mASCot
managing Autistic Spectrum Condition online together
& supporting local families

# Survey of services for children with an Autistic Spectrum Condition

## In Brighton and Hove

## Oct - Dec 2012

mASCot 19th March 2013

# mASCot

## Who we are

- Parent-led group established 5 years ago.
- More than 130 members- parents of children with an ASC living in B&H.
- Its aim is to create a place that is non-judgemental, supportive and informative.
- Active online forum and support regular coffee mornings, pub meets, activities for the children, talks etc.
- Active links with the National Autistic Society (NAS), Autism Sussex, University of Sussex, Amaze and many other organizations.
- Our ethos is to have a positive regard for all our families. We believe that people thrive with support and understanding and feel diminished without it
- We listen to what our parents say and strive to influence positive change

http://www.asc-mascot.com

# Background/ Context

## Why a Survey?

- In September 2011 CYPOSC members resolved to request that an **independent user satisfaction survey** (in relation to the overall provision for children with ASC) was to be carried out.
- The Survey was developed by the council.
- mASCot thinks that such survey was limited in scope (only looked at Seasideview and CAMHS), only to newly diagnosed children and that it took a long time to be developed and launched
- mASCot fed back concerns re: approach and scope and that responses may not be meaningful or informative
- mASCot designed and launched a more comprehensive survey.
- It took us about 2 months to develop. We actively worked with the NAS to design the survey and University of Sussex and London South Bank University to validate it.
- Sue Shanks and Andrew Wealls supported its implementation

# Survey

### When and how

- Oct-Dec 2012
- Funded through mASCot
- Distributed mainly through mASCot, but also Amaze, Pebbles and Link up. It used SurveyMonkey as engine.
- Analysis in progress
- Report to be produced and distributed.

### Content

- Diagnosis
- Education
- Associated difficulties and mental health
- Well-being

### Questions

- Gender, Age, etc
- Type of diagnosis and any co-morbidity
- Level of satisfaction in relations to services provided by Seaside View, schools, CAMHs, ASCSS, EP, SALT, etc.

## Respondents

### Numbers

- 80
- 77 B&H

### Gender

- Male 75%
- Female 25%

### Age

- 0-4 – 2.5%
- 5-9 – 43.8%
- 10-14 – 28.8%
- 15-19 – 25%

### Diagnosis

- 74.1% Seaside View

### Education

- Mainstream 65.7% : Special 26.9% (Special incl. mainstream with ASC unit)

# Key findings

## Diagnosis

- Process of obtaining a diagnosis **Difficult/very difficult – 41%**
- Support received at time of diagnosis **Bad/very bad/no support- 34%**

*“I really struggle with professionals reluctance to acknowledge less severe symptoms early on, if at all. The majority of parents find diagnosis really helpful!”*

*The diagnosis was straight forward but we had to wait a year for the assessment-far too long*

*The paediatrician that gave our son his diagnosis was excellent. It is clear, however, that Seaside view only provides a diagnostic service (at least in our case). So you are left completely powerless with the only certainty that your child has a lifelong condition but no one to help you. I feel that Seaside view should be providing a tailored plan of intervention for each child that receives a diagnosis....*

*“The follow-up was useless. A few speech and language sessions that had no impact apart from stressing my son. Seaside view appointments were few and often cancelled. No practical help and no support for the family.”*

*“It takes too long from beginning to end.”*

*I think professionals give a "label" - for example High Functioning Disorder. This condition embraces a range of difficulties, which for my daughter include: difficulties with fine/gross motor skills, Sensory difficulties which lead to ADHD and ADD type behaviours, difficulties in Speech and Language ... I do not feel the HFA diagnosis adequately describes the range of support she needs.*

*It was the most protracted and painful experience of my life.*

*Seaside View need to explain better why they are supposedly not diagnosing Aspergers Syndrome. I have informed them of this issue on their own survey.*

