

## **A BETTER LIFE – CONSULTATION WORKSHOP**

There are five themes which have been identified as being important to adults with autistic spectrum conditions (ASC's) these are:

1. Help for adult with autism where they live
2. Making healthcare better
3. Adults with autism choosing the services and help they need
4. Helping adults with autism to get jobs and training
5. Helping professional understand autism

**NB:** These questions were considered and answered by people with high functioning autism and aspergers syndrome:

### **1. Help for adults with autism where they live:**

**Making sure that people who provide help for adults with autism understand what help adults with autism need:**

- Must be acknowledged that ASC needs help in accessing services;
- Barriers to access need to be removed as ASC does not fit within LD or MH unless this is a secondary issue;
- ASC cannot be accessed against the eligibility criteria of IQ only;
- One size does not fit all; people with ASC have very different needs/service requirements;
- ASC specific service/discipline required;
- Point of entry which is ASC specific and which can signpost to appropriate services (Pathway);
- Holistic service commissioned by joint professionals

**Make sure that people who provide help for adults with autism provide the help they need:**

- Point on entry service which would focus and signpost onto other services.
- An aspergers specific service would do this based on other services mentioned dint he best practice examples within the consultation paper;
- Research on data collection/mapping of Essex to be commissioned soon will inform future service needs;

**Make sure that adults with autism can get the help they need where they live both in their home and with their day to day activities:**

- Heavy reliance on family members to maintain home and environment if service use has left home;
- Daily support for activities needed;
- Social exclusion, understanding of lifestyle needs (hoarding; depression; energy levels, organisational skills, physical support);
- Very limited lifestyles due to feelings of vulnerability
- Access to personal budgets;
- Need for advocate service to assist service users in accessing services;
- Support practically for people who are aware/trained (no current off the shelf providers) Example of floating support from Swan Housing Association.

**Make it easier for adults with autism to get help with finding a house or flat and looking after it:**

- Housing corporation to provide funding/grants to assist housing providers (not attached to LD or MH);
- Specific asperger housing;
- Current housing benefit regulations do not allow aspergers to live on within their own home? Not sure this is correct (new service provision in Harlow);
- Bed-sit type flats – limited availability;
- Single occupancy only – no sharing;
- Independent/supported living with communal areas and daily warden assisted services;
- Non specialist housing strategy – need to involve housing providers/RSL's District Council's;
- Is there any empty buildings that could be converted into appropriate housing (Transitional training/flats)
- Hampshire training/living centre transitions 6-9 months stay into supported living;
- Information sharing to educate housing providers;

### **Get help with travelling where they need to go:**

- National training need for an induction for bus drivers to understand aspergers and companion travel cards;
- Blue badge – criteria for parking to include aspergers;
- Standard policies and form completion across all methods of travel;
- Public transport is not accessible to people with aspergers, could use ECC vouchers to use taxi's where possible based on individual travel plan;
- Individual travel plans to be completed;
- Delayed further education due to lack of appropriate transport to travel to and from colleges etc;
- Could current travel companion travel extend to asperger;

### **Get help so they can do the things they like to do in their free time:**

- Need to have daily living activities taken care of so people have free time;
- Friendship schemes – circle of support (Mencap/3<sup>rd</sup> sector);
- Advocacy support;
- Loneliness is a real downfall, keeping friendships is a real issue;
- Market development for advocacy agencies/3<sup>rd</sup> sector to be asperger specific;
- County wide support networks – possible grant application for infrastructure (Anglia Autistic);

## **2. Making Healthcare Better:**

### **Make it easier for adults to find out if they have got autism and get the healthcare they need:**

- Take away the 'myths' of stereotypical aspergers – this is a barrier because one size does not fit all;
- There is a need for early assessment and diagnosis in children/transitions;
- Training required for all health professionals to understand the complexities of aspergers (nurses, gap's, doctors, reception staff, booking staff etc.)
- People need to feel confident and able to attend surgeries/hospital appointments;
- Essex Care Pathway for diagnosis and educational services to make referrals;
- Private diagnosis available – quicker;
- ECC to lead practice based commissioning via PCT's;

**Make sure that people working in the health service have information about the adults with autism who live in their area, so that they can make sure that help is available for them:**

- Appropriate and timely Care Pathway;
- M/H – cognitive behaviour therapy, relationship counselling;
- Depression is a real side effect – support for carers;
- NHS Practice based commissioning to appoint a lead on aspergers.

**Make places like doctors' surgeries and hospitals easier to get to for adults with autism and make sure that these places are easy for adults with autism to use:**

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- ECC to lead practice based commissioning via PCT's;
- Access Cards for hospital

**Help doctors, nurses and social workers who work with people who have mental health problems to understand more about autism. This will mean they can better help adults with autism that also have mental health problems:**

- PCP needs to be for high functioning and aspergers specific;
- Training an awareness;
- Autism Pathway/advocacy support;
- People without a diagnosis do not get the support needed;
- M/H issues start at a very young age.

