

**HERTFORDSHIRE COUNTY COUNCIL
CHILDREN, SCHOOLS AND FAMILIES
SELECT COMMITTEE
ON WEDNESDAY, 11 JULY 2001 AT 2.00PM**

Agenda item no:

2

**QUALITY PROTECTS MANAGEMENT ACTION PLAN TARGETS –
DISABLED CHILDREN**

Report of the Director of Children, Schools and Families

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1. Purpose of the report

At the CSF Select Committee on 28 March 2001 Members requested that this item be considered as a scrutiny item at Select Committee on 11 July 2001. The list of questions submitted by members of the Select Committee and responses to these questions are included in the body of the report.

2. Summary of Report

2.1 Disabled children were included as a new Quality Protects priority area for the first time in 2001/02. This was in response to evidence that indicates heavy demand pressures and shortcomings in the provision of services nationally. In Hertfordshire we have been implementing a county wide strategy to improve services for the last two years. This was initially funded through Joint Finance. Quality Protects and Carers Grants are now being used to cover longer term funding.

2.2 These service developments have included:

- inter-agency assessments of disabled children pilot project
- respite care places
- family based shared care services
- long term residential care places
- special needs play scheme places

Members have raised concerns as to whether this increase in resources has achieved greater equity of provision across the county, and to what extent the level of provision is meeting the needs of disabled young people to experience age appropriate leisure activities, and the needs of their parents/carers to have regular breaks. These concerns are addressed in the report.

3. Conclusion

The Select Committee is asked to consider the proposed actions contained in the main body of the report.

1. Background

- 1.1 In 1997 the Joint SSI/Audit Commission Review identified the need for a more integrated casework approach and the need to rebalance and extend services across the county. Social Services Committee in 1998 approved plans to develop and reshape services for disabled children and their families with the aim of developing a more equitable provision. The Disabled Child Strategy 1998-2001 was mainly funded through a three year joint finance plan of £900,000. These funds have now been fully committed. A Project Manager was appointed in January 1999 to oversee these developments. This has resulted in the development of a joint assessment project, as well as extending services such as respite care, shared care, play schemes and other community and home based services.
- 1.2 Services for disabled children became a new priority area for grant in Quality Protects in 2001-2. It was agreed that expenditure should be targeted at an increased provision of family support services, better integration of disabled children into mainstream leisure and out of school activities, improved information for parents and the increased availability of key workers. The Special Grants allocation of £797,000 was agreed by Executive Committee in January 2001. The amount of £260, 0000 from the Department of Health Carers Breaks funding was also reported to the Select Committee on 28 March 2001.
- 1.3 In 2001/2 £90,908 of Childcare Grant from the Department for Education and Skills has been ring fenced for developing childcare provision for children with special needs to enable their parents to access training and work. Carers Breaks funding and Childcare Grant have been bought together to fund a Project Officer post to develop term time childcare and holiday play schemes to support the objectives of both strategies.
- 1.4 The best estimate we have of the known disabled children in the county is 2184 children (the figure is based on the disability register plus those known to social workers in March 2001 but were not on the register.) National evidence about prevalence rates however indicates this figure may only represent 50% of the population of disabled children in the county. It is estimated that the number of disabled children requiring services over the next three years could increase by 10% due to improved survival rates for those with severe and complex health needs, as well as data from other local trends.

- 1.5 A new joint disability strategy will now need to be developed with health, and through the active participation of voluntary organisations, parents, carers and children. It is recognised that due to communication difficulties it will not always be possible to have the full participation of disabled children and young people, but whenever possible their involvement will be sought. This strategy will provide the basis for making bids in Quality Protects 2002-3. One of its aims will be to keep under review the equity of provision of services across the county.
- 1.6 The Hertfordshire Area Child Protection Committee will be holding a conference on 4 October in order to raise awareness around the specific issues of protecting disabled children. This conference will be supported by follow-up training in CSF running until December 2001.

2. **Scrutiny questions from the Select Committee 28 March 2001**

The Scrutiny questions are listed below. The answers to these questions are given on pages 5-10 and follow the order of the scrutiny questions.

Inter agency Assessment – we have two local projects

- How long have the projects been going, where are they?
- Have we any plans for widening this out if it is worthwhile?

Respite Care – need to get an idea of the scale

- How many families want respite care?
- What is their entitlement?
- Where is it provided?
- What is the demand - are there long waiting lists?
- What age groups is it provided for?
- How many beds are available in each quadrant?
- Is there unmet need - in some quadrants/all over the county?

