

The Isle of Wight joint strategy for children, young people and adults with Autism Spectrum Condition

2014 to 2019



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1. Introduction

This five year joint strategy has been developed in partnership by the Isle of Wight Local Authority, Isle of Wight Clinical Commissioning Group (CCG) and the Autism Spectrum Condition (ASC) strategy Writing Group. The ASC Strategy Writing Group membership comprises parents, carers, adults with autism, Hampshire Autism Society and National Autistic Society. This strategy is a collaboration between health, social care, education, voluntary sector, people with Autistic Spectrum Condition and their families and carers.

What is Autism Spectrum Condition?

For the purposes of this strategy, and in line with current national and international practice, the term 'Autism Spectrum Condition' (ASC) will be used as an umbrella term for the range of conditions within the autism spectrum, including autism, classic autism, Asperger Syndrome, high functioning autism, Pervasive Developmental Disorder (PDD-NOS), and A-typical autism.

ASC is a lifelong developmental 'hidden' disability that affects the way a person communicates with, and relates to, people and the world around them. Although some people can live independently or relatively independently, others have high dependency needs requiring a lifetime of specialist care.

People with ASC are often described as having a 'triad of impairment' meaning they have difficulties with:

- Social communication (For example, problems using and understanding verbal and non-verbal language);
- Social interaction (For example, problems in recognising and understanding other people's feelings and managing their own);
- Social imagination (For example, problems in understanding and predicting other people's intentions and behaviours)¹.

Increasingly there is evidence of the importance of sensory differences in people with ASC – meaning they can be over-sensitive or under-sensitive to particular things such as smells, tastes, colour, light, sounds or touch.

Many people with ASC have no obvious disability and find they are misunderstood. Many do not want to be diagnosed or indeed be recognised as having autism and any support that is required often falls to parents, relatives or friends. The person may also fall between services

1 Fulfilling and rewarding lives: the strategy for adults with autism in England, 2010. Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369
Accessed 16 September 2011 Fulfilling and rewarding lives: the strategy for adults with autism

and not get the right support and this can lead to further problems (including but not limited to anxiety, depression, mental health issues etc)².

No two people on the autism spectrum are the same. They each have their own individual needs, strengths, gifts and interests. People with ASC can have a wide variety of support needs and any one individual with ASC can have areas where they function well and other areas where they may need support. The term autistic spectrum is often used to reflect this variation.

People with ASC are significantly more likely to be at risk from:

- exclusion from school;
- social exclusion associated with difficulties in establishing and maintaining relationships;
- economic exclusion and unemployment;
- increased risk of homelessness;
- increased vulnerability to all forms of exploitation.

Background

The national strategy Fulfilling and Rewarding Lives presents a shared approach towards a common goal; a society that not only accepts and understands people with ASC, but also provides real opportunities for adults with ASC to live fulfilling and rewarding lives.

National law and guidance

The Autism Act was passed in 2009. This is the first single disability specific legislation and places a number of obligations on a range of public bodies to improve opportunities for people across the autism spectrum.

The Autism Act placed a duty upon the government to produce a strategy by April 2010. The strategy was published as:

- Fulfilling and Rewarding Lives: The strategy for adults with autism in England (March 2010);
- towards 'Fulfilling and Rewarding Lives': The first year delivery plan for adults with autism in England (April 2010);
- implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (December 2010).

² Department of Health, 2010. Ibid

Local policy

A vision for health, education and social care on the Isle of Wight

“It’s a small island, it could be the most autism friendly place in the country.”

The Isle of Wight Health and Wellbeing strategy 2013 to 2018 aims to improve the lives of people living on the Isle of Wight. This includes people with ASC and their carers. There are five main priorities:

- Ensuring children and young people have the best possible start in life.
- Helping and supporting people to prepare for old age and to manage long term conditions and disabilities.
- Enabling people to make healthy choices for healthy lifestyles.
- Building and sustaining economic growth for the island and supporting improved employment opportunities.
- Making the Isle of Wight a better place to live and visit.

The Isle of Wight local authority and CCG believe that early intervention has benefits in terms of developing the capacity to live a fulfilling adult life.

Our vision on the Isle of Wight is that all people with ASC, whatever their age, have the same opportunities as anyone else to live rewarding and fulfilling lives by ensuring people with ASC and their families:

- achieve better health outcomes;
- are included and economically active;
- have access to appropriate opportunities for life long learning
- are living in accommodation that meets their needs;
- are benefiting from the personalisation agenda in adult social care, and dependent on eligibility are able to can access personal budgets;
- are no longer managed inappropriately in the criminal justice system;
- are satisfied with local services;
- are involved in service planning.

