendations (at least one of which was not applicable to Guernsey), there was no information or guidance provided on what to do next. It felt like 'okay, you've got your diagnosis, so get on with it'. I have continued to see the Psychotherapist in Statutory Services (general psychotherapy), They have been very open about the fact that autism is not one of their areas of expertise. Statutory Services have not provided any specific support in relation to my AUTISM.

'That single contact with the UK Diagnostician was life-changing, and would have been whatever the outcome of the assessment.' Had I not been given a diagnosis, I would have needed to continue with my search for answers. Even though I was given a diagnosis, my personal journey was in many ways only just beginning at that point. I am still working through a process of reframing past events and experiences in this new context, making sense of my difficulties, adapting to life as a person diagnosed with autism, and exploring and devising various coping strategies. Some of this I have been doing with support from Autism Guernsey, and quite a lot of it I am dealing with independently and in my own way.

Without the support of Autism Guernsey both before and since diagnosis, I would have struggled to deal with the ongoing challenges and frustrations around liaising with different Departments, obtaining advice, etc. I very much doubt I would have been able to pursue the formal assessment despite my strong feelings that I would never be satisfied with a self-diagnosis. I would never have felt comfortable just saying I 'probably had Asperger's'.

By the time I did receive my diagnosis, I had already established regular contact with AG on an individual basis, and with the Interests Group. I'd felt a connection with others I met at the group, and that feeling of belonging was another reason I was keen to try and deal with the obstacles and undergo assessment. The diagnosis has underlined that 'belonging', and is helping me to make sense of the various difficulties I experience. That process of adapting and learning to live with my condition will be ongoing, and I will probably continue to need support at some level.

## Case study 2: Parent with Aspergers.

Andrew is a 30 year old man who was diagnosed with Asperger's syndrome 3 years ago. Andrew says 'it was helpful because at least I could find out what I was. It explained how I worked things out and what I did, especially in respect of special habits and patterns. Like the routines, the best way is that it's like a habit just going constantly over and over.

The Social Eyes Programme has helped a lot, helping me understand about how to have conversations, facial expressions and understand how to get on with people better.'

Andrew's partner said that it helped her to understand him better and especially around some of the habits he has, such as playing on his phone or iPad or not relating to her. 'He is good though because he can use some of these patterns to get up in the mornings and look after our daughter and tidy the home. This is a good way to use his routines.'

When asked what Guernsey could do better for people on the autistic spectrum, Andrew said that he thought that the Social Eyes Programme should be more widely available and that help should be offered to people with their relationships because sometimes they confuse people with autism and can cause difference.

Andrew was at great pains to point out that autistic parents, if they get the help, can learn with the routines and they can become good parents and do a really, really good job.



### Case Study 3: Young man with Autism in transition.

In 2016, a young man presented to the adult learning disability service for support, referred by paediatric services.

This young man had a diagnosis of autism, and had gone through mainstream education with 1:1 support, achieving academic success, particularly in Maths, for which he won the school prize. However, his adaptive functioning for activities others take for granted, like cooking, keeping himself safe, and socialising, were very limited compared with some aspects of his intellectual functioning.

As he didn't have a diagnosis of intellectual disability, he didn't meet the criteria for learning disability services, although the family felt he would benefit from some of the services provided for people with Autism.

This individual could, without the support of his family, fall between the gaps in services, for those with autism, who do not have a learning disability. He is currently in a work placement, with support, however has ongoing unmet needs which continue to fall to his family to meet. They receive no respite, or support work hours to help him access the community. He needs high levels support.

There is no safety net at present should his parents be unable to provide the support they currently do, should his work placement break down, or if he required clinical intervention, for example specialist intervention from a psychologist.

His family say 'His support throughout his education has been invaluable in allowing him to maintain attendance at school and thrive in some aspects of the curriculum and been helped in others that he found difficult. The support continued in further education and allowed him to successfully complete a placement with the Income Tax Office, which has now lead to a part time role on a permanent contract. This is, of course, fantastic and he is now partially supported by GET. However, we are of the opinion that cessation of all support from professional agencies would lead to a restriction on Max's potential future development. In fact, should he have no future support he has the chance of regression if there is a fall-off in support. He has the chance of bringing significant benefit to the Guernsey community but he needs to have support for that to be possible.'