

AUTISTIC SPECTRUM DISORDER
FULFILLING AND REWARDING LIVES: NATIONAL ADULT AUTISM STRATEGY
FOR ENGLAND

To: **Cabinet**

Date: **7th September 2010**

From: **Rod Craig Executive Director, Community and Adult Services**
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Electoral division(s): **All**

Forward Plan ref: **N/a** *Key Decision:* **No**

Purpose: **To inform Cabinet of:**

- **The requirements and implications from the National Autism Strategy.**
- **Progress in the development work for people with Autism Spectrum Disorder including an Autism Strategy.**

Recommendation: **That Cabinet:**

- **Notes the National Autism Strategy and**
- **Approves Cambridgeshire's Adult Autism Spectrum Disorder strategy.**

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1.0 BACKGROUND

- 1.1 Autism is a lifelong development disability, affecting people's social independence to differing levels. It is characterised by its affect on the way that people perceive and understand their daily lives, and also interact and communicate with others. People with Autistic Spectrum Disorder (ASD) experience three main areas of difficulty; social communication, social interaction and social imagination. ASD affects people within a wide range of high and normal intelligence and others with learning disabilities. An estimation of the numbers affected in Cambridgeshire is attached at appendix 1.
- 1.2 The Autism Act 2009 set out the Government's intentions. Fulfilling and rewarding lives: The National Adult Autism Strategy for England was published on 3 March 2010. A full copy of the strategy and the first year delivery plan can be found at www.autism.org.uk/dhstrategy. Guidance and the full delivery plan is due in December 2010. It will place new responsibilities and provide best practice guideline on the NHS and local authorities. The Government has committed to formally review the strategy in 2013 and take action if the improvements set out in the strategy are not delivered.
- 1.3 Cambridgeshire commenced development work for adults with Autistic Spectrum Disorder in 2009 following the identification of need in the Learning Disability Joint Strategic Needs Assessment, and the inclusion in the Learning Disability Strategy. An Autism development project was undertaken and following targeted consultation, Adult Social Care Disability Management Team endorsed a draft Autism Strategy on 1 December 2009. NHS Cambridgeshire has indicated that they would wish to see this endorsed as a joint NHS and Adult Social Care strategy. A copy is attached at appendix 2.
- 1.4 The development to date has seen, via a tender process, the appointment of a 3rd sector partnership, Red2Green and National Autistic Society (NAS). The project is funded for 2 years using Learning Disability Development Fund (LDDF). The LDP Board have also endorsed the strategy and development proposal. The project was formally launched on 19th May 2010.
- 1.5 The multi-agency ASD development group have created an action plan. The action plan is regularly updated. Work links to Children and Young Peoples Service's autism developmental work. Terms of reference and the current plan are attached at appendices 3 and 4.
- 1.6 Adult and Communities Policy Development Group considered this proposed response at its meeting on 2nd July 2010. The action plan is updated regularly and now includes actions identified Adult and Communities Policy Development Group.

2.0 **FULFILLING AND REWARDING LIVES: THE NATIONAL ADULT AUTISM STRATEGY FOR ENGLAND**

- 2.1 Key areas in the strategy include:
 - An emphasis on general awareness and improved training of frontline professionals in autism.

- Proposed actions for better planning and commissioning of services, including involving people with autism and their parents/carers.
 - Proposed actions for improving access to diagnosis and post-diagnostic support.
 - Leadership structures at national, regional and local levels for delivery.
 - Proposals for leading + reviewing the strategy to make sure that it is working (A National Programme Board, regional support + delivery plans).
 - The recommendation to develop local autism teams
 - A range of actions the Government plan to introduce including development of training to Department of Work and Pensions and packages via Skills for Health and Skills for Care.
- 2.2 The strategy states that Directors of Adult Social Services should ensure that there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. It also sets out an expectation that a dedicated ASD Commissioning plan is produced.
- 2.3 Training and Awareness
The strategy sets out a number of actions and recommendations to address the lack of awareness of autism amongst both the general public and direct frontline staff, including:
- general awareness – including expectation of ASD being part of general diversity training.
 - Work to ensure that autism is included in the core training curricula for doctors, nurses and other clinicians.
 - Autism training to be part of training for staff carrying out community care assessments.
 - Autism awareness training for all working in the public sector.
 - programmes of work to support training at a local level.
 - Training in autism for all Disability Employment Advisors (DEAs).
- 2.4 Dedicated ASD Teams
The strategy recognises the benefits of dedicated local autism teams and encourages local services to develop these. Best practice will be shared. Where local autism teams are in place these teams may:
- Provide care management functions.
 - Support to mainstream services to help them to support adults with autism.
 - Ensure that those adults who do not qualify for support from the learning disability or mental health teams to fill in the gap” created by traditional service boundaries.
- 2.5 Joint working
- 2.5.1 The strategy also seeks to ensure:
- Joint Strategic Needs Assessments (JSNAs) include autism. (Guidance to follow a protocol of what information should be recorded locally on the needs of adults with autism and how it should be shared between services).
 - The involvement of people with autism and their family/carers in the development and delivery of services.
 - The development of local autism partnership boards “that bring together different organisations, services and stakeholders locally and set a clear direction for improved services”.