# Key findings

## EDUCATION- Overall (mainstream and special)

J Quality of teaching **Good/very good- 72%**

J Teaching stuff **Good/very good- 75%**

L Process of obtaining statement **Difficult/very difficult – 44%**

*I have had to write a lot of it myself in order to explain my sons needs accurately. There is a lot of chasing up required by us as parents and we have to coordinate responses of professionals involved with child otherwise their comments wouldn't be considered. Its left to parents to coordinate.*

*It took too long - it could have been set up so much sooner. Parents should know what options they have - I did not know that I could look at more specialist provision - I feel my child missed out on support available.*

*The insisted on saying 'moderate' learning difficulty when his condition is obviously NOT moderate. They have finally backed down*

*Turned down for a statement as the powers that be decided he was not severe enough*

L Receiving provisions on statement **All -25%**

*Some because we are providing it at home at our own cost.*

*I say most because I am not there to see what goes on and he is would not always communicate if there was a problem*

*Difficult to know. Not much communication with school as to whether they are carrying out the interventions in the provision part of Statement or whether Teaching assistant is being supplied. my son just says " I don't know" if I ask him if someone was with him!*

# Key findings

## EDUCATION- Overall (mainstream and special)

- Bullying **50%**

*He was being bullied for several years without us and the school knowing because he was being verbally abuse.  It only came to light when a major incident happened at school with him and the child who had been bullying him.*

*I had to pull him from primary school and home educate for 9 months*

*It wasn't dealt with appropriately by the mainstream school*

*in primary school not really acknowledged until yr 6 when was dealt with.  Continued into secondary school improved since yr 9. Generally due to him being different & not having same social skills*

*(bullying)...started at Primary school & continued into secondary school. Has improved since year 9.*

*At Primary school there was a game played in the playground where students followed my son around and tapped him on the back because this would flip him into a rage if they continued to do it.*

- Exclusions, part-time schedule **34%**

*(exclusion)....due to reacting badly to stressful situations/bullying. Whilst not condoning his actions I do feel if situations dealt with earlier he may not have reacted as he did*

*At primary he was part time   and in yr 7 was excluded from school trip on medical grounds*

*In the mainstream school which he attended from 2010 Dec-2011April, I was with my child in the classroom, because the school did not have necessary staff to give him 1 on 1. Even with my support, my child was only allowed to stay till lunch time at school.*

*We have agrees that fixed term exclusions are preferable to internal exclusions, hence they are quite frequent*

*When the school can't cope with the child they will phone to ask me to pick him up. If I refuse and say he should be at school I am criticised and told that my child is making himself unsafe!*

# Key findings

## EDUCATION- Mainstream Schools

J 1:1 support **Good/very good- 67%**

L Communicating approach and strategies **Bad/ Very bad 49%**

L Professional Expertise available to your school **Unsatisfied/ very unsatisfied 45%**

L IEP and Acquiring social skills **Bad/ Very bad 36%**

*Our son's school is excellent for neuro-typical children but fails to meet the needs of children with special needs. They simply do not have the expertise to really maximise potential in children with ASC and the strategies they apply do not take into account that autistic children are actually all different .... In terms of developing social skills I think schools in general unfortunately completely lack the expertise in terms of what approaches to implement and paradoxically they would provide the best setting to address such difficulties.*

*Staff show v.poor understanding of ASC; communication school and home is not good!!!*

*....Although the care, provision and support at the school is excellent it is a frustration to not have any protocol for monitoring progress and having strategies communicated or recorded. With no concrete written plan I worry that a change of staff could mean the excellent support he is getting at the moment could completely fall apart. It is down to the quality of the individuals currently working with our son.*

*The teaching and individual teachers have been very good but not specifically for our child. Teachers do not really know how to include a child with SN and access to the curriculum is inconsistent. The 1-1 support assistant has done her best but is untrained and unqualified and has at times been left to 'do the teaching' or engage our child in alternative activities. SEN support has been appalling. Communication only occurs when we request it or there is a specific problem. The school head has rarely communicated with us about our child's development or lack of.*

*The feeling of not being listen to by your child's school is the worst thing. Communication is paramount in having a good partnership with the school.*

