

## Intelligence Report - November 2015

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All our reports can be found at [www.healthwatchderbyshire.co.uk/reports](http://www.healthwatchderbyshire.co.uk/reports)

### Current Areas of Work

#### Discharge from Hospital

We continue to feed evidence into the Health Improvement and Scrutiny Committee's review of Acute Hospital Discharges (this review was planned as a result of evidence presented by Healthwatch Derbyshire), which is looking at the current processes used to discharge patients, identify delays and other obstacles, and ascertain potential improvements which could be implemented to achieve a more efficient discharge process and better patient experience.

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#### Acquired Brain Injuries Service Evaluation

This report has not been published due to the sensitivity of the information in the report, i.e. the majority of information is provided through detailed patient stories which could lead to people being identified. Our findings supported the guidance outlined in NICE QS74.

#### Recommendations made:

- More work needs to be done to prevent head injuries falling through the net. This will undoubtedly involve the engagement of GPs in education and training to recognise and diagnose head injuries, but also more timely investigations and treatments by A&E departments.
- There is a need for better co-ordinated services, to ensure positive outcomes for people with head injuries which should include any rehabilitation/support package post discharge.
- There is a need for families and carers to be recognised and, if appropriate, involved in the investigation, treatment and care of someone with a head injury.
- The availability and accessibility of information and support around brain injuries needs to be evaluated to see if it is adequate to meet the needs of both the patients and their carers, and should encourage self-referral. Information should be transparent about waiting times.

We have received a responses from Chesterfield Royal Hospital NHS Foundation Trust, NHS England and a combined response from the four Derbyshire CCGs through GEM.

Several recommendations from the report are picked up in the CCG's responses as requiring further development. These are information and signposting on discharge from hospital and training for GPs to be more readily able to recognise signs of brain injury. The response concludes by saying that, "The Healthwatch Derbyshire report offers evidence to support Health and Social Care Commissioners to revisit the current structure

and function of acquired brain injury services in Derbyshire, with an aim of developing a more coherent service which supports a person and their families to better effect.”

The NHS England response also makes practical suggestions regarding the issue of GP training surrounding acquired brain injury.

### **Further Action Required**

Subsequent actions in line with these responses have been followed up by Healthwatch Derbyshire with GEM, who have sent an acknowledgement and stated that an update will follow.

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### Carer's Discussion Paper

We continue to work proactively with, and monitor the impact of, this Discussion Paper which was published in 2014. The Discussion Paper summarises the comments and experiences of the carers we engaged with as part of a themed engagement activity, and gives a real and authentic insight into the experiences of carers when using health and social care services.

For a summary of responses to the paper and to assess the impact it has had, please go to: <http://revamp.healthwatchderbyshire.co.uk/wp-content/uploads/2015/08/Carers-Discussion-Paper-Summary-of-Actions.pdf>

We held a Young Carers Summit, in partnership with DCHS, on the 27th July 2015. This was a multi-agency summit to focus attention on how to improve support for the 1,600-plus young carers in the county. The aim was to kick-start greater awareness of the plight of young carers, aged 5 - 18 years, whose childhood is affected by caring responsibilities at home for another family member because of disability or illness, as well as young adults, up to 25 years, whose chances of employment and building relationships are severely affected by caring for someone at home.

All participants made a commitment to raise awareness within their own organisations and to look for opportunities to extend the support available to young carers. Each representative at the meeting made a pledge about how they would progress this work.

This commitment and the pledges made were reviewed at a further meeting on the 30th October 2015.

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### Homecare Services Report

This piece of work was designed to engage with users of domiciliary care services and their carers, friends and family in order to strengthen their voice and to play an active part in how domiciliary services are delivered and designed in the future. It was published in June 2015.

Overall respondents were positive with the majority indicating that they were very satisfied/satisfied with the care they, or their loved one, received.

Of the three main negative themes identified the lack of consistency with the carers visiting the service user was the most common issue. Some dissatisfaction was reported

with either administrative functions or poor communication with managers. There was also some dissatisfaction with lack of consistency with the timings of the home visits.

The full report can be found here:

<http://www.healthwatchderbyshire.co.uk/2015/05/home-care-services-service-user-experience-report/>

The response from Derbyshire County Council stated that although the report was very positive, all of the suggestions for improvement will be shared with managers and staff and, where possible, responded to.

It was also stated that, “As part of our commitment to continuous improvement we will distribute the feedback to all of our home care service locations with an expectation that the Registered Manager will provide an action plan to respond to comments and concerns.”

“The results of the survey will be shared with all of our care workers as part of their team meetings and this will both support engagement with developing action plans for improvement and reinforce the positive feedback about good practice that people have shared. This information will also be shared with the Care Quality Commission on inspection.”

