



“Someone to check that you and your child are doing OK”

Discharge and support from Royal Alex Children Hospital - December 2015

1. Introduction

1.1 What Amaze does

Amaze is Brighton and Hove ‘one stop shop’ for parent carers of children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Since 1997 Amaze engages parent carers at all level of services provision for their child or young person, for themselves and for the whole family. The aim is to increase parent carers' resilience and confidence which in turn have a direct effect on the lives of their children and the children themselves. As from last financial year (2014/2015) in line with the new Children and Families Act, Amaze is supporting families, and children and young people with SEND themselves, up to the age of 25.

1.2 What PaCC does

The Parent Carers Council (PaCC), hosted by Amaze, is a city-wide engagement group with 270 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs. PaCC also has 7 partners, some of them service providers, others community groups formed by parent carers. The PaCC gives a voice to parent carers using different engagement methods as for example focus groups to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve health, social care and education services for disabled children.

1.3 Parent Carers' engagement through CCG

The local Clinical Commissioning Group (CCG), through its Engagement Gateway Contract, funds Amaze and the PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children (*See Annex 1: How Amaze and PaCC engage with parent carers*). As a result the local CCG is provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local NHS services. In addition the local CCG's understanding of the needs of disabled children and their parent carers is improved, and health services are correspondingly made more responsive and are targeted to actual need. And finally parent carers feel that their views are valued and that they can influence decision making regarding local NHS services, and help effect change. PaCC and Amaze provide regular feedback and updates on the engagement work to parent carers through the termly newsletter and through social media.

1.4 Parent Carers and discharge from Royal Alex Children Hospital (RACH)

In 2012 Amaze and PaCC carried out a consultation on provision of health care, available in Brighton and Hove, for children with disabilities and additional needs. Among other services parent carers were able to comment on RACH. Parents talked about their experiences on accessing the hospital and provided ideas and suggestions on how to improve the service. The full report, 'Talk Health' ([See Annex 2: Talk Health](#)) and the Talk Health Feedback ([See Annex 3: Talk Health Feedback](#)). Recommendations from the report and follow up have been passed on to health care professionals and to the local CCG.

The Talk Health report highlighted the fact that the new RACH, including children's A&E department, was a great facility to have in the city but the parking facilities were poor. As a result of Talk Health parents who have blue badges are now allowed to jump the queue. When this works it is of great relief/benefit to families with disabled children.

Parent carers were very positive about the community nursing team which provided excellent support to parent carers in their homes. To further improve that service parent carers commented on the necessity of specialist disability liaison nurse that parents could contact at any time. (S)he could be also able to give direct advice over the phone or contact another professional for advice if required.

Talk Health found out that some parents felt unsupported prior to diagnosis and also called for better communication between different professionals, for example between RACH and Seaside View. Following the report series of 'parent journey training' was delivered to RACH staff. Parents' voice on how RACH is run was enhanced by a PaCC Parent Rep sitting on the Disabled Children's Acute & Community Liaison Group.

