Anne Hunt, Stella Elston and Jo Galloway

Voices for change

Current perception of services for children with palliative care needs and their families

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Executive summary

There have been considerable changes in policy and in the manner in which health and social care services are commissioned and delivered over recent years. In addition, there have been a number of new developments in the provision of services specifically for children with life-limiting disease. Previous research has found that supportive services have been fragmented and difficult to obtain. The aim of this study was to explore the current perceptions of parents and professionals regarding the accessibility and delivery of services to families of children with life-limiting or life-threatening conditions.

Questionnaires were sent to organisations and individuals on the ACT database with the request that these be cascaded on to relevant professionals and parents of children with life-limiting and terminal illnesses. Questionnaires were returned by 272 parents and 144 health and social care professionals. Numerical and qualitative analysis of the data suggested that more services of all kinds are still needed, that these should be easier to access and that a greater level of co-ordination between different services is required.

A large proportion of parents and professionals identified services that they needed but were unable or found difficult to obtain. The most frequently identified un-met need was for respite care, a need that was almost equally distributed between help at home and respite away from the family home. Other needs expressed were for social and emotional support, more specific information about services and how they might be accessed, easier and quicker response to needs for housing adaptations and for equipment, more continuity of care and better co-ordination of services. Lack of resources and funding were seen as significant barriers to care. Overall the picture was one of statutory services which were characterised by delays, a lack of information and bureaucracy.

Services described as working well for some parents included children's hospices, aspects of respite provision (when it was available), health care and educational support. Individually, occupational therapists gained the greatest praise. Parents described their own "persistence" as a quality that worked well for them and that was seemingly essential in obtaining the services that were needed.

One solution to the fragmentation of services identified by many parents was to a have a named person, or key worker responsible for helping them to access and coordinate the services they need. Many professionals also proposed a key worker concept within a "one stop shop" where different agencies could work together with shared budgets and more integrated working practices. New legislation now provides the context in which this can be brought about.

Introduction

The provision of palliative care services to children and young people with life-limiting conditions has undergone significant growth over the past 15-20 years. However, the NHS framework within which this development took place has recently undergone immense change and reform, particularly in the way local community services are commissioned and run. For children and young people with life-limiting conditions much of the care is in the home, with parents carrying out complex procedures previously carried out in hospital. Undoubtedly the growth in children's palliative care has helped many families, but there is a widespread perception that there remains a significant shortfall in the range and accessibility of appropriate services for these families.

The aim of this study was therefore to explore current perceptions of the accessibility and delivery of relevant services to families of children with life-threatening conditions and, in view of the fact that local services were increasingly becoming the responsibility of Primary Care Trusts, to gather information on the extent to which GPs were currently involved with these families. The intention was to provide a detailed and reliable evidence base that related to the current health system so that a case could be made for improvements to the organisation of children's specialist services. The study was commissioned by ACT in August 2000, and commenced in December 2000. It was funded by The Community Fund (England) and The Tedworth Trust, without whose generous support this research report would not have been possible.

Methods

Questionnaires were sent to:
- all Child Development Clinics (CDCs) registered on the ACT database,
- all Children's Community Nursing Teams registered on the database,
- all Parent Support Groups registered on the database,
- all parents, individual professionals and services on the ACT membership list.

Approximately 1400 questionnaires were distributed to the above, and each group was asked to cascade the forms on to other professionals, parents and young persons.

Quantitative data was summarised. Qualitative replies to open questions were coded (categorised) using the qualitative analysis programme Nud*ist and data analysed for dominant and recurring themes.

Where tables do not add up to 100% this is because there were a number of non-respondents.

Results

1.0 Demographic data

Replies were received from 272 parents / carers / young persons and 144 health care professionals / social workers / support group workers (Table 1). The overall return rate (assuming that all the questionnaires were distributed) was 29.7%.

Table 1. Respondents to Awareness Campaign questionnaire

PARENTS	270 (99%)
OTHER CARERS	2 (1%)
HEALTHCARE	132 (91.7%)
OTHERS	12 (8.3%)

KEY
PARENTS
PROFESSIONALS
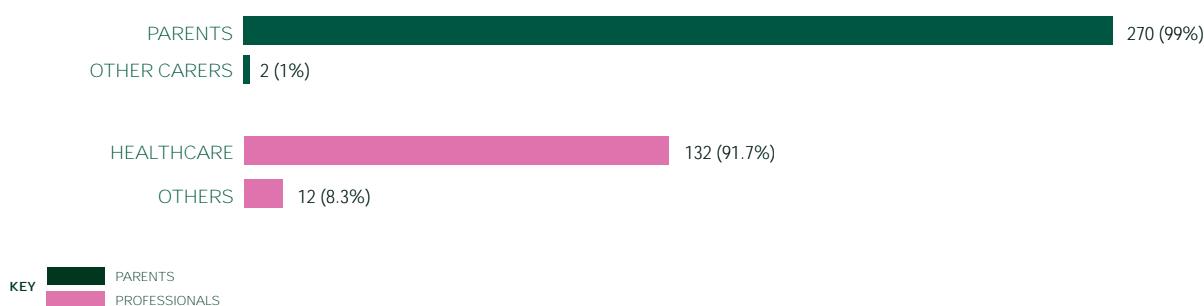
Only a minority of parents recorded the child's diagnosis. The diagnoses of 95 children were recorded and these are listed in table 2.