### **Further Action Required**

We will follow up on any action taken in the autumn. We can also report that the Improvement and Scrutiny Committee - People have put Homecare on their agenda for next year to revisit this work.

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### **Autism Pathway Report**

The purpose of this Service Evaluation was to give parents and carers the opportunity to talk in more detail about their experiences of the Autism Pathway in Derbyshire. We looked at the experiences of the pathway, not at particular professionals, departments or issues.

As the pathway operates differently in the North and South of Derbyshire, due to how services are organised, we conducted the study countywide, but also compared experiences between the North and South.

This Service Evaluation gathered qualitative accounts of 26 parent carer experiences of Derbyshire County Council’s Autism Pathway over a 12 month period.

### **Summary of Findings**

Several overarching themes emerged during the Service Evaluation, these were:

- Education
- Impact on families
- Communication
- Waiting times
- General Practitioners
- CAMHS

- Diagnosis
- Support for parent carers during and after diagnosis

There wasn't a substantial difference between the experiences of parent carers in North Derbyshire compared to South Derbyshire.

#### Education

- All parent carers recalled experiences of education.
- Parent carers reported that there needs to be an improvement in support and recognition of the signs of Autism in Education.
- Parents felt that their child was not receiving adequate and/or sufficient support to meet their child's needs. This impacted on their child not wanting to go to school, being bullied and socially isolated, or even temporarily suspended due to teachers not being able to handle the child's behaviour.
- Parents also felt that they hadn't been listened to.
- Parents spoke about a reluctance of schools to make referrals to the educational psychologist.
- There were some examples of good proactive help given to parent carers by staff, but this was not consistent.

#### Impact on Families

- The impact on families was discussed in most interviews. Most parent carers expressed difficulties dealing with the situation, and feeling at crisis point.

#### Communication

- There seemed to be a lack of clarity amongst parent carers as to who was the first port of call to trigger a referral to the Autism Pathway.
- For the majority of parents it was stated that there was some form of communication breakdown at some point during the Autism Pathway. Issues in communication ranged from parent carers being unaware they were on the ASD pathway, causing a sense of confusion and frustration of what was going on, to errors and delays in the administration process.
- Parents stated that they had to repeatedly tell their experience to different professionals.

#### Waiting Times

- All parent carers stated that they had experienced significant waiting times to see various professionals.
- Some parent carers however understood the pressures that certain departments were under.

#### General Practitioners (GPs)

- Some parents felt that GPs were hesitant or unaware of who and where to make appropriate referrals to so that parents were quickly and efficiently being directed to the correct part of the system for help.
- Some parents spoke highly of their GP and found them very understanding.
- There was frustration amongst some parents that their GP has said that a referral would be made to a Paediatrician, but when appointments were chased up months down the line no referral had been made.

#### Child and Adolescent Mental Health Services (CAMHS)

- Some families also had contact with CAMHS.
- The majority of these experiences were recalled by participants in the North.

- When there had been CAMHS intervention with families, from the interviews it didn't seem to have been explained clearly to parents as to what the link is with the Autism Pathway.

#### Diagnosis

- There was an overwhelming sense that all parents wanted to know if their child was autistic because of the impact this would have on their child's future in terms of education, employment, relationships and if they would be able to live independently.
- Parents made positive comments regarding the autism diagnosis appointments.
- There were mixed feelings about the amount of information given. Some would have preferred detailed information whereas others were happy with what they were given.
- Those families who received a diagnosis felt they could move forward in getting the right support and intervention for their child. They felt relieved.
- A large number of parents said that their initial instinct was right and wished that the professionals would have taken this on board much earlier in the process.
- Some stated that information was not given to them in plain English, some parents felt that it was meaningless because they didn't understand.

#### Support for parent carers during and after diagnosis

##### During diagnosis:

- Many parent carers said that they were offered some sort of support whilst they were going through the pathway.
- Others said they found great difficulty in getting appropriate support, or knowing where to get it from.
- Some parent carers stated that they were referred for inappropriate support.
- A large number of parents said they were unaware at which point the Autism Pathway had started.
- Parent carers interviewed found the pathway very difficult due to the amount of clinicians, professionals and assessments involved. There was a sense of confusion and lack of understanding as to where they were in the process.
- Parent carers felt they had to find out a lot of information themselves.
- All parents stated that they were the experts with their child and they knew them inside and out. There was a feeling that not all professionals listened to their views and some were quick to say that parents shouldn't want to label their child.
- It was stated that there was a lack of sibling support.

##### Post diagnosis:

- All the parent carers who had attended the Autism Workshop or Understanding Autism Course (the details of which course or workshop was attended was not clarified with participant who tended to refer to them both as workshops) spoke very positively of them in North and South Derbyshire.
- Some parents shared their positive experience of getting support from a clinician at a support group.
- Parents commented on how great it was to be able to visit the clinician to get advice on different matters relating to their children on the Autism Spectrum.
- Only one parent carer spoke about being offered a follow up appointment after the diagnosis.
- Some parent carers didn't feel they received support post diagnosis, i.e. they weren't invited to attend the workshop/course, or weren't signposted to support.