The My Life, A Full Life programme, is the Isle of Wight’s response to improve the way people experience living healthily and well on the Island through the integration and co-ordination of care and support across a number of organisations, including the CCG, IW NHS Trust, the council and the voluntary and private sector. The programme includes:

- promotion of self-care and self-management, including healthy lifestyles, proactively managing their health and wellbeing and access to information and advice;
- ensuring at times of crises there is a co-ordinated response to meeting peoples’ needs;
- encouraging locality working ensuring that support is delivered as close to home, to enable people to remain in their own homes and communities for as long as possible.

We will work and engage with this programme to ensure that people with autism lead healthy, well and fulfilling lives.

Local consultation

Through 'Autism Participation – Have Your Say' we consulted people with ASC, their parents and carers and the professionals who work alongside them on what they would like to see in a strategy. To do this we undertook a seven week consultation process with over 160 people providing us with their views and recommendations.

The consultation feedback highlighted that people with ASC and their parents and carers felt that accessibility, consistency, communication and co-ordination were extremely important. There should be no postcode lottery on the Island. Instead there should be a comprehensive consistent support system responsive to the needs of the individual wherever that support was delivered. Professionals needed access to better training to ensure they improved their awareness of the needs of people with ASC and were able to keep up to date with current research and developments. It was strongly felt that support should not just be available to those in crisis. ASC is a life long condition and there should be open access to support, information and advice on behaviour management throughout the life of a person with ASC.

The full report can be found at:

www.iwight.com/documentlibrary/view/autism-consultation-report

Where are we now?

National picture

Over the past few years, public awareness about ASC has grown. There has been an increase in the identification of ASC and diagnosis in children and young people.

It is estimated that more than half a million people in the UK have ASC. This is equivalent to about one in every hundred people or one per cent of the population³. However, more men than women have ASC (1.8 per cent men compared to 0.2 per cent women). It is also estimated that just under 50 per cent of adults with ASC also have a learning disability.

Local picture

Using this data we can estimate that on the Isle of Wight there are 1,400 men, women and children with ASC. If this accurately reflects prevalence, local data shows that only a very small proportion of people with ASC on the Isle of Wight are known to local services.

Local challenges

The current financial climate is very challenging, with the Local Authority needing to make savings across the council of 28 million pounds over the next three years from April 2014 to March 2017 and there are no additional resources to implement the autism strategy. However Fulfilling and Rewarding Lives and the Isle of Wight Strategy for People with Autism Spectrum

3 Brughat, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J (2009) Autism Spectrum Disorders in adults living in households in England. Report from the Adult Psychiatric Morbidity Survey 2007. www.ic.nhs.uk/asdpsychiatricmorbidity07

Condition provides a real opportunity for the needs of people with ASC to be recognised to enable us to think about autism in everything we do.

This Isle of Wight Strategy for People with Autism Spectrum Condition is intended to provide a framework that local commissioners and providers can use to ensure that people with ASC have the same opportunities as everyone else. This framework will adhere to the National Institute for Health and Care Excellence Quality standard for Autism – QS51, which can be found at: publications.nice.org.uk/autism-qs51/list-of-quality-statements

What have we done?

We have established a team of committed individuals who have developed this strategy and are now working on the draft implementation plan to accompany it. The group is a partnership between adults with ASC, family carers health, education, social care and the voluntary sector.

We have developed strong partnerships, not only on the Isle of Wight, but across the neighbouring local authorities of Hampshire, Portsmouth and Southampton. This partnership working has helped to identify ways to work together, share learning and to commission services more effectively.

We are developing a Hampshire and Isle of Wight Autism Directory of information for people with ASC with our colleagues in Southampton, Portsmouth, Hampshire, Portsmouth University and the Hampshire Autistic Society.

We are ensuring we have a training strategy in place to raise ASC awareness among health, education and social care staff including those who will be directly assessing people with ASC via a community care assessment.

We are now able to offer free e-learning – A Basic Introduction to Autism - to all social care providers (both large companies and those working as individual personal assistants).

We have improved our diagnostic service for children and young people and have established a diagnosis service for adults on the Island, this includes the availability of social care support immediately post diagnosis.

We have developed a clear diagnostic pathway for both adult and children's services to meet the needs of adults and children and young people on the Island – these diagnostic pathways will be published with the strategy implementation plan and regularly updated.

The Clinical Commissioning Group is working with GPs to provide training to ensure they are aware of the pathway for children and adults and that training has taken place ahead of the pathway for adults which commenced on 1 April 2013.