# Key findings

## EDUCATION- Special Schools

J Relationship with you **Good/very good- 86%**

J Overall satisfaction **Good/very good- 77%**

J Communicating child’s progress **Good/very good- 71%**

J IEP **Good/very good- 64%**

*My son's present school is an autism-specific environment. In mainstream school, I was horrified by the lack of awareness and understanding.*

*I am very happy with my son's school*

*... everyone who comes into contact with my child has training and expertise in dealing with autism. In the mainstream environment, no-one understood him, and ignored my attempts to explain his needs.*

*Everyone, from Headmaster to TA to lunchtime assistants are totally committed to supporting the children and a delight to be with. Support is fantastic and the parent support meetings I am sure would be beneficial to any parent/carer with an autistic child.*

# Key findings

## Associated difficulties

- Many families not received help for associated difficulties (eating, sleeping, toileting, attention and concentration etc.) **39%** (or gone private **12%** )

## Mental health

For mental health issues, when they did receive help, satisfaction level for the support received is varied

| | **Good/very good** | **Neither good or bad** | **Bad/very bad** |
|---|---|---|---|
| **Seaside View** (18) | 72.2% | 11.1% | 16.7% |
| **CAMHs** (30) | 40% | 33.3% | 26.7% |
| **Private** (8) | 89.5% | 12.5% | 0% |

*I think that services are set up to provide some support only at crisis point. More should be done to prevent children with autism developing mental health issues.*

*i have asked written and pleaded to have some help with my sons aggression camhs gave one session of family therapy and then referred us to asc support service but i would like some ongoing help for my son to help him manage his anxiety and aggression*

*When we had a crises when my son had suicidal thoughts and we needed help straightaway I found it very difficult to get support because first I was told he need a social worker but his needs were not sufficient to have one and because nothing had happened.  But lucky the National Autistic Society were brilliant and gave me advice and contacts.*

*Camhs told me there was little their service offered for children with ASC.  I was given some generic social story type advice.*

# Key findings

## Well-being

Quality of life and well-being of your child and your family? **Good/very good- 52%**

*Our quality of life is very good despite all the battles we have to fight with service providers. It could be even better if there was a culture a true partnership with families!*

*at the moment things are very calm but we do get to crisis point and have asked for help from camhs on several occasions but to no avail*

*Our son's quality of life is good but running a home programme and financing it ourselves is hard on family life.*

*50/50 If our child with Aspergers is coping we cope if not it can bring us to our knees*

*We are isolated, stressed and dependent on weak resources. We feel we are left to cope alone.*

*We just about stay above the surface at times with the help of a lot of positivity! Mostly that comes from the help and support of voluntary/ community initiatives such as Mascot and Link- Up.*

*Generally good but can be like living on a roller coaster not knowing how he will react to situations. However as he has got older & learned strategies to help him manage his condition the bad time are less but when they come can be more intense*

*(very good) Through our own hard work and building up a good network of support around us.*

*I am a single parent of 3 young children and my son has challenging behaviour so its not easy.*

# Key findings

## Well-being

L Overall satisfaction with public service provision **Bad/ Very bad 43.5%**

What would improve the quality of life and well-being of your child and your family?

***After school club and social activities***

***More support in school***

***meeting group(s) outside of school, for children from mainstream school,***

*Social skill club or group.*
*Our views to be taken into account by the school*
*Aspirations to be higher for children with autism*

***Less of a need to fight for what our child clearly should receive to address her needs in Education.***

***some ongoing help with anxiety and aggression and social skills***

***More support and understanding from school and the public.***

***An understanding in the Council of ASC. And an LEA not scared of Schools.***

***Better consultation of parents by school***

***Extra help in the home***

***More help and understanding from professionals. I am exhausted and stressed because I have to constantly fight against a system where I feel judged.***

***People having more knowledge on ASC, how it affects the child and family. Most important being listened too - if I say I need help it means I really need help and I am the expert of my child's needs please listen to what I have to say.***

# Your thoughts?

# Thank you

## Contact Information
www.asc-mascot.com

**Sam Bayley**
Chair of mASCot
sambay66@yahoo.com

**Monica Marchi**
Vice-Chair of mASCot