- Improved access to diagnosis for adults with suspected autism. This includes recommending the appointment of a lead professional to develop a local diagnostic and assessment service for adults with suspected autism.
 - That a diagnosis of autism will trigger a community care assessment and a carer's assessment.
- 2.6 The statutory guidance due in December 2010 will set out the type of information that should be provided to adults with autism and their parents/carers once they have been diagnosed. It is likely to cover in more detail information about
- a) providing services for diagnosing autism in adults;
 - b) identifying adults with autism;
 - c) carrying out needs assessments for adults with autism;
 - d) planning appropriate services to young people with autism as they move from children's to adult services;
 - e) local planning to provide appropriate services to adults with autism;
 - f) training of staff who provide services to adults with autism;
 - g) local leadership regarding providing services to adults with autism.
- 2.7 Many of the key recommendations / elements from the National Strategy are already in place as a result of the recent development work. Set out below are some of the implications for Cambridgeshire with *comments as to the current situation in italics*.

3. IMPLICATIONS

3.1 Resources and Performance

- Finance – ***some implications***

i, Existing resources are already being used for adults with autistic spectrum disorder who meet adult social care eligibility criteria.

ii, The development project is currently funded by the Learning Disability Development Fund (LDDF) at an annual cost of £30,000. The project is due to be completed by July 2011, and the shape of future services will be determined by experience gained from the current project

iii, Commissioned Advocacy and Information services have been extended in order that people on the Autistic Spectrum can access these services.

- Property + Facilities – ***none***

- ICT – ***some minor implications.***

i, SWIFT data recording needs to include recording of ASD

ii, Website material may need to be amended to maximise access by people with ASD.

- Best Practice – ***some implications***

i, Preventative agenda – best practice cited includes access to information, low level support, 3rd sector support, travel training, access to housing.

The current project in 3rd sector starting to offer some of these but is funded by LDDF for 2 yrs only. Some limited access to Supporting People services. It will be important to consider needs of ASD in the Transformation/ Universal services work being undertake and make reasonable adjustments accordingly.

3.2 Statutory Requirements and Partnership Working -

- Statutory Requirements – **Significant Implications**

Whilst the strategy itself is not legally binding, local authorities are expected to follow it. The guidance due in December 2010 should provide clarification.

i, Ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.

The Director responsible for Commissioning in the new Adult Social Care structure will be formally responsible for this work

ii, an expectation that a dedicated ASD Commissioning plan is produced.

The recently produced ASD Strategy broadly matches the areas in the national strategy – it can be reviewed in light of the guidance due in December 2010. It may be necessary to develop further the action plan into a Commissioning Plan as it becomes clearer what the expected timescales for delivery are.

iii, Statutory bodies are expected to include ASD in general diversity training. Some revisions to CCC Diversity training may be necessary.

A series of ASD awareness was undertaken last year. A bitesize 1 hr awareness sessions could be run by the project worker if required for existing staffing. ASD awareness can be offered to existing Diversity trainers if required to ensure future diversity training includes ASD awareness.

iv, Access to Community Care Assessment and self directed support / Specialist Team option.

LDP Teams currently pick up “vulnerable adults” not eligible for other teams. The option to develop a dedicated team or dedicated staff within teams needs to be explored following the restructure of Adult Social Care. It will consider this issue and provide guidance as to what steps might need to take place to achieve best practice.

v, Support at Transitions

Young people with ASD are included in the Council’s protocol if they are likely to need social care support. Best practice cited in strategy notes need for low level work i.e travel training and buddy type schemes – not currently available. Options to look at support via Connexions may need to be explored.

vi, Awareness training

Training and workforce development - Care Management and frontline workers. A subgroup has identified 5 levels of training need and have sourced some resources. Preparatory work has been commenced. This can be revised once Skills for Care have produced their guideline/ packages. Issues are being considered however more dedicated time in order to ensure we meet guidance and any deadlines that may be issued. User + carer involvement will need to be instigated in this work.

The Government committed £500,000 to support a programme of training for health and social care professionals however this is likely to be used in the development of national guidance and training programmes.

- Partnership Working – **some implications**

- i The existing multi-agency group includes all key players

- ii, Planning and Joint Strategic Needs Assessment data

- Our current LD JSNA includes sections on ASD. However data collection does need to be addressed to ensure we record those being assessed and provided with support. SWIFT recording as yet does not include ASD identification, however action is being undertaken to address this. Tthis is also key at the transitions process.*

- iii, Diagnosis and Pathways– *NHS Cambridgeshire and C+PFT are aware of these but may need to review their plans and timescales in light of the strategy. A draft pathway has been developed and ongoing discussions are underway.*

3.3 Climate Change - **No implications**

3.4 Access and Inclusion - **Some Implications**

- i, Information +and Advocacy

- The current contract for Advocacy services has been extended to include people with ASD.*

- Some work regarding the range of information available has been undertaken and further work is planned as part of the Putting People First – Transformation preventative agenda. Joint work is likely to be needed to meet the guidance on the range of information that should be provided to adults with autism post diagnosis and in order for an assessment to be undertaken. CCC web information is now linked to other websites. .*

- ii, Employment – support to access

- The Department of Work and Pensions (DWP) will be receiving additional training to explore the implications. Links between the project and local DWP Partnership staff have been established.*