Diagnoses / diagnostic categories	N
Neuromuscular disease – Duchenne muscular dystrophy, spinal muscular atrophy	39
Neurodegenerative / progressive metabolic disease e.g. Batten's, Sanfilippo, glutaric aciduria, Leigh's, adrenoleucodystrophy	15
Cancer, leukaemia	11
Cerebral palsy, profound handicap, hydrocephalus	10
Rett Syndrome	8
Cardiac disease (2 with associated brain damage)	3
Cystic fibrosis	3
Connective tissue disease / Marfan's	3
Home ventilated	2
Renal disease (on dialysis)	1

Table 2. Diagnoses/diagnostic categories of children

Many professionals did not include their role or area of work. Appendix A lists the roles of the professionals where these were recorded. The area of the country from which parents and professionals responded are listed in Appendix B.

2.0 Obtaining services

2.1 The "named" professional
Parents were asked if there was one named person or service they could relate to for organising care and support (response categories were *Yes or No).* Professionals were asked approximately how many families, in their experience, have a named professional or service they relate to for organising care and support (response categories were *All, Many, Half, Less than half, A few or None).*

Less than half the parents (48.3%) had a named individual or service through which they organised care and services. In comparison, 77.1% professionals replied that 50% or more of families in their experience had a named person or service (Table 3).

Where tables do not add up to 100% this is because there were a number of non-respondents.

Table 3. The presence of a named professional or service to facilitate care and services.

YES	48.3%
NO	46.3%
NONE	2.1%
A FEW	4.2%
LESS THAN HALF	11.8%
HALF	9%
MANY	38.9%
ALL	29.2%

KEY PARENTS
PROFESSIONALS
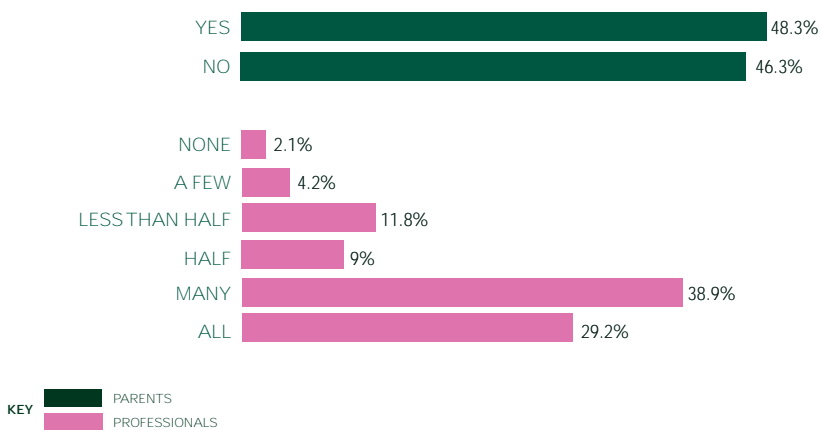
2.2 Availability of services

Parents were asked to tick which of the services listed they used. Professionals were asked to tick which of the services were available to the families they cared for, and if their provision was adequate. Results are listed in Table 4.

Table 4. Services availability and adequacy.

Services	Parents	Professionals	
	Used %	Services available %	Services adequate %
Respite			
Children's hospice	53.7	72.2	25.0
Other respite away	27.2	66.7	12.5
Respite at home	26.5	68.1	18.8
Nurse	48.5	90.3	27.8
Community nurse (paediatric not specified)	26.5	61.1	
District nurse	8.1	28.5	
Ward nurse	5.1	34.0	
Health visitor	2.9	7.6	
Other nurse (CLIC, Lifetime, outreach etc)	11.4	27.8	
Therapist	88.2	11.8	
Physio	69.9	56.9	
OT	53.3	52.1	
Speech	26.5	50.0	
Doctors			
Specialist paediatrician	62.5	68.1	25.0
Local hospital paediatrician	47.4	87.5	39.6
Community paediatrician	21.0	77.8	33.3
General practitioner	47.4	76.4	13.9
Pharmacy	51.5	71.5	26.4
Social work	54.8	84.7	12.5
Local authority	35.7	48.6	
Hospital based	9.6	31.9	
Other social worker (hospice, Sargent etc).	1.8	6.9	
Appropriate education	62.9	87.5	37.5
Advice on employment	2.9	38.2	6.3
Advice on careers	6.6	35.4	7.6
Support group	29.4	58.3	10.4
Psychological support	14.0	68.8	14.6
Provision of aids and equipment	61.8	88.9	27.8
Adaptations to house	38.2	71.5	11.1
Advice on housing and finance	19.1	85.4	40.3

2.3 Services that were needed but unavailable or difficult to access

Parents were asked whether there were services that they wished to use but were unable to obtain. Professionals were asked whether there were services that the children and families they cared for needed to use but were unable to obtain. Open replies were invited.

Nearly half of the parents (47.1%) and 58.3% professionals identified services they wanted or needed but which were unable or difficult to obtain. 17.3% parents replied that they were happy with the services they received at present. The qualitative analysis is reported under Section 6.

3.0 'How the System Works'

3.1 Health System

Professionals were asked whether they felt that the development of Primary Care-led purchasing (e.g. Primary Care Groups and Primary Care Trusts or Local Health Care Co-operatives) had made it easier, harder or not changed for:

- families to obtain services
- professionals to obtain services on behalf of families

The results are listed in Table 5

Where tables do not add up to 100% this is because there were a number of non-respondents.

Table 5. Effects of change to Primary Care-led purchasing of services.

