Cornwall and Isles of Scilly Health Action Zone

Children & Young People's Programme

Specialised Equipment for Children with Complex Needs:

An Evaluation Report

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Contents

Executive Summary

Specialised equipment is key to many children with complex needs living as full and as independent a life as possible. However, studies have shown the provision of such equipment is often haphazard and uncoordinated. This case study describes the progress of a HAZ-funded project designed to scope the services presently available and make recommendations for improvement.

The project had its origins in a difficult operational context. Services have largely been developed in isolation and whilst examples of good practice are apparent there has been an evident lack of multi-disciplinary working and communication. Working practices, organisational ethos and the availability of resources vary, for instance, on an inter-agency basis and moves towards joint working therefore carry perceived threats as well as opportunities. Given this context the achievements of the project are the more notable.

One year into the project it finds that a detailed understanding has been gained as to the situation both locally and nationally and that consultation & research has not only established an understanding as to present shortcomings but also achieved progress towards an agreed model for development. This focuses on a centralised multi-agency facility, funded jointly and incorporating a single method of ordering, delivery, recycling & storage and a comprehensive IT system able to track equipment Significantly, the preferred model presaged national guidelines which now give further imperative to such change.

The project demonstrates clearly the importance of clarity of purpose and the role that internal evaluation can play in this process. It stresses the significance of communication and consultation in establishing trust and understanding and the real achievements that can be made with dedicated staff resources and effective networking. It again demonstrates how time-consuming this process typically is and has shown how HAZ funding, by releasing resources, can make a real difference to the ability to actually take work forward. The HAZ has also played a key role at Programme level in enabling people to meet , share and develop ideas.

It also reveals a critical need for such projects to have real strategic support on an inter-agency basis and dedicated access to a steering group capable of making formal decisions and financial commitments. The lack of such a group has been a long-standing cause for concern and proved wasteful of both scarce managerial and practitioner time. Significantly, the projects themselves have taken the initiative in trying to rectify this situation. The willingness to act in partnership has now to extend to senior levels of management if significant change is to occur.

It is important that the impetus gained in this area via HAZ funding is consolidated rather than placed to one side. The achievements of the project to date suggest both that the information gathered and the contribution that the project lead can make should be seen as a resource on which the new national requirement for integrated community equipment services can draw and a cornerstone from which to take developments forward. This would demonstrate that the HAZ philosophy of learning from change has really been recognised in the wider policy arena.

Specialised Equipment for Children with Complex Needs

1. Introduction

The Specialised Equipment Project is one component of the Children and Young People's (CYP) Work Programme. The overall aim of this Programme is to "enable children and young people to get the most out of their lives, improving their health, doing as well as they can at school and giving them opportunities to achieve their full potential and make informed choices about their own future."[1]

Within this Programme of some twenty-three projects[2], supporting partnerships and local HAZ Fellowships, the provision of services for seriously ill children at home was identified as one of 6 early result areas included in the HAZ Plan. It was thus one of a number of projects identified by stakeholders as potentially significant even before HAZ funding was approved and intended to take "forward key pieces of work much (more) quickly than would otherwise have been possible."[3]

This was reinforced by early approval. HAZ status was awarded in May 1999 and the umbrella project entitled "Specialist Support at Home for Very Ill Children", submitted by the Deputy Director of Nursing at the Royal Cornwall Hospitals NHS Trust (RCHT) with Cornwall Healthcare Trust (CHT), Social Services, Voluntary Organisations and the Diana Children's Community Nursing Teams (DCCNTs) as named partners, received funding in July 1999.

The project was in fact made up of three distinct components; specialised equipment, respite care and neo-natal outreach. This report focuses solely on the first of these three components. It builds on an earlier report which described the activities of this project (Clapperton & Butler, 2001) by introducing a more evaluative and analytical approach to the achievements to date. Specifically, it looks at the way in which this work was developed, the extensive needs analysis that was undertaken and the establishment of options for reforming the system by which specialist equipment could be provided. Firstly, in order to understand its origins it is necessary to understand a little more about the initial background and this is outlined briefly below.