Shared Care

- How many carers have we?
- Is this a countywide resource?
- What does the waiting list mean?
- How successful is shared care?
- Can some groups of disabled children not access it, is this taken into account when allocating respite care?

Long term care

- Will the new 7 bed unit meet the demand?
- Is there a waiting list
- What other facilities in the county do we have?
- What kind of young people need long term care?

Play Schemes – “571 new places”

- how many places do we have in total?
- Are these in specialist or integrated play scheme?
- Are there any parts of the county where there is a shortage of integrated schemes or specialist schemes?
- Do these schemes operate weekends/summer holidays only/ all holidays, including half term?
- Do they open all day/ half day?
- Are there any problems with play schemes e.g. staffing, venues, working with the Districts?
- Are these new places funded by the District Partnerships administering the Carers Grant?

3. Responses to the Scrutiny Questions

3.1 Inter-agency assessment project

3.1 Two pilot projects have been running in Hertford/Ware and Hemel Hempstead since 1999. The aims were to co-ordinate initial assessments of newly diagnosed children with disabilities under the age of 5 years, to reduce duplication between health, education and social services, now CSF, and to create a more holistic and client centred process. Approximately 30 children have now been seen in this way, and the teams have developed integrated care planning and review procedures with these children.

3.2 The last project evaluation report in June 2000 identified a number of positive outcomes. For parents these included appreciation of the role of the co-ordinator and the integrated approach. For professionals these included increased understanding about each other’s roles and responsibilities, and improved communication and trust. Recommendations for streamlining procedures further included:

- adapting the overall process to reduce professional time for those children with less complex needs.
- improving the preparation of parents about the process prior to the session
- streamlining the joint report writing process

A central message from the evaluation was that this approach takes longer to plan and pull together than single agency assessments, but adds value over time.

- 3.3 A final stage of evaluation is currently taking place, seeking the views of parents, including those who have now experienced the joint review process. Initial feedback appears positive, and the resource issues are now being identified for expanding this approach to other areas of the county and to a wider age range of young people. It is planned for this report to be ready in the autumn 2001. This approach also needs to be reconsidered in the light of the new Children, Schools and Families structures as well as the evaluation of the New Assessment Framework pilot.
- 3.4 Hertfordshire County Council obtained Department of Health Early Excellence Centre funding for a new Children's Centre in St. Albans, which is due to open in September 2001. This will be the new base for the Muriel Green Nursery, the opportunity class, the child development centre and new low cost day care, with an overall ethos of joint work and inclusion. Meetings are planned to look at extending the joint assessment approach with the multi-disciplinary team there, but modifying the approach to match existing resources.

4. Residential Respite Care

4.1 Occupancy has increased significantly over the last two years due to the provision of additional funds to increase the numbers of places. The table below details the number of respite beds (month of May 2001) by quadrant, the number of families the respite units were working with, and the number on the waiting list.

Quadrant	Organisation	Location	Beds/Day Care Places	No. of Children	No. on W/L
West	Harpenden Mencap, Stairways,	Harpenden	4 beds/1 day care place	33	5
West	CSF, Woolmer Drive	Hemel Hempstead	7 beds	40 respite/12 day care	0
South	NCH Adrian Road	Abbots Langley	3 beds/5 day care places	34	0
South	(HEALTH) Nascot Lawn	Watford	6 bed/11 day care	38 respite 11 day care	0
East	Jubilee House Care Trust	W.G.C.	5 beds/day care places	53	5
North	CSF, Mendip Unit	Lonsdale School, Stevenage	3 bed increased to 4 beds from 28/5/01- weekends & school holidays	19 respite, 3 outreach	0

4.2 Information on unmet need is currently collected on a snapshot basis from all residential respite units through waiting lists for in-county services. However this is not sufficiently robust for us to identify trends. More systematic ways of collecting this information will now be implemented from September 2001 by ensuring the monthly collection of data from the units.

4.3 Waiting lists have now built up for the first time in the west and east quadrants and consideration is being given to setting up admission panels, possibly involving health, to improve consistency in decision making. Parents have expressed concerns at the reduction in flexibility over dates since the units' occupancy has increased and proposed a more user-friendly approach (e.g. a "swop shop" to enable parents to swop respite breaks at short notice). This proposal is currently being planned to be piloted at one of the respite units.

