

**LEGACY**

**The Croydon Children's Fund**

**Reflections On  
Working With  
Children With  
Disabilities**

**November 2007**

# Croydon Children's Fund

## Reflections on Working With Children with Disability

### Projects/Services which have received funding from The Croydon Children's Fund

THEME	PROJECTS	
	STATUTORY	VOLUNTARY
YOUTH CRIME	<ul style="list-style-type: none"> <li>Youth Inclusion Support Panel (YISP), Youth Offending Team (YOT)</li> </ul>	<ul style="list-style-type: none"> <li>Junior Youth Inclusion Project (JYIP), Croydon Youth Development Trust (CYDT)</li> <li>Croydon Young People's Project (CYPP), SOVA</li> <li>RUOK, Victim Support</li> </ul>
OUT OF SCHOOL ACTIVITIES/ PLAY/ PREVENTATIVE WORK		<ul style="list-style-type: none"> <li>Valley Park TOC H – Peppermint Centre</li> <li>Together in Waddon</li> <li>Croydon Community Bus</li> </ul>
WITH BME CHILDREN		<ul style="list-style-type: none"> <li>Beat the Street, Croydon Youth Development Trust (CYDT)</li> </ul>
PARTICIPATION		<ul style="list-style-type: none"> <li>Croydon Xpress, Croydon Voluntary Action (CVA)</li> </ul>
IN SCHOOL	<ul style="list-style-type: none"> <li>Reaching Out, Borough of Croydon (Education)</li> </ul>	<ul style="list-style-type: none"> <li>Place2be</li> <li>Voluntary Reading Help</li> </ul>
WORKING WITH CHILDREN WITH DISABILITIES	<ul style="list-style-type: none"> <li>Integrated Therapy, Primary Care Trust (PCT) (Group A)</li> <li>ADHD Development Worker, Borough of Croydon (Ed Phyc)</li> <li>Willow – Bereavement, Primary Care Trust (PCT)</li> </ul>	<ul style="list-style-type: none"> <li>Garwood Foundation, Rutherford School</li> <li>Croydon Mencap, (Benefits programme)</li> </ul>
PARENTING		<ul style="list-style-type: none"> <li>Parentline Plus (PLP)</li> <li>PATCH Project at Croydon People's Housing Association (CPHA)</li> </ul>

**Notes:**

- Many of the projects/services cross over these themes, but this gives some indication of their primary functions
- All of the projects/services above were funded from the outset in 2003/04 until 2007/08 unless otherwise indicated below
- Beat the Street, Parentline Plus and Voluntary Reading Help were funded from 2003/04 until 05/06
- Place2be was funded from 2003/04 until 06/07
- RUOK received a one off payment in 2004/05 and is being funded in 2007/08

## Key Messages From Children's Fund Projects & Evaluators:

- **Value the child** - see the child first, not the disability. Challenge negative attitudes about disability and don't stereotype and make judgements. Promote a more social model of disability.
- **Take into account children and young people's ideas** - ask them what they want. Consult the children, not just the parents/ carers. Need creative approaches to do this and, depending on situation, provide rewards for participation.
- **Listen to families** - let them be heard. Allow parents to make informed decisions. Give practical strategies rather than just booklets of information, and respond to parents wanting more training – they often feel professionals get training, but they don't.
- **Promote staff motivation with team building exercises and activities.** Professionals need good supervision so own personal judgements/ attitudes don't negatively impact on work.
- **People in management positions should go out to see what professionals do at the ground level and go to visit projects.** Higher management and budget holders also need to visit families to see what they are coping with.
- **Families need continuity regarding service provision** - not short term funded projects. Continuity of funding ensures quality staff stay in post and can work more effectively with families, and families are not continually asked for the same information by new staff.
- **Avoid duplication** - need awareness of what's out there. Services need to be joined up so families are not asked the same questions time and time again. Agencies need to share information with families' consent.



*Projects/Service providers discussing issues at Networking Lunch*

## Star Examples From Children's Fund Projects

### ★ ADHD Development Worker

The key aim of the project has been to develop a Borough-wide strategy for young people with ADHD and their families.

#### Three Key Successes:

- Developing a comprehensive service provision that engages with a diverse spread of stakeholders on a number of levels. Numerous new services have been locally pioneered in this field - Croydon ADHD Network, ADHD Forum, ADHD Parents Group, ADHD Family Fun-day – which should in the long-term ensure that the project informs and assists a very wide cross-section of the community.
- Training courses, workshops and literature have been developed and are offered extensively and in a wide variety of formats to suit particular contexts e.g. library loans, DVD, information packs. Diversifying the provision for parents and building an Internet resource have been identified as areas for future attention.
- The Croydon ADHD Network team brings together professionals for regular meetings around individual children's specific cases and for inter-disciplinary information sharing and planning. This is a potentially very beneficial model that could inform and influence policy.