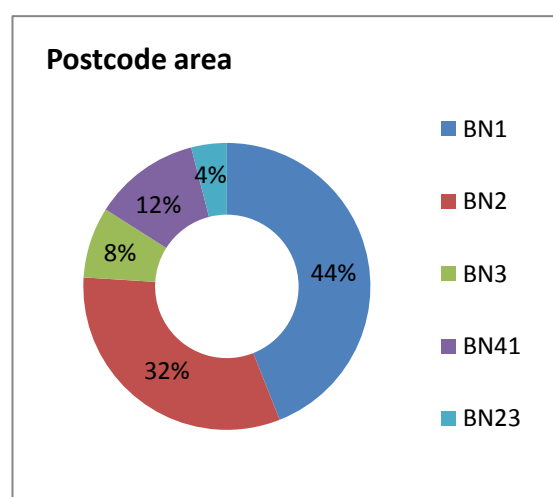
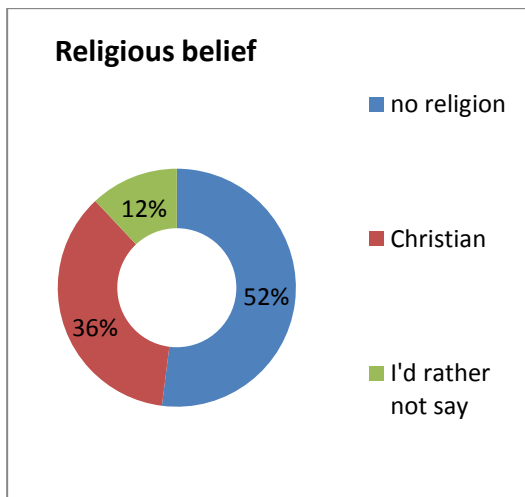
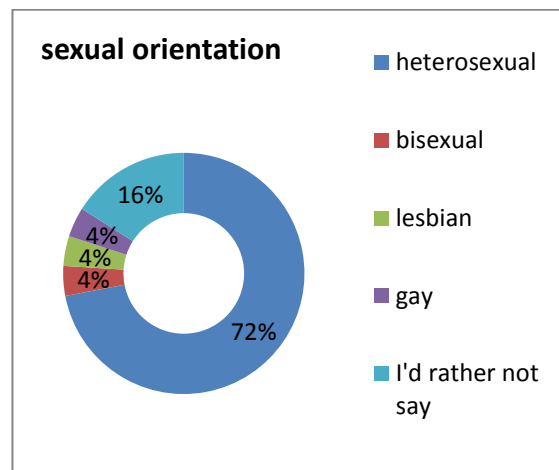
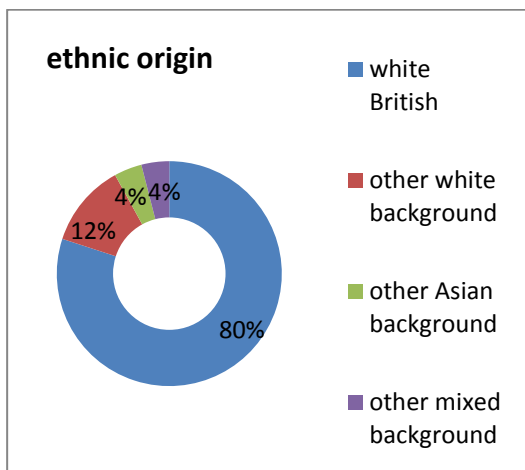
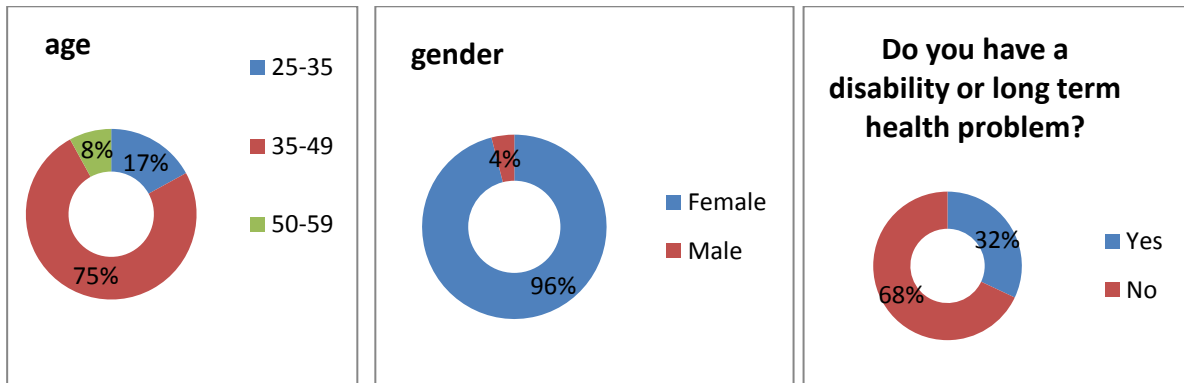
With this new consultation we wanted to find out about parent carers, their children and their families' experience of being discharged from RACH, specifically on follow up and support received once they were sent home. The 2005 Barnardos report 'From Hospital to Home' lists some very important factors when looking at discharge and support, specifically the need *"to understand the local community and the range of services available to meet health, housing and social care needs; to ensure individuals (children and young people) and carers (parents and extended family members) are actively engaged in planning and delivering the care; the role of parents and other carers is recognised and their own rights for assessment and support acknowledged and met; ensure effective communication between primary, secondary, social care, education and voluntary sector to focus care on meeting the needs of the individual child and their family"* ([See Annex4: From Hospital to Home' page 57](#))

What's the situation with parent carers, their children and RACH?

