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ACTing to Support Parents with Learning Disabilities

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CONTENTS

Introduction	1
The Lives of Parents with Learning Disabilities	4
Recommendations	7
Overview of Three Years' Work:	
Year One	8
Year Two	12
Year Three	18
Further Reading	31
Appendices 1 and 2	33

ACTing to Support Parents with Learning Disabilities

INTRODUCTION

This project was based on the premise that “good enough parenting by people with learning disabilities is related to the amount of support available to the parents and children from social and family networks” (Family Policy Studies Centre/Joseph Rowntree Foundation 1997). The prime objective of the project, therefore, was to help parents with learning disabilities to achieve ‘good enough parenting’ with the support of volunteer parents. The project was a partnership between the Ann Craft Trust (ACT) and Home-Start Nottingham. A model of support was developed and implemented over a three-year period and currently still continues (*see guide on ‘Setting up a Volunteer Support Programme for Parents with Learning Disabilities’ available from the Ann Craft Trust*).

The overall aims were:

- To develop a comprehensive support scheme for parents with learning disabilities, to enable them to parent more effectively.
- To evaluate the scheme with input from people with learning disabilities themselves, the volunteers and the referrers.
- To produce a report, with recommendations, from the evaluation of the scheme.
- To disseminate the recommendations of the report as widely as possible.

The final report begins with answers to the specific points identified in the guidance supplied by the Family Support Grant Programme; then considers certain aspects which characterised the lives of parents with learning disabilities; it is of importance to be aware of these when supporting the parents and their children. Recommendations are included.

An overview of each of the three years follows, with evaluation of the key objectives, both qualitative and quantitative, along with comment from the parents, volunteers and referrers in years two and three.

- **Methods of evaluation on the success of the project – qualitative and quantitative results**

As already described, the evaluation was both qualitative - as in the interviews of families, volunteers and the referring agents - and quantitative (see the statistical information within this report).

All staff members and volunteers attended training courses (by ACT, Home-Start Nottingham and Dr Sue McGaw, Cornwall and Isles of Scilly Learning Disability NHS Trust) to prepare them to work with parents with learning disabilities – this averaged 15 people. Some members of staff, volunteers and parents with learning disabilities also attended a course run by Advocacy in Action – 15 people were generally present, and included two parents with learning disabilities; a crèche was available for the children.

All those present declared their satisfaction with the courses. They felt that they had learned a great deal, particularly from the person with learning disabilities who carried out part of the training for Advocacy in Action.

- **What changes have been measured in:**
 - **parents' attitudes to children and to parenting**
 - **parents' knowledge**
 - **parents' self esteem**
 - **parents' behaviour and parenting skills/practice**
 - **children's behaviour and self esteem (where appropriate)**
 - **children's views of their parents (where appropriate)?**

This project was set up to help parents with learning disabilities to parent their children satisfactorily, and to enable the children to stay with their parents, we were therefore primarily concerned with the first four objectives on the above list.

Through the reports from the volunteers to the co-ordinator and the interviews held by the ACT consultant, it was felt that the parents were very anxious to care for their children but they were often fearful of being seen as inadequate. They were generally very willing to accept support and advice. It is, of course, part of their difficulties that they may not have much knowledge or self esteem, which has a deleterious effect on their parenting practice. When the link with the volunteer was well established, and with the support of Home-Start group work, most of the parents felt much more confident and showed willingness to deal with problems they had avoided before. The referring agents were also pleased with the help offered to the families and felt that having the support of a volunteer parent strengthened the parents. Many of the mothers, in particular, have shown more confidence and self-esteem.

This project did not measure the behaviour of the children or their self esteem but, through work with the Play Centre and at the Home-Start groups and outings, the behaviour of these children was noted to be very good; they seemed to play happily and enjoyed their interactions with other children. The Play Centre programme, in particular, addressed the question of child behaviour and discussed with the parents how they could best deal with any difficult behaviour.

- **How were these changes measured? Is there any evidence for a lasting effect of our intervention over time?**

This project is seen as a long-term initiative and it is difficult to measure any lasting effect of Home-Start intervention at this stage. However, over the period concerned, a number of families had their children returned from care; had children de-registered with respect to child protection and had care orders reduced. The project will continue to work towards maintaining this progress, but at this stage, we would like to record that working with parents with learning disabilities takes patience and a consistent approach, with careful repetition of advice and information to ensure lasting effects. This takes time.

- **Have there been any negative or unexpected outcomes?**

There have not been any negative outcomes as such, but there have been disappointments. On a number of occasions, it was not possible either to make a link with a parent(s) or maintain a link because of the fact that they failed to keep appointments, this despite considerable persistence by the co-ordinator. On one occasion it was felt that the mother had been

persuaded to have a volunteer that she did not really want, on another that the parents just wanted to keep out of touch with everyone and anyone who might perceive that they were not coping. At other times it was just felt that the parents had no concept of time or need and, in view of the value of trained volunteers, it was just not possible to expend further effort on families where volunteers were not seen to be of value. Sometimes this was a considerable disappointment to all concerned.

One happier, and rather more unexpected outcome, was the value placed on the volunteers by the referring agents. We had believed that this would be helpful but had not anticipated quite how pleased the social workers and health visitors would be to have this additional support for the families in their care. Without exception the referring agencies wish this project to continue.

- **What proportion have come from minority ethnic backgrounds?**

With regard to the take up of our service by black and minority ethnic groups, Home-Start has a non-discrimination policy, with a history over twenty-five years. The referring agents were aware of this and that, of course, it applied to this project. However, all the families referred to the project have been white British.

- **Did you involve volunteers in the project work?**

The volunteer parents were central to the work of this project. Volunteers were linked to each family and visited their homes to offer support and advice.

- **Sharing Good Practice**

The work of this project has been shared with many agencies in Nottingham and Nottinghamshire through the ACPC multi-disciplinary training programmes over the last two years and is to continue next year. Papers on the project have also been presented at a number of conferences over the past two years and will continue throughout the next year. Practice relating to work with parents with learning disabilities will be presented to Home-Start nationally at the National Convention in April 2005 and regional Home-Start seminars are currently being planned (see page 18).

THE LIVES OF PARENTS WITH LEARNING DISABILITIES

This project has not only proved to be of value to the parents with learning disabilities and their professional supporters, but also instructive to those of us who have been involved. We have learned a great deal, through working alongside the parents, and sadly we have also seen at first hand the difficulties they face in the community.

In the first place, their difficulties are not just - and, I would maintain, a great deal less - to do with having a learning disability, but far more to do with the fact that they are rarely supported or even accepted by the community, and sometimes even their families. Almost all the families with learning disabilities have faced disparagement, if not downright hostility. There have been windows broken, doors damaged and even physical attacks. One friendly and co-operative family was so intimidated by physical abuse from hostile neighbours that they fled to the mother's family. In their absence, their home was broken into, a fire in the children's room destroyed their posters, a doll's house was smashed, the parent's clothes were ruined through defecation, and every item of any value was stolen. The family, who had been coping really well with the support of the volunteer, was devastated, and it has taken another year of hard work to restore their confidence in a new area where finally it looks as though they have a kind neighbour and a helpful local shop.

If this was a single episode, perhaps we could regard it as an unfortunate aberration, but sadly it is not. In addition, not only are the parents targeted for abuse, but also their children are bullied at school (whether they show any signs of disability or not), which adds further strain to their parents' lives. Some schools have been very helpful, but a not insignificant number have given little attention to either the needs of the children or their parents - these families seem all too easy to ignore.

One of the conclusions, which followed from this work, is that volunteers are very valuable in such situations. They can be alongside the families during these periods of crisis, giving comfort and support, helping them at meetings with social services, or schools, writing letters to housing departments and even approaching the police where appropriate.

In the end, however, this is just attending to the problems once they have arisen. It is clear we must work much harder towards changing attitudes and educating the public - particularly our children - that being different is something to be appreciated and not scorned. Nottingham has a policy of integrated schooling, so there is a great opportunity to educate all the children to value the children with special educational needs at their school, and also to understand the needs of children who may have learning disabled parents. Much support is offered with respect to the academic curriculum, far more support needs to be given with respect to social issues. Teachers need to encourage other children to offer support - an attitude of co-operation benefits *all* children. Schools also need to make sure that children who have parents with learning disabilities are given information in a form that their parents will understand and, where relevant, ensure that help is offered with homework. Some of these children are of considerable help to their parents and, as they grow older, a good deal of their time may be given towards tasks in the home, it is therefore tragic if they also become victimised.