2. Increasing awareness and understanding of ASC

Fulfilling and Rewarding Lives says:

Frontline staff, from GPs to benefits advisers, acknowledge that their understanding of autism is limited. While most professionals know something about autism, they do not necessarily understand how autism affects people.

The first, and fundamental, step is to increase awareness and understanding of autism across all public services.

It is essential that autism awareness training is available to:

- everyone working in health or social care;
- staff carrying out community care assessments;
- students undertaking social care core training;
- all staff in the criminal justice sector;
- all Jobcentre Plus disability employment advisors.

What people on the Isle of Wight told us during the consultation

“More awareness and people willing to see past my Aspergers to the person I am.”

- There was clear indication that improved training was the key to enhancing the experiences of people with ASC and their families. Training not just for the professionals but for universal services, potential employers and the public..
- Professionals in all related fields need training to enhance their knowledge and raise their awareness and understanding and ensure they are more responsive to the needs of people who have ASC.
- Joint training of different professional groups would enable collaborative approaches and enable seamless support to be delivered. Many respondents highlighted how powerful training delivered by parents, carers and people with ASC themselves was, after all, they are the experts by experience.

- Parents and carers reported how valuable they had found the training provided to the carers of individuals with ASC to assist them to support the person they were caring for, as was the opportunity to enable them to discuss issues with other parents and carers within these training sessions.
- It was made clear that above all professionals need to listen to people with ASC, their parents and their carers.
- It was agreed that there is a lack of information regarding ASC and this needs to be addressed, through education, training and the provision of up to date information and advice.

From this information we will:

- work towards improved partnership working across health, social care education, voluntary services, parents and carers and the individuals themselves – placing the person with ASC at the very centre of planning their support;
- develop opportunities for workforce training for health, education and social care staff, which aims to develop awareness of the needs of individuals with ASC and their families.
- ensure that accessible information is developed for people with ASC and their families regarding what is available on the Island including the route to diagnosis, support available following diagnosis and access to education, health and social care;
- develop a comprehensive training strategy for the health, social care and education workforce and promote accessible training in ASC awareness throughout the wider community;
- ensure that there are key professionals across the Island who are ASC aware and can support the needs of individuals with ASC who access their services including housing, education and the criminal justice system;
- ensure those working directly with people with ASC are able to access more detailed training to support them in their role;
- work with colleagues in Southampton, Hampshire and Portsmouth to develop an accessible Hampshire and Isle of Wight Autism Directory – designed to be a ‘one stop shop’ for ASC information.

3. Developing a clear and consistent pathway for diagnosis of ASC

Fulfilling and Rewarding Lives says:

For many adults, receiving a clinical diagnosis of autism is an important step towards a fulfilling life. It can not only help them and their families understand their behaviour and responses, but should also help with access to services and support, if they need them.

Currently, diagnosis can be a complex and lengthy process. Adults with autism talk of having to battle hard – sometimes for years – to get a diagnosis, and then finding that diagnosis is being challenged when they try to access services.

Fulfilling and Rewarding Lives makes recommendations for changing that process to develop a clear and consistent pathway for diagnosis in every area, and:

- increasing capacity around diagnosis;
- ensuring a diagnosis is recognised as a reason for a community care assessment or reassessment; and
- providing relevant information to adults with autism and their family or carers **at the point of diagnosis** to help them understand the condition and access local support.

What people on the Isle of Wight told us during the consultation:

“Having a diagnosis meant those involved in his care can understand and respond appropriately to his considerable behavioural issues, and has promoted tolerance and patience from friends, family and school.”

- The route to obtaining an ASC diagnosis assessment, the diagnosis itself along with the services and support available post diagnosis has room for improvement. Gaining an ASC diagnosis is a complex and difficult journey for many, especially for adults. There is a need for a clear pathway to diagnosis and support to be developed.

- Professionals involved need to be clear about the pathway to diagnosis and the process, pre and post diagnosis, to enable them to provide up to date information to parents, carers and people with ASC.
- The waiting time is too long for an ASC diagnostic assessment. A diagnosis is crucial for early interventions to take place, to ensure people with ASC are able to maximise their potential. Diagnosis should be multi-disciplinary and concentrate on a holistic assessment of the individual concerned.
- Professionals should be able to make referrals for any support required, and a follow up meeting should be arranged where parents and carers can again talk to professionals once they have had time to consider the implications of the diagnosis.
- There needs to be the development of person centred information packs to explain the route to obtaining an ASC diagnosis assessment, the diagnosis itself, the services and support available after diagnosis.
- There should be opportunities for parents and carers to be offered training to enable them to understand and manage the diagnosis and also to form links with other parents for support.
- Support is patchy; the service you receive can depend on where you access it. There needs to be consistency across the Island and communication between agencies needs to be improved.