	Parents	Professionals
EASIER	1.4%	2.1%
UNCHANGED	61.8%	58.3%
HARDER	20.8%	21.5%

KEY — PARENTS / PROFESSIONALS
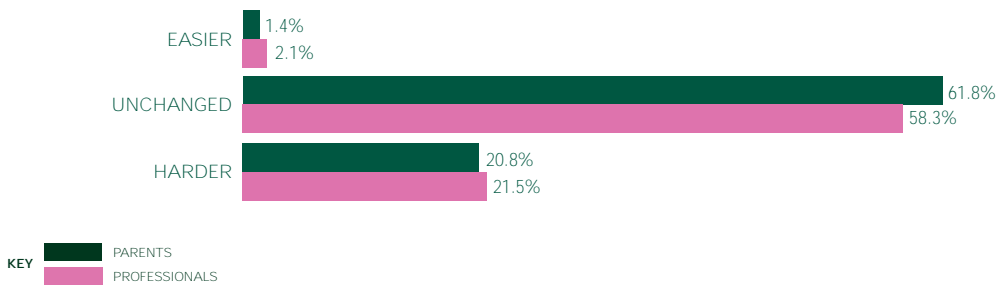
Several respondents replied that it was too soon to tell or that the PCG / PCTs had not yet been implemented in their area.

3.2 General Practice involvement in care

Parents were asked if their GP was significantly involved in the services and care they received. Professionals were asked how many of the families they care for received significant input from their GP.

In 34.2% of cases, parents reported that their GP was significantly involved in the services and care they received. However, 62.9% reported that their GP was not significantly involved.

In agreement, just over half the professionals (50.7%) reported that less than 50% of families had the significant involvement of the GP in the care and support of the child (Table 6).

Where tables do not add up to 100% this is because there were a number of non-respondents.
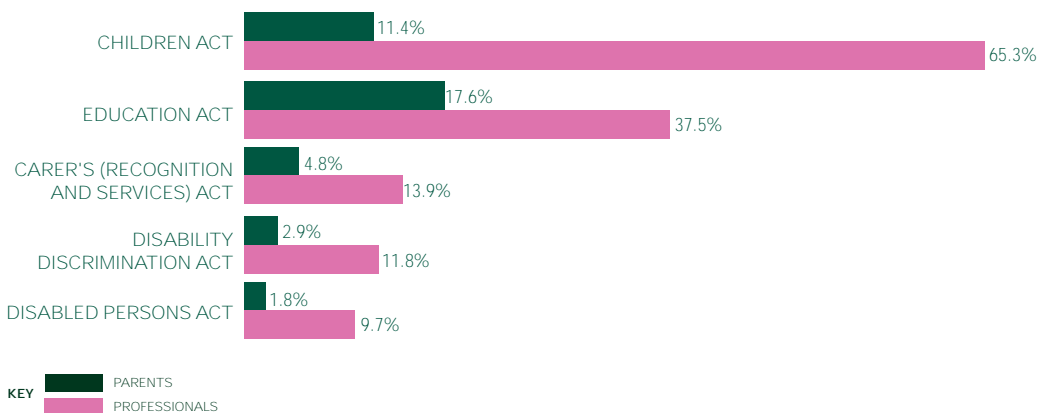
Table 6. General practitioner involvement in care and services received by families

NONE	1.4%
A FEW	25%
LESS THAN HALF	24.3%
HALF	14.6%
MANY	24.3%
ALL	3.5%
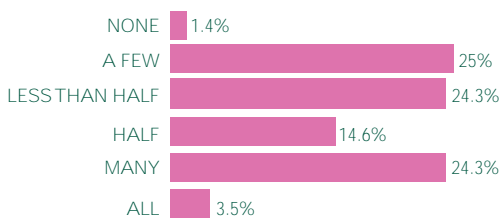
3.3 Use of legislation

Parents and professionals were asked if they were able to make use of the legislation listed here in Table 7. Overall 68.8% professionals and 25.4% parents had made use of at least one of the Acts.

Table 7. Legislation used by parents and professionals in the acquisition of services for the child and family.

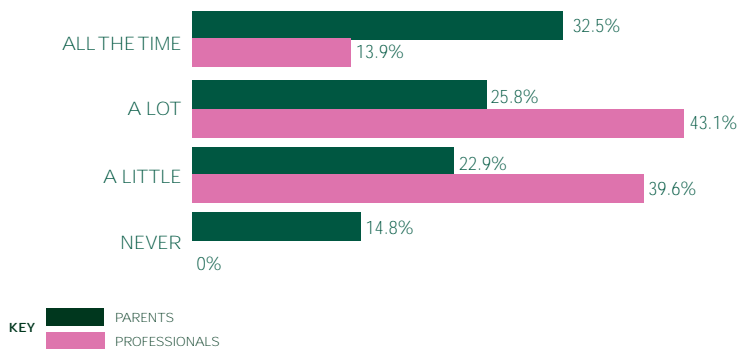|	PARENTS	PROFESSIONALS
CHILDREN ACT	11.4%	65.3%
EDUCATION ACT	17.6%	37.5%
CARER'S (RECOGNITION AND SERVICES) ACT	4.8%	13.9%
DISABILITY DISCRIMINATION ACT	2.9%	11.8%
DISABLED PERSONS ACT	1.8%	9.7%

KEY
PARENTS
PROFESSIONALS

3.4 Barriers

Parents and professionals were asked if they met barriers when trying to access care and support (Table 8).

Where tables do not add up to 100% this is because there were a number of non-respondents.

Table 8. Extent to which barriers are experienced by parents and professionals in accessing care and support services

ALL THE TIME — PARENTS 32.5%, PROFESSIONALS 13.9%
A LOT — PARENTS 25.8%, PROFESSIONALS 43.1%
A LITTLE — PARENTS 22.9%, PROFESSIONALS 39.6%
NEVER — PARENTS 14.8%, PROFESSIONALS 0%

KEY
PARENTS
PROFESSIONALS

When categories were grouped in to "never or a little" and " a lot or all the time" over 50% of parents and professionals met barriers a lot or all the time.