A second point of discussion has been to do with how the parents are perceived by the authorities. Most of the statutory workers who referred families to Home-Start have been of considerable support to the families, but there has been some evidence that parents with learning disabilities are subject to a far greater degree of scrutiny, which is not always to their advantage. They should not have to provide evidence that they are better than the norm! While it is of value to have a clean tidy home, there was sometimes considerable emphasis on

this; and one mother faced disapproval because she smoked in the house. This is hardly confined to parents with learning disabilities, and while some parents might not be worried by such criticism, this mother was upset and anxious.

The parents talked a lot about how well their children were doing, how forward they were, anxious to be seen as good parents because they were fearful of losing their children into care, and indeed, a number had already lost more than one child through adoption or fostering. One young mother's baby had been taken from her at birth and, although now returned, she worried continually. It is, of course, true that some parents with learning disabilities will not manage the difficult and demanding role of parenting but they do deserve a chance to try without the feeling that they are being continually judged. This is where the role of volunteer parents can be so valuable, they are there to support and encourage: working alongside the parents, they are not seen as a threat.

A third point has been the realisation that there is seldom an holistic approach which would encompass the whole family: teams for disability, children in need, child protection, and also education do not appear to work together in a way that would benefit the family as a whole. One social worker told me that she could no longer even make a referral direct to the adults' team: 'it has to go through the GP... we do the work with the child and nobody does anything with the parents...' We felt quite strongly that a 'family' key worker would be of real benefit to parents with learning disabilities and their children. It would also help if a transitional worker, perhaps someone from Connexions, was available to help the older children.

In addition, sometimes many workers are involved, so many that the parents may not be at all clear who they are or what they are there for. As well as those listed in the above paragraph, there may be midwives, health visitors, housing workers, outreach workers for family centres and nurseries, along with Sure-Start, Mencap and other voluntary organisations (I do not exclude Home-Start!). And while this might seem a great deal of support, it can be counter productive and confusing for the parents. Again, it would be of real value if there were one key worker who could liaise with all the others and ensure that there was a consistent approach. It seemed obvious that while the workers may have the best intentions, they may not have been working to the same criteria – different disciplines may have a different agenda.

Another discussion we have had over the last two years concerns an outcome, which we had not anticipated; this was the number of large families referred to the project. We had assumed, wrongly as it turned out, that referrals would come for new mothers, perhaps expecting their first baby, or perhaps a baby and toddler. We did have a few of these, though even here, it was often a mother (and sometimes a father) who had already had children removed, so they could not be seen as beginners. It had been hoped that the volunteer would help the new mother and father with childcare: offering encouragement on a regular basis so that a good pattern of parenting would be established. The fact that many families had several children, two with five and seven respectively, made this way of working much more difficult. These families certainly needed and valued volunteer support, but it was much more a question of averting difficulties and plugging gaps than setting up good systems which would result in long term parenting skills. One of the volunteers, however, did manage to set up a way of paying bills and attending appointments for one of the largest families. This at least ensured that the parents and children got to clinic and hospital appointments.

We had a number of comments from referrers with regard to these 'late' referrals: 'well I would actually like to see parents with learning disabilities flagged up when the mother first was pregnant, and we could get whatever they need for support in place prior to birth... we

are not very good at ensuring that they have got the support before the babies come along... They get into difficulties, problems arise and then obviously sometimes the children end up with children protection orders... I feel it is too late once they have the child and the problems exist – something needs to be in the pipeline before that.’

RECOMMENDATIONS

- Making an early identification of a parent or parents with learning disabilities prior to the birth of the first baby – an early programme of child care and support would help to establish a good pattern of child care.
- Establishing a protocol for inter-agency working through the appointment of a ‘family’ worker, who would have key responsibility for the whole family, (parents and children), liaising with other workers and including the family in conferences to set up support.
- Ensuring that a consistent programme was agreed with the family and all the involved workers, both professionals and voluntary, so that they would be working with the same principles in mind and towards the same result.
- Keeping good records, along with regular reviews to identify good practice and reveal gaps in services.
- Keeping, readily available, a list of resources identifying workers and organisations that can help support parents with learning disabilities.
- Establishing outreach work to ensure the inclusion of parents from other ethnic groups in supportive work for parents with learning disabilities.
- Continuing a programme of support by volunteer parents to work alongside parents with learning disabilities. This is not seen as provoking anxiety in the parents, and is also of value to the professionals.
- Establishing a multi-disciplinary programme of training to ensure that staff and volunteers are aware of the needs and difficulties of families with learning disabilities, and which indicates ways of offering support that does not undermine their confidence and self-esteem. These training sessions should include people with learning disabilities (courses have been set up in Nottingham and Nottinghamshire ACPC training programmes).
- Finally, and most challengingly, attempting to establish a programme of work with local communities and schools to try and improve the way that families with learning disabilities are treated. If we are to change attitudes, we must start now – with the children. In relation to one of the questions posed in the guidelines: It is not only the attitudes of the parents with learning disabilities towards their own children we must be aware of, but the attitudes of the outside world towards them.

OVERVIEW OF THREE YEARS' WORK

YEAR ONE

The ACTing to Support Parents with Learning Disabilities Project made a positive start. Volunteers were recruited and trained in the first quarter (April to June 2001), and the Project Co-ordinator was appointed in June 2001 to support the work with learning disabled parents. She took up her post at the beginning of July but also attended the special training on working with parents with learning disabilities during June.

A number of meetings were held with social services and health services staff during the first quarter of year one to ensure that all the relevant personnel were aware of the aims and objectives of the project. There was a very positive response.

Two other organisations, Advocacy in Action and the Play Centre for Children were involved in the second half of the first year when the families had been linked with volunteers.

A very experienced Advisory Group (*Appendix 1*) was set up to offer support and to monitor progress. This was of great value to the project.

Progress of the Project against Agreed Objectives:

- 1. To ensure that the Project could adequately assess the quality of the parenting scheme.**

All relevant agencies, including personnel from Nottingham City Social Services Department and Health, were contacted and invited to meet prior to the setting up of the project. Many of the professionals who attended these meetings have now become members of the Advisory Group.

The Consultant from the Ann Craft Trust carried out ongoing monitoring. This included quantitative statistical data on the families, the volunteers and the referring agencies. Qualitative data monitored the progress of each family/volunteer link, identifying the success or shortcomings of the planned aims and giving careful attention to the opinions of the family, the volunteer and the referring agent.

- 2. To ensure that the scheme is providing a service that is appropriate, responsive to the needs of users and is of good quality.**

The work of the project was continuously monitored and evaluation of the results reported.

Each family had a plan of work agreed by all parties: the referring agent, the Home-Start Co-ordinator, the volunteer and most importantly, the family themselves. Monitoring of the work has been carried out by the ACT Consultant. There were regular discussions with the Co-ordinator and Home-Start Manager, along with semi-structured interviews with the volunteers and the families. With the agreement of the volunteers and the families, these discussions were tape-recorded. Continuous assessment made for a flexible approach which ensured greater overall success.

The work was presented at the Advisory Group meetings for comment and advice.

3. To provide volunteers to successfully support parents with learning disabilities.

An advertisement for volunteers, interested in supporting parents with learning disabilities, was placed in the local press, paying careful attention to equal opportunities. The volunteers were interviewed by the Home-Start Manager.

The volunteers underwent the full Home-Start Preparation Course (1 day per week for 10 weeks), and in addition attended a Workshop run by Dr Sue McGaw. Finally, they had two half-day training sessions with the Consultant, Ann Craft Trust. Home-Start Co-ordinators also attended these special training sessions. The volunteers expressed themselves as being satisfied with the training given and six volunteers became available to link with an appropriate family. There was also a later training course led by Advocacy in Action (see page 11).

Volunteers were supported on a weekly basis by the Co-ordinator, who was recruited by Home-Start Nottingham and the Ann Craft Trust for this purpose. The Co-ordinator was supervised by the Scheme Manager on a monthly basis.