From this information we have:

- ensured the development of an effective diagnostic service for the Island which positively meets the needs of children and young people with ASC;
- developed a clear diagnostic pathway for both adult and children's services to meet the needs of children, young people and adults on the Island – these diagnostic pathways will be published with the strategy implementation plan and regularly updated.

We will:

- ensure that information regarding that pathway is available to all professionals, people with ASC and the families of children and young people with ASC;
- promote awareness and knowledge of ASC among health, education and social care staff through consultation and training;
- work to ensure people with ASC and their parents and carers are provided with clear person centred information and advice regarding diagnosis and post diagnosis support;
- work with partners to review and ensure the diagnostic needs of children, young people and adults with ASC are being met;
- ensure the delivery of a comprehensive diagnosis service for the island which positively meets the needs of children young people and adults ASC.

4. Supporting access to health and social care

Fulfilling and Rewarding Lives says:

Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need. This strategy sets out to change this and ensure that adults with autism are able to benefit fully from mainstream public services by:

- reiterating the Equality Act 2010 requirement for services to make reasonable adjustments for adults with autism;
- enabling adults with autism to benefit from personalisation of social care; and
- improving transition planning to give people with autism the right start in their adult life.

What people on the Isle of Wight told us during the consultation:

“Autism is a life long disability and therefore the support must be also.”

“Many of the difficulties for people with autism come where organisations don’t work well together or have differing criteria for services and support”.

- Respondents greatly valued patience, understanding and knowledge and saw practical support, a non-judgemental attitude and the provision of information as important to them. Most of all people wanted to be listened to.
- Professionals in all areas need access to better training, to increase their awareness and ensure they keep up to date with current research and developments. Basic awareness and diversity training should be available for all and taught in schools to develop children’s understanding and support for their peers.
- Support should not just be available to those in crisis, there should be open access to support, information and behaviour management throughout the life of the person with ASC.

- There is a need for greater collaboration between agencies and stakeholders to develop person centred support that recognises how the condition can debilitate an individual, particularly those with high functioning ASC, and the need to provide support in the areas of skill development to maximise opportunities for future independence and ultimately less reliance on services.
- The advent of personal budgets and the flexibility of being able to design individual support packages was welcomed.
- There was a lack of knowledge regarding the support available from Community Wellbeing and Social Care, those who had benefited felt the service in both adult and children's services was overstretched.
- In health and social care there is a need to make reasonable adjustments for those with ASC – i.e. reduced waiting times and all written communications to be in accessible language and recognition of how anxiety levels can be raised through concern about the unknown.

People with ASC should be able to experience:

- skilled and knowledgeable social work assessment;
- a personalised support plan;
- support to access personal budgets where eligible for social care funding.

“In all cases where I have ticked excellent or good it is because we have received kind, caring and understanding care.”

From this information we will:

- ensure that all health and social care staff are aware of the need to have an awareness and understanding of ASC and are provided with opportunities to access learning resources commensurate with their learning needs;
- ensure health and social care commissioners understand that ASC is a life long condition that may require ongoing support throughout an individual's life and that support needs to be responsive to changing needs;
- encourage commissioners to explore how providers of health and social care can make the necessary adjustments to enable people with ASC to access their services;
- develop closer working relationships across health and social care to enable the provision of person centred seamless support responsive to individual need;
- ensure that accessible information is available to people with ASC and their families and carers regarding access to support from health and social care;
- continue to develop support through personal budgets for those with eligible needs ensuring that the process recognises and meets the needs of people with ASC;
- ensure that people with ASC and their families have a say in the design of future health and social care services.

5. Education and training for people with ASC

Fulfilling and Rewarding Lives says:

Help people with autism make the most of their talents by getting the same opportunities for education and further education as everyone else.

Change the way that mainstream education services are offered to enable ease of access.

Educational settings need to make reasonable adjustments for people with autism to reduce barriers to completing courses, attaining qualifications and the social aspect of college life.

What people on the Isle of Wight told us during the consultation:

“My diagnosis helped school to deal with me much easier. Rather than just saying I was disruptive or hyperactive, they could offer the support I needed. It also helps me explain my behaviour to people when I notice they are offended by something I have said or done.”