2. Methodology

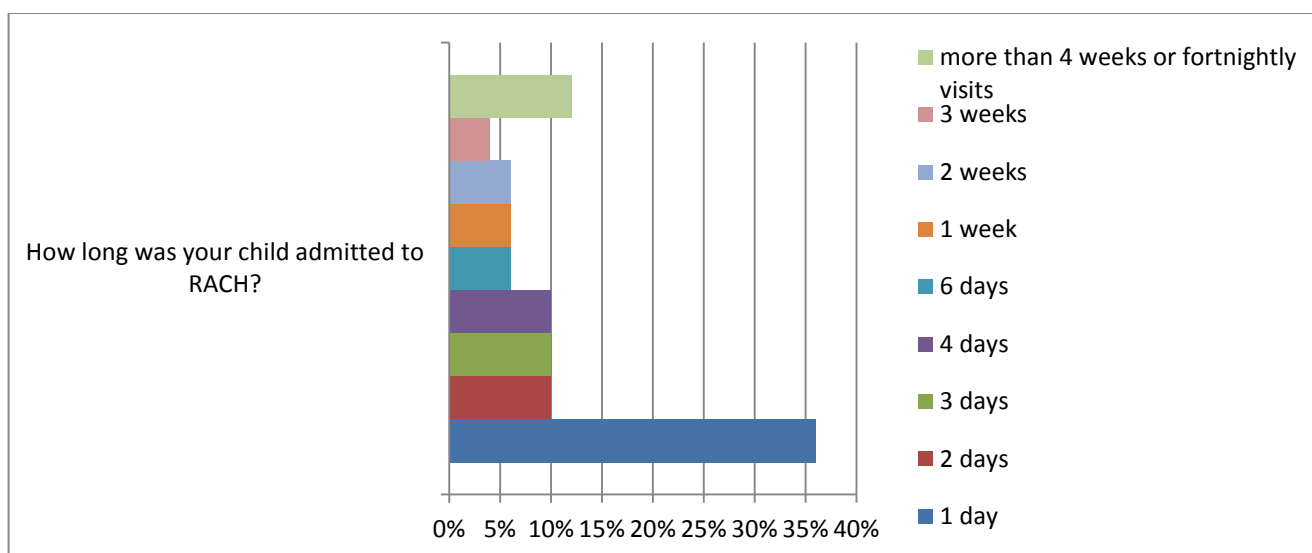
This consultation was discussed and planned with two Amaze staff one who used to work at RACH. They helped with looking into possible questions we wanted to explore. In addition the Amaze database manager elaborated the final questions and emailed them to those parent carers who had visited RACH during the past 12 months. The online questionnaire ([See Annex 5: questionnaire](#)) included both multiple-choice and open ended questions and it was posted on PaCC and our Partners' Social Media. 30 parent carers completed it. We also organised a small focus group attended by 6 parent carers. Responses received from the online questionnaire were collated into a summary ([See Annex 6: summary](#)) and used to write this report.