4.0 Qualitative analysis

Qualitative replies were received under the following headings:

Are there services that you (your children and families) need to use but are unable to obtain?

- If you meet barriers what are they?
- What effects do the problems in obtaining service have on family life?
- What effect do the successes in obtaining services have on family life?
- What is the one change that you think would improve the situation for families most?
- Any further comments.

4.1 Un-met needs

Respite care

The most often mentioned un-met need quoted by both parents (n=69) and professionals (n=51) was the need for respite. For parents this was almost equally distributed between the need for help at home (n=33) and respite away from the family home (n=26), though others were not specific about the place (n=29).

"Respite provision which is suitable for our child is difficult to find, as she needs nursing care, but also needs a lot of stimulation."

"We need assistance in the home, respite in the home, respite away from the home, regular nursing support, a social worker. We have had to seek the services of a charitable organisation to receive help in the home, this provided us with 2 mornings a week and has recently stopped due to staffing. We feel strongly that this service should be available."

"The children have been approved for 24 hour care (nursing) when at home. The LHA have yet to provide the nurses and we are disgusted at the lack of co-ordinated effort and attention given."

Professionals also cited the need for "respite care" (n=31), help in the family home (n=15), respite away from home (n=11). They remarked on the difficulty of supplying qualified nursing care at home to manage the nursing and medical needs of the children.

"If a family requires respite care but care could be of a clinical nature with the child, then social services respite will often not be accepted. Social services also cannot legally employ nursing staff."

Social and emotional support

Both parents (n=14) and professionals (n=14) cited a need for emotional support for families and children.

"There are so many things that change when your child is diagnosed with a terminal illness. Especially being a single mother with a child who is terminally ill. There are lots of people all at once telling you things you have to do and places you have to get in touch with. But nobody has helped me live day to day with every day worries about surviving all your debts and all the physical problems and also the emotional worries you have. You're sort of left in limbo hoping someone will tell you who there is out there to help, as I do not have a lot of other help."

In response to the question of whose role it is to provide emotional support to families, professionals wrote –

"The most difficult area to access is counselling and emotional support. My role is advisory, and liaison time and the geographical area do not allow me to develop counselling support..."

"Many families we work with who care for a child with a degenerative condition often live with the minimum of help and very little access to long term planned support. Often I am the first social worker they have contact with, it seems remarkable how many children with life limiting conditions seem to receive such limited social/emotional support."

Social work support
Several parents wrote that they needed help from a social worker, but there had not been one appointed to the family.

"We have never been offered help from a social worker, even though we have asked several times. It feels like I am fighting a battle all by myself, without any training or preparation for this. I sometimes feel like screaming, but no one would listen anyway. So why bother."

Professionals appeared to confirm that local authority social service departments were not equipped to support families of children with life-limiting illness.

"Local authority social workers seem to be non-existent, therefore families rely on the charity social worker to sort things out. Respite care and holidays are sorted out by charity based social workers."

4.2 Barriers to obtaining or providing care
There were many barriers to obtaining and providing care described by the respondents. Parents had numerous examples of the difficulties they encountered in accessing services:

Lack of funding and lack of resources
A significant barrier to service delivery described by both parents (n=66) and professionals were lack of funding and resources (n=87).

"I seem to be constantly reminded about people's budgets. While I appreciate there is always a shortage, I know families around the country in similar situations receiving much better service than my son. I only want what's best for him. After his death I want to be able to remember the good times, not all the time and effort I spent trying to get care for him."

"All the health authority tells us is that 'there is only so much money in the pot, you know'. 'It costs too much to train carers for decent respite'. 'It is a mother's job to look after their children not the health service'. 'Try not to get so upset'. These are all comments I have heard from our health authority."

"We were assessed as needing a ceiling lift put into the house in April 2000 which would take my son into his bedroom upstairs. The council will not finance the costs and so I still have to carry my son by myself down stairs and lift him into a stair lift to get him upstairs. This has caused me long-term health problems but nothing has been done about the problems. Respite care here is used by children with slight disabilities and not children with severe medical problems."

"There are budgets for things that won't suit my child – e.g. there is money to send certain children out of the county to appropriate schools, but not to help my child stay at her local school with appropriate support."

Characteristics of service delivery

The picture provided by the replies of parents is of services which are largely characterised by:

● Delays (n=73)
The service is slow to respond.

"It took more than a year to have home adaptations made. This meant we were lifting and carrying our daughter up and down stairs, caring for her toilet needs in a cramped space. We have spent considerable sums of money on a chiropractor with our bad backs as a result of lifting and handling. The younger siblings were sometimes required to aid in our daughter's care. Both parents were needed for most care which meant the other/younger children had to fend for themselves."

"My son's mobility is very poor so I have been pushing for transport to and from school. It has taken the education people almost a year to decide that my child would benefit from transport."

● Lack of information (38)
A lack of information was also seen as a barrier to obtaining services. Information is not readily forthcoming, and this lack of information offered to parents is in keeping with the overall impression conveyed of service providers that are not proactive in offering services to families.

"Information about service providers is very fragmented. There is no one agency to oversee all our needs. We do our own research and chasing up to get anywhere. The whole situation is a quagmire and would easily deter and demoralise the not-so-determined amongst us. Indeed this has affected us just so in the past."

"I do not know what I am entitled to as I do not really know who I am supposed to get in touch with."