- Having an ASC diagnosis enables those working in primary and secondary mainstream education to identify the unique needs of the individual. Education staff need to be ASC aware, not just the teachers but ancillary staff as well. Lack of understanding and knowledge can lead to an individual being labelled as ‘a naughty child’.
- Where education staff are understanding of ASC, and when strategies to enable the young person to learn how to deal with the educational environment are put in place, young people with ASC have a more positive experience at school.
- The overwhelmingly clear message was that parents feel school staff needed training, they need to be ASC aware, their training needs to be regularly refreshed and encompass the whole school approach so that all who come into contact with children and young people with ASC are aware of how they may impact on that person. The training needs to be two fold both learning how to support children and young people with ASC within school but also specialist knowledge with regard to how to identify children and young people who may need a further assessment to ensure their potential is maximised.

- There appears to be an expectation that the child should fit the provision rather than an emphasis on person centred education where the provision is designed around the child.
- There is a lack of coherent communication between agencies. There needs to be greater collaborative working, especially involving health, social care, education and families.
- Smaller class sizes were thought to be important particularly in secondary schools where children and young people can become lost in the large noisy environment. Teachers in special schools and specialist units are highly valued.
- There is a need to acknowledge the difficulties experienced by those with high functioning ASC who are academically bright to ensure that their social education is delivered alongside their academic one.

From this information we will:

- work in partnership with education providers to ensure that all schools are ASC friendly schools where children and young people with ASC are able to work in an inclusive environment and access the right targeted support to help them learn and develop;
- ensure there is a universal level of ASC awareness available for all school staff, including ancillary workers to support them to be able to make reasonable adjustments to ensure children and young people with ASC have a positive school experience;
- continue to support the development of appropriate support in education settings that meets the needs of children and young people with ASC, and helps prevent bullying;
- ensure information is provided for parents and carers to enable them to understand the systems and processes in place to support their child.

The Isle of Wight review of provision for children and young people with special educational needs and disabilities 2011 can be found on iwight.com

6. Transition

Fulfilling and Rewarding Lives says:

Help people with autism make the most of their talents by getting the same opportunities for education and further education as everyone else.

Transition planning should act as a route to access support in further and higher education.

What people on the Isle of Wight told us during the consultation:

“It is important that the person with autism is at the centre of any plans and discussions that are held. Making sure that their views are listened to and respected.”

- Transition (moving from children’s to adult services), can be difficult.
- Sometimes a person needs support from more than one organisation, the focus needs to be on the individual as their needs should always be more important than the organisational needs.
- People with ASC thought that they and their family/carers should be listened to and that there was a need for more expertise with regard to transition planning and education for individuals with ASC as a whole.
- Many people felt the process to be rushed and last minute, which is especially concerning as change can be so difficult for people with ASC. Therefore one of the main areas of need highlighted was improvement in planning, ensuring multi-disciplinary involvement from an early age.
- There is a need to promote ASC awareness amongst employers and further education colleges to support the process of transition.
- There is a need to develop a clear person centred transition pathway, delivered by well trained and well informed ASC aware individuals, that is well documented, the process well advertised and conscious of those individuals who do not meet eligibility criteria so they can be signposted to available avenues of support.

From this information we will:

- develop links with education providers to enable improved communication and information sharing;
- enable access to ASC awareness training for all school and further education staff to support them to be able to make reasonable adjustments to ensure students with ASC have a positive transition experience;

- work with partners within children's services and ensure support for those in transition through to adulthood ensuring that young people with ASC benefit from developments in transition processes and are enabled to make informed choices about all aspects of their education, health and social care needs;
- continue to support schools in carrying out learning difficulties assessments through the Education Participation Team and ensure that people with ASC have access to information about available education, further education, training and support on leaving school on the Isle of Wight and where appropriate, the mainland;
- ensure that transition reviews are person centred and address further education and employment issues for people with ASC;
- ensure that people with ASC have an opportunity to prepare for work and further education and develop their social skills through programmes of learning and support systems within education provisions.

7. Helping people with ASC into work

Fulfilling and Rewarding Lives says:

The ability to get, and keep, a job and then to progress in work is the best route out of poverty, and a central part of social inclusion. We know that adults with autism are significantly underrepresented in the labour market and we are committed to doing more to help adults with autism into work. This strategy focuses on four aspects of our activity to support adults with autism:

- ensuring adults with autism benefit from wider employment initiatives;
- personalising welfare and engaging employers;
- improving existing provision;
- developing new approaches that will better support adults with autism.

What people on the Isle of Wight told us during the consultation:

“One person who will help them at work, for example, tell them when the Christmas party is – help them decipher a rota etc.”

