

## PATIENT AND PUBLIC INVOLVEMENT FORUMS

### Summary of Derby City Patient and Public Involvement Forum activities

Derby Hospitals PPI Forum, Central Derby PPI Forum and Greater Derby PPI Forum

#### Derby Hospitals PPI Forum

Hygiene – Forum members have just taken part in PEAT visits – Patient Environment Activity Team.

Diabetes – worked with other orgs to discuss the problem of Adolescents missing appointments and not taking due to concerns about weight gain

#### Central Derby PPI Forum

Hospital Bedside Entertainment System – working with the Trust to let the public know about the costs of this system.

Patient Participation Groups (PPG) – working with the Primary Care Trust to encourage GP Practices to set up these PPGs. The Forum worked with Greater Derby PPI Forums, Derby PCT and Derby CVS to organise an event last November for existing PPGs and Practices interested in setting up PPGs. This event was very well attended. Both Greater and Central Derby PPI Forums are keen to keep up this work and work with the PCT to support PPGs and help GP practices set up PPGs.

#### LIFT project – Austin Estate

The Forum is working with the PCT to make sure that adequate consultation takes place about the move of the Village Street and Sinfon surgeries to a new site on the old Homelands School Tennis Court. There are issues around access and transport. The Forums will be present at an event planned by the PCT for 6<sup>th</sup> August at St Giles' Church, Village Street, to answer questions and concerns of the public about this project.

#### Greater Derby PPI Forum

PPGs as above

Advanced Access – system of booking GP appointments. A questionnaire has been designed by the Forum and sent to Practice Managers. The Forum will meet soon with the PCT to discuss this and future work.

#### Substance misuse

The Forum is researching what services are available and whether or not there are adequate resources for drug and alcohol services.

#### Access to paediatric community based therapy services for local families/carers

The Forum has produced a questionnaire which is currently being circulated to as many groups as possible in order to gain a fair picture about these services.

LIFT project Alvaston/Bouton the Forum is working with the PCT on the consultation process for this project.

#### Central and Greater Derby PPI Forums Community Engagement Subgroup

This is a newly formed subgroup with the aim of engaging meaningfully with the community.

All Forums are working on raising their profile in the community, for example, by holding meet and greet sessions at community centres and by attending community events.

Contact Beccy Humphrey at the Derby Office for more information

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## **Access to Paediatric Community Based Therapy Services for local families and carers.**

The Greater Derby PPIF is currently active in collating the views of families/carers of children within the local area who have accessed or are waiting to access a community based therapy service for the children that they support.

The forum have produced a questionnaire, which is being distributed to as many different possible groups in order to gain a fair picture of how the families/carers perceive these valuable services to be working for them in supporting the needs of their family. The forum has contacted Greater Derby PCT raising general questions in order to gain an understanding of the service that the Trust are providing for children in the community.

From initial responses received there is a clear difference in perception of these services between the families/ carers who receive the services and the PCT who provide the services.

Families/ Carers feedback from the questionnaires indicates inequality in the delivery of services received amongst the respondents, with access to the services varying between a matter of days or in other cases years from their child's initial referral to gain access to the paediatric assessment of needs. Many pointed out they knew that their Childs needs had significantly changed due to length of time on the waiting list. Respondents felt there is a lack of consistency in service delivery i.e. therapy plans are not adhered to once set and a lack of continuity of therapists as a result of staff shortages were recurrent comments noted.

The individual service providers initial responses to the PPIF questions indicates that the services operate a waiting list policy, which they state provides assessment within a set period of up to 18 weeks. This does not correlate to the completed questionnaires received by the PPIF, which has prompted the Forum to continue to review in more detail these services in order to gain a clearer understanding of the services and the discrepancy identified.

In order to distribute the questionnaires the PPIF has been linking with local support networks and groups, contacting them directly and explaining the forum's role and our current workplan, this has been covered in monthly newsletters which the groups circulate amongst their membership.

## **Removal of DASG services for Derby City Families due to lack of local funding from relevant authorities.**

As a result of formulating these links it has been brought to the forums attention a reduction of support services to Derby City families/ carers of children with Autistic Spectrum Disorders by the DASG as a result of lack of funding to support the continuation of this work.

The work of the DASG is valued by both local professionals in Social Services, Education Services and Health Services and as well many local voluntary organisations and groups, their services are used and enjoyed by the many families/ carers and children they support, however due to lack of funding these services are to be discontinued to Derby City Families, from Easter 2005. However the work of the DASG will continue for Derbyshire County Council families/carers due to receipt of funding being received by them to specifically fund continuation of there work in the Derbyshire County Council area.

(Reference copy of letter to Social Services detailing services to be withdrawn due to lack of funding).

Difficulties gaining access to local support services encountered by families/carers of children with ASD in Derby City currently identified, (this does not include difficulties in accessing Health Services or Educational Services):

- Many families/carers of children who have and ASD who live in Derby City have only been able to access support services from DASG in recent years.
- Social Services have a Disabled Children's Team, provide Outreach Services to families of disabled children, however, due to the current criteria for access to these services, they are not made available to most ASD children's families/carers, who are usually being told that their children's needs do not fulfil the severity criteria.
- Clinical Psychology at the Derby City Children's hospital produce an Autism Contacts sheet for families/carers of ASD children, this lists DASG as the only local support for ASD children, their families/carers, for Derby City families/ carers this is now unavailable due to lack of funding from relevant local authorities.
- No alternative support service has been developed to replace DASG for Derby City Families/ Carers, leaving many without support both immediately or in the foreseeable future.
- The National Autistic Society do not provide any support services locally, their helpline recommends families to contact the DASG for local support. Nottinghamshire County Council and Nottingham City Council currently hold accreditation and the licence to provide National Autistic Societies, The Early Bird Schemes and The Help programme, however they have funded the training, development and staff costs for these projects and these services are only accessible to their residents. Therefore it is not possible for Derby City Families/ Carers to access these even on an intermediary basis.
- Umbrella receives funding to provide support services for families of children with special needs, they are currently reviewing the waiting times for access to their volunteer service, sitter service and free times schemes, which have long waiting lists, again families waiting years to access support. Umbrella do not provide the services which DASG provided and they are not ASD specific.