



Parent & Carers Council

Annual Report 2001 - 2002

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difference

WWW.Parent-cc.co.uk

Parent/Carers Link Workers

Nirmala

- PCC representative working across City/County border.
- Particularly interested in Health related issues.
- Regularly discusses PCC/child/carer issues with between 15-20 parents a week.

Glynis

- County PCC representative particularly in N.W. Leicestershire.
- Working mainly to promote Post-school placements/Transitional planning, leisure and respite issues.
- Meets with approx. 30+ parents per week. Active member of Ashmount "Mums for Mums" Support Group—which meets fortnightly at Loughborough Health Centre.

In process of contacting Charnwood & N.W. Leicester M.P.'s to make them aware of our children's future needs. This includes Accountability plan for our children's future and the need to look at existing day-care. The present formats requiring re-evaluation and discussion needed for new formats.

Theresa

- City based representative.
- Areas of special interest include: Downs Syndrome and Respite Care.
- Attends Parkfield Nursery Support Group monthly and monthly Downs Syndrome Support Group. Meeting with up to 30 parent/carers per month.

Is a core member of Therapy Strategy Group and has been involved throughout development of new Therapy Strategy.

Fatima

- City based representative.
- Aware of cultural isolation of many parent/carers, available to talk to other parent/carers looking for advise, support or a listening ear.
- Active in raising awareness of PCC's activities to Asian Carer Groups.

Jane

- County based representative, but provides support/representation across City/County.
- Much experience in Education based topics, especially Statement of Educational Needs and parental representation. Also has specific interest in Autism issues.
- Is able to reach over 50+ parent/carers through weekly activities evening at Whitwick Leisure Centre and various meeting attended as PCC representative. Member of Education Forum Group meeting monthly with County Parent Partnership Officer.

Mrs Lia

- City based representative working closely with Fatima.
- Again working to promote awareness of disability issues especially within Asian Community.
- Regularly attends Mother and Toddler Groups, Parents Support Groups (including 'Red Cross Special Needs Family Support Centre' at Oadby) and 'Adhar' Project, Highfields, Leicester.

Sheila

- County based, particularly Loughborough area.
- Skilled in counselling for parents/carers under stress. Extensive experience with Cerebral Palsy, working with both families and children.

Has been working on 1:1 support with families under stress and reducing social exclusion through lack of recreational opportunities for children with disabilities.

Neil

- County based representative.
- Particularly interested in needs of male carers/parents. Autism/Asperger Syndrome of particular interest.
- Regular attendee of Asperger Syndrome Support Group, meets on a regular basis many parents. Provides important input into consultation issues, providing a male viewpoint.

Khadija

- City based representative, who attends many City based Groups.
- Able to work with other Asian representatives to encourage awareness and openness of all disability issues.

Janet

- Works within both City and County, with access of up to 100 people per week.
- Primary interested in Autism issues, has extensive knowledge of working with younger children.
- Main involvement to raise awareness of the role of the PCC. Passes on information to wide audience of both 'professionals' and parents and circulates feedback.

Phil

- Represents PCC through his work through the Fathers Group held monthly at Red Cross, Special Needs Family Support Centre, Oadby.

Karyn

- Karyn works in both City and County.
- Her main input is providing advise and technical support. She has extensive expertise regarding behavioural support and provides advise support to parents where required.

Kathy

- Working as Chair requires involvement throughout City & County.
- Responsible for majority of administration and co-ordinating dialogue between parents and service providers.

People we reach

One of our main objectives is to try to share information with as many parents/carers as possible. Those who are registered on our database are quite used to receiving mail shots from us either as a 'blanket' mailing, or as a topic of specific interest to their circumstances or location. We often will combine these with information from other agencies, such as 'Contact a Family' or 'VAL' (Voluntary Action Leicester). We are very aware that even if a piece of information is not relevant to the recipient, many of our leaflets etc. are passed on to others at the 'school gate's or within Support Groups.

We have produced two newsletters this year at Easter and just before Christmas. The first newsletter went to 500 addresses on our database, the last Newsletter was mailed to over 1000 members. This number also includes a number of Groups and also interested Statutory Agencies who are registered as Associate members of the Council. We are also grateful to the schools who requested copies to send home with their students.

Our database is fully compliant under the Data Protection Act and we are staunchly protective of our members details. They are held on one computer, with access available to only one Committee member. We will gladly forward any information on behalf of other agencies, but never divulge any membership details.

Through maintaining this strict policy, we have been able to collect much information regarding the needs and aspirations of both parents, carers and the young people they are responsible for. This gives us enormous credibility and influence when assisting in future planning or lobbying for change and recognition of their collective and individual needs.

February sees the launch of our web-site. This has been designed and managed by Ramesh Mistry using Lottery Funding and on behalf of all of the committee we thank him. This web-site is primarily to share information received. It will contain online copies of newsletters, details of forthcoming events and any news relevant to our work. Hyperlinks to other sites of interest will be added as we find them. (Recommendations gladly accepted). Any parent/carer who wishes to add to the site will be welcome to contact us. The site is another way of parental views being heard and presented to a wider audience.

Parent & Carers Council Web site

WWW.Parent-cc.co.uk

Empowering Parents/Carers

Since May 2000, we have been able to provide a platform for the views of parents/carers to be represented across the City and County. Their voices have been heard and subsequently they are able to express their views on the issues that affect their daily life. Some of these issues relate to contentious, painful topics that we aim to present in a calm, measured, but firm manner. Our volunteer representatives work either directly, or indirectly with parent/carers and where necessary provide support if required to enable them to attend any forum to enable their direct participation.