4. To ensure appropriate referrals to the scheme by all relevant agencies.

Personnel from both Social Services and Health, and associated workers were fully committed to the work and selected members joined an Advisory Group. This group, along with the volunteers collaborated on the preparation of the Referral Form, Planning Form and the form, which the family completed, with the help of the Co-ordinator. These forms were based on the model already used by Dr Sue McGaw for her work in Cornwall. The forms were approved by the professionals and volunteers and met the needs of the families. Copies of the forms are included in the guide on 'Setting up a Volunteer Support Programme for Parents with Learning Disabilities'.

The Advisory Group discussed the appropriateness of referrals and it was clear that far more referrals would be made than the project could accept. It was decided that Home-Start had the relevant experience to judge which families would be most likely to benefit from the support of a volunteer, but following completion of the referral form, there was discussion with the referring agent and the family concerned.

5. To provide support for five to six families.

The first five referrals were made and the Co-ordinator assessed the referrals and visited the families.

Once a decision was made that a family could benefit from the support of a volunteer and the family had agreed, the Co-ordinator selected the most suitable volunteer and identified, for both the volunteer and the family, the specific help that the family needed, always keeping in mind that Home-Start's first aim is to befriend and support the parents.

The enhancement of parenting skills, along with the positive development and safety of their children was regularly monitored by Home-Start. Families were consulted as to how they felt about the support of the volunteer and whether they felt more confident about their parenting.

Comment on the First Year

The first year was completed satisfactorily, although it became clear that linking the families was going to take longer than originally envisaged. It was felt, however, that it was very important to ensure that the preparation was thorough and that the procedure from referral to linking was given sufficient time to be certain that the families fully understood and agreed with volunteer support.

Regular meetings of the Advisory Group were held throughout the year which kept all relevant personnel fully informed about the progress of the project.

Home-Start Volunteers were linked with the planned five families, while the Co-ordinator supported a sixth mother. The two children of this mother were in foster care but it was hoped that Social Services would allow her to have her children back home (family 2). This mother attended all the training/consultancy meetings held with Advocacy in Action (see below), and greatly benefited from having the support of the co-ordinator at case conference meetings. If the children are returned, volunteer support will be provided. In one case (family 5), following a number of visits by the co-ordinator, it was decided that a volunteer could not be linked with this single mother because the grandmother, who was also involved, was not in agreement. A further referral was accepted and linked (family 7). Brief notes on the families follow. They are known by number only to preserve confidentiality.

1. Father and mother, both with learning disabilities; two sons under 5, the younger has learning and physical disabilities.
2. Father and mother, both with learning disabilities; two sons under 5, the elder has Fragile X syndrome. The father, however, has left the marital home and the boys are currently in foster care.
3. Single mother with learning disabilities; one son and one daughter, no obvious disabilities.
4. Father and mother, both with learning disabilities; one daughter and one son. The daughter is partially blind.
5. Single mother with learning disabilities; one son and an expected baby.
6. Father and mother, both with learning disabilities; both also have health problems. There is one son and two daughters. The son has a learning disability.
7. Father and mother, both with learning disabilities; four sons and one daughter. The four school aged children all receive extra help at school.

Ethnic Background: All the parents are white British.

Referral Agents: Three Health Visitors and four Social Workers.

Volunteers Provided: Families 1, 3, 4, 6 and 7 linked with volunteers.
Family 2 supported by the co-ordinator.
Family 5 **not** linked because it appears that the grandmother wishes to support the mother herself.

Advocacy in Action

Following discussion, it was decided to delay the full involvement of Advocacy in Action until the families had been linked with volunteers, so that the families, if they chose to do so, could participate in the training and consultation. This was a wise decision because two of the mothers in particular attended every session and visibly gained in confidence, finally being able to say in a group setting how they felt about caring for their children and the responses they had received from the statutory agencies. One of the mothers brought her small daughter to the Home-Start crèche, and although they had never been separated in this way before, it was a tremendous success for both of them. The mother now feels able to leave her daughter with someone else without the anxiety that her daughter would be distressed or that she would be judged inadequate, and the little girl participated in this new experience with every evidence of enjoyment. The other mother in the group displayed a talent for expressing feelings in pictures which, it is hoped, will be developed for the help of other parents in the future; Advocacy in Action have expressed their wish to involve her in some future training.

The Play Centre for Children

The Play Centre for Children remained involved with the families in year 2 setting up a short programme of work with them.

Qualitative data was collected by tape-recorded reports during monthly meetings between the ACT Consultant, the Home-Start Manager and the Project Co-ordinator. Interviews with the referral agents, the volunteers and the families themselves (with their agreement) commenced in Year Two. A base line was established at the beginning of the project through the completion of a referral form by the referring agent, a form completed by the family referred with the help of the co-ordinator, and finally a planning form for the volunteer to work through with the family.

YEAR TWO

The ACTing to Support Parents with Learning Disabilities Project maintained steady progress. Regular meetings were held between the project co-ordinator and the research consultant and between the co-ordinator and the volunteers, and the co-ordinator made regular visits to the families to ensure their satisfaction with the service Home-Start was providing.

Progress of the Project against Agreed Objectives

1. To Provide Support for up to Ten Families over two years.

The Co-ordinator visited twelve families in the last year. Most of the links, once established, have been extremely successful, but there was one difficulty which, though foreseen prior to the project has, on occasion, proved impossible to overcome: that of ensuring the parent will be at home when the co-ordinator and/or the volunteer visits. With three of the families, despite considerable persistence by all concerned, it was not possible to continue the link because the parents/mother was never in. Sometimes, of course, this is the parent's way of saying they do not want a volunteer, but it is also true to say that for some people with learning disabilities, knowing the time is a difficulty in itself. For example, one mother, who was felt to really need (and she said she wanted) a volunteer was almost never in. It took a number of visits for the co-ordinator to find her at home when she was trying to make the initial assessment visit, it took even longer to finally link a volunteer, and subsequently over many weeks the volunteer only found her at home on one occasion. This is very discouraging for a volunteer and finally, with regret, it was felt that the volunteer could best be used by linking with another family.

2. Evaluation of the Scheme to Provide a Model of Good Practice to be Disseminated in Year Three.

As detailed above, the ACT consultant carried out evaluative interviews during the second year; the first interviews were with the volunteers, then families currently linked with a volunteer were interviewed and finally the professionals who referred these families to the project were interviewed. All of these interviews were taped. The project co-ordinator was present at the family interviews.

Some dissemination of the work of the project, which was not expected to operate until the third year of the project began in year two. During meetings held with members of the Health Action Zone in Nottingham, the consultant was asked to assist with multi-disciplinary training for both city and county professionals, so that information on the early recognition of the needs of parents with learning disabilities could be passed to social workers, health visitors, community learning disability teams, family and day care centre workers and members of the voluntary sector. Working alongside a clinical psychologist and a community nurse, four training sessions were set up; two for the city and two for the county of Nottingham. The co-ordinator of the project also contributed to this training, along with Advocacy in Action. The workers who attended the training days showed considerable interest in the project and felt that the support offered by Home-Start in enabling parents with learning disabilities to cope with the, sometimes, complex task of bringing up their children was of considerable value.

Links with Other Organisations: Informal discussions about the project were held at meetings of the National Working Group on Child Protection and Disability, and by the consultant with

professionals who have heard about the project and expressed an interest, the latest being Leicester Mencap.

Links also continued with Advocacy in Action who provided training and support for the project and the Play Centre in Nottingham which provided courses on parenting for the parents with learning disabilities being visited by Home-Start volunteers.

3. To Provide Additional Volunteers to Support Parents with Learning Disabilities.

Volunteers continued to be trained by Home-Start, and a further two volunteers joined the first group to support parents with learning disabilities.

4. To Ensure Appropriate Referrals to the Scheme by all Relevant Agencies.

As already noted, an Advisory Group, which included members from both social services and health services staff was set up at the beginning of year one. During year two a number of referring agents were interviewed. These staff members came from both social services and the health service. In view of their satisfaction with the project, referrals continued to come forward. Regular meetings were held throughout the second year. This ensured that all relevant personnel were kept fully informed about the progress of the project.

Report on Families for Year Two

1. Mother and father with learning disabilities; two sons under 5, the younger has learning and physical disabilities:

This family was linked from November 2001 to March 2002. The link was ended because they failed to be at home for a considerable number of pre-arranged appointments. The volunteer was very anxious to support this family but finally it became clear that they were trying to avoid all contact. They did not keep appointments with other agencies either.