"Information regarding entitlement to care, social services and allowances has not been readily forthcoming. These have locally been accessed by learning about them first from support groups and the muscular dystrophy family care officer."

● Bureaucracy (n=35)
Both parents and professionals described a service rife with bureaucracy.

"Bureaucracy is rife and only serves to place more obstacles rather than help. It also creates frustration and mistrust amongst service users. We have used a single agency system while we were overseas and it was much simpler to access services."

"I need approx.10-20 hours a week to have someone to care for, mainly to cuddle, my son so I can provide a normal family life for the rest of my family i.e. shopping, cooking meals, caring for my other child. This support was provided by a charity until recently, when their 'non-lifting policy' prevented any physical contact with my son."

"The red tape of bureaucracy and the endless filling in, it seems, of forms, is very

stressful, because on occasions, we have found the invasive scrutiny of our personal details quite humiliating."

"With my daughter's medical needs most services are not insured to cover us. I think this is very unfair as my child has disabilities as well as medical needs."

Professionals wrote-

"No services are available readily without carers having to go through a system of form filling, discussions, arguments and repeated requests."

"When requesting funding for essential equipment and respite care, this has to be requested and justified every time even though the child involved has huge medical problems which are unlikely to change."

● There was also the perception that services are not supplied willingly (n=23). Parents described services that do not appear responsive or proactive and stated that they have to "fight for everything"

"Parent carers of terminally ill kids have to fight for everything as all the relevant people you need to help think it is a waste of money, because they do not know if the child will live long enough to reap any benefit."

"We have had to fight hard for everything we have got. It has made us totally distrusting, of many services who all seem to be defending their budgets. It seems that money is the top priority and services seem to go to the people who shout loudest. God help the people who are unable to fight for themselves. It is always difficult to find out exactly what you are entitled to. All this at a time when you should be concentrating on caring for your terminally ill child."

4.3 Organisation of care
Both parents and professionals described characteristics of the way services were organised (or not organised) that became barriers to care:

Contacting the right person
Contacting the "right" person was a major problem for parents. It took the form both of not knowing who to contact and not being able to contact the person they needed to speak to – for example messages would be left on answer phones and no one returned the call.

"Over the past 2 ? years I have gone from one professional to another trying to access the right one – often I found the best source of information was through the parent support group."

"We have been waiting over a year for a hoist, my son is 4 stone, I am 7.5 stone and 4'8in tall. I have injured my spine but I am still begging for the equipment – why? Half the problem is being sent round in circles to get the person responsible for the equipment or service."

"The simplest things always seem a battle – getting in touch with the right person, explaining the situation, and waiting for them to call back."

Boundary disputes and inter-agency difficulties

Professionals (n=24) wrote about the arguments that might go on between the various agencies responsible for providing care to families:

"We work across two local authorities. One has continuing care, the other does not. The families that receive continuing care are very happy with it. The services is flexible, possibly down to the person who co-ordinates. The problems arise when social services become involved and spend time trying to avoid either funding jointly or providing their own service."

"The system is run by dedicated, overworked professionals who have to 'make do' with minimal resources. We continually come up against barriers 'this should come out of health..... social services....education budgets, not ours' etc. etc."

"Financial barriers, waiting lists for services, battle between health, social services and education about whose responsibility to provide services."

"... this places a huge burden on families who already have to cope with an exceptionally difficult situation. They should not feel they have to fight for everything. It is not good for anybody to witness the inter-agency wrangling which happens so often now."

Families too were aware of the wrangles (n=9)

"… health and education authorities each say the other is responsible for providing services. Have to travel to different hospitals for different equipment – one for shoes, one for seating, one for wheelchair etc."

"As J is in the early stages of his condition and no one knows how long he will live or what course his disease will take, we find services unwilling to commit to help with care. He also has tremendous sleep disturbance and night-time care is expensive. He does not have specific nursing needs so we are passed from Health to Social Services and vice versa."

Lack of understanding

Parents commented on personal qualities of professionals that became a barrier to providing care for their children. The major category was "lack of understanding".

"I've been left very out of pocket trying to find the help required, frustrated by the lack of understanding from the medical team, and the unwillingness to refer to colleagues for more suitable treatment. This is an on-going battle."

"No one seems to understand the physical and emotional drain looking after a terminally ill child has on a carer, and the strain on the family. Constant obstacles are placed to prevent children getting rights."

"Lack of understanding by professionals about what it is like to have a child who has a life threatening condition. I often feel that people just do not believe me."

Professionals too remarked on lack of awareness and insight of other professionals:

"Individual workers often show a lack of insight or unwillingness to be involved – often workers fail to appreciate the importance of what to them seem minor aspects of the care of a child at home."

"... lack of willingness from professionals to empathise with families and understand the stress they live with."

"Difficulties with other health professionals who fail to understand that children are not mini adults."

4.4 Effects on the family
The major effects described by both parents and professionals were:
- increased emotional stress and strain (parents n=81; professionals n=72)
- having to fight for things (parents=42; professionals = 15)
- financial strains (parents=35; professionals = 23)
- restrictions on life (parents = 40; professionals = 9)
- family friction and strain on marriage (parents=20; professionals = 30).

Stress and strain
"Lack of sleep and constant fighting for help put a huge strain on us as a couple and a family. Our son is hyperactive and has some behaviour problems which are difficult to cope with on no sleep. The struggle to find a doctor to take responsibility for J makes us feel very alone and at times helpless."

"We are totally stressed, my wife and I live on a knife-edge, the children fit constantly. We have not been away together for many years, and are also financially stretched. We had to find £40,000 for the adaptation plus £20,000 for the vehicle."