- Those who responded felt that people with ASC had a lot to offer the work place. Raising awareness among employers, ASC aware individuals in Job Centre Plus, supported employment projects and further education colleges would be key to supporting them in gaining, maintaining and progressing in employment.
- It was felt that education services should be proactive in assisting people with ASC to develop employment skills so they were work ready. A good starting point would be to help the individual hone their specialist skills, identify what they are interested in to support the development of work choices and plan a career path.
- People with ASC would like to see information about how to access employment. They would like to see employers given access to training to make them ASC aware and enable them to make reasonable adjustments in the work place so that the environment is less challenging to a person with ASC - enabling them to become and remain economically active in their community.

From this information we will:

- ensure that young people and adults with ASC have accessible information about employment programmes and benefits advice;
- in partnership with children's services and education, ensure that work placement programmes for young people in schools include appropriate opportunities for those with ASC;
- ensure that reviews are person centred and address employment issues for people with ASC;
- ensure that the No Barriers Supported Employment Scheme and other supported employment programmes are enabled to assist people who have ASC into employment, and enable staff to receive appropriate ASC training;
- work with partners in the SHIP (Southampton, Hampshire, Isle of Wight and Portsmouth) Strategic Employment group to ensure the needs of people with ASC are considered as part of its work;
- establish partnership working with the Department of Work and Pensions (DWP) in the Strategic Employment Group and Job Centre Plus to ensure their staff are ASC aware;
- work with employers on the Island and offer training to support them to be able to understand the needs of people with ASC and to be able to make reasonable adjustments in the work place;
- ensure that people with ASC can benefit from self directed support and individual budgets where eligible to help them into work or other meaningful occupation;
- ensure the availability of assistive technology, for example, for travel training or keeping people safe.

8. Getting the right housing

Fulfilling and Rewarding Lives says:

Local areas should enable adults with autism and their families to have greater choice and control over where and how they live.

The needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities.

Support should be available for adults with autism who want to, or have to, live independently – both on an ongoing basis and during the transition period to a new home.

Adults with autism and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.

What people on the Isle of Wight told us during the consultation:

“More housing options with specific support for people with autism”

- Those who responded felt that the lack of available housing can mean people with ASC are placed inappropriately in settings unable to meet their needs.
- Specific housing support is required from appropriately trained staff to help people with ASC gain greater independence and help with housing dilemmas such as dealing with neighbours, obtaining social housing, help organising living space and support to be less reliant on parents and assisted living.
- People with ASC want access to information about the housing that is available to them, advice on entitlements and support with applying for housing.
- Staff in housing support services and residential care staff should be ‘ASC aware’. This would help housing and support providers to assess and support people more effectively.
- People are concerned about the suitability of large and mixed residential homes that support people with ASC.
- Future housing provisions should be planned by learning from other successful models of housing.

- Advice and support is needed for parents who can no longer provide a home for their son or daughter.

From this information we will:

- work with housing and support providers to ensure the housing needs of people with ASC are taken into account in housing plans;
- ensure the availability of assistive technology extends to people with ASC;
- ensure that care and support plans identify the preferred housing and support option for people with ASC. This includes planning for young people in transition;
- where possible, support people with ASC to move from residential care to independent living;
- ensure those living in residential care have access to appropriately trained and supportive staff teams who understand and are able to meet their needs;
- ensure people with ASC and their families have clear information about housing options;
- support housing providers to raise the awareness and understanding of ASC among their staff.

9. Community life - developing and maintaining independence, a meaningful social life and friendships

Fulfilling and Rewarding Lives says:

All adults with autism are entitled to be able to live fulfilling and rewarding lives within a society that accepts and understands them. This includes having relationships and social networks.

The focus is rightly to make it easier for adults with autism to be fully included within society.

The goal is to move from fitting people into services to fitting services to meet people's needs.

What people on the Isle of Wight told us during the consultation:

“Treating people as individuals with unique gifts and needs”

- 69 per cent of respondents to the consultation cited a lack of understanding in the wider community as a barrier to social development for people with ASC. The overall theme of responses was lack of training, lack of funding, lack of resources. There is a perception that there is no support available and a lack of accessible information with regard to assessment, housing support and access to health care. In order to improve this situation people with ASC wanted to be included in the planning for future services and support systems.
- The introduction of personal budgets enabling individuals to tailor their support in a person centred way was considered as a positive step.

- Developing self help and independence skills at an early age builds a foundation for independence in later life. There was a lack of opportunities to develop independence, particularly on leaving school and an over reliance on families to provide this support. It should be recognised that many individuals with ASC are supported by older parents who cannot continue to provide the intensive support often required by those living at home, independently and even those in residential care.
- Training is required for both the general public and those working directly with individuals with ASC. The introduction of a buddy system of volunteers to support integration into existing universal services may be of benefit.
- Good communication and working together between parents, education and other professionals to enable the individual to realise their potential utilising person centred approaches rather than a one size fits all regime is required.
- Increasing public awareness of the needs of people with ASC was again seen as the key to improving social opportunities. Respondents had found pockets of excellent support but this was not consistent. Raising awareness would reduce anxiety around supporting and welcoming individuals with ASC into social settings, which in turn would enhance their experiences by breaking down barriers.