2. Mother and father with learning disabilities; two sons under 5, the elder has Fragile X syndrome:

This family has continued support from the co-ordinator because the two boys are still being fostered. The father has now returned to the home and the boys come home for up to two days each week while the parents are being assessed as to whether they can have the children back. A court hearing is to be held to make a final decision.

3. Single mother with learning disabilities; one daughter and one son, no obvious disabilities:

This single mother was referred in October, and following a number of failed visits throughout November and December, the co-ordinator finally met the mother in January. Again after a number of attempts, the volunteer was linked in February. The volunteer, despite a number of visits, never managed to see her again, and regretfully the link was abandoned at the end of March.

4. Mother and father, both with learning disabilities; one daughter and one son, the daughter is partially blind:

The family were referred in October and linked with a volunteer in November. The visiting went very well for a number of months but finally in March it began to break down, and the family failed to be in when the volunteer called. They also failed to keep appointments with an outreach worker from the family centre and withdrew their son from the nursery. There was a considerable concern about their finances, there were large rent arrears and it was thought that because of this they were trying to avoid all contacts. It was very sad that the volunteer was unable to maintain a link with this family as there are also concerns about the children.

5. Single mother with learning disabilities; one son and an expected baby:

Although it appeared at the initial assessment visit that this young mother wanted a volunteer, she was never linked. It seems that her mother raised objections.

6. Mother and father with learning disabilities, both also have health problems; one son and two daughters, the son has a learning disability:

This family was referred in November 2001 and linked in December. It has been a tremendous success. The volunteer formed a close relationship with the whole family, particularly the mother, and visited on a regular basis. The social worker was delighted with the progress the family made, particularly in the way that the mother gained in confidence through the support of the volunteer. The following statement came from a 'Looked After' Review Report: 'During previous reviews there have been discussions regarding A's need to develop more confidence in her own abilities and strengths and to develop independence in terms of activities and friends outside of the children and W (her husband). With the support of Home-Start workers she has done so and now presents as happier and more confident in her own abilities and strengths. This has clearly been positive not only for A in her own right but also for the family as a unit.'

7. Mother and father with learning disabilities, both also have health problems; four sons and one daughter, one son has learning disabilities and another son has behavioural difficulties:

This large family was referred in November 2001 and linked in January 2002. There were some very complex needs but the family accepted and appreciated the help of the volunteer who, working alongside the parents, helped with the children's school work in addition to assisting the parents with a number of problems including reading and writing deficiencies and paying bills.

8. Mother and father with learning disabilities; three children under five:

The referring agent did not pursue this referral.

9. Single mother with learning disabilities; a daughter and a son with no disabilities:

The family was referred at the end of May and linked with a volunteer in June. This was a very successful link, the young mother was very isolated in the community and much appreciated having a volunteer to talk to, and help her with her very bright but somewhat

difficult to manage young daughter. The volunteer also supported her at meetings with the school.

10. Single mother, but with a partner who spends a lot of time with her; two sons, the elder has delayed speech:

This mother was referred at the end of May and linked in July. This has been a very successful link. The family was very isolated and vulnerable in their community and the volunteer's support has been invaluable. The mother was able to talk to her and share her feelings about her family and her neighbours. The referrer had some anxieties about her neglect of the children and hygiene in the home; this is still under review. Currently the co-ordinator is visiting as the volunteer's mother is very ill.

11. Single mother expecting a new baby:

New referral waiting to be linked.

There was also one family waiting assessment.

Short Notes from Interviews with the Currently Linked Families, the Volunteers and the Referrers

Family 2

Family comment: 'Yeah, we're doing everything what the social workers want us to do so we just can't wait till they say we can have the boys back ... And when I'm really upset I phone Jo (the volunteer) up and have a little chat, don't I?'

(About the Home-Start course the mother attended) 'Since I done that course, it brought me out of my shell a bit more. That time we had to do role play – they proved me people who's got learning difficulties can do things... now I met Kevin (Advocacy in Action) I was talking to him and he said not to let anyone put themselves higher than me. I put them on my level now – that helped me.'

Volunteer comment: (The volunteer for this family is the co-ordinator for the project. She held onto this referral because the children had been taken into foster care and it was not considered appropriate to link a volunteer at that time. As it has transpired, the family need a great deal of support, they see the two boys regularly now, but there are considerable number of conferences and meetings concerning the court case which the co-ordinator is best able to support her through.)

'These cause H (the mother) much distress, as the meetings are long and hard to follow. I act as her advocate and try to ensure that she is clear about what is being said and that at all times she is given the opportunity to say anything she would like to.'

Referrer comment: (The referrer is a Health Visitor). 'Jo has been a tremendous support to H, mostly emotional and as an advocate for a lot of the meetings she has been to, and reading reports to her and accompanying her to solicitors and things like that, so it has been tremendously helpful ... It has been helpful to me too, because she is able to go every week and I haven't got the time ... Jo and H have a good bond now, and its been brilliant.'

Family 6

Family comment: (about their son J) ‘He’s okay but there was bullying – Jo and Liz (the volunteer) helped me out on that because we did not know how to approach it, which I’m grateful for ‘cos Liz helped to write a letter for me. I would have just been plodding on and coping with it... and the two times I went to school and just like they were blanking me all the while saying nothing like this happened. Then we decided to make a letter to the Education Authority... Liz took notes of what I was saying and put in the proper wording. I would not have been able to do it and then we had a big meeting... seems to be okay now... no complaints about it now. They done things and we get letters like anything.’

Volunteer comment: ‘Following a meeting at the school when – finally – there has been attention paid to the fact that J (the son) was being bullied, J has not wet the bed once. I think since I have been visiting, she has more confidence in speaking to people, like at the school. If she has someone next to her, she can really come out of herself, but on her own she gets nervous.’

Referrer comment: (The referrer is a Social Worker) ‘The change in A is unbelievable. I mean previously the family would ring me about anything ... panicking about it. And we’ve gone from that to A having a problem with the school, ringing me and saying, “look I’ve got this problem with the school but I’ve sorted it out and I spoke to the school.” Even speaking to the special education teacher. The things that she’s done... I don’t think she ever thought she’d be able to do these things. The change has been huge in terms of her own self-esteem and getting out there and meeting people – its great ... And I can really rely on Jo and Liz to pick up on any of the subtle issues I might not see ...’

Family 7

Family comment: ‘He’s (the volunteer) been very helpful, we like him to come, the boys like him. He nags me to do things.’ (Said by the mother laughing).

Volunteer comment: ‘I feel it will take time to make the relationship, I listen and do not like to ask questions, sometimes I may do some prompting but I do not ask direct questions ... They do not have the television on when I visit and they welcome me and offer me tea I am trying to read to her (the little girl) but its difficult with all the children there – they all want attention. They need loving care – I do think that C and D (the parents) love them – but perhaps do not have all the parenting skills – how many of us do? But with not reading or being able to discuss things with anybody, it’s much more difficult. I feel they do the best they can – but they do need support.’

Referrer comment: (The referrer is a Health Visitor). ‘ They always say positive things about Barry (the volunteer)... I mean they are very up front and know how to say what they don’t want... because they used to be quite open with me... Is it Barry that’s helped C (the father) sort out his money? Because he seems to have this system when he gets his money from the benefits – he has a board and put all his money out on this board, and so he know what he has to pay...’

Family 9

Family comment: ‘K (her little girl) is not happy at the moment – she’s being bullied. They’ll (the school) not listen, so Pam (the volunteer) went with me and they said they’d let me know... and now I’ve heard something... She’ll (her little girl) not listen to me. She

listens to Pam... she had a paddy the other day but I paid no attention ... Pam helps me with my appointments...

Volunteer comment: ‘I like visiting M, the baby is lovely and the little girl just needs some attention. I visit at different times, so that I can see M and the baby alone sometimes and then at other times I play with K when she gets back from school, she likes the attention. I think her behaviour will be less difficult when M does this too.’

(Pam also supported Family 1 from October 2001 to March 2002).