Parents feeding into the evaluation of the project appreciated the non-judgemental professional advice and information they received during the meetings from the ADHD development worker and other professionals (such as a dietician and an Occupational Therapist) attending the meetings.

They also valued the opportunity to share their problems and experiences with other parents in a sympathetic and confidential environment. They felt that meetings helped to reduce their stress levels and build up their confidence. They also praised the ADHD fun-day and the film course initiated by the ADHD development worker as opportunities for their children to make friends and build up their confidence. Parents therefore asked for more regular fun-days and projects such as the film course to help children feeling less isolated. One parent said: This is the first time the borough has had a dedicated service – the thought of it being taken away is frightening”.

The evaluation team interviewed members of the ADHD Forum who included: Two staff of the Youth Inclusion Support Panel (YISP), one member of Children and Adolescent Mental Health Service (CAHMS), one member of the School Nurse Team and one representative of Croydon PCT about the impact they thought ADHD Development Worker had on their service. The stakeholders thought that the work had a positive impact on their service. They felt that they always received useful information from various groups and therapists, that it helped to educate parents as well as the relevant professionals and that the forum offered important networking opportunities. As a result they were now more aware of services available to parents of children with ADHD and their insight into issues around ADHD had increased. Some also reported an increase in confidence when dealing with families asking for advice and support. Stakeholders recognised the benefits of having coordination in the area of ADHD. One person felt that: “By bringing agency networks into regular

contact with one another, there is increased knowledge, awareness of roles and stronger links for clients.” The provision of the ADHD Forum and the training programmes offered by the Development Worker was most noticeable in schools – several CAMHS workers felt it is now much easier and more productive working with teachers and SENCOs (Special Educational Needs Coordinators) around ADHD issues.

Information and literature available to parents is very clear and is broken down by the different stages of diagnosis and treatment. It is important to have consistency between clients and ensure they are properly directed to other appropriate services. The parents group is seen as providing a much-needed extra dimension to the more clinical services that have typically been offered in the past.



*ADHD Development Worker: Dance Workshop*

## ★ Integrated Therapy

The project aims to broaden access to therapy services for a wider group of children with Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) and their families, and to develop a multidisciplinary approach to meeting the needs of these children.

The project works to treat the child holistically and for the Speech and Language Therapist (SALT) and the Occupational Therapist (OT) to work together and with the wider multi-disciplinary network. They have formed a range of specialist services, including specialist groups called SPOT (Speech & Language and Occupational Therapy) Groups. Parallel to the SPOT group, regular group sessions are held with parents, which also gives parents the opportunity to meet and share experiences. The frequency and length of programmes are greatly dictated by the needs of the child and the family. Much work is being carried out with broader stakeholders and professionals including regular service planning meetings, development and presentation of training material, therapeutic packages (e.g. groups and clinics) and case discussions.

The evaluation team interviewed mothers whose children had been attending the SPOT groups. The mothers interviewed all emphasised how much the children look forward to coming to the group and how much they enjoy it. They come to SPOT in the morning and all go to school afterwards. The mothers thought the workers were dedicated and suggested good strategies. They developed a customised programme for each child. They have learnt a lot about stimulation and relaxation.

The workers have time with the parents and see the children in school so the strategies can be broadly applied. One parent talked about her child responding well to a personal checklist instead of a visual timetable. Another parent mentioned how much a lap weight has helped her son being able to sit still longer at home and school.

The evaluation team also spoke to five CAMHS (Children and Adolescent Mental Health Service) workers that sit together on the Croydon ADHD Network and to the team-leader of the Autistic Spectrum Disorder (ASD) Virtual Team. The Integrated Therapy Project has increased the amount of joint working between professionals and shared highly specialised knowledge with the ADHD network, families and other professionals. The ASD team leader reported: "parents and professionals both say they get lots of ideas from their workshops to use with the children." This is making the treatment of ADHD and ASD more holistic and effective, particularly in the most complex cases for example those in the neuro-developmental clinic.

Several CAMHS workers said their work in schools had been significantly helped by the support of the Occupational Therapist and Speech and Language Therapist – advice over the telephone being the most convenient. The waiting-time needed for consultations has been reduced by the closer working relationships between stakeholders and the Integrated Therapy Team.

## ★ Mencap

Mencap helps parents with disabled children to access the benefits they are entitled to. This enables them to 'purchase' the support they need. The project has 98%-99% success rate in awards of benefit after an initial screening where 13/100 are accepted. They have never lost an appeal.

The project provides a very flexible service: by means of outreaching to existing parent groups and providing advice and support in home visits it takes clients individual needs and situations into consideration. Mencap also continuously works towards better awareness and greater understanding of issues around learning disabilities by other agencies and the public.

There is no comparable service available in the Borough. It is well documented that families caring for children with disabilities can experience financial hardship often due to one parent being unable to work. By ensuring that the appropriate benefits are claimed it helps to alleviate and reduce financial hardship.