"Most of the time trying to obtain services is more of a stress than it is worth. Trying to cope with taking your child for dialysis 3 times a week, looking after 2 other children, spending most of your time in hospitals, house chores, giving medication and injections on time is enough to cope with without the headache you get with trying to obtain services."

4.5 What works well
Parents described those services which worked well for them. Notable amongst these were the children's hospices (n=42), various aspects of respite provision (n=26), health care (n=25) and education (n=21).

"Help to adapt the house, with a ground floor extension, has been wonderful (noisy nights confined to downstairs). Use of a Hospice as a family to relax and unwind while "special" child is well cared for. Use of the Lifetime Service reduces need for hospitalisation, and makes obtaining practical care, equipment etc. easier."

"I now have an excellent team of carers, but had to reach crises point before this came in. Martin House Children's Hospice is my main lifeline and we both look forward to our visits."

"I feel I am lucky living where I do, as we have got the support from Honeylands Children's Centre, without which I am not quite sure how I would have been able to cope. Also with the support of hospice care enabling us to spend time as a family / in respite – but together."

"Little Bridge House Children's Hospice is the only place where we have received support. Our Health Visitor and Social Worker never get in touch with us, and when things get difficult we are not heard. Only Little Bridge listens and tries to help."

Individually, occupational therapists gained the greatest praise.

"When things are organised and happen right it is wonderful and we feel the system somewhere works (usually via the occupational therapist who tries so hard)."

"The local O.T. is excellent, but she is often let down by her back-up services."

Persistence
Parents described their own "persistence" as a quality that worked well for them (n=21). They learned to use both orthodox and unorthodox methods, and although this was sometimes criticised, it seemed to be essential.

"Being persistent but polite and grateful for any help we are given. Asking for help from Community Nurse, she knows the right people!"

"Preparation – lots of research on my part, including quoting legislation. Persistence – endless letters, phone calls, building up network of people key to services we need. Perspiration and sheer bloody mindedness, sustained by other parents who understand."

"Shouting and making loud noises to the authorities all the time! If families don't complain nothing happens to help to ease their situations in most cases."

Although it was necessary to make a fuss to get what they needed for their child and family, parents recognised that the ability to articulate and / or fight for what they needed could put them at an advantage over other families.

"Why do some families get everything and others nothing, it seems the more you shout the more you get, but if you do not complain you get nothing, all should be treated alike."

"I do not mean to sound completely negative. We have had some good help and support, but most of that is from other parents/charities experienced therapists, most of the time we are left feeling exhausted, frustrated and unheard. We are intelligent and articulate, how do other people manage, who perhaps cannot express themselves, or won't. You have to keep fighting – we should not have to. Our child won't improve, services should. Special needs children are poorly served."

Professionals were sympathetic with the need of families to fight for services, but some recognised cases in which it could have a detrimental effect on family life – as did the parents.

"Families who are already stressed reach breaking point. They expend all their energy fighting the system instead of enjoying whatever time they have left with their child."

"Parents have to be very persistent to get appropriate services, some just give up, others go on crusades, family life suffers, marriages break up, other children in the family suffer."

4.6 What is the one change that would most improve the situation for families?

A situation has so far been described in which services are often difficult to access and where parents frequently have to fight for what they need. In the process they are subjected to further stress over and above that of caring for their child with life-limiting disease and anticipating their death. The way services are delivered increases their distress. When parents were asked what change might improve their situation most, the following answers were given:

Services

Parents again requested more respite facilities; at home (n=35); away from home (n=16); and in a place unspecified (n=13). Also figuring highly (as it was in un-met needs) was the need for social and emotional support (n=21). The need for adaptations to housing was also mentioned by many parents (n=20), though issues around housing were rarely mentioned by professionals.

Housing adaptations

"We are currently (2.5 years) fighting for an extension for our daughter. She is now becoming too heavy for me and I will be unable to do this beyond another 6 months. Space and privacy is what she needs otherwise we must consider the option of care away from home. It is so important that we continue as a family (my other children are devoted to her) and that we can carry on doing things normal families do. We would try to have more carers for C and with the extra space our own life would not be disrupted."

"Getting a stair lift for my daughter. If I could change one thing it would be to get a disabled facilities grant for a stair lift when C was 16 instead of having to wait until she was 18."

Delivery of services

Many parents (n=73) wrote about the manner in which services were organised and the way they might be improved. Continuity of care was an issue for them with multiple professionals involved in the delivery of care to the family.

"A way of co-ordinating and streamlining all the services. We are now in contact with so many different people, all responsible for different services and it can be frustrating and confusing trying to work out who fits where and who can offer what."

"Co-ordination of services so that you only need to explain once what is required – not 4 or 5 times, depending on what department it is."

One solution parents envisaged was to have one person (the key worker) responsible for helping them to access and coordinate the services they needed.

"No 'one' change would be enough. It needs to start by having one Key Worker introduced from the early stages who is well trained and can access 'the maze' on behalf of the family. From education statementing, benefit entitlements, equipment, wheelchairs, seating, car seats, incontinent aids, adaptations, as they become needed, not 3 years after when the family unit is falling apart through 24 hour stress and demands, physically and mentally,"

"To have one contact point to access all services. So often you find yourself chasing around or being passed from one service to another. Services do not liase well and often do not appreciate the urgency of situation when you have a life threatening condition."

"If every family could have a Key Worker to whom they addressed problems, knowing that person would follow up, organise services, be a buffer at points of conflict, who had a thorough overview of the situation, that would take so much pressure off."