From this information we will:

- support the development of ASC awareness and understanding in organisations and for staff who provide social and leisure opportunities;
- ensure that people with ASC, who are eligible for adult social care, have their social needs assessed by staff who are ASC aware and have appropriate training;
- develop a social care pathway which enables those eligible to be enabled by appropriately trained staff to access and make positive use of a personal budget;
- explore the use of assistive technology to help people with ASC become more socially independent or remain safe in their own home, their family home, supported living or residential home;
- support providers and voluntary organisations to understand how to make reasonable adjustments under the Equality Act 2010 which will help people with ASC;
- work with people with ASC through the user led organisation to understand what they would like to see on the island to enhance their quality of life.

10. Criminal justice system

Fulfilling and Rewarding Lives says:

It is essential that autism awareness training is available to all staff in the criminal justice sector.

Teams that work within criminal justice agencies, such as the Criminal Justice Liaison Teams, should ensure that they have access to the expertise to support adults with autism.

Developing pathways through the criminal justice system for adults with autism will help identify key players locally who may be required to work alongside criminal justice staff.

What people on the Isle of Wight told us during the consultation:

“Willing to understand and open to learning”

- Although there were positive developments with regard to ASC awareness within the Island’s police force, there is a need for a greater awareness and support for people with ASC throughout the criminal justice system.
- The introduction of the ASC alert card as a means to alert criminal justice professionals of the need for support, sensitivity and understanding was highlighted as good practice.
- There needs to be a clear diagnostic and care pathway for those with ASC in the prison service.
- There is a varied level of knowledge among staff in all services, therefore people working in the criminal justice system would benefit from training in understanding ASC.
- There is a need for ASC-specific support to be made available when a person with ASC is in the criminal justice system.

From this information we will:

- work with the Hampshire Autistic Society to promote ASC training opportunities to those working in the criminal justice system on the Isle of Wight;
- promote ASC training opportunities to those working as appropriate adults in the criminal justice system on the Isle of Wight;
- develop partnership working between services to support people with ASC who are victims, witnesses or perpetrators of crime;

- work to develop a clear pathway and support for people with ASC who are in the criminal justice system;
- make sure that the Alert Card Programme and the ASC Passport are well publicised to enable people with ASC to use them if they wish to.

11. Keeping people safe

Fulfilling and Rewarding Lives says:

To safeguard and protect adults with autism who may become vulnerable and enable them to live safely in their local communities and not be constrained by hate crime and discrimination.

People with ASC have the right to live in safety and be free from hate crime, discrimination and abuse. Adults with ASC can be vulnerable both within services and in the community. People with ASC may misinterpret other peoples' intentions. They can take written and spoken words to be literal truth and be taken advantage of as a result. People with ASC can also be worried about displeasing people which can lead to risk and vulnerability in relationships.

What people on the Isle of Wight told us during the consultation:

“More people need to go into schools, and talk to the children about these conditions. This will give children a wider understanding of these conditions and maybe allow them to be more tolerant of the children with these conditions.”

There is a need to improve general public awareness and understanding about ASC. Basic awareness and diversity training should be available for all and taught in schools to develop children's understanding and support for their peers.

Parents were concerned that the attitude of the public stigmatised individuals as they did not understand their needs.

From this information we will:

- work with the police to develop a Safer Places Scheme on the Island. The scheme provides safe places, in the community, where vulnerable people, including people with autism can go if they feel threatened and be supported to contact a trusted individual;
- work with the Local Safeguarding Adults Board to ensure that they are aware of the needs of people with ASC and they are included in any plans;
- work with our partners in health to develop telecare and telehealth solutions that have been shown to help people with ASC to manage their own anxiety levels;
- ensure access to suitably trained advocates is provided where appropriate;

- work through the Local Safeguarding Adults Board to review existing multi-agency safeguarding training to ensure the policy takes into account the needs of people with ASC. This will ensure people with autism are fully involved at each stage of the safeguarding process leading to improved experiences and outcomes;
- work with the safeguarding vulnerable adults service and local safeguarding board to empower people with autism to lead change and speak out when things are not right with their lives.