We rely upon our members to contact us in order to prioritise areas of need/concern. We are able to respond to most requests due to the varied skills of our representatives. Our belief is that parent/carers are better able to form effective partnerships in their child's care if they are kept informed and allowed opportunity to question and discuss as equal stakeholders. This can only be achieved through a network of resource and support that we aim to facilitate.

It is now a legal requirement that parents/carers are consulted at all stages of provision of care and/ or facilities. The past year has seen the growth of a network enabling this dialogue. Within a short space of time we have more than 300 parents who have been involved in providing feedback on the many issues we have been asked to comment on. This is a phenomenal achievement, and has ensured that a hopefully representative viewpoint is available when required. Thank you to all—you know who you are..... We hope to implement change through participation and draw your attention to the list at the back of report giving brief details of our activities this year.

Somewhere to turn

Despite our glowing achievements of sharing our members views with anyone willing to ask... Our most important and satisfying role is that of supporting others who turn to us for help and support. Sometimes it is just a simple information request; other times it is a complex cry for help. Through our network of volunteers, we are able to respond quickly and appropriately. We operate a 'buddy' system and attempt to match any request with an appropriate volunteer. Each volunteer has different skills and we have a system of referral that hopefully works for both location and suitability. This is by nature a very demanding part of our work, but we now have three contact numbers and hope to be available when required. We operate using mobile phones, which allows a rotation of staffing if required, as **all** of us are carers and still suffer our own crises! We will always return a phone call/message which ensures that costs to the caller are kept to a minimum.

Many new friendships have been formed through our work and our feedback is positive in that we are not seen as being an exclusive club! One of the main problems faced by parent/carers is that of isolation and we are able to help break the cycle of loneliness by offering mentoring and support from someone who has understanding and insight through personal experience.

Dear Member,

This year has flown by, with us all carried on a wave of enthusiasm and hard work. It had not occurred to the committee members until we sat down to reflect upon our achievements, exactly how busy we have all been. When Lesley Ellerby and Charles Huddleston prepared the document (Parent & Carers Testimony-PACT) in 1999-2000 outlining the problems facing parents/carers; I really do not think that any of us had any idea how far it would lead us. Nearly two years on we are an organised group who have the capacity to network with nearly 500 parents sharing a common bond.

We are not a formal 'institution' and are perceived and used differently by many people. To some parents we represent an information source. To others we provide direct contact to support and help whenever we can. Many are aware that we are able to make our opinions heard in many arenas and use us accordingly. Some just know we are there, hopefully read the newsletters and aren't too surprised when we telephone or write to them canvassing opinions!

My thanks go to all of the parent representatives who have worked so hard over the past months to build up our reputation. No two of our volunteers work in the same way, yet all of them are crucial to supporting our work. There are no paid workers or offices and whilst all expenses are reimbursed, 100% of all monies raised are used to maintain our work on behalf of parents. There are also other parents/carers who give up their time to represent us across the City and County and on behalf of the Committee I wish to thank them.

I personally feel that one of our greatest achievements this year was to enable parents (who were bewildered by the events surrounding the management of their children being treated for epilepsy); to form a parental sub-group to engage in dialogue with the Health Trust. These parents have formed an organised, structured group which has been able to collate parental concerns and provide feedback via newsletters and a web site.

Finally, the most positive aspect of our work is that the feedback received from our members is that any representation we provide is not perceived to be tokenistic. Our representatives have been made to feel welcome and that their views have not only been listened to, but accepted as part of true partnership working.

Our main aim next year is to reach yet more parents/carers and hopefully get to know better the needs and aspirations for their children. I hope that we are perceived as being open and welcoming and remain accessible to all who choose to contact us.

Kathy Pearson
Chair

The Future

The main objective for the next twelve months is to increase our membership and widen our availability. All parent representatives have been tasked with raising our profile and encouraging membership. They will feed into groups of other parent/carers at schools, support groups and local networks. This will also be achieved by further distribution of leaflets containing registration forms. Our intention was that for the first year leaflet distribution would be fairly low key as we did not want to be inundated in our early days and potentially not be able to maintain our commitment. Part of our Lottery Funding is for translation and printing of literature and this is in progress at the moment. Obviously the web-site should provide another avenue of contact and will be updated on a regular basis. We have also been included on the **Infolinx** information systems available at local libraries.

As from Easter 2002 the **Disabled Children's Database and Information Service** begins to take form and the PCC will be very proud to be a valued partner. Many of our parents/carers have been involved in planning and shaping of this innovative service and realize that this will provide a much needed central point of reference for information. We will maintain our close links and do all we can to support the sharing of information. Also, we shall continue to emphasize the benefits of having a fully maintained database to support parental lobbying for future service provision based upon need.

We have been forging links with other parent/carer groups outside of Leicester and are exploring the possibility of becoming a national group, with Leicester PCC as the lead. Our first outside group would be known as '**Parent & Carers Council—Calderdale**' This will hopefully be finalized soon and will only help to increase our partnership principles and raise our public profile.

Any support by parents/carers is most welcome and we recognize that often time is the most important and scarce commodity available. As a family or carer leisure is often overlooked and has long been considered a secondary consideration. Thankfully times have changed and the importance of a break from the daily grind is recognized. With this in mind the PCC has decided to explore the possibility of purchasing self-contained holiday facilities for use by its members. We are looking at raising money to purchase accommodation which will be suitably adapted and maintained and will be situated at sites promoting inclusion of all children regardless of need or disability. We have a number of positive offers of assistance and will be looking for fund raising ideas in the Spring—any offers or ideas welcome.