### **3. Adults with autism choosing the services and help they need:**

**Making sure that adults with autism can get person-centre plans and are in control of their lives. Person-centred plans are documents that say what things people want to do and what help they need to do this:**

- Person centre plans are not available to people with aspergers – assessments do not look at support required;
- Independent consultants provide this type of planning;
- What happens – follow post plan in terms of the support required? It will support people on making decisions;
- Co-ordination through an Essex specific service and ensure the assessment is correct;
- Tony Philips (Realife) independent consultant able to undertake PCP's.

**Provider better help for people with autism as they leave school and start doing new things:**

- People who are going though transition – connexions advisor requires specific training on support;
- Joint approach from education for children and adults curriculum;
- Independent living/social skills courses specific to aspergers for self esteem and independence.

**Make it easier for adults with autism to find someone to speak for them or help them to speak for themselves:**

- Asperger specific advocacy support (prevention). This support should offer the transfer of knowledge to provide reassurance and direction. TO make mistakes and being able to feel safe and learn from the experience;
- Market development in training current 3<sup>rd</sup> sector advocacy agencies. Patrick Sims from NAS provides training 15<sup>th</sup> October in London;
- Shenfield aspergers/Safe – funding to assist provision of training
- Co-ordination of Essex aspergers groups to share knowledge/experiences.

**Make sure that adults with autism are asked how they think that services they use could be improved:**

- Essex working group – does this duplicate regional working?
- Better communication/dialogue with NSA/Safe – sharing of information;
- Provide Essex network, regional, central support network;
- Diagnosis provides the care pathway
- Accessible mechanisms of feedback using plain English;
- Partnership boards are LD focused and information needs to be provided for all not just LD.

#### **4. Helping adults with autism get jobs and training:**

**Make sure that adults with autism can get the help they need to find and keep a job:**

- Appropriate jobs to be considered based on skills and potential – not everyone with aspergers wishes to work with computer software;
- Connexions needs to understand aspergers when considering potential jobs;
- On job training for staff members of potential employment to understand aspergers;
- Benefits are reduced once a job is taken, it is then very difficult to obtain benefits if the job is lost;
- High levels of work place bullying due to lack of understanding;
- Carers allowance/benefits stopped once s/user reaches 60 – this does not mean that aspergers has gone away;
- Volunteer work has less expectations on service users than paid employment;
- Women with aspergers are dealt with very differently than men with aspergers (inequalities);
- Supported interviews, employment/aptitude tests – one size does not fit all;
- Short term work trials to ensure both service user and employer are happy;
- LA's – how many people with aspergers employed?
- Employment strategy to include aspergers.

**Make sure that employers know about autism:**

- Awareness training required for all staff;
- Publication via media on awareness, good news stories to be shared;
- DDA act for ASC and need a legal view on the impaction mentioned;
- Supported interviews – communication needs
- Reasonable adjustments by employer to allow employee to work within role effectively;
- Understanding of employers regarding 'recruitment campaigns' - BT

**Make sure that adults with autism can get the benefits and tax credits they need:**

- Carers allowance impacted upon at the turn of 60;
- Social enterprises/co-operatives to provide social skills training/support;
- If employed – not seen as vulnerable and requiring services so support network is withdrawn , leaving people further vulnerable;
- Once employed – benefits withdrawn, re-entry into system is difficult/lengthy;
- Training required for professional staff to understand aspergers and the need for better/appropriate communication;
- Benefits – rules either do not apply to aspergers (without LD/MH attachment) or they apply differently and are very confusing;
- Form completion – very difficult as questions are non appropriate based on social disability not medical disability;
- Advocates for aspergers;
- Work capability assessment – staff require training to assess if s/users can actually work.

**Help adults with autism to get the training and education they need:**

- Trained support for attendance to college's/universities;
- Training of professional staff to understand the need for flexibility, accessibility, policies/procedures; flexibility in courses;
- Student support inaccessible due to lack of understanding aspergers;
- Good practise/communication for all (sudden changes i.e. Room change is hard to understand/deal with at short/no notice);
- Helper allowance/social support;
- People with aspergers develop at a slower pace in terms of emotional/social;
- Need to relax rules/change eligibility post 19 that you have to pay as emotionally and socially people with aspergers do not develop at the appropriate rate against their age;
- Advocacy support required to detail educational outcomes within PCP;
- Many people with aspergers leave school with only basic skills/minimal GCSE results or no qualifications. Adult services need to expand to include 16+ as good practice;
- Specific classes within mainstream education to be aspergers specific 'Norfolk Rug Room';

## **5. Helping professionals understand autism:**

**Give people like employers and the police more information about autism:**

**Teach people like social workers and people who work in places like colleges, housing offices and jobcentre plus about autism:**

**Make sure that new social workers, doctors and nurses are taught about autism as part of the training they have to do before they can start their new job:**

- Training required on challenging behaviour/aspergers;
- Alert cared run by charities (Autism Anglia);
- Diversity officers at police constantly requesting training but have no funding. Safe happy to provide but no FOC;
- Needs to be government led that all professionals within emergency services are trained to understand aspergers;
- 5% of all people in prison have a learning disability due potentially to misunderstanding of community living, challenging behaviours;
- Police need appropriate advocates to assist adults with aspergers;
- Forms within the prison service are not written/accessible for all
- Post 18 adults not allowed to speak on behalf of family members however people with aspergers do not develop at the same rate and therefore need family members to speak on their behalf.