



## **Moving Forward, Supporting Change: for Children & Young People with Autistic Spectrum Conditions in Brighton & Hove**

**mASCot** are a parent-led voluntary group working with families affected by autism in Brighton and Hove.

Following on from our 'Autistic Spectrum Condition (ASC) Overview' (November 2011), this document summarises the key issues faced by the families we support and makes recommendations for improving school and community-based services for children with ASC.

**mASCot** have close to 100 members and have conducted research which reflects findings from the National Autistic Society (NAS)

**Autism affects over 1 in 100 people.** With a population of 273,000 people in Brighton and Hove (ONS 2011) this equates to **2,730** people in our local area needing access to local, specialised services for autism.

Families in Brighton and Hove recommend:

- improving the quality, quantity, accessibility, and availability of services;
- Improving the education and training of individuals to work more effectively with children with ASC;
- creating appropriate school environments

### **1) Evaluating: The first step to improving services is to find out what works well and what does not**

For the last year we have been actively campaigning for the City Council to undertake their own research to robustly evaluate the quality of existing services for children with ASC, by engaging with the service users themselves.

**mASCot are** continuing to press for a full and independent review of all ASC services spanning education, health and social care. Education remains the main hub of all the services for children and young people with ASC and must therefore be central to any review.

**We recommend** the City Council ensure that parents/carers of children and young people with autism are actively involved in designing an open-ended survey. Results should be analysed both quantitatively and qualitatively and findings should be made transparent, accessible and open to scrutiny by all interested parties.

### **2) Moving forward by ensuring that all interested parties are included and empowered**

**mASCot are** ensuring that the voices of our members are heard by raising awareness nationally, and by supporting parents in improving outcomes for their children. We are also making our voices heard locally in the key areas of education, health and social care and will continue to do so.

**We recommend** that Brighton and Hove embrace a culture of openness, transparency and inclusion. Parents/carers of children and young people with autism must be included on all Boards that make decisions about autism. In partnership with parents, services can be properly evaluated and re-designed.

### **3) Supporting change**

**mASCot are** bringing together experts, professionals, therapies and interventions that we, the service-users have evidence are effective for our children and young people.

**We recommend** that service providers in Brighton and Hove support change by appointing an independent 'Autism Tsar' to work with us to pull together all children's and adult's services for ASC.



## EDUCATION – Our children are the adults of the future

- **SEN Statements:** The law states that SEN statements should be specified and quantified in setting out provision for a child's individual needs.

**mASCot are** working with parents regarding the wording of statements and will support them in seeking legal advice to protect the rights of their children.

**We recommend** the LA ensures that provision is specific to the individual needs of the child regardless of the existing resources available. The Local Authority must make schools accountable for meeting needs.

- **Individual Education Plans (IEPs):** All children with ASC should have an IEP. The provision of an IEP should be on a child's statement. Parental input should be actively sought and targets on an IEP should be SMART, frequently monitored and reviewed to form the basis of a targeted approach of interventions by all involved agencies.

**mASCot are** helping parents to ensure children have appropriately written, monitored and reviewed IEPs.

**We recommend** the sharing of good practice across all schools in the writing of IEPs for children with ASC. The LA must ensure that schools are held to account.

- **Exclusions:** Children with ASC are still being excluded from school at a disproportionate rate.

**mASCot are** continuing to support parents in exclusion meetings and will assist parents in seeking legal advice where appropriate.

**We recommend** the LA ensure that all exclusion procedures are lawful and that Governors are trained in ASC so that they can come to a fair and non-discriminatory decision.

- **Unlawful Exclusions:** Informal (unlawful) exclusions are still frequent yet go unchallenged.

**mASCot are** continuing to collect data from parents regarding the use of unlawful exclusions and reduced time-tables in Brighton and Hove schools. We will feedback our findings to the Children's Commissioner.

**We recommend** a clear procedure for parents to report unlawful exclusions and reduced timetables is urgently put into place. The LA has a responsibility to ensure the law is upheld and that schools are accountable for the safety of children not at school during school hours.

- **Teachers and Teaching Assistants** do not have sufficient training for a full understanding of ASC.

**mASCot are** supportive of the PaCC recommendations (2010) of an independent review of SEN practice in all schools to look at the nature and effectiveness of the training that teachers, TAs and INAs receive.

**We recommend** the LA keep records of which schools/staff have undergone training. Records should be available to parents/carers to enable them to make an informed decision about choice of school.

- **Social skills:** School staff are not equipped to plan programmes to help develop the social skills that ASC children find so difficult.

**mASCot are** working with independent specialists and other agencies who provide social skills interventions. Our members are evaluating the effectiveness of these interventions.