3. Demographics



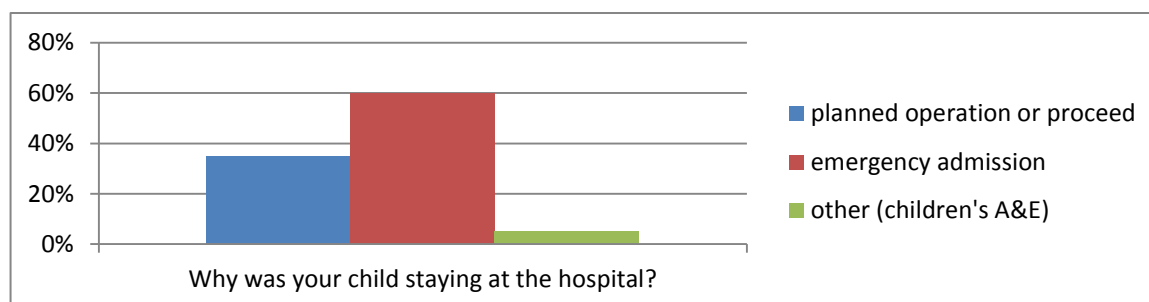
4. Findings

4.1 How long was your child admitted to RACH?

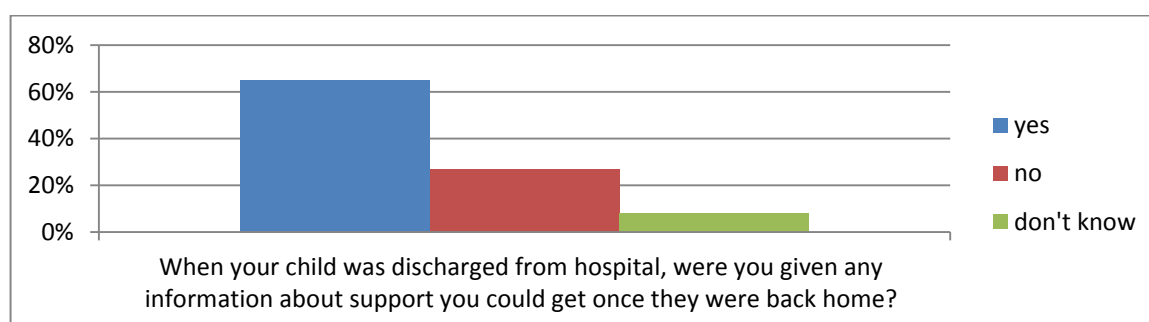


A considerable number of parent carers and their children spend a long time in the hospital. That underlines how important discharge notes and information, follow up and support are. In addition some parents reported that there is little support for parents who get stuck in the hospital for long time.

4.2 Why was your child staying at the hospital?



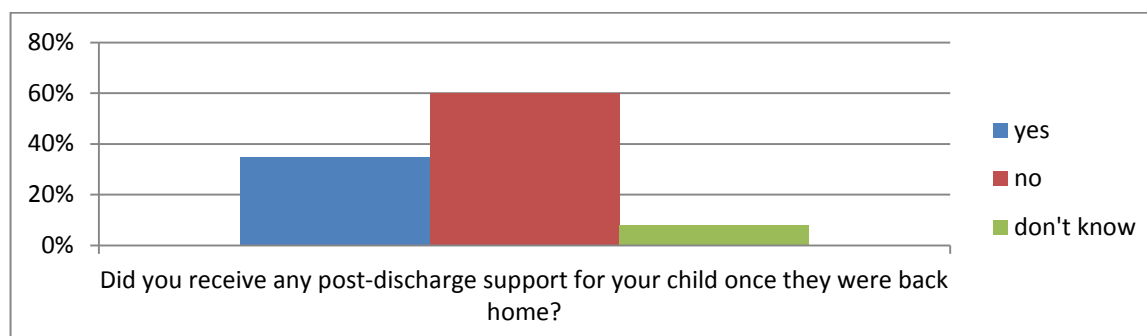
4.3 When your child was discharged from hospital, were you given any information about support you could get once they were back home?



Approx. 30% of the respondents reported that they didn't receive – or they don't know if they received - information on support once they were discharged. Further information below (4.5)

highlights the stress and uncertainties caused by not knowing what is going to happen after parents and their children leave the hospital.

4.4 Did you receive any post-discharge support for your child once they were back home?



Nearly 70% of respondents reported that they didn't receive – or they don't know if they received - support once they were discharged. Parent comments below (4.5) emphasise the feeling of been abandoned or left in the dark about their child's health.

4.5 If you answer to the last question 'Yes', could you tell us one thing that was great and one thing that could have been improved or wasn't done at all but would have been helpful?

4.5.1 Positive:

RACH's services seem quite teamed up. Hospital staff know about Amaze and are confident on passing on information. One parent who, due to her child's condition, visits the hospital very often commented on the fact that nurses are very friendly and provide entertainment, for example materials which her child can play with. She feels supported and looked after.

Useful and friendly advice and support is critical due to the long-time some children and their parents spend in the hospital. One parent commented: *"I was able to speak to helpful and polite nurse on the ward several days after the admission"* And good and clear information about support after discharge is very valued as a satisfied parent fed back: *"I had contact numbers for 24 hour if I had any concerns"*

Parent carers would like ongoing support from specialised and dedicated team so that once at home people feel reassured and not abandoned. A respondent to our online questionnaire commented: *"The paediatric diabetes team carried out home visits for more training. Daily phone calls to monitor progress for the first week that then became weekly over the coming weeks until we were happy not to be called. Contact with other members of the diabetic team for training. Assistance with training school staff for return at school"* That was reiterated by another parent's comment: *"Help with Diabetes 1 diagnostic fantastic"*