"Having a central Key Worker to liase with all agencies would alleviate some pressure. We should be putting our energies into caring for and nursing our child, not dealing with incompetent services."

"That there could be someone who would do all the fighting for us. We do not want to remember our child's life as one long battle with social services."

Professionals (and some parents) described something beyond, though including, the key worker. They described systems in which the different agencies worked together, often from a central point (referred to as the One-Stop Shop) and with shared budgets.

"A joint children's trust which incorporates all children's services, acute and community, to enable them to work together without barriers. I would love to take a blank sheet and re establish services in a planned co-ordinated way."

"More co-operation between the agencies. In our county we are currently working across agencies to improve services for respite care for the families in line with the government initiative 'Partnership in Action'. The request many families have given is one referral point for the services so all have more chance of an equitable service, and one professional to be named as the key worker."

"To have named co-ordinators of care. Establish full multi-disciplinary team work. Look at centralising multi-disciplinary professionals to increase communication."

"We need more one-stop clinics in GP surgeries after hours including advice from physio, OT, dieticians, speech therapists. All the above services need to make themselves more accessible to families."

"A one-stop shop for services."

Shared budgets
Many identified the need for joint funding across health, education and social services.

"A commissioner looking at children respite care services with joint responsibility of social /education / health. A budget between all services. Local coordination for the families."

"Tri-partite funding between health, education and social services. Teams of carers trained to care for children with complex needs."

"Joint funding between health and social services so that children do not fall between the categories of health versus social need for respite care. Less strict identification of 'health' needs, i.e. children who have multiple disabilities including quadriplegia, swallowing difficulties etc. but are classed as no nursing need."

Discussion

Over ten years ago Woolley and colleagues (Woolley et al., 1991) interviewed parents of children with life-limiting illness and reported what parents experienced as "the complex and often distressing job of obtaining help". Similar findings were described by While and colleagues (While et al., 1996, While et al., 1996). Though there is limited literature since regarding the delivery of services for children with life-limiting disease, there is considerable overlap between our findings and those reported in regard to the care of families of disabled children (Appleton et al., 1997, Curran et al., 2001, Haylock et al., 1993, Hollingsworth, 1992, Sloper, 1999, Sloper and Turner, 1992, Yerbury, 1997). Many of these papers suggest the need for inter-disciplinary and inter-agency working and the appointment of key-workers and / or care-coordinators to support the families in accessing the services they require. In 1997 a joint working party from ACT (The Association for Children with Life-Threatening and Terminal Conditions and their Families) and the Royal College of Paediatrics and Child Health (RCPCH) advised that each family should have a key worker. In addition they advised that area (regional or district) coordinators should be appointed to oversee and manage care for children with life-limiting disease and their families (ACT/RCPCH, 1997).

Addington-Hall et al (1992) conducted a randomised controlled trial of coordinated care for adult patients requiring home-based palliative care. They found few significant differences between the nurse coordinated and control groups. As an explanation they suggested that because the coordinated service did not have a budget it was unable to obtain services that were required. In addition they suggested a degree of conflict between the roles of nurse coordinator and the nurses' professional skills. Key working or "coordinated care" without the organisation to support it would seem to leave the worker very much in the same position as the family itself, having to work within a system that is ill-equipped to provide the service (Mukherjee et al., 1999).

Although there has been some progress over the last ten years with the establishment of a number of inter-disciplinary paediatric palliative care and Diana Nursing teams (Davies, 1999, Lewis, 1999, Wallace and Jackson, 1995), this survey suggests we still have a long way to go.

Partnership and integration is high on the Government's modernisation agenda, with the overall aim for the National Health Service of being a joined-up, user-centred service (DoH, 1998). From April 2002 Primary Care Trusts took over management of primary care services (in England). Many of these have now also taken over responsibility for community child health services, such as children's community nursing, disability services and continuing care.

In 1998 the discussion document 'Partnership in Action (New opportunities for joint working between health and social services)' (DoH, 1998) was published. This document provided the basis for possible action to address some of the problems revealed both by this survey and earlier work.

The document states that all services should be "built around the needs of those who use them" (DoH, 1998 section 1.2). However, it also states that there were boundaries between services which (as we have seen in this study) could present major obstacles to working in partnership across agencies. The discussion document claimed that major structural changes would not be the way forward but would be likely to result in increased bureaucracy, be expensive and disruptive to introduce. A "better course" was suggested, "less bureaucratic, more efficient for users, carers and staff who are often as frustrated as the people they are trying to help by failures of the system" (DoH, 1998 section 1.4).

The document proposed joint working on a number of levels (DoH, 1998 section 1.6)

- Strategic planning
- Service commissioning
- Service provision

Health authorities, social service departments and Primary Care Trusts should work together towards shared objectives. To enable this the government proposed removing existing constraints in the system and providing means by which agencies could commission and provide services across boundaries more effectively (DoH, 1998 section 1.7). Whilst so far most experience lies in the area of mental health services, the document suggests there are "significant advantages for children's services in the proposed changes" (DoH, 1998 section 1.8). To support the changes, National Service Frameworks (NSFs) would be drawn up and be "key components in enabling authorities to deliver better services" (DoH, 1998 section 3.14). Close working arrangements are being encouraged for services for children (DoH, 1998 section 3.15, DoH, 2001a).