Referrer comment: (The referrer is a Social Worker) ‘There was an incident a couple of weeks ago, she needed to go up to the school to talk to one of the teachers and Pam went with her and supported her and I think that helped her because I think that sometimes – especially when she is talking to qualified people – she can feel quite intimidated and feels that her point of view is not being listened to, so she feels Pam can advocate for her. From what M told me, she’s getting the support she requires, like on occasions when Pam’s taken K out just to give her a break in the summer holidays and things like that which she has appreciated.’

Family 10

Family comment: ‘Its good, Laura (the volunteer) visits me... she’s been ever so great. Keeps me company. Home-Start’s been ever so great – they’ve been fabulous.’

Volunteer comment: (It was not possible to interview Laura in connection with this family because her mother is very ill. Jo is currently visiting the family, but expects Laura to resume visiting soon as her mother seems to be recovering).

(Laura also supported Family 4 from October 2001 to May 2002).

Referrer comment: (The referrer is a Health Visitor). ‘Because of her learning disability, she needs Laura or Jo to give her support with all these meetings she is going to have to go to – the core group and the child protection conference... I can only say that it appears to be very positive and looking at how she was this morning, it looks as though they have a very good relationship and it seems very beneficial. For this family its (Home-Start) very, very helpful... I hope the workers that are with her will remain the same... someone like her needs stability. Sadly working with families with learning disabilities is always extremely difficult.’

The project completed its second year satisfactorily, fifteen families were referred to the project, twelve were linked, four were closed (including some families from year one) and three were not linked. During March 2003, the co-ordinator received three further enquiries with a view to referral.

YEAR THREE

Progress of Project against Agreed Objectives:

1. To continue to support five families in year three.

The project more than achieved this objective and supported eleven families in the third year. At the official end of the project on 31 March 2004, seven families continued to be supported with two more pending. An evaluation of this support follows.

2. Negotiate ongoing funding of the Nottingham scheme with local funders.

Presentations of the project were given to both the City and County of Nottingham Social Services, along with discussions with the Health Authority. All the professionals who referred families, plus members of the Advisory Committee and other involved professionals stated their willingness to support the scheme and some sent letters of support. £11,000 was obtained from trust funds and Home-Start Nottingham will continue the project, at least part-time.

3. Produce a report, including a guide which will allow other voluntary agencies to duplicate the project across England: Setting up a Volunteer Support Programme for Parents with Learning Disabilities.

This is available from the Ann Craft Trust.

4. Disseminate the report as widely as possible.

As stated previously, dissemination of the work of the project began at the end of year one when both the County and City of Nottingham ACPC training officers requested seminars for their staff on supporting parents with learning disabilities. Both the Consultant, the Co-ordinator, Advocacy in Action, along with a Consultant Psychologist in Learning Disabilities have carried out a number of training days. These sessions were well attended and the evaluation was excellent. The consultant has been asked to continue training on the ACPC Programme commencing in September 2004. In addition, the Consultant has given a number of papers at conferences including Bexley & Bromley Citizen Advocacy on support for parents with learning disabilities, the ACT conference 'Putting Research into Practice' and a workshop will be presented at the Home-Start Convention in April 2005. It is also planned that the consultant and the co-ordinator will present training sessions at Home-Start Regional Meetings.

Monitoring and Assessment

Quantitative and qualitative data were collected throughout the term of the project to ensure that quality work and an appropriate service, responsive to the needs of the users, was carried out.

Evaluation was on-going: the ACT Consultant, the Home-Start Manager and the Project Co-ordinator met regularly, as did the co-ordinator and the volunteers, and a record was kept at each meeting on the progress of each link.

During the first half of year two and the second half of year three, interviews with the volunteers, families and referring agents were carried out by the ACT Consultant to evaluate the work of the project and assess the satisfaction levels of all concerned (all interviews were

taped with the permission of the interviewees). These interviews have contributed to the content of the final report (see below for extracts from these interviews.).

Sharing Practice Locally

We have made links with Sure-Start, and all the statutory agencies in Nottingham/ Nottinghamshire involved in working with people with disabilities. We have also recently become aware of Mencap work in this area to help learning disabled parents, and have made contact with some of their workers.

Advocacy in Action

Advocacy in Action have continued their work with the project and have been involved in multi-disciplinary training to inform and support workers in the field. This includes both the voluntary and statutory sectors. They have also prepared an on-going training programme for Home-Start staff and volunteers.

The Play Centre for Children

The Play Centre for Children provided three full day sessions for the parents with learning disabilities and their children who are linked with Home-Start. Four parents and eight children were involved. The parents had special discussions with two workers to explore issues around childcare and challenging behaviour while the children had full use of the play centre and were supervised by four trained play workers. The Play Centre are continuing to work with the parents with learning disabilities on understanding and managing difficult behaviour with respect to their children.

Report on Families for Year Three

Interviews were held with all the families, the volunteers and the referring agents during the second and third years, and taped with their permission. It was clear that the families were very happy with their link to Home-Start, the volunteers were valued as being 'someone to talk to', 'she listens to me', 'he helps with the bills' and the children also seemed to enjoy the volunteer visits very much. The referring agents felt that their work load was considerably reduced once a volunteer had been introduced into the family; for example, the mother would phone the volunteer if she was having difficulties, rather than one of the professionals. The volunteers too expressed their satisfaction with the work that they were doing, it was generally felt that the families enjoyed their visits and trusted them to help when things became difficult.

As already described, nearly all the families were having difficulties with neighbours, who were abusive and in some cases this extended to damage to their properties. Many of their children, whether disabled or not, were being bullied at school, and this was a constant source of anxiety to their parents. In these cases the volunteers and the co-ordinator of Home-Start were able to offer considerable support and encouragement. In four of the families assessment took place to try and find out whether the parents would be able to look after their children, and whether their children would be safe; in one family, two of the children are still being fostered, in another family, two of the children are being care for by a family member, two other families had their children returned. Home-Start supported these families during this process. This is particularly important when children are returned home.

Group Work

In addition to the planned one-to-one work with the families, Home-Start has identified the need for including the parents in group work outside the home so that they can meet other parents and develop their social skills. The training carried out with Advocacy in Action and the study sessions with the Play Centre have been very valuable in enabling the parents to express themselves and in involving their children in play with other adults and children. The parents were also invited to attend the Home-Start Play Group held weekly during term times (one or two mothers have attended); on these occasions they also met other parents and were welcomed without reserve. These group activities have been very important in increasing the self-esteem of the parents who attended. One mother in particular, who attended all three groups, has greatly increased her ability to cope with her difficulties and express her feelings. Many also went to the Home-Start Summer Outing and one mother attended a music space course for herself and her small son – both enjoyed it enormously and want to repeat the experience. These are major achievements for parents often reluctant to join in activities with other families. In addition, the professionals who work with the families have noted their increase in confidence, and have appreciated the fact that the co-ordinator and sometimes the volunteer will accompany the families to difficult meetings, enabling the parents to understand what is going on and to express their views.

Brief Statistics on the Families Linked during Year 3

No. of Families Linked: 11

No. of Parents:

Mothers: 11, age range 23-44, with 1 age not known

Fathers: 7, age range 34-50, with 2 ages not known

Learning disabilities:

Mothers: 7 moderate and 4 mild learning disabilities

Fathers: 4 moderate and 3 mild learning disabilities

Physical disabilities:

Mothers: 1

Fathers: 0

Ill-health:

Mothers: 3

Fathers: 3

No. of children: 27 (plus 1 baby expected), age range from 7 months to 17 years

Gender: 19 boys and 8 girls.

Those on Child Protection Register: 14

Type of Abuse: 9 neglect
5 physical abuse
0 sexual abuse
0 emotional abuse

No. of children being assessed: 2

No. of children being fostered: 2

Ethnic backgrounds: all parents are white British

Referral Agents:

Social workers:	6
Health Visitors:	4
Self-referral:	1

Brief Notes on Linked Families (identified by number only)

2. Mother with moderate learning disabilities and father with mild learning disabilities. There are two sons under 5, the elder has Fragile X syndrome. Both children have been fostered and are on the Child Protection Register for neglect. There is a long running court case, which should reach a final solution in court in June 2004. Meantime the parents are being visited by the Co-ordinator.