*Integrated Therapy: SPOT Group*

## ★ Willow

In the needs assessment carried out by the evaluators with children, bereavement (death of family members and of animals) and fear of bereavement proved to be the top of many children's lists of things that made them feel unhappy in their lives. Willow works with children with life-limiting or life-threatening conditions and with children affected by the loss and change of a disabling condition and with their brothers and sisters. Willow also works with children who have experienced the death of a sibling through a life limiting or life threatening condition.

Emotional support is provided to the children, through individual sessions or group work and a wide range of methods are used to explore issues that may affect children experiencing loss and change such as drama, story, movement, puppets, art and photography.

Willow's approach is flexible and client led; they engage with children and their families to suit individual needs. Creative approaches are used, especially in situations where words cannot be found, and dramatherapy is particularly effective for working with children who are non-verbal.

In the needs assessment undertaken by Development Focus evaluators in mainstream schools the death of family and pets and the fear of bereavement was the top of many children's lists of things that made them feel unhappy in their lives.

Where necessary Willow works in partnership with schools and special schools around the disability or

bereavement of a pupil offering advice and support for staff and information and training to suit each specific context.

Willow is one of the few services nationally that provide pre-bereavement support for children.

### ★ Garwood

The Children's Fund pays for monthly creative workshops carried out with children of Rutherford School with profound and multiple learning disabilities, physical disabilities and complex medical needs. The workshops focus on enriching sensory experiences for the children.

- The project has, through innovative workshops, facilitated interaction and creative expression with children with complex and multiple disabilities. This broadens children's experiences using music, drama and arts as a creative learning media.
- The workshops build on the specific sensory experiences that different children with different disabilities can respond to. For example using colour, sound, texture, movement and light. It allows children to have more interaction and control over their reactions, for instance moving in and out of the sound-beam or switching on and off to initiate a response.
- They have a realistic involvement of parents and siblings, and community members by seeking their involvement in certain activities and events held in the school and in the community. Events have included a family barbeque and an Easter celebration in the local church using swathes of material and drama.

### ★ Junior Youth Inclusion Project

The project highlights the importance of training and educating the staff, parental involvement so that the child's situation is more fully understood, linking up with specialised agencies and having suitable transport and facilities for all their activities.

### ★ Croydon Xpress

Croydon Xpress held a 'You Matter' event to explore issues facing children and young people with complex special needs in Croydon. The event followed the style of the Xpression Zone events that ensure that children and their families have a say and that their voices are heard in the broader policy debates in the borough and specifically fed into the broader stakeholder conference on disability. Croydon Xpress workers also felt it important to work with siblings of children with complex special needs to understand their perspectives.



# Tips For Project Workers & Managers

The following analysis was carried out by project workers from a range of Projects funded by the Croydon Children's Fund about what helps and hinders the process of involving children and young people with disabilities.

## What Hinders Working With Children With Disability?

- Lack of understanding and knowledge of staff
- Fear of labelling/ stigmatising by bringing children into say a crime prevention project
- Uncertainty over funding
- Lack of suitable facilities i.e. toilet and kitchen
- Lack of support and commitment from staff and agencies
- Cognitive disability means young person cannot reflect on their behaviour and affect change if they want to
- Disability is a relative concept, and thresholds (of disability) are agency specific. Agencies do not have common thresholds
- Waiting lists are long
- Community awareness about project
- Project can get bogged down by paperwork

## What Helps?

### **On Funding:**

- Having time to put on events and publishing opportunities for involvement
- Having access to advice and support on funding and publicity
- Looking creatively at ways to promote the organisation

### **On Working together/ Sharing skills and resources:**

- Knowledge of other services so that organisations can work in an integrated way, for example Willow offers child bereavement services to schools and could support other groups that wanted this type of service, also ADHD Development Worker has produced an ADHD Booklet that is available for other projects
- Greater awareness from multi-agency staff of Integrated Therapy remit, and better support at management level thereby improving access to integrated therapies.

### **On Staff/ Organisation Capacity:**

- Organisation taking on staff with disability knowledge
- Mentoring for staff on disability issues
- Ensure adequate facilities are available for group work

### **On Parental Involvement:**

- Parents with children with disabilities lobbying for service provision – “fighting the cause”
- Ensuring that parents are represented on groups that are responsible for decisions on funding and strategic direction

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children's fund

## What is the Children's Fund?

The Croydon Children's Fund programme was introduced in 2003. The fund was primarily set up to develop services for children at risk of social exclusion in all local areas, aiming to provide better increased co-ordinated preventive services. Funding is targeted at children and young people aged 5-13 years old and also their families.

The fund is part of the Government's strategy to tackle disadvantage and inequality arising from child poverty and social exclusion, through addressing national priorities including improving school attendance and attainment, improving health (including mental health) and reducing crime and anti social behaviour.

A key element of the programme is that services are locally determined according to local need and planned in consultation with children and families from the outset. In Croydon a comprehensive mapping and consultation exercise was undertaken to find out the views of children, young people and their families and this was used in the development of the initial three-year strategy for the Croydon Children's Fund.