- Any provision of advice and information and assessment for social care will need to explore support to employment.*

- Aspirations is only service dedicated for ASD - not currently funded via ASC although some applications for Self Directed Support for individuals have been made.*

3.5 Engagement and consultation - **Some Implications**

- i, Involvement of users and carers

- Family carers are part of the multi-agency group. It has been agreed that user involvement is done outside of the formal group using the local NAS branch which are well represented. The recent launch event was used to seek views on the issues and priorities for development work and further events will be built into the development project.*

Source Documents	Location
Fulfilling and rewarding lives: National Adult Autism Strategy for England	CC1311 Castle Court Geoff Sherlock, 01223 715672 Geoff.sherlock@cambridgeshire.gov.uk Jean Clark 01223 715956 jean.clark@cambridgeshire.gov.uk

Estimated number of people of working age with Autistic Spectrum Disorder in Cambridgeshire by district

District	Total 18-64 years	People with ASD IQ<70	Kanner Autism	Other Spectrum Disorder	People with LD IQ>70	Asperger Syndrome	Other Spectrum Disorder	Total People with ASD
Cambridge City	82,180	160	40	120	580	300	290	750
East Cambs	47,380	90	20	70	340	170	170	430
Fenland	54,170	110	30	80	380	200	190	490
Huntingdon	102,880	210	50	150	730	370	360	940
South Cambs	87,010	170	40	130	620	310	300	790
Peterborough	100,145	190	50	140	710	360	350	900
Cambridgeshire Total	473,755	940	240	700	3,360	1,700	1,660	4,300

Source: Adapted from Paul Shattock & Paul Whiteley, "The changing prevalence of autism?", Autism Research Unit, University of Sunderland & Cambridgeshire County Council Research Group, mid-2006 population figures.

Appendix 2

Cambridgeshire County Council Adult Support Disability Service and Cambridgeshire NHS

Joint Health and Social Care Strategy for Adults with Autistic Spectrum Disorder 2009/10 – 2011/12

Disability Management approved 1.012.09

1. Introduction

1.1 This Strategy document focuses on adults with a range of Autistic Spectrum Conditions / Disorder (ASC / ASD). This includes the definitions of 'Autism', 'High Functioning Autism' (HFA) and 'Asperger's Syndrome'. The Strategy does not cover children or young people. Children and Young People Services (CYPS) are undertaking work on the development of a Care Pathway and strategy for children and young people on the autistic spectrum. Whilst the strategy does not specifically cover young people in transition to adult services (aged 16 to 18) strong links are being forged between the two pieces of work to ensure a co-ordinated response.

1.2 This document does not make a special case for people with autistic spectrum condition but seeks to clarify how national policy applies and make clear what support and services people can reasonably expect to access.

1.3 Consultation

1.3.1 In preparing this strategy we have:

- looked at existing services and services and the issues and gaps in provision where currently known,
- set out proposed actions to address some of these issues

1.3.2 The strategy has been developed during the DH consultation period of "A Better Future" the governments draft national strategy and takes account of this draft document.

1.3.3. A targeted consultation was undertaken and amendments have been made from responses. It has been endorsed by the Learning Disability Partnership Board, the Councils Disability Management Team and is proposed as being adopted as the joint Adult Health and Social Care's strategy for the next 2 years.

1.4 A key element of the strategy links to the short term, 2 year, commissioned project that will inform and direct the future development of support and services for people with autistic spectrum condition (ASC). Following this project the strategy will be reviewed and updated. More details can be found in section 3.0.

2.0 Background

- 2.1 Autistic spectrum condition (ASC) or disorder (ASD) is a lifelong developmental disability, characterised by its affect on the way that people perceive and understand their daily lives, and also interact and communicate with others. Both Department of Health documents – “A Better Future” (DH 2009 – consultation paper) and “Better Services for People with an Autistic Spectrum Disorder” note that people with ASC experience three main areas of difficulty. These areas of difficulties are social communication, social interaction, and social imagination. Managing the perceptual and sensory differences that underlie these is a major challenge to addressing the social difficulties.
- 2.2 People with ASC have a range of needs that will not be addressed by one agency. Within the current arrangements the needs of people with ASC are not easily met by the current service provision in either adult mental health or learning disability services. While some have a diagnosis, others do not for a variety of reasons. Irrespective of diagnosis, all need sensitive management, developed with the full involvement of parents and carers. Appropriate management can reduce the barriers to learning and help people with autism achieve their potential. Not all adults with ASC, particularly those at the more able end of the spectrum receive appropriate support services because they do not meet the social care eligibility criteria to qualify for learning disability or mental health services. Some people with an ASC who need services fall through the gaps created by traditional service boundaries. There are a number of ways to prevent this and joint working protocols provide some of the strongest examples
- 2.3 Policy requires public bodies to identify, assess and meet the needs of the local adult population and this should include people with an ASC. The Joint Strategic Needs Assessment (JSNA) for learning disability included data on the demography of ASC in Cambridgeshire. It estimated that those with high functioning autism (IQ>70) includes people with Asperger Syndrome (36 per 10,000 population) and other spectrum syndrome (35 per 10,000 population) and we would expect there to be around 2,650 people in this category. These individuals may not fit the learning disability criteria for services but may still have considerable support needs.
- 2.4 Services and supports should focus on supporting each person’s inclusion in society. New approaches to funding and support such as direct payments and individual budgets should be made available to people with ASC in the same way as everyone else. However the community as a whole needs to include people with ASC it is not just a health and Social Care responsibility. A key part of the project will be to support and develop the ability of the community to meet the needs of people with ASC.
- 2.6 Some people with ASC who need services fall through the gaps created by traditional service boundaries. Strong protocols that cover assessment, diagnosis, joint working arrangements, care pathways and decision-making can give more clarity about how people get access to a service. People should be able to access the same services as anyone else. The Disability Discrimination Act and the Disability Equality Duty underline the need for all services to understand, and respond to, the needs of disabled people. This