6. Mother with mild learning disabilities and father with moderate learning disabilities, both also have health problems. There is one son with learning disabilities and two daughters who have no learning or physical difficulties. This family are progressing very well. *This link has now ended.*

7. Mother and father both with moderate learning disabilities and health problems. They have four sons and one daughter. The four school age children receive extra support at school, the second son has learning disabilities, the third son has had periods of being excluded from school due to behavioural difficulties, and the fourth son is to have an operation on his palate to deal with speech problems, the eldest son and the daughter do not have any learning or physical difficulties. This family has complex needs. *This family now has a number of outside agencies offering support and the Home-Start volunteer has withdrawn with the family's agreement as it appears that he has now fulfilled the role he was assigned to complete.*

9. Single mother with moderate learning disabilities. There is one daughter and one son, with no disabilities. The children are currently in the care of her twin sister. This is not a legal decision but one arranged by social services, and the mother's solicitor is currently asking for clarification. The project has felt some reservations about the actions of the social services. *As this mother no longer has any children with her, the volunteer has withdrawn, but should the situation change, Home-Start will be willing to take a re-referral. The co-ordinator has been keeping in touch with the mother.*

10. Mother and father both with mild learning disabilities. There are two sons under five, the elder has delayed speech. Both boys are on the Child Protection Register for physical abuse. They were briefly fostered but have now returned to their parents.

12. Single mother with moderate learning disabilities. There is one son with learning disabilities and one daughter without disabilities. The son is on the Child Protection Register for neglect.

13. Single mother with mild to moderate learning disabilities. There is one son with her but she has had three previous children removed. Currently her son is on the Child Protection Register for physical abuse.

15. Mother and father both with moderate learning disabilities. There is one son and a baby expected. Both parents have had several children removed previously for neglect and

the son was on the Child Protection Register for neglect – he has now been taken off the register and the family seems to be doing well.

17. Mother and father both with moderate learning disabilities. Father also has some mental health problems. There is one son who was originally fostered after birth, but is now at home with his parents, he is on a care order as the mother has three brothers who are schedule one offenders. This was a self-referral via their solicitor. They have had two children removed and adopted.

18. Mother and father both with mild learning disabilities. There are seven children from 4 to 18 years, four boys and three girls. The eldest daughter has now left home, the second son and one of their twin daughters have learning disabilities, the others do not have learning or physical difficulties. All the children living at home are on the Child Protection Register for neglect. *The volunteer has now been withdrawn as the mother was very rarely there when she visited. In addition the youngest child is now going to school. Interestingly this mother had a Home-Start volunteer a number of years ago and thus was happy to have another one, but now that the children are older and at school, she seems to go out a great deal. Her husband is seldom there.*

19. Single mother with moderate learning disabilities. She has one son. She was visited by the co-ordinator of this project but as there was no volunteer available, she was supported and linked by another Home-Start co-ordinator. *Not interviewed by the ACT Consultant in relation to this project.*

Short Notes from Interviews with the Currently Linked Families, the Volunteers and the Referrers

With regard to the families, most of the interviews involved discussions about their family situation, their children and daily life, the short notes here outline their current position, and then pick out specific comment that identifies what has been of particular help, how they felt about their volunteer and Home-Start. The volunteers were asked about how they felt about the help they were able to give, and referrers were also asked whether they felt Home-Start had been able to help the family in their care.

Family 2

The parents are waiting to see if the court will allow them to have their two sons back, or keep to the status quo, ie. having the boys with them for two days a week, while they spend the rest of the week with the foster parents. Social Services have applied for the boys to be adopted. Considerable anxiety was expressed on the original referral about the health and development of the boys, along with worries about hygiene in the home. There were also concerns about the mother's health and the family's isolation and vulnerability in the community. It is fair to say that most of these anxieties still exist, though to a lesser degree. The compromise of foster and parental care has seemed to work, and although the parents still want the boys back home full-time, they have settled into this way of working without much difficulty. Adoption is a much worse scenario for them and upsets them greatly. The home has improved to some extent with both parents trying to keep some order. They are somewhat less isolated and the mother attended Home-Start group meetings with every evidence of pleasure. The Home-Start co-ordinator accompanies the family to meetings and to the Court hearings.

Family Comment: The mother: ‘... we just wait to get the boys back. I’m so stressed, I don’t know whether I’m coming or going.’ Re. Home-Start: ‘I have more support for me, I can talk to Jo. I can trust Jo. I can’t trust very many people. Earlier – with the disability team, there was another Jo. I trusted her but – she, well I don’t trust her no more. She really upset me, so I can’t trust her.’

Volunteer Comment: ‘...the Social Services still want adoption and I think perhaps they are losing sight of what is best for the boys, who are close to both their parents and their foster parents. In fact the youngest boy has been with the foster parents since he was a baby, and to move them again to adopted parents is unlikely to be beneficial to them... I think that the fostering with the parental visits are a good compromise.’

Referrer Comment (Health Visitor): With regard to the anxiety of Social Services about the disorganisation within the home: ‘...they’re living in such a small house, that somebody like you or me would have difficulty in being organised within that space, with very little storage and a very small living area... without Home-Start, they would be in a worse situation. I always feel that Jo has taken on the role that I, possibly, would be maintaining... I know they are getting good support from her... oh yes, I’m sure, that one-to-one support is what they need.’

Family 6

The family was referred because of anxiety about the care of their son, who has learning disabilities, their need for support with reading and writing, and their vulnerability within the community. They have made tremendous progress, despite great stress and anxiety when they were attacked by neighbours. The parents are very supportive towards each other and their children; they have also had difficulties with the bullying of their learning disabled son and their elder daughter, but have now learned to deal with this in a very positive way. They made a strong connection with the volunteer and this factor was of great importance in their recovery during a very difficult period in their lives. Their last child has now started school and it was felt both by the family and Home-Start that they were now functioning very well and could do without the volunteer’s regular visits. They said, however, that she would be very welcome to come and see them any time!

Family Comment: About the volunteer, the mother said: ‘she’s been lovely. Liz has been great. She helps us a lot. To me, we’ve had more support through all what we been through from Home-Start than all the authorities what gets paid for doing it. Liz did wonders too... well, we went through a lot, didn’t we? She got the backlash when we was in right tatters and mmm, she right boosted us up. She says - come on, we’re not going to let it get to us. She did help with ringing the authorities and finding out what rights we had. She got in touch with the police for me, didn’t she?’

The father said: ‘She’s one of the kindest people what can walk in here. She’d sit down and if there was a problem, there’s not a way round that she can’t sort out. If she can sort it, she’ll do it, if she can’t do it, she’ll find a person what can tell how to do it.’

The mother added: ‘She used to say ... ‘I’ll get on to them tomorrow, but you’ve got to help me out as well...’ (Liz was very conscious that while helping the family, she needed to encourage them to help themselves, and she was very successful in this approach.)

Volunteer Comment: ‘I think it has been good because when I think how they was when I first went to visit, especially A (the mother) to what she is now. I have seen a big change in her. You know what she went through with the school – when they went to another school – H (the older daughter) had a bit of an upset and she went home and told them about it. Her Mum went straight down to the school and spoke to the teachers and sorted it all out...and,

you know, whereas before she would have stayed at home and sat being worried about it and panicking about it, being anxious, but she went straight down and dealt with it... she was really proud of herself for doing that.'

Liz has also visited families without learning disabilities and was asked how this compared with her current work. She said: 'I don't know...well, I think the way I communicate and the things we do when I've been round... but I think with them I felt very comfortable with them...its been quite honest. And they've always known I am a Home-Start volunteer and they've never misinterpreted my role... But it was good for me as well, I've really enjoyed it.'

Referrer Comment (Social Worker): '...they've had a lot of problems with the house, they were both physically assaulted in the garden and they had to move and Home-Start have been really helpful because when I'm here ringing housing, I can't be there so the Home-Start worker has been at the house. And A was quite anxious about going back to the original property in case there were people around – to get clothes and that and I think the Home-Start worker went with her. They do rely on Home-Start, and it's helped me a lot really. I can get on with things without constantly going out to them... this incident put them back a little bit which is understandable, but A's (the mother) confidence in her own abilities had just grown and the course work she has gone to at Home-Start helped a lot... I have been involved with the family for four years, and the importance of Home-Start is the consistency... well, I mean we are paid to be there but the fact that the volunteer is not...'