2. The Development of the Project

A review of children with high dependency needs in Cornwall (Yerbury 1998) together with other local and national research (Nash 1998, DoH 1998) had identified that families and children with limiting and/or life-threatening illnesses required a more flexible support network than was currently provided.

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[1] Cornwall and Isles of Scilly Health Action Zone Plan September 1999.
[2] Counting, for umbrella projects, the several distinct components.
[3] Letter to all children's HAZ stakeholders 19.8.99.

Social Services, the RCHT and CHT thus developed a joint project[4] "aimed to provide specialist care in the children's own home, including individual support and relief for families and their children". The project was intended both to build upon, and be significantly strengthened by, Cornwall's already successful bid for DCCNTs[5]. It is important to appreciate that the initial bid thus focused on the needs of a group of perhaps 30 or 40 children with very severe needs who fell within the remit of the Diana Nursing Team.

It hoped to address four of the five CYP Programme[6] objectives:

1. Services that are easy to access
2. Improved co-ordination of services and better inter-agency working
3. More children living in a safe and secure setting
4. Services which are designed with children and young people in mind.
   and "to a lesser degree"
5. Services that promote health and get in early to solve problems[7].

The relevance of the first two of these to specialist equipment defined at the outset as including:

- Appliances as supplied by occupational and physio-therapists
- Aids to activities of daily living in the home
- Technical equipment for nursing care (such as suction machines) and
- Consumables for hi-tech care such as gastronomy and naso-gastric tubes

is immediately apparent. For the bid describes a "generally agreed" situation where provision, made by a variety of agencies, was "often haphazard, uncoordinated, often leading to delay, duplication and frustration for healthcare professionals and families alike".

The initial bid for specialist equipment also suggested (in sustainability terms) that all organisations would continue to fund equipment as at present. However, it was "hoped that at the end of 3 years…. there could be a cost saving or, at the very least, a decline in the steep increase in costs of providing such equipment by all agencies." However, it was thought that the "provision of equipment to the families and children at home may demonstrate a more robust way of financing the service, which may require refocusing or transfer of existing resources. This (would) depend on the outcomes and recommendations of the project."

2.1 Initial Aim

The aim of the project was thus:

- "to scope the services presently available across all relevant agencies and report accordingly, making recommendations for improvement following consultation across all agencies."

The expected outcomes were:

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[4] The existence of three distinct parts to the bid means it is difficult, in retrospect, to examine the context for each component. For instance, a number of partners to the bid are described but the actual engagement of partners may not have been constant across the three components, volunteer input, for example, focused around respite care.

[5] Application for HAZ Funding May 1999

[6] Proposed for and agreed by the first Stakeholder Workshop held in February 1999 as "things we need to get right" and translated into objectives in the HAZ Plan. These were also used as criteria for assessing bids.

[7] Again, it should be remembered that these relate to the bid as a whole and one would not necessarily expect them to be met by each component project in equal measure.

- "a streamlined, co-ordinated service provision, understood and agreed to by all agencies and
- an efficient, accountable and cost effective service that provides sound budgetary information and allows for pro-active financial planning".

The outcomes, together with further information contained in the bid, suggest that the project as originally conceived aimed, in fact not only to review current arrangements and suggest improvements but also to actually bring about change. Thus the proposed milestones suggest not only a preliminary report regarding the status quo, followed by an agreed action plan to improve the service across agencies but also, by the end of the project (March 2002), "systems in place with a clear operational policy agreed across agencies and budgetary information available". Similarly, the proposals for checking whether the project had been successful suggested one would be able to see *effective*[8] provision of equipment and, indeed, some17.5% of the budget for the project was allocated to pump priming equipment for specifically identified urgent equipment[9].

Connections between the three parts of the project appeared tenuous, the only explicit link, beyond focusing on the same client group being that the neo-natal outreach service was expected also to "benefit" from the equipment project. Specialist equipment was also the largest component of the overall bid, accounting for some 69% of the total funding awarded, with the majority of the money dedicated to staff resources. In the event the three projects within the bid have evolved largely independently and this evaluation focuses solely on specialist equipment project. Given the timing of the report, it also focuses on the first phase of the project which has concentrated largely on establishing current needs and service arrangement. The findings of this phase contain important lessons both for the next stage of this project and for many other inter-agency initiatives.