means that day, employment, leisure and education services (as well as all other public services) must make reasonable adjustments to facilitate the inclusion of those people with ASC who are disabled within the meaning of the Act.

- 2.8 Good local services only exist where agencies work well together. This includes those with a role in: learning disability, mental health, primary care, adult services, services for young people, housing, support providers, treatment services, along with people with an ASC and families. An effective commissioning strategy will build the local infrastructure and capacity of local providers. This will help to stop over-reliance on single, specialist providers

3.0 ASC Project

- 3.1 Our first step and key to the success of this strategy is the appointment of a short term commissioned project. This project includes the appointment of a Development worker and establishing a multi-agency group to overview and assist with the wide ranging initiatives that are needed to improve access to services and support for people with ASC. The project will:

- raise public and professional **awareness** of autism,
- **promote independence**,
- assist people in **achieving life choices and gaining social inclusion**.
- Inform future developments.

It will also:

- Develop an **effective working partnership**.
- Develop **collaborative practice** with other agencies and services such as health, social work, speech and language therapy, voluntary agencies.
- Work alongside other agencies in **supporting families and people** with ASC.
- Provide a framework for **professional development**.
- **Build the capacity** of services and organisations so they can provide appropriate support

- 3.2 Whilst the project lead is an external commissioned organisation, the projects success will be dependent on close work with a wide range of other partners. The Disability service will have a role as commissioner and active partner in driving up awareness, and equality of access to universal and specialist services. The use of a multiagency group to steer the work and monitor the project will ensure that close links are maintained with all statutory bodies, voluntary and provider organisations and people with ASC and their families. The project will:

- ensure we have greater information about ASC.
- enable us to have a clear, locality wide structure through which ASC is championed
- build a picture of the total local population of people with ASC and their needs.
- Actively develop local providers so that they know how to provide individualised services.

- set an expectation that providers work in partnership with both other providers and other agencies.
- 3.3 This Strategy therefore proposes that, following appointment of the lead organisation, we will work closely with the interagency project group to develop an action plan that reflects the needs of people with ASC and their families. We will monitor closely the required outcomes for the commissioned service. The next section, based on the broad themes from “A Better Future” includes some of the areas that are likely to be included in the multi-agency action plan.

4.0 Key Themes – issues and proposed actions.

It is anticipated that the following will become key elements of the project / interagency group’s action plan.

4.1 Social Inclusion:

- Access to support
- Housing
- Leisure

4.1.1 Access to support - Referral and Assessment

Once an individual leaves education, people with higher functioning autistic conditions and Asperger’s Syndrome may not meet Fair Access to Care criteria for eligibility to social care services. Many do not have a Learning Disability or a diagnosable mental illness, and most do not fall within the Physical Disability Teams. The pathway into Adult Social Care for people is not always clear. Where an individual does meet eligibility criteria their needs will be assessed in the normal way and access to Self Directed Support will be facilitated (More detail relating to Self Directed Support is in section 4.3).

4.1.2 Cambridgeshire’s current working position in relation to adults is:

- Some people with Asperger’s syndrome /HFA will have mental health needs best met within primary care mental health services and should be accessing those services via their GP.
- If a person with Aspergers’ syndrome or HFA has mental health problems which meet the criteria for treatment by the mental health trust then they will receive treatment via mental health trust services.
- If a person with Asperger’ s syndrome /HFA has a need for social support that is not related to a mental health issue and meets the social care criteria of the council ie substantial or critical need, then the person will have their social care needs met through the Learning Disability Partnership under the arrangements in place for 'vulnerable adults'. LDP health professionals are not normally expected to work with people in this group. However there may be exceptional circumstances when this is appropriate and LDP health professionals should consult their line manager and professional lead if such circumstances arise.

It is recognised that the above arrangements are unlikely to meet all the needs of all Cambs people with Asperger’s syndrome /HFA.

4.1.3 Low level Need.

Social Care assessments may not recognise that high academic achievement can mask an unseen inability to cope with such things as being an independent traveller or being included in the community. This is also a major issue for carers - if the person they care for does not meet our criteria they themselves have great difficulty getting a carer's assessment as well as concrete support only available following assessment.

It is anticipated that during the life of the project signposting, advice and information will be available from the ASC Development worker. Access to universal services and other advice and information should also be available. Section 4.4 covers awareness and training for these services.

4.1.4 Housing and Support

Adults with ASC tend to have difficulty accessing assistance with housing and appropriate support. Nationally more than half of the people with ASC are still living with parents. Those who are living alone in the community may not cope very well and require a lot of support.