- 4.4 The amount of respite is allocated according to the assessed needs of the child because this is a needs-led service. In practice, the amount of respite offered in each respite unit ranges from 17 night per year to a small number of over 100 nights per year, where the risk of family breakdown is very high. There are no plans to lay down a level of entitlement to services.
- 4.5 There is still a high demand for these services due to a number of reasons:
- There are still insufficient alternative community support services (e.g. care at home and shared care). Development to both these services has been slow due to recruitment difficulties.
 - There are a number of children who have high needs because of behaviour problems or physical care needs who cannot be easily accommodated in respite services
 - Meetings with carers, more accessible information and publicity about the Carers Grant has led to increased demand.
- 4.6 Respite Care is provided for children aged 5-19 years. It is recognised good practice current practice for residential respite to be only considered for children under the age of 10 other than in exceptional circumstances.

5. Shared Care

- 5.1 This service offers family based after school, weekend and/or overnight care to disabled children across the county. The post of Shared Care Manager has led to improved standards and consistency.
- 5.2 Shared care places are distributed across the county (month ending May 2001) as follows:

Quadrant	Number of carers	Number of children placed	Number on W/L
West	35	38	28
South	26	31	28
East	36	49	41
North	29	51	49
TOTAL	129	174	146

- 5.3 The number of children receiving this service has increased from 163 (October 1999) to 174 (June 2001). There are more children placed in the East and North than in the West and South (reflecting the higher level of provision of residential respite units in the west and south). 12 new assessments of carers are currently being carried out. Carers are given an allowance of £3.20 per hour.

- 5.4 The waiting list shows the numbers of children who have been assessed and referred as suitable for this service. There are now systems in place to ensure new referrals are appropriate and to review the waiting lists regularly. The average length of wait is about 12 - 18 months though a few young people wait much longer. There has been variation across the quadrants as to whether families are offered alternative services while they wait e.g. residential respite. Steps are now being taken to ensure that a consistent approach is taken across the county.
- 5.6 The service is very successful for those families who link with a carer, as these relationships are often long term, and become a good safety net for parents. Carers become like extended families in the best matches and have stepped in for emergencies such as ill health or bereavement. Parents like the informal support and flexibility.
- 5.7 The main difficulty has been recruiting sufficient carers to meet the demand. Young people with challenging behaviour, severe physical disability and teenagers are difficult to place in family settings, though some early placements have "grown" with the child. Recruitment is carried on throughout the year but the recruitment campaign will be linked to "Shared Care Week" in September in order to maximise publicity. In addition, a study into the different options for improving recruitment is planned, including looking at the allowance rates for shared carers.

6. Long Term Care

- 6.1 An analysis of residential provision (including out-county placements) carried out in 1998 indicated that we would need 12 in-county long-term places. As a result, two houses in Ripon Road, Stevenage are being adapted to create a new 7 place unit, with the aim of reducing the numbers of young people having to be placed out of county, in expensive placements which are often at great distances from their families. The projected opening date for this service is September 2001. In addition, there are 4 beds for disabled children needing full time residential care in the CSF unit, The Gables, near Hoddesdon.
- 6.2 Many of the young people requiring this type of care are those with autism and behaviour difficulties whose families struggle increasingly as they reach adolescence. Proposals for alternative community services to assist in meeting the needs of this group are outlined in 8.4. In the future any assessed need that cannot be met will be collected routinely under Phase 3 of the Oracle system which is planned to come on-stream later in the year.

7. Play schemes

7.1 The Quality Protects target of creating 571 new sessions funded through the Carers Grant was exceeded last year, as 655 additional sessions were made available. A further 440 sessions were run at Easter 2001, funded from the 00/01 Carers Grant. Sessions of over 3.5 hours have been counted as new places. The hours that play schemes operate differ from scheme to scheme. The average scheme runs between approx. 10.00 - 3.30.