Whilst at that time the legislative framework limited the capacity of health authorities and local authority departments to work in partnership, the NHS Plan (2000) introduced the concept of Care Trusts. Subsequently, the legal framework for their enactment was set out in Section 45 of the Health and Social Care Act (2001b). Care Trusts are statutory NHS bodies, jointly governed by representatives from the NHS and local government. They are formally established through an application to the Secretary of State, which must be made jointly by both partners (Local Authority(ies) and NHS bodies) (DoH, 2001c)

Care Trusts could be established on a voluntary basis and in partnership where there is a joint agreement at a local level that this model will offer the best way to deliver better health and social care. Once a Care Trust is agreed, partners work to a written local agreement, setting out resources, ways of working, board arrangements etc. By joining together teams and resources, Care Trusts will provide a more responsive service, with a "one-stop shop" approach. The first four demonstrator sites were established in April 2002 in Bradford, Camden and Islington, Manchester and Northumberland. In the main, these and other named prospective sites are set up to meet the needs of those individuals with learning disabilities, mental health problems and older people. Surely, given the evidence in this report, they must be the way forward to meet the needs of children with life-limiting disease and their families too.

It is now time for action or as Sloper et al (1999) puts it "Real change not rhetoric" (Sloper et al., 1999). Yerbury (1997) makes recommendations with regard to the organisation of supportive services for disabled children which could equally well be applied to children with life-limiting disease. Based on her review of child disability teams she recommends

- A district inter-agency strategic planning forum
- An external management group to include both parents and line managers.
- A team leader to coordinate the multi-agency service
- Joint funding and budgetary control
- Regular operational meetings to review policy and procedures, with built in audit.
- Joint working and case reviews.
- Parents as full partners with professionals
- Having a base
- Adequate training for prospective key workers, a point also emphasised by Mukherjee et al (1999).

Elements of a possible model for paediatric palliative care supportive services are suggested below.

Role of area coordinator /manager
- Accountable to management team
- Receive referrals to service
- Arrange for multi-disciplinary needs assessments and care planning
- Oversee case meetings
- Manage / coordinate different elements of services
- Draw up budget
- Purchase / commission services
- Authorise expenditure
- Manage database of families and service providers

Roles of key worker
- To 'go-between' family and coordinator
- Advocate for family
- Emotional support for family
- Enable access to information
- Enable access to services

Service needs
- A place / a base / a "one stop shop". (Could be stand alone or sited in health centre/ children's centre / hospice / hospital / school etc)
- Administrative / secretarial / budgeting / IT support
- Multi-disciplinary /multi-agency team – and access to other relevant professionals.
- Access to information of all kinds, housing adaptations, equipment, transport, benefits advice, appropriate education, leisure, medical and nursing care, respite, hospice, practical help in the home, emotional support for all family members and significant others, bereavement support etc
- Appropriate education and training
- Psychological support

Research needs
- Education and training needs of coordinators and key workers
- Evaluation of services and outcomes. Need for development and testing of appropriate outcome measures
- Economic analysis of costs and benefits.

Conclusions

Little change has been reported in the experience of parents and professionals over the last ten years, despite a considerable increase in the number and range of support services. Whilst there is a high interdependency between the functions of the supportive agencies, in many cases they do not currently seem to work in partnership to meet the needs of families. Government policy now provides the means by which some of the barriers to working in partnership can be dismantled. We now have "new opportunities". Let us pursue them.

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Appendices

Appendix A
Roles of professionals responding to survey

Where tables do not add up to 100% this is because there were a number of non-respondents.

Profession	N	%
Paediatric community nurses	24	25.3
Nurse specialists	11	11.6
Other nurse	10	10.5
Paediatricians (community)	9	9.5
Nurse managers of services	8	8.4
Paediatricians (specialist / hospital)	6	6.3
Social Workers	6	6.3
Support group workers	5	5.3
Specialist health visitors	3	3.2
Medical geneticists	2	2.1
Practice based health visitors	2	2.1
Occupational therapists	2	2.1
GP/hospice doctor	1	1.1
Physiotherapist	1	1.1
Total	95	

Areas of the country from which parents and professionals responded

Where tables do not add up to 100% this is because there were a number of non-respondents.

	Parents		Professionals	
	N	%	N	%
Somerset & Avon	18	7.4	7	7.0
Devon	19	7.9	1	1.0
Cornwall	9	3.7	2	2.0
Dorset	3	1.2	1	1.0
Wilts	4	1.7		0.0
Hants	6	2.5	3	3.0
Sussex	13	5.4	5	5.0
Kent	9	3.7	3	3.0
Surrey	5	2.1	4	4.0
London	7	2.9	12	12.0
Middx	2	0.8	4	4.0
Berks	1	0.4		0.0
Essex	19	7.9	1	1.0
Herts		0.0	1	1.0
Beds	2	0.8	1	1.0
Bucks	2	0.8	3	3.0
Oxford		0.0	1	1.0
Hereford		0.0	1	1.0
Leics	3	1.2	2	2.0
Glos	6	2.5	1	1.0
Lincs	4	1.7		0.0
Notts	4	1.7	2	2.0
Northants	2	0.8	4	4.0
Suffolk	2	0.8		0.0
Norfolk	1	0.4		0.0
West Midlands	2	0.8	7	7.0
Stafford		0.0	1	1.0
Lancs	7	2.9	3	3.0
Greater Manchester	3	1.2		0.0
Yorkshire	52	21.5	4	4.0
Tyne and Wear	7	2.9	3	3.0
Merseyside	4	1.7	5	5.0
Cheshire	2	0.8	2	2.0
Derbyshire	2	0.8		0.0
Shropshire	1	0.4	1	1.0
Cleveland	1	0.4		0.0
Cumbria	1	0.4		0.0
Wales	7	2.9	4	4.0
Scotland	11	4.5	9	9.0
N. Ireland	1	0.4	2	2.0
Total	242		100	

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