4.1.3 Access to Leisure

Projects like social and education groups appear to help people get connected and stay well. People with ASC can experience considerable difficulty in accessing appropriate leisure and recreational facilities. Girls/young women with ASC experience particular difficulties given their smaller numbers and some of the behaviour traits of clients within this group

Proposed Action

- There is a need to explore the need for programmes / access to support young people with autism moving into independent living accommodation. This is likely to include awareness raising with Supporting People, Residential Supported Living providers and District authorities.
- The project will also explore ways in which the local community can become involved to highlight the need for specific support to enable the client group to enjoy a wider access and choice to leisure and recreation including local theatres and concert halls, which will promote social inclusion.

4.2 Health

- Diagnosis
- Interface with Mental health services
- Access to general healthcare

4.2.1 People on the autistic spectrum and their families say knowing where to get diagnostic help, getting help in a timely way and receiving post-diagnostic support and information are all important. The policies place this responsibility with health commissioners. Mental ill health can result from not understanding social situations, feeling isolated by ones perceptual and sensory differences and not getting timely and /or long-term support.

- 4.2.2 The Royal College of Psychiatrists Report (April 2006) 'Psychiatric Services for Adolescents & Adults with Asperger's Syndrome and Other Autistic Spectrum Disorders' recommends to health commissioners that they should ensure that there is access to local, basic diagnostic expertise that allows a firm diagnosis to be made in clear cut cases. Where the diagnosis is uncertain there should be access to secondary diagnostic expertise to enable further assessment to take place.
- 4.2.3. For some people with an undiagnosed Autistic Spectrum Condition (ASC) their desire to have a formal diagnosis is very important to them and their parents/carers. It can answer many questions and assist them in beginning to understand why they behave, react and respond to situations in the way that they do and to develop coping strategies. Without a formal diagnosis, individuals have no 'proof' of having a disability and so have no access to claiming welfare benefits or accessing support.
- 4.2.4 A referral for a diagnosis, usually at the request of the individual or their parents, can depend on where you live, how knowledgeable the GP is about autism, the determination of parents/carers to pursue a diagnosis
- 4.2.5 People with an ASC may also be at risk of having poorer access to healthcare (diagnostic overshadowing etc). Health Action Plans or care plans can help to address these especially when help is given by Health Facilitators (or other specialist health staff) that understand the associated health issues. Awareness by health staff of the needs of people with ASC will improve access and the quality of healthcare considerably.
- 4.2.6 The NSF in mental health applies to everyone with mental health needs, regardless of additional or underlying conditions. This means that someone with ASC with a mental health condition should have access to the same mental health care as anyone else. Mental health needs are common in people with ASC who may suffer from depression, anxiety and obsessive compulsive disorder. The way they are treated, however, needs to take account of their ASC as traditional models of treatment may not be suitable for people with ASC. ASC can sometimes be mistaken for schizophrenia. There is, however, no data on the number of people with ASD using mental health services
- 4.2.7 Preventative services.
Access to low level preventative and health promoting activities is equally as important as it is to the general population.

Proposed Action

- To formulate a clear diagnostic pathway that is accessible and available to all those who need it and request it.
- To explore the training / awareness needs of healthcare professionals.
- Support wider providers/ community to understand the specific needs of people with ASC to facilitate equality of access.

4.3 Choice and Control

- Person Centred Planning and Self Directed Support
- Transitions Planning
- Advocacy
- Involvement

4.3.1 Person Centred Planning and Self Directed Support

Equality of access to assessment is a right and any barriers to this need to be identified and addressed. Staff's knowledge and understanding of the specific needs of people with ASC is key to enable this. The new Self Directed Support approach to funding and support will be made available to people with ASC where their needs meeting Fair Access to in the same way as other client groups.

4.3.2 Transition Planning

Early intervention can enable young people and adults to gain more independent living skills and by helping to maximise the individual's potential they are more likely to lead a more fulfilled life, achieve their life choices and become integrated into the community. Early acknowledgement of the parent/carer's and siblings' needs can enhance the carer(s) capacity for offering continued support to the client and help the whole family to lead a more 'normal' life. These needs often centre around the need for information and support from other families rather than what we might consider to be formal 'services'

Once the young person reaches 16 it is reported that it is difficult to find appropriate services and resources, particularly where there are no additional learning disability or mental health problems. The majority of children on the Autistic spectrum will be included in mainstream school and some will have a Statement of Educational need. Those pupils with more complex difficulties may require Special School Education.

Young people needing Adult Social care will be picked up by the Transitions Team, within adult Disability Service. All individuals will have access to the Connexions service.

Proposed Action

- Provide ASC awareness training to Care Managers and Financial Assessment and Benefit advisors.
- Look at current resources and shortfalls to support and sustain young people upon leaving school e.g. independent living skills; travel training; preparation for employment.
- As part of transition school leavers could be referred to the Project where the young person and parents are agreeable.
- That the multi agency group considers how these services could be better resourced.
- To establish proper protocols, which identify a clear referral pathway.