7.2 Play Schemes that meet the needs of children with disabilities fall into 2 main categories:

- **Specialist play schemes** are provided for disabled children only. There are now approximately 10,754 specialist play scheme sessions in the county. The provision of specialist provision has now improved and there are schemes in all districts. The schemes are mainly run by voluntary organisations. Appendix 1 shows the breakdown by district. Some other play schemes also take non disabled siblings and children of volunteers with a view to offering a more integrated service, but they do not offer open access. They are run by voluntary organisations, or district/borough councils in some areas.
- **Inclusive mainstream provision** is “open” to all children. Some schemes are open access and do not require booking. These services are run by a variety of private and voluntary providers. Some are provided primarily to give children increased opportunities for a range of leisure activities, while others are aimed at meeting the needs of children whose parent(s) are working. Most District/Borough Councils operate holiday play schemes and they vary in the amount of provision offered, both in terms of numbers of places and weeks of the year that services run. Schemes for over 8’s do not have to be registered and have no set limit for those attending. It is difficult to comment on the number of places in inclusive schemes for children with disabilities but low staffing levels and open access means numbers of special needs children that can be accepted are very low. As a part of Hertfordshire’s Childcare Strategy new or expanding providers of care are advised to include higher levels of staffing in their business plans and grant applications for a proportion of children to meet particular needs. One of the main gaps in the Inclusive provision run by district council schemes is the lack of facilities adapted to meet the needs of young people with physical disabilities

- 7.3 Recruitment has been difficult and slowed development in the number of new places created last year. Staff also need more specialist training to cope with the special needs of different groups of children e.g. those with Autistic Spectrum Disorders, behaviour difficulties, sensory impairments etc. Many of the services require financial assistance to increase staffing levels and access specialist staff training in order to support more disabled young people. Funds are available to support staff recruitment, training and for additional places to be developed in 2001/02 and beyond through the Early Years Child Care Grant.
- 7.4 A number of new places have been funded through the childcare grant, administered through the County and District Partnerships. Additional places have also been funded through the Carers Grant fund, but strong links with the Early Years Partnerships ensure that all special needs developments are co-ordinated and best use is made of the available funds. It is planned to build on these strong links and partnership arrangements with the district councils.
- 7.5 One of the aims of a new strategy for disabled children will be to quantify in more detail which district councils schemes can accommodate children with different sorts of special needs e.g. physical, learning, sensory and behavioural. Development plans can then be agreed through County and District Partnerships accordingly, to ensure that more inclusive provision is offered across the whole county.
- 7.6 One of the successful bids under the Quality Protects programme 2001-2 was £20,000 for Support Services for developing play and leisure facilities for disabled young people. In addition there was a bid for a Sports, Arts, Leisure and Culture Officer to work with looked after children. The Project Officer will be working alongside this post holder to take forward the Inclusion agenda by ensuring improved access and choice for disabled young people in their leisure time activities. Another proposal made during consultations with parents was the possibility of setting up a befriender scheme for disabled young people. The options for developing this proposal will now be explored, including using befrienders to support the use of leisure activities by disabled young people.

8. Issues raised by parents and carers

- 8.1 In the various meetings and consultations with parents and voluntary organisations in the past year the following issues have been most frequently raised:
- Inadequate planning information on the different incidence of disabilities
 - Lack of equity of services across the county
 - Some groups of children have less provision than others
 - Difficult and lengthy process to get an assessment from local teams (including assessments from occupational therapists)
 - The inflexibility and inconsistency of services

- Lack of good information for parents
- Liaison and joint work with health needs to be improved
- Concerns about transition
- A training gap – the need to include the parents’ perspective in the CSF disability training programme

More information about these issues and possible ways forward are outlined below.

- 8.2 The inadequate planning information on the different incidence of disabilities has been raised by parents. The Children in Need Survey 2001 (a national survey which we are required to complete in the autumn) has for the first time a more detailed breakdown of disabled child categories. We are planning to make use of the survey analysis which will give us the total number of children in each disabled category known to the quadrant teams, also their age, gender, ethnicity and location. In addition the survey will provide a snapshot picture of disabled children in receipt of services during the survey week. The register for children with disability will also be improved in order to provide more detailed and up-to-date information. The register includes children who are not in receipt of services from CSF and therefore usefully supplements the CSF information on disabled children.
- 8.3 One of the service gaps parents expressed concern about is the lack of respite support services for children with challenging behaviour (including autistic children and Asperger’s). Funding from Quality Protects (£36,000) has been made available for the development of flexible family-based respite services, including home care, for children with ADHD and other complex behaviour problems. An action plan for addressing this gap was presented to Children’s Joint Commissioning Board in March 2001 and subsequently to the Parents Advisory Group in June 2001.
- 8.4 Parents also told us that they feel the process of getting an assessment from local teams is a lengthy and difficult process with many bottlenecks and tight gate keeping. One of the aims of CSF was to improve our response to requests for help and this issue requires further work. Progress made on responding to referrals will need to be reviewed.
- 8.5 There have been concerns about increased demand leading to some service inflexibility, as well as some inconsistency in response across the county. Steps being taken to address these issues include:
- More user friendly approaches being tested out (e.g. respite care “swop shop” so parents can swop respite care at short notice)
 - Review of waiting lists for shared care to reduce the numbers on the list and the waiting time, and to ensure that alternative support services are considered for families during the waiting period.