- In South Derbyshire participants particularly stated that they had difficulty accessing support services as they weren't local to them. Most of the activity took place in Derby City, Matlock or Chesterfield. To parent carers the term 'local' meant within their district.
- Parents said that they really valued access to parent led support groups, they found that they could learn new coping strategies, meet new friends and share similar stories.

A large majority of experiences related to education which is technically beyond the remit of Healthwatch, however we would be willing to work with agencies to address this area.

**Recommendations made (full recommendations can be found on Page 22 of the report):**

- Increase awareness in education for teaching staff to recognise the signs of autism and to implement the appropriate support.
- Increase provision in appropriate support/advocacy for parent carers with children and the Autistic Spectrum and co-existing mental health problems.
- Increase provision of information to guide the parents through the pathway, to include the roles of the different professionals, what should happen at each assessment and local/national information.
- Ensure parent carers are aware that follow up appointments are available following diagnosis, when they are available and what their purpose is.
- A single point of contact, where the parent carer could communicate in order to be kept up to date with where they are in the process, and where they can access support to avoid getting to 'crisis point'.
- More courses need to be offered to parents whilst they are going through the pathway to help them with coping strategies.

**Current Status**

This report has been published with a response to the recommendations from the Derbyshire Children's Autism Co-ordinating Group. It can be found at:  
<http://www.healthwatchderbyshire.co.uk/2015/11/autism-pathway-report/>

"The group will be reviewing progress in early February, to look at what has changed as a result of this feedback. At our last meeting in October, Clinical Psychology reported that they had already improved their information pack for parents carers in light of the report." Linda Dale, Head of Commissioning and Partnerships Children's Services, Derbyshire County Council.

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Child and Adolescent Mental Health Services (CAMHS)

There are two reports, one for the North and one for the South of the county due to different service providers. The reports illustrate experiences of using CAMHS in Derbyshire, as told by young people, parents, carers and professionals.

Qualitative accounts are given in 29 interviews in total. Many of these interviews were conducted at CAMHS clinics, which gave the benefit of being able to talk to participants about their experiences at the point of service delivery.

## Summary of Findings

The experiences suggest that some parts of the service work well, and others not so well.

The clearest example of this relates to the relatively high number of negatives, compared to positives, regarding referrals and diagnosis. Sometimes participants spoke about a real challenge to get into the service in the right place, at the right time - although there were positives in this regard too. All comments regarding diagnosis were negative.

Conversely, there were many positive comments regarding quality of staff, the quality of the service and the seemingly positive impact for those using CAMHS, with only a few examples of negative experiences.

In short, the information suggests that the main difficulties lie in getting into CAMHS and going through the referral and diagnosis process. Once participants were 'in' the CAMHS service, they were generally very positive about the experience.

## Recommendations made:

Based on the information provided in both reports, the recommendations are that service providers consider the following (recommendations were subtly different in the North to the South, the list below is a combination of both):

- The referral system and the difficulties highlighted in getting referred to CAMHS.
- The adequacy of the support and information offered to young people, parents and carers, both before, during and after CAMHS.
- The frequency and duration of appointments and the involvement of young people, parents and carers in the choices that are made.
- The implications of delayed diagnosis on both the young person and the parent or carer.
- Appointment timings are reviewed to allow improved access to appointments out of school/work hours.
- The unique situation of children in foster care.
- The implications of placing young people in out of county beds.

## Current Status

Both reports have been published with responses from Service Providers and Commissioners. <http://www.healthwatchderbyshire.co.uk/2015/09/camhs/>

The reports were discussed at the Health and Wellbeing Board on the 10<sup>th</sup> September 2015 and have been fed into and acknowledged in the Future in Mind Transformation Plan which addresses the recommendations in its content.

The HWB have requested a repeat of the engagement activity in 2-3 years to establish if this plan has been effective.

Progress on the recommendations will be monitored.

## Cancer Services Report

This report explores the experiences of 102 patients who have accessed a wide range of cancer services. It looks at what works well, and what could be improved.

The amount of feedback collected over the course of 102 interviews was enormous. This report has been compiled by reviewing all of the feedback, which was then themed to reflect the main topics that arose. The feedback which was neither positive nor negative was then excluded. This report contains comments given when there was an experience that was particularly positive or negative. As a result, this report has two functions, firstly to highlight the topics most relevant to cancer patients, and secondly to give a real flavour of positive and negative experiences surrounding each topic.

This report is intended to provide service providers and commissioners with some useful insight into experiences of cancer services in Derbyshire, and we hope will support service development plans and provide suggestions for improvement.