4.4 Awareness raising and training

- Public awareness
- Training the workforce

4.4.1 Public Awareness

As citizens we interface with a wide range of organisations and individuals. The broader awareness of the general population will benefit people with ASC however it would be a mammoth and unrealistic task to expect any project to be too far reaching. It will however be important to maximise opportunities to raise general awareness as well as target sessions or training to some specific community groupings.

4.4.2 Advocacy

Some individuals will need support to access mainstream services. In order for people on the autistic spectrum to access mainstream services a greater awareness of their needs and difficulties is needed.

Proposed Action

- Identify ways to and undertake general awareness and targeted awareness in the community.
- Explore opportunities to deliver awareness sessions to staff and professionals involved with higher functioning individuals particularly the emergency services, police, judiciary, and probation where many staff may currently have limited understanding of able autism or how to recognise the condition. This will enable more appropriate responses and support in dealing with the individual identify availability / access to existing advocacy services.
- Explore options to facilitate access to CCC commissioned advocacy services, to include some lower level access for those not meet eligibility criteria.
- Explore option to provide training to Advocacy service to provide access to ASD
- Explore development of information packs / web pages and include more links to relevant web sites from the Councils web pages and an on line referral system.
- Review and revise Autism Awareness Training planned for workers in local agencies

4.5 Access to Training and Employment

- Access to support and training
- Awareness of employers

4.5.1 Local supported employment and other specialist employment services should have the competence to support people with ASC into paid work. Nationally it is calculated that 94% of the working age ASC population are unemployed and are on long term welfare benefits, such as Income Support and Incapacity Benefit. The National Autistic Society's report 'Working For Autism?' found that

- Only 33% of employers surveyed had sufficient autism awareness and knowledge to support a client with ASC to find suitable employment.
- 42% said they had been unable to place any ASC client in employment or training.

- 46% attributed their failure to assist ASC clients into employment on employers negative attitudes and ignorance towards autism.

Proposed Actions

- To work with New Deal, Job Centre Plus disability employment agencies and private ASC providers to promote the positive advantages of employing someone
- Explore opportunities to develop autism awareness training sessions with local Job Centre Staff, employer forums etc.
- Explore the opportunities to extend the current commissioned “support into employment service to cover people with ASC.

4.6 Carers Support and Short Breaks

4.6.1 It is widely recognised that ASC has a significant genetic component. It may well affect others in the extended family in varying degrees. This could therefore have an affect on the effectiveness of services in establishing, and maintaining relationships with family carers. The need to improve consultation, involvement and partnership working with people with ASC and their carers has been highlighted by our local ASC organisation. The proposals below will meet this need. The key support family carers need are:

- The right to an assessment
- Information
- Short breaks

4.6.2 Respite and short breaks play an important and vital role in carer support and can be a cost effective form of support that can divert a family crisis. Supporting the person to be more independent outside -or within - the family home also allows the carer to go about their own affairs - without the need for any formal services. Carers of adults with ASC can access Carers Direct payments if the barrier to their break is financial. Many carers have used this most creatively but the difficulty is in getting the carer's assessment as highlighted above.

Proposed Action

- Examine more inventive ways of providing respite and carer breaks, using the Carers' Grant where possible. This may include placement with families, local weekend stays or, as independent living skills increase, pairs of clients may be able to support one another with minimum support.
- Work with carers as active partners to improve access and awareness.

5.0 Monitoring

5.1 This strategy starts to set out Cambridgeshire's health and social care s broad strategy to improve access and support for people with ASC. As one of the key elements of the development project is to identify the issues and needs of people with ASC in Cambridgeshire it cannot be too prescriptive or specific at this stage. As knowledge of the local population needs improve the related action plan will be revised and developed.

5.2.1 A multi-agency group will oversee the commissioned development project. The inaugural meeting took place in October 2009. This group will develop and monitor an action plan. The aims of the group are broadly to:

- develop and improve local services
- develop an effective working partnership with people with ASC and their parents / carers.
- To develop collaborative practice with other agencies and services such as community health, social work, speech and language therapy, voluntary agencies.
- To work alongside other agencies in supporting families and people with autism.
- Make recommendations as to how organizations pathways and protocols could be improved to better meet the needs of people with ASC.
- To provide a framework for professional development.
- To build the capacity of establishments to provide appropriate support
- Link to OCYPS care pathway developments
- Link to Safeguarding Board and developments

5.3 Reports will be fed through to the following groups:

- Cambridgeshire County Disability Management Team
- Learning Disability Partnership Board
- Transitions Board

5.3.1 The commissioned provider and project lead will also be formerly contract managed by the Disability Service.

Contact for further information:

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Appendix 3 **Terms of Reference**
Cambridgeshire Multi Agency Autistic Spectrum Consortium

Aim

To work strategically to:

- Develop and improve local services.
- Develop an effective working partnership with young people and adults with ASD and their parents / carers.
- To develop collaborative practice with other agencies and services such as Police, Probation, Emergency Services, community health, social work, speech and language therapy, voluntary agencies etc.
- To work alongside other agencies in supporting families and people with ASD.
- Work with agencies to improve access to diagnostic services.
- Make recommendations as to how organizations pathways and protocols could be improved to better meet the needs of people with ASD.
- To provide a framework for professional development.
- To build the capacity of statutory bodies, establishments and services to provide support awareness and information.
- Link to Children's and Young Peoples' Service care pathway developments.
- Link to Safeguarding Board and developments.
- To act as a steering group to the AS Development Worker.

