

**Deputation to the Council regarding
Hawthorn Family Support Centre**

Samantha Grundy – Acting Chair and Parent

10th September 2008



www.leedsmencap.org.uk

Leeds Mencap, Londesboro Terrace, East End Park, Leeds, LS9 9NE

Registered Charity Number 1091809

My Name is Samantha Grundy and I am Acting Chair of the Trustees for Leeds Mencap.

I moved to Leeds in 1991 to work for Leeds City Council and met my husband at work. Our Son Daniel was born in 2001.

Much to our surprised he weighed only 4lb's and was rushed straight to intensive care. We both took one look at him and were bowled over with love.

The Doctor told us that he might not make it through the night and ... that he had a genetic disorder which meant that he was disabled.



He made it through to the next day and the next but then they discovered that he had a hole in his heart. Later still... and more bad news as they discovered that he had suffered major brain damage and would have additional learning and physical disabilities to cope with.

The days past and Daniel grew stronger. At 6 months he under went a 10 hour heart operation and finally we all arrived home



The hospital had taught us how to nurse Daniel but we were now left at home with a tiny baby who was too weak to support his head or lift his arms. We faced a future of having a child who could not talk, walk, eat, drink or use the toilet. We loved Daniel so much but the future did look a bit bleak.

We also discovered that some of the public and some of our friends had a major problem with accepting people with a disability. Luckily it was at this point we discovered the Hawthorn Family Support Centre.

Hawthorn is a centre for families with young children who are disabled. We found families going through experiences just like ours. We were able to make a network of new friends, other parents and carers who I can still call on at anytime, benefits and rights advice and most importantly the staff taught us how to play with Daniel...



how to encourage him, learn with him and recognise when he had made progress, they gave us back our little boy, he was not a patient to them but simply a kid. The Staff had the skills and understanding to guide us through this difficult time.

Hawthorn is only one of the projects which run out of Leeds Mencap's building but as the biggest day time user the finances of the whole centre are currently underpinned by Hawthorn's grant. I must stress however that our overheads are incredibly low and in our opinion we offer excellent value for money.

On a weekly basis over 170 families, citywide use the centre – over 140 children visited this summer

I want to thank Leeds City Council for their support of Hawthorn and Leeds Mencap. For over 40 years you have funded the project. I think we should all be proud of this support.

- The council have not commissioned a Hawthorn style project and the existing grant will end in November.
- We were not consulted on the details of the specification.
- We were surprised that a Hawthorn style of family support was not included in the package.
- We considered bidding but felt that the proposed services did not meet the needs of our parents, carers and children
- The requested services were not backed with adequate financial resources.

Leeds needs an early support project. We know from our families the importance of this support. We know how much stress is placed on families

when they have a child with a disability. Support at this key stage in life gives the families a solid foundation on which to build, giving long-term stability. This early support can not be provided for in the children's centres simply due to numbers involved to form cohesive parent support groups and the need for highly specialist experienced staff. (We are not criticising the Children's centres in anyway by saying this.)

8 out of 10 families with a child with a disability admit to being at breaking point*.

Each child with a disability who ends in care will cost social services £100 – £200,000 per year. How many families have been kept together through your support of Hawthorn for those 40 years.

The loss of the grant for Hawthorn has forced us to look long and hard at the service we provide. It is an opportunity for us to forge new partnerships and take a fresh look at what we do. We have already undergone a transformation, we now have a chief exec with a business background, we have a successful fundraising team, for every pound received in the form of a grant we raise a pound from donations... so now we have to raise double this amount.

Leeds Mencap only runs projects that the people we support want and need. We only do this where there are no other services. If we fail to ride out this storm and have to close, over 400 families will lose desperately needed services.

So what are we asking for? We understand the need for change and fully support the development of services in Leeds and the move to commissioning of services; however the needs of the families we work with has not changed. We are driving towards a long-term sustainable funding partnership but this has been made more difficult by only being given 5 months notice... BUT the most important thing is that you commission a Hawthorn style of project offering parent support. If we don't run it, no problem. The important thing is that the work continues and family support is available.



I am very lucky that I have a partner who can support me both financially and emotionally. But this experience has very nearly broken me and my family. Hawthorns was the most important help we received.

How difficult is it then for single parents, those without a secure income, those families with more than one child and even more than one child with a disability and how much more difficult will it be without a Hawthorn Family Support to help?

Thank you for your time.