Family 7:

This family has five children and were referred for a number of complex difficulties; the children had some educational problems at school, one has learning disabilities, one has behavioural problems and one has speech difficulties; there was also concern that the children did not get to school or nursery; both the father and the mother have health problems in addition to their learning disabilities and need help with reading, writing and dealing with appointments. There were also two house moves while Home-Start was involved and this has been an ongoing pattern due to hostility in the community. This presented the volunteer with a significant challenge, particularly as the link was made when there were already so many children and it was difficult to alter the pattern of parental behaviour. One of the anxieties that Home-Start felt was the fact that the third son 'D' seemed to be scapegoated by both parents, this was registered by the volunteer who tried to model some appreciation of this young boy.

Sure-Start has now taken up this family, the youngest child is attending nursery, and after two years of really difficult work, it was felt that Home-Start could now withdraw.

Family Comment: The mother said about the volunteer: 'yes, he's been reading letters and reading with the kids.' This interview was very limited because a couple of local teenagers arrived and although they did not pay much attention to the parents, I felt that discussion about the family situation was not appropriate. The parents seem to like the volunteer's visits but it appears that he is valued most by the children.

Volunteer Comment: 'I felt I had been making some progress but since they moved house, they seem to have given up... I was disappointed because D (the scapegoated son) brought his book to me and had picked up some complicated words, and then the disappointment on his face when, after he told his Dad, once again he was rejected... of course with his parents having their own reading difficulties, they cannot help him... I feel sorry that I cannot do more, but perhaps they need more help than Home-Start can give them?'

The co-ordinator said that the volunteer was very conscientious in his work with this family over a period of two years, and it was with his support that D had been assessed. The volunteer has now been linked with another family.

Referrer Comment (Health Visitor): ‘Home-Start has been very helpful with this family, they liked the volunteer’s visits, though C (the father) likes women best! ... I am not happy that they do not have any social work support, I think they should be registered as ‘children-in-need’ ...they are always being targeted by the neighbours and this affects the children too, though I think they are happier back in this neighbourhood because they know more people here... I think they have improved over the last year but they still need support of some kind, and probably always will... but this project has been helpful to parents with learning disabilities. I think it is very important because there is often nowhere else to go...’

Family 9:

This is a single mother with moderate learning disabilities, who has had her two children (now aged 7 and 3) removed by social services, and fostered through an informal agreement with her twin sister, who has no children of her own. We have had considerable anxieties about this arrangement as the twins do not get on, and it is left to the twin sister to decide when, how often and for how long the mother can see her children. It has been stipulated the mother cannot see them on her own. The twin sister was offered a house if she took the children and the little boy was offered a nursery place – this was not offered to the mother. A solicitor is now acting on behalf of the mother to try to establish her rights. Until this has been resolved, the volunteer has been withdrawn. Should the mother have the children returned and wish for a Home-Start volunteer again, a re-referral would be accepted.

Family Comment: About Social Services: ‘Social services aren’t listening. I’ve rang them up and they put the phone down on me...’ Understandably, it was very difficult to get the mother to talk about anything other than her difficulties with social services and seeing her children, but she did indicate (nodding) that she liked the volunteer’s visits.

Volunteer Comment: Re. the mother and her twin: ‘I know they have arguments... and once when I was there S (the twin) said I don’t want M (the mother) seeing T (her son) without her daughter being there – which means when her daughter is at school, M can’t see her son during the day... this does not seem fair... and then there’s the debts that S has got... I worry about it all.’

Referrer Comment (This was the Senior Social Worker, not the referrer who was on sick leave): ‘I know M (the mother) said that the volunteer was a marvellous help, she was an enormous support, she felt she could talk to her... and she felt she needed that support and it was helpful to her, and to be honest with you, because there is a lack in the children’s services and the adult services, it was a Godsend she were there...’ Re. the removal of the children: ‘its what’s called a private arrangement fostering between them. Section 9 of the Children Act, it will just be a private arrangement between them.’

Family 10:

There were concerns about the hygiene and household tasks, along with safety in the home, and both the isolation and vulnerability of the family in the community. The front door had been smashed and the home broken into and things were stolen. The police also had to deal with a threat to fire-bomb the house. Both parents have mild learning disabilities and the elder son has delayed speech. There was anxiety about physical abuse – perhaps rough

handling, or some non-accidental injury – and both children were put on the Child Protection Register. They were also fostered briefly, but as the parents co-operated fully with the authorities, the children were returned. Throughout Home-Start was fully involved.

Family Comment: Mother about the volunteer: ‘J’s helped me out a lot, come and talked to me and at meetings... and that’s helped me a lot, because I get very upset and very shaky. I don’t get loud but I...J has to calm me down... and Home-Start’s been fabulous.’

About her new front door: ‘yeah, I been waiting for that for ages, its made the house a lot warmer and its safer, before you lock it you have to push the handle up to lock it and its got two security locks, at the top and the bottom, and I’ve got a peephole, so I don’t have to let in anybody I don’t want to. That’s the good thing about it. About her neighbours: ‘I’ve had people what’s threaten me – people what I had to have a new door for cos’ they smashed the window in my old one. I had to get environmental health up because of the noise what was happening during the night and in the early hours of the morning, really loud music and screaming and that...’

‘I’m happy at the moment, happy with Home-Start...’

Volunteer Comment: The volunteer had to give up visiting due to difficulties of her own, so the Co-ordinator has been visiting in her place, she feels the family are doing well and Social Services are happy with their progress. Step Forward, a teaching support group, have also been visiting, along with Inclusion Support to help with the children.

Referrer Comment (Health Visitor): With regard to a question about support from the other agencies and whether Home-Start is still needed: ‘Oh yes, yes, I think the emotional support’s needed, and I think when the other agencies do stop visiting, I think Home-Start will continue... I refer other families to Home-Start... but ... I think sometimes probably parents with learning disabilities, depending on how severe they are, seem to be missed out by agencies. They struggle and I think there is that gap that needs to be filled, and I think that at this moment in time, it is the voluntary sector that are taking on board the difficulties... I would like to see parents with disabilities flagged up when the mother was pregnant.’

Family 12:

This young single mother has one son with moderate learning disabilities who was on the Child Protection Register for neglect, and was expecting a baby when she was referred. The volunteer was linked just before the baby was born – this was a girl. She has no support from her son’s father and no contact with the baby girl’s father. Concerns centred around the feeding and hygiene with regard to the baby and the neglect and appropriate control of the little boy. There were worries about the mother’s ability to look after the home (her last house had been very dirty and unhygienic, though so far this new house had been in a better state), her lack of budgeting skills, and her isolation and vulnerability in the community. It was noted that she was grieving over the deaths of both her mother and stepfather in the last two years.

Family Comment: Re. the volunteer: ‘Yeah, I find it easy to talk to her and all that. I like her coming. She’s coming today at 2 o’clock... she’s helped me quite a lot with tidying up and that. And she’s gone out on walks with me... when she’s here sometimes, she’ll take A (the baby) and give her big hugs and that... And when I was in hospital, she came to see me as well, and she even came to see me the day after she was born.’

Volunteer Comment: ‘Well the neglect, I must say it’s not exactly wilful. Its not that she doesn’t care, but her way of... well she just makes perfunctory moves to tidy up, but if you do

it with her... she likes someone to do it with her. I can sympathise actually, I find it easier to get on with things that way... but you have to pick your way across the floor sometimes! In some ways I think something like a home help actually would be of more use to her than anything else!’

Referrer Comment: The original referrer has now left the office, so I spoke to the family’s current social worker: ‘We’re involved with Home-Start because, well, we’re trying to get her less dependent on the statutory agencies and get her to use community resources... and I think she did need quite a lot of befriending and I think she lost – I think it was her mother – but also to support her in her care of D (the little boy)... just perhaps feeling you’re not totally on your own, I mean for single parents particularly, it can get very difficult...D has just been de-registered though his sister is still on the register. She was registered at birth, but we are still having issues with the household being – well she seems unable or unwilling – she’s got the skills to do it, to keep the house in reasonable order... but well, its too dangerous there is so much clutter and all sorts on the floor.’

‘What I do like about Home-Start is that you do seem to get one consistent worker, what I have not liked about another organisation - maybe they are having teething problems with this particular project they are doing at the moment – but S (the mother) has had several different people in sometimes...’

Re. the mother’s vulnerability: ‘oh yes, people take advantage of her, borrow things and that, and, of course, she agrees. She does not have the confidence to say no, and, of course, she wants to have friends. So having a volunteer is helpful.’