2.2 Background

Increasing numbers of children are benefiting from advances in neonatal medicine, technology and healthcare techniques. This has lead to gradual changes in special health needs, life expectancy and the number of children living in the community with complex multiple needs. For many of these children, specialised equipment is central in enabling them to live as full and as normal a life as is possible[10].

In line with this, equipment design and manufacture has undergone commensurate development. In the field, for example, of specialised seating:

> "Equipment has changed over the last few years moving away from single purpose items that meet either a health or a social need to multi-function chairs that meet a range of needs. This has lead to increasing confusion as to which agency has responsibility for the provision of items such as specialised seating."

For a child with complex needs living in Cornwall, such equipment continues, however, to be provided from a variety of sources including Health, Education, Social Services and charities. Whilst locally based research has suggested that the

[8] Author's emphasis.
[9] £85,500 was allocated to the special equipment project in July 1999. £9,000 worth of specialised medical equipment was purchased from the project budget in year one prior to the appointment of the project lead.
[10] See Clapperton K & Butler A (2001) op.cit.

response is often confused, inefficient and inequitable. Parents, for instance have reported difficulties in obtaining the right equipment, in equipment arriving too late to benefit the child and delays related to arguments over the source of funding. Meanwhile, those providing services to children in the community found little equipment of even a basic nature available for speedy access (Nash, 1998, Yerbury, 1998).

This is not purely a local problem, nor indeed a problem confined to specialist equipment for children. The initial bid stressed the need to share project outcomes with adult services locally and with other children's services nationally, suggesting that such problems are manifest across the country. Meanwhile, the Department of Health's recent Guide to Integrating Community Equipment Services (DoH, 2001a) acknowledges the need nationally to streamline provision.

2.3 Appointing a Project Lead

The Project Lead took up post in May 2000, some ten months after the bid had been approved. For the first seven months in post she was seconded on a part-time basis only but both the process of secondment (whereby it is difficult to detach oneself from other responsibilities) and location within a system at full-stretch (so that the post holder in effect retained and even increased her original workload) made the situation untenable. A full-time secondment was thus created[11] from December 2000 until March 2002.

2.4 Defining Need

This appointment marked the first real opportunity, post-funding, to examine the project remit. It was facilitated by the fact that C&IoS HAZ had placed considerable emphasis on learning from change and building evaluation capacity and dedicated resources were thus available within this Programme to assist projects in defining and understanding their approach. It resulted in a widening of the brief in response to the Project Lead's concerns that it would be inappropriate to focus just on the equipment needs of a very small target group and a different method for others.

This revision immediately raised another problem. If the project was not to focus just on those children with the most severe needs then how was it to define the target group. In the first instance there is no agreed definition of "complex needs". In the second, Cornwall, despite the fact that it is a requirement under the Children's Act, doesn't currently have a multi-agency register of disabled children. Identifying the number of children to whom any agreed definition of complex needs would then apply to is thus difficult because:

- each agency collects its own data but there are no data systems in place to identify children who have services from more than one agency
- agencies have different geographical boundaries (Clapperton, 2000, p2).

Here the "quarterly pro-forma meetings" established by the Programme Lead and the Programme Evaluator proved critical for they provided an opportunity for project leads to network, share ideas and discuss common problems. In this instance, it was soon realised that two projects within the Children & Young People's Work Programme, the Joint Agency Strategy and the Specialised Equipment Project,

[11] With a different partner agency.

shared a common need to be able to define and target children with complex needs[12].

Estimates were drawn initially from the Disabled Children's Model – Numbers and Categories (DOH 1999). This was then assessed for accuracy against local Education, Health and Social Services figures, a complicated process owing to the different categorizations used and the fact that the severity of disability was often not quantified. Information was thus assembled as to the number of children with a statement of Special Educational Need[13], children receiving services from a Consultant Paediatrician, children receiving services from Social Services and children receiving support from the Family Fund[14]. Information form these two sources suggested an estimated 700 - 900 children with complex needs living in Cornwall. However, not all of these children necessarily have a need for specialised equipment and a small proportion may only have a temporary impairment associated with an acute medical condition. The process was, in the words of the Project Lead,

> "a nightmare …… in the end we had to make an informed guesstimate using all of the date we'd gathered as each agency worked to slightly different definitions of complex needs and each had different ways of recording. Gaining an accurate reflection was difficult to achieve."