- 8.6 Parents report a lack of good information for parents, carers and children. While there is a range of material there is no overall system for ensuring it is both up-to-date and easily accessible. A survey of the material available will be undertaken and plans drawn up to address the gaps and improve the information available. This work will involve parents, carers and young people.
- 8.7 Another issue was our joint working with health and the need for improved co-ordination (e.g. speech therapy). This will be included in the joint review of the disabled children's strategy in order to seek a more co-ordinated approach.
- 8.8 Parents were concerned about disabled young people making the transition to adulthood, feeling that the move often from one service to another presented them with many barriers. CSF is planning to implement its transition protocols (drafted with health and Adult Care Services) pending the issue by the DfES of the Code of Practice on the Assessment and Identification of SEN. Transition Workers will be in post in the autumn and work is currently underway to ensure a co-ordinated approach across the relevant agencies.
- 8.9 A further issue was a need for training for CSF staff to include the "parent's perspective", to understand how it really feels, in their words, "to be on our side of the bars".

9. Financial Implications

- 9.1 The financial proposals outlined in this report are already in core budgets of the Children's, Schools and Families Service for 2001/2, as well as additional funding from Quality Protects, Early Years Child Care Grants and Carers Breaks.
- 9.2 Any further proposals will be developed for disabled children services with financial implications, which will be presented to members as part of the budget process.

10. Conclusions

10.1 Although considerable progress has been made in the development of services for disabled children the following issues need to be addressed:

- Better information for the planning and monitoring of services
- Inequity and gaps in service provision
- Recruitment adversely affecting the development of community support services by both statutory and voluntary organisations
- Inconsistency, inflexibility and length of wait for services
- Improved, up-to-date and accessible information about services
- Improved co-ordination of joint working arrangements with health
- Inclusion of the parent/child perspective in the disability training programme

10.2 Under the current Quality Protects Management Action Plan we are already committed to the following tasks:

TASK	COMPLETED BY
Monitor quality and timely responses re assessments	November 2001
Report on options for Panels for Residential respite, implement proposal	Sept 2001
Implement pilot scheme of "Swop Shop" re flexible respite care	Sept 2001
Review and implement consistent approach to shared care waiting lists	Nov 2001
Improve choice & range of sports & leisure services for disabled young people	Mar 2002
Complete feasibility study into Befriending Scheme	Jan 2002
Work with voluntary organisations to address recruitment problems	Nov 2001
Play Schemes: fund in priority areas and develop integrated services	Mar 2002
Complete Action Plan re Support Services for Young People with Challenging Behaviour & develop services	Mar 2002
Review current information services and explore existing and new approaches to dissemination of information	Sept 2001
Implement and monitor transition protocols	Jan 2001
Implement multi agency transition service 15-21	Feb 2002
Review of joint assessment project model with recommendations for future development	Sept 2001
Roll out improved training programme for disabled children services	June 2001- March 2002

10.2 The Select Committee is asked to consider whether the following actions should be taken in the light of evidence gathered during the scrutiny exercise:

(1) A review of the Disabled Child Strategy 1998- 2001 to be carried out and reported to Cabinet. The review to include:

- Progress made in developing the service and outcomes achieved
- Shared Care: study into the different options for improving recruitment
- Information: initial analysis of information from the Children in Need Survey 2001 to be used for improving strategic planning

(2) A joint strategy for disabled children for 2002- 2006 to be developed with health, parents, children and voluntary organisations and reported to Cabinet.

Background papers used by the author when compiling this report:

Report to Social Services Committee 6 January 2000 : Update on the Strategy for Children with Disabilities

Report to Joint Social Services and Education Committee 26 January 2000: Quality Protects Management Action Plan and Special Grant: 2000/2001

Department of Health: Circular LAC (2000) 22: *The Quality Protects Programme: Transforming Children's Services 2000/01* (November 2000)

Report to Children, Schools and Families Select Committee 28 March 2001: Quality Protects Management Action Plan Objective 6 – Services to Disabled Children.

If you would like to know more about the issues referred to in this report please contact Gill Webster (Tel: 01707 280613)