**We recommend** the LA specify and quantify social skills on a child's statement as appropriate for the individual child and arrange suitable provision to meet the needs of that child.

**HEALTH AND WELL-BEING –The right support at the right time**

- **Diagnosis:** 34% of parents had to wait three years or more for a diagnosis after first raising concerns (NAS). Some children present with difficulties but without a diagnosis, receive no help.

**We recommend** ASC specialists are consulted early in the assessment process so that ASC is one of the first possibilities to be considered to enable early intervention. If there is no clear 'label' for a child, difficulties should be clearly described so that parents can access the help they need. Privately sought opinions and assessments should be respected.

- **Post-diagnosis:** Our members report being given information leaflets post-diagnosis, but still not knowing what services are available to their families or how to access services.

**We recommend** providers proactively advertise their services for ASC via schools and health centres and that there is transparency regarding what can and what cannot be provided. Clearer information should be made available about referral procedures, with the option of self-referring.

- **Planning:** Not knowing what to expect is particularly difficult and stressful for a person with ASC.

**We recommend** practitioners provide a detailed breakdown of what to expect during consultations, appointments and meetings so that parents can help to prepare their child in advance.

- **Needs-led, flexible, diverse services:** Our members are not able to find the right support, at the right time for their children. ASC-specific support in Brighton and Hove is inadequate and limited in scope:

**What? - We recommend** that commissioning of services is based on identifiable needs. Additional services must be commissioned where there are identifiable gaps in provision. No intervention for ASC should be promoted unless there is robust evidence of its effectiveness. Strategies for overcoming difficulties should be evidence-based and practised in-situ. Consultation time should be spent on actively helping children overcome difficulties, not reviewing and completing paperwork.

**Where? – We recommend** that practitioners show an understanding of the importance of the child's comfort rather than expecting the child to fit in with the service. In clinic settings it is important that the child's sensory sensitivity is taken into account, and there should be a safe space to release stress in a controlled way. Practitioners should offer home visits or school visits for those children and young people who cannot access clinic settings.

**When? - We recommend** a drop-in service for urgent cases and crisis support and parents should also be available to be contact practitioners by phone/email. For some services, there are long waiting lists which create further difficulties for families. Appointment times should be flexible because, for some children, missing time from school can be upsetting to their routine. The duration of a course of support must be based on need and identifiable progress, not on completion of an allotted amount of weeks/hours.

**How? - We recommend** practitioners are flexible in both the type of provision and means of delivery – support must meet an individual's needs, be age-suitable and suitable to the child or young person's



cognitive and communicative ability. Our children are individuals, and as such there should be some choice for the individual child and family.

### **SOCIAL CARE - Autism has an impact on the whole family**

- **Assessment:** The majority of mASCot families have never had their care needs assessed.

**We recommend** that any family with a child with autism is given the opportunity to have an assessment, taking into account the needs of the whole family. We support PaCC recommendations that for families who are not necessarily in a critical situation, circumstances can change and needs vary accordingly. Periods of support and assistance should also be made available to such families.

- **Access to services:** 74% of people caring for someone with autism get no support from their local authority (NAS). Our members report not knowing what services are available or how to access them.

**We recommend** clarity regarding what services are available, who can access these services and that service providers ensure there is consistency in the provision offered to families.

- **The right support:** mASCot members report being unable to get the right support for their family.

**We recommend** better, faster access to respite care and short breaks. There is a need for more specialist social care services. There needs to be a more personalised, responsive, holistic, consistent approach to provision.

### **A HOLISTIC APPROACH – Autism affects us every day in every way**

- **Communication:**

Health, social and education services must work **together with parents**. There is a need for better communication between practitioners, schools and parents. Practitioners need to work with schools and provide training in how to meet the child's needs. There must be transparency in correspondence and communication between all parties.

- **Working together:**

mASCot support PaCC findings that parents are still not being acknowledged for their expertise on their children and are not being listened to. Professionals must fully involve those with autism, and their families, in designing the services and the support they need so that services meet locally identified individual needs. Any ASC-specific statutory agency group should actively seek to draw on the expertise of parent/carers and specialist agencies such as Autism Sussex and the NAS.

The child's needs and views must also be sought and provision considered from the child's perspective.

- **A wrap-around service:**

Our children's disability does not disappear when they leave the school premises, nor does it fit within the normal working day or week. We recommend a wrap-around service. Children with ASC have difficulty generalisation from one setting to another, therefore, on-going support at home is also essential.