12. Supporting the carers and families of people with ASC

Fulfilling and Rewarding Lives says:

Crucially, we will also ensure there is more effective, more tangible support for the families and carers that do so much for adults with autism; they must not be allowed to struggle on without our help.

What people on the Isle of Wight told us during the consultation:

- Most of all, carers wanted to be listened to and acknowledged as experts by experience with regard to the people they are supporting.
- Patience, understanding, knowledge, practical support, non-judgemental attitude and the provision of information were what made services good or excellent.
- Opportunities to meet with other parents both socially and as a support group and also to attend various courses to support parents to understand ASC were valuable sources of assistance.
- The information available is very generic and not person centred enough. Information packs and a database are needed that provides information regarding what support is available on the Isle of Wight and how to access it.
- There was a need to recognise that many individuals with ASC are supported by older parents who cannot continue to provide the intensive support often required by those living at home, independently and even for those in residential care.
- Support should not just be available to those in crisis, there should be open access to support and information throughout the life of the person with ASC.

From this information we will:

- ensure that carers of people with ASC are aware that they are entitled to a carers assessment enabling their needs to be assessed either alongside the person they are caring for as part of the community care assessment, or separately if they choose to do so;
- continue to improve and establish, pathways for providing information, and support to both new and existing carers and ensure it is widely available;
- review our training for the health and social care workforce to raise awareness of carers' needs including those of young carers;
- review current and future commissioned carers' services in order to ensure the support provided meets carers' outcomes;

- support the carers' group which is part of the Isle of Wight user led organisation People Matter to be involved in the development of future carers support;
- develop training to support carers in their work.

The Carers plan 'Working Together With Carers for the Isle of Wight 2013 to 2016' can be found on iwight.com.

13. Next steps

Fulfilling and Rewarding Lives says:

Change needs to be driven locally, through strong local leadership.

Local authorities should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.

It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally.

The key is that local partners come together in one place to discuss priorities and challenges together: how that might be done will need to be determined locally.

We expect each local area to develop its own commissioning plan around services for adults with autism that reflects the output of the Joint Strategic Needs Assessment (JSNA) and all other relevant data around prevalence.

In order to develop this strategy the views of people with ASC and their parents and carers were considered a priority from the outset and involvement was secured by carrying out the ASC consultation in 2011. The consultation collected views on the issues that people wanted to see addressed in a strategy for children, young people and adults with ASC on the Isle of Wight.

During the consultation people with autism and their families told us that good experiences for people with autism and their families depends on the following being in place:

- ASC aware, supportive, understanding and actively-listening staff within all services that have direct contact with people with ASC.
- Early ASC recognition, leading to a timely diagnosis, identification of post-diagnostic support needs by means of a community care assessment where applicable and establishment of intervention if required.
- Resourced and appropriate school placements within mainstream and SEN schools – where teachers and staff are ASC aware, make adjustments and are skilled in supportive interventions.

- Open collaboration and clear communication between organisations, and the person with ASC and their parents/carers.
- Activities and places to go where social opportunities are available, either ASC specific or mainstream.
- Eligibility to statutory services or signposting to alternative available resources and/or services.
- Clear, accessible information and advice on volunteering, employment, benefits, education, housing, support services, therapeutic interventions and activities for people with ASC.
- An ASC aware community where support is available to employers, universal services and the public at large to enable them to make reasonable adjustments to make the island a less challenging place for people with ASC.
- The main objectives of the Isle of Wight Strategy for people with Autism Spectrum Condition are:
 - increasing awareness and understanding of ASC;
 - continue to improve our clear and consistent pathway for diagnosis;
 - improving access to support in education, health and social care;
 - helping people with ASC into further education and work;
 - supporting people with ASC to live fulfilling and rewarding lives within their community.

How will we make this happen?

This is the beginning of our journey to enhance the experiences of children, young people and adults with ASC and their families on the island.

We will:

- develop a clear action plan to identify how we will implement the objectives of this strategy and monitor progress;
- ensure that the needs of people with ASC and their carers are included in the Joint Strategic Needs Assessment to inform future planning and commissioning;
- report on the implementation of the Isle of Wight's ASC strategy to the National Autism Programme Board as required by the Department of Health;
- work to ensure that mainstream services are accessible to people with ASC;
- support voluntary and third sector organisations to develop local services for people with ASC;
- shape the market to ensure providers are aware that they need to deliver support which has clear outcome measures relevant to the needs of people with ASC;
- ensure that providers understand the diverse needs of people with ASC, and have the appropriate level of ASC knowledge and skills to help meet these needs;
- continue to place people with ASC and their families and carers at the centre of our work and future planning and endeavour to involve people with ASC and their families in the development, commissioning and review of services.



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