



BRIDGWATER PARENT SUPPORT GROUP 14/06/2017

Members of this support group run by the Parent Carer Forum shared their concerns and experiences with Healthwatch Somerset. Many of the group had common issues with assessments and having their needs met at GP surgeries.

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Finding Your Way Bridgwater

Eight people attended the group held at Sydenham Children's center, Fairfax Road, Bridgwater. The group meets on the second Wednesday of each month.

Bridgwater Parent Support Group is for parent carers of children and young people aged 0 to 25 with additional needs and disabilities. The group is linked to the parent carer forum and feedback issues and concerns to them. The group gives parent carers an opportunity to relax, chat, and share experiences and strategies that work. Have your voice heard. Signposting to local services, organisations and groups. Help shape local services, Guest speakers. Meet like-minded people.

Healthwatch Somerset

Healthwatch is the official framework through which local people can have their say about health and social care services. Healthwatch works on behalf of the whole of the community children, young people and adults and needs people to tell it what is going on in the health and social care services in their area. Healthwatch can tell services about patient experiences of care and hold them to account; it can also enter and view services such as care homes and hospitals, observe what is happening and report back to commissioners.

People can feel excluded from services and we know that access to services and treatment is not always equal to all, so Healthwatch also has a signposting function to navigate the health and social care system. Healthwatch Somerset is independent, transparent and accountable and powerful, with the strength of the law and the national influence of Healthwatch England behind it. Healthwatch Somerset is provided by The Care Forum.

W: www.healthwatchsomerset.co.uk

W: www.thecareforum.org

BRIDGWATER PARENT SUPPORT GROUP

Contact Claire Cole Tel: 07704405324 E: c.m.cole20@gmail.com www.bridgwaterparentsupp ortgroup.com

The engagement

We explained the role of Healthwatch Somerset and the work they are currently doing. The group were then keen to share the experiences that they had and it became clear that many were commonly shared among the group.

You Said.....

- It had been a struggle to find out information and help before coming to the group.
- Parent said that an ADOS assessment was started in June 2016 and their child was diagnosed with autism. They then had to wait for a second assessment which took months. The second assessment involved speech and language professionals, occupational health, a pediatrician and an educational psychiatrist and was not done until May 2017. This process presented a lot of extra work and stress for the parent, and it was difficult to find time to fit it all in around caring responsibilities. They are still waiting for the report.
- Two members of the group said that it had been very difficult to go through the EHCP (Education Health Care Plan). Two parents said that although her child had complex needs such as autism, anxiety disorders and sensory processing disabilities, the EHCP was rejected as they were making some progress in school.
- Several members of the group noted that being an unpaid carer was often not recognised as a valued role when it came to claiming benefits.
- One carer raised that carers needs, and the needs of the person they care for, who has an autistic spectrum condition, was often not met at hospitals and there was a lack of understanding from staff about the difficulties that can arise.
- In contrast an experience was given noting that Musgrove Park Hospital had been proactive and considerate of their child's needs.
- Several of the group raised issues with GP surgeries. It was reported by a parent that Redgate Medical Centre (Bridgwater) had not understood the difficulties that waiting caused a child with autism. When the carer had asked the receptionist if they could wait in the car until the GP was ready she was told this was not possible. The carer noted that the environment was too distressing for their child to wait in.
- North Petherton GP surgery was criticised for being strict on 15 minute appointments, which was not enough for parents of children who have communication difficulties or processing difficulties such as autism. More understanding of these needs and flexibility needs to be present with GPs and front of health staff.
- Parents reported that they did not know if their GP surgery had a carers' champion.
- One parent of a child who has autism said that an LED sign at Bridgwater Community Hospital was causing their child distress. When mentioned to the reception staff they were understanding, but did not know how to turn the sign off.

- Overall parents were in agreement that more needs to be done to ensure patient environments do not cause unnecessary distress to those with autistic spectrum disorders.
- Parent noted that some children with autism need regular contact with health professionals before they can trust them and feel comfortable in the environment.

** comments received



The group agreed that patient environments need to consider the needs of those with sensory processing, communication or autistic spectrum conditions and that often, a health professional understanding of these conditions needed to be enhanced. It was also thought that GPs needed to clearly identify their carers' champions, and ensure they had the skills and knowledge to support carers. In addition more awareness of autistic spectrum disorders was needed by front of house GP surgery staff.

The group were keen to be supported by Healthwatch Somerset to gather more information about these issues from the group, and other similar groups around the county with the aim of reporting the issues and recommendations to the Clinical Commissioning Group and the Health and Wellbeing Board.

Healthwatch will.....

All the feedback Healthwatch Somerset gathers is analysed and used to inform the Healthwatch Somerset's quarterly reports, which are shared with Healthwatch Somerset partners including Somerset Clinical Commissioning Group, the Somerset Health and Wellbeing Board, Somerset County Council, the Care Quality Commission, NHS England and Healthwatch England. The quarterly report is also presented to the Healthwatch Somerset's Executive Group to propose further uptake of the issues identified in the report. The report will be available on the Healthwatch Somerset's website. (<u>www.healthwatchsomerset.co.uk</u>) and circulated to our mailing lists via the monthly e-bulletin.

Looking forward....

Plans for future work between Healthwatch Somerset and the Finding Your Way Groups.

Healthwatch Somerset have informed the group about our 'Community Pot' application process. The 'Community Pot' can support groups to gather, widen and report on the feedback from its members. The group was also attended by members of the Somerset County Council's Engagement and Participation Team (Special Educational Needs) who would be keen to contribute to this research giving the young person's perspective.

We also welcome and encourage members of the group to continue to contribute their feedback to us using the communication methods included at the end of this report.

Healthwatch also supports members of community groups to become Volunteer Champions so that they can represent the experiences and needs of their community group. If you would like to find out more about volunteering with Healthwatch, please contact us using the details below.

Tell Us Your Story...

Healthwatch Somerset wants to hear from you about your experiences so that we can tell services your needs to create the best local services.

Email us at info@healthwatchsomerset.co.uk

Call us: 01278 264405

Write to us at: Healthwatch Somerset, c/o Somerset Rural Youth Project, Unit 2 Suprema Estate, Edington, Bridgwater, TA7 9LF

Or visit our website to find out more at: www.healthwatchsomerset.co.uk