Membership

- Senior Manager - CCC, Disability Service, **Chair**
- Consultant lead- Cambridge + Peterborough Foundation Trust
- Management Representative - Red2Green
- Regional Manager - National Autistic Society
- Disability Service Workforce - CCC
- Commissioning Manager, - CCC, Disability Service
- Carer representatives, - Cambridge NAS branch
- Representative - Children and Young People's Service
- Provider representative
- Commissioning lead - Cambridgeshire NHS,
- ASD Development Worker - Red2Green
- Community Cohesion - Cambridgeshire Constabulary
- Partnership Manager - Job Centre Plus

- User voice – fed in via consultations and Cambridge NAS branch

Reports to

Adult Disability Management Team
LDP Board
Transitions Board

Key to responsible lead:

- National Autistic Society – **NAS**
- ASD Development Worker Red2Green – **ASD Dev't**
- CCC Adult Social Care Service Development / Commissioning Manager – **CCC Disability**
- CCC Adult Social Care Workforce Manager – **Workforce Dev't**
- Department of Work + Pensions Job Centre Plus Partnership Manager – **JC+**
- Cambridge Autistic Society branch - **Cambs NAS**
- Cambridge and Peterborough Foundation Trust - **CPFT**
- Cambridgeshire Multi Agency Autistic Spectrum Consortium – **All**

	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
1.	<u>Awareness raising and training</u>					Priority area
a	Identify ways to and undertake general awareness and targeted awareness in the community.	All ASD Dev't		Apr 10		Commenced Also see health section Subgroup agreed 1 – 5 levels of training and awareness Launch event + press release
		CCC		May 10 Sept 10	Cllr briefing	Report to Cllr's July 10 Cabinet Sept 10
	- explore e learning package + how they might be adapted/ made available	NAS CCC Workforce Dev't ASD Dev't	Existing packages	Mar 10		Considered including in dev't prog Examples available
	- Implement sub group action plan to include: -offer Diversity trainers ASD training -off 1hr Bitesize sessions	ASD Dev't Workforce Dev't	ASD Dev't	2010 /11	No's of training sessions provided	Contact made Courses being offered. 1st vol sector course run ASC – 2nd course planned

	(level 1 training)					
	Explore use of e learning on CCC Intranet	Workforce Dev't		Autumn 2010	CCC staff have access to materials	
b	Explore opportunities to deliver awareness sessions to professionals involved with higher functioning individuals particularly the emergency services, police, judiciary, and probation.	Consortium to engage with profs to indentify opportunities	Existing models and materials: eg autism alert cards	May 10 June 10 On-going	More appropriate responses and support in dealing with the individual identify.	Susan linked to Custody suite. Issues raised + links to Cambs Constabulary made.
		LDP/CPFT staff (Health Ops grp)	Existing staff			Copy of material for Criminal Justice system obtained and distributed. Details of Conference cirtulated
			<i>DH material</i>			DH material being planned
c	Review and revise Autism Awareness Training planned for workers in local agencies / providers - dev't of levels 2- 5 training -	Workforce Dev't ASD Dev't also see choice and control		April 10		Sub group agreed 5 levels of training (1- 5 dependent on skills need)
		Workforce Dev't		April -		Review in process
d	Explore option to provide training to Advocacy service to provide access or people with ASD	CCC Disability Workforce Dev't	Materials and existing programmes	Jan 2010 Mar 10	Advocates trained + confident in working with pw asd. Increased access to advocacy services	Completed Access to CCC training offered to Advocacy staff
e	Explore development of information packs / web pages and links to relevant web sites	ASD Dev't to collect information to be collated by consortium	Existing materials	May 10	regular reviews undertaken	Links between sites completed
	Council's webpage re info + referral process.	CCC Disability		June 10		CCC webpage done Pathway to be inserted

	Link with Transformation Information Project to ensure developments meet the needs of people with ASD and their carers.	CCC Disability		Autumn 2010	Information developed meets ASD needs	
f	Facilitate access to CCC commissioned advocacy services, to include some lower level access for those not meet eligibility criteria.	CCC Advocacy services to inform consortium	Existing contract	Oct 09	Amendment to contract No's accessing service	Access agreed - Speaking Up revising publicity material and are flagging up access at presentations.
		ASDDev't		April 10		Link to advocacy established
g	Explore training packages for providers working with those with high needs	CCC Disability	Existing	Dec 09	PPS material obtained	Completed
		CCC Disability				<i>To raise at DMT</i>
		Workforce Dev't	Existing / bids for funds		Training revised / commissioned	
2. Social Inclusion						
	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Explore programmes / access to support young people with autism moving into independent living. To include: - links / awareness raising with: Supporting People /	ASDDev't	Autism awareness raising programmes. Adult Development Worker. Identify A.A. raising needs	Autumn 2010	Recording activities happening and participation. Autism awareness programme	Attendance at Housing Info workshops (June / July)
		ASDDev't				Needs flagged up + demography data sent to Disability Housing Network
		ASD Dev't				Housing Info pack to be added to the CCC website to include