Community nurses are seen as indispensable support after discharge and until the post-operation situation has settled: *"The community nurses were great"* and also their support role: *"Community nurses can spot check sats and provide reassurance"*

4.5.2 Need to improve:

Some parents felt that they are sent home with minimal information. One parent commented: *'I just got a discharge letter and basic medications...I felt a bit lost'*

Whilst another parent would have liked some more information on the drugs to administer to the child: *"I got a prescription to give him tami flu but it was hard giving him it as it wasn't very nice. It would have been nice to get some advice on how to give it to him if it wasn't liked"*

A clear post-discharge care plan could save much stress and confusion. A parent felt she didn't receive the right information and support following her child's operation. On discharge the parent was told to call the ward if the wound got infected and not to remove the dressing until the stitches were due out until a week later. When the wound started to leak through the dressing, the parent called the ward and was directed to A&E to be seen by ENT doctors and then to the GP practice nurse who wasn't able to provide her with the right dressing: *"The ward staff did phone us back with suggestion when I said the wound was infected. In hindsight, I should have just gone to the chemist in the first place, I guess they may have told me that he (my son) needed seeing at hospital but maybe he would have had the helpful dressing from day 2 of the infection instead of starting on day 5"*

A parent suggested that it would be good to receive extra information and contact – with discharge notes - for other organisations that could support and help once out of the hospital.

More support would be good, probably difficult to get a nurse to visit but perhaps an email or a phone call: *'Someone to check that you and your child are doing OK'*

Another parent complained that she didn't experience a good post-discharge support as: *"The equipment that they sent us home with didn't have the appropriate accessories and 2 weeks later I'm still waiting"*

One parent whose child needs to go to the hospital every other week complained that the communication is very poor. She emails the hospitals but doesn't receive replies. She actually formally complained about the lack of communication. She added that it took a year to treat her daughter's condition and during that time she felt left out and not informed on what was going on.

Communication between professional is paramount as children need to see many different people in different departments. A respondent to our online questionnaire told us what troubled her was the: *"Discrepancy between what has been advised and agreed with consultants and nurses on HDU and respiratory consultant and community nurse team, without the latter even looking at my daughter or discussing with us. On more than one occasion we have been made to feel bad parents by following directions of HDU about wearing oxygen or drugs when the doctor and community team just wanted to override those arrangements without discussing with us or HUD or examining our daughter"*

For those parents who visit the hospital quite often communication between professionals needs to improve: *'Sometimes I have to organise appointments myself, and after there is not follow up'*

Referrals and clearer care plan were underlined by some respondents. In fact it was reported that once a child received his/her care plan Social Services would say: *'we can't afford that'*.

It is paramount that the discharge plan is met by Social Services as parents struggle around money for support. A participant to our focus group would like a prompt response from the Social Services team which, according to her are *'very slow on providing support'*.

A few respondents commented that Direct Payment and DLA forms are too complicated and they would like to receive more support with filling the forms in.

A more effective and speedy referral, better transparency of after care, what's going to happen, what support parent carer should expect is highlighted by a parent carer: *"Referral to mental health (dealing with diagnosis) is useless as 6 months wait and still dealing with ramifications 2 years on"*

A parent commented on confusion between different agencies and on parents not being properly involved: *"Nutricia homeward trying to get the NHS to pay for unnecessary prescriptions by sending them to our GP was not great"*

5. Recommendations

- **Discharge notes to be clear and concise. Notes to include detailed information about drugs to administrate**
- **Clear and concise referrals and care plan so that professionals and parent carers know what support has been put in place and what's going to happen next**
- **Better communications between professionals themselves so that the pathway from clinical/hospital to social care support is well planned and clear both for professionals and for the child and the child family**
- **Discharge notes should include a 24 hours number to call in case of emergencies.**
- **Discharge notes to include information and contact for other organisations which can provide support, as for example Amaze DLA project and parent carers' community groups**
- **Post discharge support to be provided, when possible by community nurses or when there is limited capacity by follow-up phone calls and/or emails**
- **Ongoing and adequate support and communication to be in place for those children and their families who will need to visit the hospital frequently**

6. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: Talk Health

Annex 3: Talk Health Feed Back

Annex 4: From Hospital to Home - Barnardos

Annex 5: RACH Survey 2015

Annex 6: RACH Survey Results