## **Summary of Findings**

### **Referrals and Diagnosis**

- Several participants spoke about their experience of diagnosis being triggered by routine screening, and gave other examples of prompt and speedy diagnosis.
- Other participants spoke about apparent delays with referral and treatment.
- Some experiences describe difficulties and delays within primary care created by symptoms being attributed to the wrong condition.

### **Choices**

- Many participants told us that they felt their choices, post diagnoses, were explained well, and they had choice when there was a choice to be made.
- There were some specific negative issues relating to choice for cancer in pregnancy, and prostate cancer treatment.

### **Dignity and Respect**

- There were very few accounts given from participants about events that had compromised their dignity and respect.

### **Communication**

- Some participants felt that in hospital their cancer diagnosis had not been delivered sensitively.
- Other participants felt that the number of staff involved in their care resulted in communication problems between professionals which gave an inconsistent message to the patient.
- Many participants spoke of good communication between primary care and hospital, and good communication between a hospice and primary care.

### **Quality of Care**

- There were very few accounts given from participants about events that they felt represented poor quality care. Out of the accounts given, one related to prostate cancer and one to laryngectomy patients.

### **Family Involvement**

- There were very few accounts from participants about events that they felt had not involved their family, although one participant spoke of their son being given the news of the cancer diagnosis before the patient.

### **Equipment and specific needs**



- Some participants told us of issues and challenges to do with the order and supply of equipment.
- Laryngectomy patients also described some other issues with understanding their specific needs.

### **Nursing support**

- Mainly, participants had a clinical nurse specialist and spoke favourably about the care and support they offered, and the care offered by Macmillan.
- Many participants had seen a clinical nurse specialist and had telephone contact details for when required, and felt that they got back promptly to patients when messages were left.

### **Information**

- Some participants felt that they had received plenty of information and had been signposted to support groups. Others had the opposite view. Several suggestions from participants emerge from this section, which will be highlighted in the report recommendations.

### **Hospice Care**

- Some participants felt that the word 'hospice' was associated with a place you went to die, which did not represent the range of work done by hospices in the experience of those participants. Suggestions were made about rebranding. Unanimously positive feedback was given regarding the hospices used by participants.

### **Recommendations**

Based on the information provided, Healthwatch Derbyshire would recommend that the providers and commissioners of relevant services in Derbyshire consider the following:

1. That newly diagnosed cancer patients receive the right information at the right place, delivered by the right person and at the right time for them after their diagnosis.
2. That special consideration is given to the specific and detailed information required by women experiencing cancer in pregnancy.
3. That special consideration is given to the specific and detailed information required for specific cancer types, such as prostate cancer.
4. The specific needs of laryngectomy patients are recognised (where necessary in policy and procedure) and are delivered through training and awareness raising.
5. That all staff involved in communicating sensitive information and informing patients and their family of a cancer diagnosis do this in a consistently sensitive and appropriate way.
6. Steps are taken to ensure that every patient visit is as straightforward and streamlined as possible in terms of travel, parking and time in clinic plus wait for any medication.
7. That hospices consider their branding, and how to raise referral rates from Healthcare professionals and to develop a wider awareness of the portfolio of services offered.
8. That specific steps are taken to ensure that information and signposting is thorough and routine.

## Current Status

This report has been published with responses from service providers and commissioners. We are chasing a few final responses to include in the report, but it can be found at: <http://www.healthwatchderbyshire.co.uk/2015/11/cancer-services-in-derbyshire/>

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## Recent Enter and View Reports

- Chesterfield Royal Hospital NHS Foundation Trust Eye Clinic  
<http://www.healthwatchderbyshire.co.uk/2015/07/chesterfield-eye-centre-eye-clinic-enter-and-view-visit-report/>
  - Canal Vue Care Home (re-visited planned Oct 2015 to check recommendations have been implemented).  
<http://www.healthwatchderbyshire.co.uk/2015/05/canal-vue-care-home-enter-and-view/>
  - Whittington Care Home  
<http://www.healthwatchderbyshire.co.uk/2015/06/whittington-moor-enter-and-view-report/>
  - Brimington Care Centre  
<http://www.healthwatchderbyshire.co.uk/wp-content/uploads/2015/10/Brimington-Care-Centre-Final-Version.pdf>
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## Upcoming Reports

- Learning Disabilities and reasonable adjustments in universal services - to be published December 2015/January 2016.
- Physical Disabilities and reasonable adjustments in universal services - to be published December 2015/January 2016
- Ashlee Care Home Enter and View visit - to be published December 2015
- Ashcroft Care Home Enter and View visit - to be published December 2015

## Current Priorities

- Exploring access to dental treatment on the NHS.
- Engagement activity with Children and Young People.
- Raising awareness amongst the general public of the need for service re-design and the importance of their contribution to the discussions taking place.