	providers. - District Councils housing Transition team - workshops for carers + people with ASD	CCC Disability	Disability Housing Network + CDM Housing	Summer 2010 Autumn 2010	Increased knowledge of access to housing + support	options, Homelink, SP floating support + estimation of Housing benefit entitlement
		CCC Disability		Autumn 2010 Post Cabinet	SP Commissioning Body to receive strategy	
b	Explore ways for local community services to promote inclusion to include: Challenge identified lack of awareness of A Alert card <i>Promote access to Keeping Safe Card (for those without diagnosis)</i>	ALL Consortium	Individual expertise and their networks	Autumn 2010	Feedback at consortium meetings	<i>also See Awareness raising training + Safety</i>
		Cambs NAS CCC Disability		Spring 2010		- Met with Grand Arcade - Improved web pages links - Info sent out
				Summer 10		- Police doing awareness re Keeping Safe Cards
		LDP Board		Sept '10		Planned session on Community Safety – Sept 29th
3. Health						
	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Formulate clear diagnostic pathway that is accessible and available to those who need and request it.	ALL Cross agency CPFT		Autumn 2010	Increase of range of adults gaining recorded diagnosis. Recorded increase level of diagnostics	Redraft circulated for comment Revised
	Identify current diagnostic availability in other local authorities	NAS				Examples available
	Discuss with commissioners	CPFT		May 2010		AZ initial discussion with NHS Commissioner

b	Explore the training / awareness needs of healthcare professionals to include:		A.A programme and assessment training.	Autumn 2010	Recorded participation in AAR and assessment training	Part of National Strategy
	flag up to new Health Strategy grp	CCC Disability	Adult Development Worker post	March 2010	Increased interest in people to develop their knowledge and skills	completed
	Link to Cambs community service	Dev't worker				
	Link to LD Hospital liaison posts	Dev't worker				
c	Flag up to DES training group to explore revision of training GP practices	CCC Disability	LDP team staff / PCT lead	March 2010		<i>Contact made but it is not possible to do health check for asd unless has ld.</i>
d	Support wider providers/ community to understand the specific needs of people with ASC to facilitate equality of access by: - Launch event - Production of good information - Use of plain English information	ALL Cross agency	Media, NAS and local campaigns, Events.	Maintain momentum. On-going to Community. Always changing	Feed back from service users and wider community Increased knowledge of professionals	Article in press – March 2010
						19 th May well attended
4. <u>Choice and Control</u>						
	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Provide awareness training to Care Managers and Financial Assessment and Benefit advisors.	Those people with experience in AAR in cross agency organisations	Existing and new programmes	Autumn 2010 – current and on-going	Recorded participation in all departments	May training completed

b	Look at resources and shortfalls to young people leaving school e.g. independent living skills; travel training; preparation for employment.	Current providers and cross agency	Existing models	Autumn 2010	Collation of research	Also See 5 d
c	Establish protocols, which identify a clear referral pathway. - user version needed	ALL Cross agency	Existing models	Autumn 2010	Agreed/collaborative referral pathway	Draft pathway
d,	Views on shortfalls established: - table consultation		Launch event	May 10		Chart completed List send to Single Equality lead
	- follow up event in Oct/Nov			Autumn 10		
5. <u>Access to Training and Employment</u>						
	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Work with all employment agencies and private ASC providers to promote the positive advantages of employing someone by:		ASC providers Connexions, Jobcentre + and the Consortium	On-going		
	Distribute Don't Write Me Off campaign	CCC Disability		Dec 09		Material distributed to Employment group
	Develop new materials		Disability Employment grp			Part of National Strategy

b	Explore opportunities to develop autism awareness training sessions with local Job Centre Staff, employer forums etc.to include: - Identify key people within these organisations	Consortium CCC Disability Employment group	As above and those with experience of delivery of AAR	On-going		MC+JC met Job Centre+ Partnership Manager Flagged up training + review of work benefit issues
c	Explore the opportunities to look at into employment service to cover people with ASC.	Engage with current providers –				Flagged at Employment group
d	Raise at Adult learners group	Adult Learning CCC Disability		July 10		Completed
6. <u>Carers Support and Short Breaks</u>						
	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Examine access to + options for respite and carer breaks.	Current providers and their criteria	Carers grants NAS branch	Autumn 10		Subgroup to be established
b,	Work with carers as active partners to improve access and awareness.	Carers network and cross agency	NAS branch for information to the consortium			Guidance produced re allowable disability benefits to offset charging
c,	Raise awareness: - Carers Newsletter	ASD Dev't	Carers Project + groups	Mar 10		Completed
d,	Information / Coping strategies					
7. <u>Safety Issues</u> (see also section 1 training)						

	Action	Responsibility Key person/s	Resources	Target Date	Evidence / Indicator Outcome achieved	Progress / Comment
a	Explore and address issues / actions to include:					
	- Make link to Safeguarding Board.	CCC Disability			SOVA Board + User Group aware	Initial links made
	- Flag up needs to Police Community Cohesion	CCC Disability		June 2010		Links established
	Link re PCSO's training needs	Red2green ASD Dev't				
	Use of Social Networking Site guidance	CCC Disability	Existing	May 2010	On websites Available for providers	DMT April 2010 ASSMT June 10 Revised version for comment – Final sent to group for adoption.