Family 13:

This single mother, who has Asperger’s syndrome, was referred soon after the birth of her son, but she has already had three other children removed. Her son was on the Child Protection Register for physical abuse, apparently because she had children removed before. The social worker said the care of this baby was good but that she struggles with routines and has no concept of time. She keeps the home spotless but because she does things very slowly and methodically, it takes her a great deal of time, so it is often difficult for her to get to appointments, etc. Her son has now been taken off the Child Protection Register, and he is not considered to be a child-in-need, so only Home-Start and the Health Visitor now have contact. There was also some anxiety about the father of the baby who has been causing some trouble.

Family Comment: Re. the volunteer: ‘I like when she visits, yeah I do... I can get on with things while she looks after him. Not always, we’ll sometimes sit and talk and that. Not go out shopping... well, yeah, eventually...’ This mother is gentle and friendly but does not say much, though she has talked a lot to her volunteer. Her past history is very sad.

Volunteer Comment: ‘It is difficult because of her Asperger’s, because she goes very slowly with everything. As her son gets older, her ability to cope may be less. She has lost three children already because as they got older she just couldn’t hurry to do things in time – she has to do things in a certain order. She desperately wants to hold onto C (the little boy) but when he has to go to nursery or to school, it may be impossible for her to get him ready in time. At the moment he goes to Toddler Group on Tuesday afternoons, but he is often still in his pyjamas and D (the mother) in her nighty when I call.’

Referrer Comment: The referrer, a social worker, has gone on maternity leave. As there is no allocated social worker, I interviewed the mother’s health visitor.

‘I am aware of her past difficulties and her anxieties concerning the father of the baby, but I know she considers the volunteer to be a friend and having her visit has made her feel more independent... I think the project is very valuable for a parent with a learning disability, particularly if it is a mild disability, as these parents often get missed until something goes wrong.’

Family 15:

The family were referred following a residential assessment in Manchester when their son was seven months old, but both parents, who have moderate learning disabilities, have had children removed from previous relationships due to neglect (the mother had lost three children and the father had lost two). This baby was on the Child Protection Register for neglect and on an interim care order. There were considerable concerns about appropriate care of the baby, his hygiene, and emotional care and development, and also general neglect. There was also concern about the parent’s reading and writing skills, their own health care and isolation in the community.

The mother is now pregnant again.

Family Comment: Re. having a volunteer: ‘I wasn’t too keen on it at first, but then, you know – I really enjoyed it, and I go on day trips and stuff like that, and I get quite a lot of help. I meet other families and got on well with one of the families. And I’m going back to my music therapy.... We played the guitar, he (the baby) played the drum, he loved it. Soon as he knew the music was there, he went mad. When we went in there and he saw the instruments, he was on the go... There’s not really much about this area...’

Volunteer Comment: ‘Her relationship with her husband is up and down. He was arrested for hitting her and at the moment they are officially separated, but he is usually with her ...’
‘the little boy is now on a supervision order, this was reduced from a care order... she has already asked if the new baby will be removed when it is born...’

Referrer Comment: (Social Worker) ‘...this is a particularly difficult family situation and I appreciate the problems it does cause for the volunteer as well – the difficulty we had was that we had a care plan when the family returned home that meant they were being policed as well as supported because we had to be clear about what they would do when they were back in the home environment, and we had to have a situation where they were being seen every day. They have actually got a tremendous amount of support from Home-Start, and they are quite happy about this involvement – the volunteer’s role is not to actually challenge them about issues and she is very easy to get on with... but really I think these parents need to be flagged up much earlier, its too late when they have a child and the problems exist, they need to be in the pipeline earlier.’

Family 17:

This family had heard of the project and made a self-referral through their solicitor. They had a baby son aged 9 months, and the local authority had applied for a care order in respect of the baby because of concerns about his safety. The mother has four brothers, three of them are Schedule 1 offenders but she has cut herself off from her family, she herself was abused by the grandfather and has a history of self-harm. Both parents have mild learning disabilities. There were concerns not only about the safety and development of the baby, but also with regard to the parent’s emotional well-being and the upkeep of household and family routines. The couple have been together for twenty years and have had two other children removed and adopted.

Family Comment: ‘Yeah, we referred ourselves, yeah, its good, yeah, its fine.’

The rest of the interview was about what was happening to their Child Benefit, which they had not been receiving, about the court process, and about the baby’s toys, etc. They also indicated that they would like to attend the next Home-Start parenting course.

Since the interview, both parents have attended the Friday morning drop-in at Home-Start – it is quite unusual to have a father attend.

Volunteer Comment: When the family was first referred, there was no volunteer available so the Co-ordinator visited for the first few months. A volunteer has just been linked, but too recently to interview. The Co-ordinator noted that the parents have quite a volatile relationship. A few weeks ago, they were going to split up, then the father had a breakdown and was taken to hospital for assessment. Following that incident, he came home and his wife said he was fine and ‘a great husband and father’ so it seems all is well again. They have welcomed the volunteer.

There is no referrer comment since they referred themselves!

Family 18:

This, with seven children, was the largest family referred to Home-Start. The parents have mild learning disabilities, their second son has moderate learning disabilities and one of their twin daughters has ‘some’ learning disabilities. The youngest child was four years old when the family was referred, so this was expected to be a short link, and in fact only lasted for six months as the mother, who was identified as the parent needing support, was rarely in, and it was felt that the volunteer was becoming very discouraged. The concerns largely centred around the health and development of the children, particularly the youngest. Household routines and some hygiene concerns were also identified, along with reading and writing skills. There was also great concern about domestic violence, namely the violence of the second son, and sometimes the eldest son towards their mother, apparently the eldest daughter has now left home because of this. They are also considered to be very vulnerable within the community. This complexity of concerns within this family, which are of considerable duration, made it extremely difficult to identify a plan of action.

Family Comment: The mother shared a great deal with us about her children and her husband. With the exception of the second son, who seems to worry her a great deal, she appeared to accept all her other difficulties with considerable calm. She was a very quiet, gentle woman and said: ‘its nice to have someone to talk to, but when D (the youngest son) goes to school, I’ll have more time to myself. I’d like to get a job...’ She also said that although all the children were on the Child Protection Register, there were plans for them to come off.

Volunteer Comment: There is no volunteer comment as this had been ended before .the interviews.

Referrer Comment (Social Worker): ‘She needs on-going support, though Home-Start is only going to be there for a few months anyway...but really if Home-Start tried to get some of the basics sorted – it’s a small part of it really. But you never know, someone working alongside J (the mother) quite a bit...’ The volunteer would have been happy to do this, given half a chance!

At the End of the Project

When this project officially ended on 31 March 2004, **seven** families were still linked with Home-Start volunteers. These included:

No. of Parents:

Mothers: 7, age range 23-38
Fathers: 5, age range 34-50, with one age not known

Learning Disabilities:

Mothers: 5 moderate learning disabilities and 2 mild learning disabilities
Fathers: 2 moderate learning disabilities and 3 mild learning disabilities

Physical Disabilities:

Mothers: 1
Fathers: 0

Ill-Health:

Mothers: 1
Fathers: 1

No. of Children: 10 (plus 1 baby expected). Age range 7 months to 7 years.
Gender: 9 boys and 1 girl.

Those on Child Protection Register: 7

Type of Abuse: 4 neglect
3 physical abuse
0 sexual abuse
0 emotional abuse

No. of children being assessed: 2

No. of children being fostered: 2

Ethnic Background: All parents are white British

Referral Agents:

Social Workers: 3
Health Visitors: 3
Self-referral: 1

Final details on families visited during this period:

Families 10, 12, 13, 15, 17 and 19 linked with volunteers. Family 2 supported by the co-ordinator.

Families 6, 7, 9 and 18 now withdrawn.

Families 20 and 21 were visited by the co-ordinator but not linked. Family 20 was never in, and despite the fact that the co-ordinator kept the referral open when the mother went into hospital, no phonecalls or letters were answered, and again there was no-one in. Family 21 was referred as a single mother, but after agreeing to have a volunteer, she then decided against it as her partner had returned. Families 22 and 23 are waiting to be linked (as a postscript, family 23 has now been linked).

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Appendix 1

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Appendix 2

Project Staff Team

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