- **Expertise:**

ASC presents in different ways and practitioners need to treat each child or young person as an individual and establish a relationship of trust with the child and family. Anyone who works with a child or young person with ASC should have received high-quality training as part of their equality and diversity training. On-going training should involve parents and professionals working together and sharing expertise.

- **Evaluation:**



## Key Area

## mASCot Recommendations

All provision must undergo regular monitoring and robust evaluation. Existing data collection models are readily available.

### Education

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|-------------------------------|--|
| <b>SEN Statement IEPs</b>     | <ul style="list-style-type: none"> <li>• The LA should ensure that provision is specific to the individual needs of the child.</li> <li>• The LA must make schools accountable for meeting needs</li> <li>• All children with ASC should have an IEP. The provision of an IEP should be on a child's statement</li> <li>• Targets on an IEP should be SMART, frequently monitored and reviewed</li> <li>• Good practice should be shared across all schools in the writing of IEPs</li> <li>• The LA must ensure that schools are held to account</li> </ul> |
| <b>Exclusions</b>             | <ul style="list-style-type: none"> <li>• The LA must act to stop children with ASC being excluded from school at a disproportionate rate</li> <li>• The LA must ensure that all exclusion procedures are lawful and that Governors are trained in ASC</li> </ul>   |
| <b>Unlawful Exclusions</b>    | <ul style="list-style-type: none"> <li>• The La must have a clear procedure for parents to report unlawful exclusions and reduced timetables</li> <li>• The LA must ensure the law is upheld and that schools are accountable for the safety of children not at school during school hours</li> </ul>  |
| <b>Teachers, TAs and INAs</b> | <ul style="list-style-type: none"> <li>• The LA should keep records of which schools/staff have undergone training.</li> <li>• Records should be available to parents/carers to enable them to make an informed decision about choice of school</li> </ul>   |
| <b>Social Skills</b>          | <ul style="list-style-type: none"> <li>• The LA should specify and quantify social skills on a child's statement</li> <li>• Provision must meet the needs of the individual child</li> </ul>   |

### Health and Well-being

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|--|---|
| <b>Diagnosis</b>                             | <ul style="list-style-type: none"> <li>• ASC specialists should be consulted early in the assessment process to enable early intervention</li> <li>• Difficulties should be clearly described so that parents can access the help the child needs, regardless of diagnosis</li> <li>• Privately sought opinions and assessments should be respected</li> </ul>  |
| <b>Post-Diagnosis</b>                        | <ul style="list-style-type: none"> <li>• Services for ASC should be advertised via schools and health centres</li> <li>• Transparency is needed regarding what can and what cannot be provided</li> <li>• Clearer information about referral procedures, with the option of self-referring</li> </ul>   |
| <b>Planning</b>                              | <ul style="list-style-type: none"> <li>• Practitioners should provide a detailed breakdown of what to expect during consultations, so parents can prepare their child in advance</li> </ul>   |
| <b>Needs-led, flexible, diverse services</b> | <ul style="list-style-type: none"> <li>• Commissioning of services should be based on identifiable needs.</li> <li>• Additional services must be commissioned where there are identifiable gaps in provision</li> <li>• No intervention for ASC should be promoted unless there is robust evidence of its effectiveness</li> <li>• Strategies for overcoming difficulties should be evidence-based and practised in-situ</li> <li>• Consultation time should be spent on actively helping children</li> <li>• In clinic settings the child's sensory sensitivity should be taken into account, and there should be a safe space to release stress in a controlled way</li> <li>• Practitioners should offer home visits or school visits for those who cannot access clinic settings</li> <li>• There needs to be a drop-in service for urgent cases and crisis support</li> <li>• Parents should also be able to be contact practitioners by phone/email quickly</li> <li>• Appointment times should be flexible and not only in school hours</li> </ul> |



		<ul style="list-style-type: none"><li>• The duration of a course of support must be based on need and identifiable progress</li><li>• There should be flexibility in the type of provision and means of delivery to meet an individual's needs: age-suitable and suitable to the child's cognitive and communicative ability</li></ul>
<b>Social Care</b>	<b>Assessment</b>	<ul style="list-style-type: none"><li>• Any family with a child with autism should have a family assessment</li><li>• Periods of support and assistance should be made available to families if/when they need them</li></ul>
	<b>Access to services</b>	<ul style="list-style-type: none"><li>• There should be clarity regarding what services are available and who can access them</li><li>• Service providers should ensure there is consistency in the provision offered to families</li></ul>
	<b>The right support</b>	<ul style="list-style-type: none"><li>• Better, faster access to respite care and short breaks</li><li>• More specialist social care services</li><li>• A more personalised, responsive, holistic, consistent approach to provision</li></ul>

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**References:**

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