This stage of the project also saw the development of the so-called AAAQI-Model. This is essentially a tool by which project leads were encouraged and helped to think clearly about the aims of their project, the activities that were required to fulfil these aims, the assumptions on which they were built, the type of questions they would need to ask to establish whether they had been successful in meeting these aims and the kind of indicators or measurements they would need to put in place in order to measure progress.

This established that the first phase of the project needed to concentrate on establishing how the existing system operated and where changes might be needed[15]. The next stage of the report thus focuses on the discussions that were held with local service providers, schools and users, together with the cost of the current system and information as to how this responsibility is discharged in other parts of the country.

[12] This same forum has also enabled links to be made latterly to two other key HAZ projects with a similar client-focus, children in special schools & the voice output devices project.
[13] Excluding those with mild or specific learning disabilities who are considered less likely to require the services of an agency other than education.
[14] An independent organisation funded by central government to assist families of children with severe disabilities via grants and information.
[15] The AAAQI is designed to help projects structure the approach to evaluation, capture the way in which the project changes and evolves and explore the reasons behind these changes. It is an iterative process and the original AAAQI model is in the process of amendment.

3. Informing the Model

3.1 Talking to Local Service Providers

The first six months of the project was taken up essentially with understanding the systems currently in place and establishing stakeholders' views as to their strengths and weaknesses. Individual meetings were held with more than 70 members of staff across all agencies and levels, including consultants, therapists, specialist nurses, managers, head teachers, stores staff and GP's.

3.11 Establishing current service provision

A first key output was an understanding of current service provision. This information has already been provided in the project report of November 2000 (Clapperton, 2000) but broadly there are three main statutory agencies concerned with equipment provision in Cornwall.

Social Services provides a countywide service in which children with complex needs, apart from those with emotional difficulties, come under the remit of Community Care Services. At the point of referral, each child or young person is allocated a Care Manager according to his or her GP surgery. Should specialised equipment be required, the Care Manager in most instances will request that the Paediatric Occupational Therapist for that area complete an assessment of need.

Equipment transactions are handled centrally in Truro but then distributed to the relevant area office satellite store where an OT or technician arranges delivery to the home. Equipment is provided on a long-term loan basis and, where possible, all items are recycled at Central Stores. During the financial year 1999 – 2000, a minimum of £65,000 was specifically spent on "children's" equipment[16] the majority being accounted for by seating (39%), and equipment for personal care (34%) or moving and handling (18%)

The majority (2/3rds) of child healthcare provision in Cornwall is contracted by the Cornwall and Isles of Scilly Health Authority to two local trusts: Royal Cornwall Hospitals NHS Trust (RCHT) which covers both in-patient acute care and ongoing support in the community for children with complex health needs and Cornwall Healthcare Trust (CHT) which encompasses community hospitals, mental health and learning disabilities. Services in the east of the county are contracted to Plymouth Hospitals Trust (PHT) and North Devon Healthcare Trust (NDHT). The Trusts operate different criteria and there is also significant confusion regarding the exact contractual responsibility PHT, NDHT and RCHT hold for the provision of equipment to children living in Cornwall.

Within the county children requiring equipment to maintain/manage their health at home may draw on a variety of sources including the ward prior to discharge, the Diana Team, CLIC (Cancer & Leukaemia in Childhood) nurses, the Neonatal Outreach Team or one of the Paediatric Therapists, depending on need[17]. Innovative services in the community such as the Diana Team are being developed in response

[16] It should however be noted that many children might also use items of "adult" equipment, which are not included in this figure.

17 Unlike adults, there is no contract in existence for the CHT loan store at Bodmin to supply children's equipment on a short term basis, RCHT is often therefore left to fund the vast majority of items.

to need. However, agreements as to the responsibility for provision of equipment for use at home have not as yet been formalised. Arrangements with GPs in particular are reported as inconsistent. Larger items of medical equipment may be funded from a variety of sources but again a lack of guidelines means provision varies across the county.

"Therapy" equipment required by children living within the managed area of RCHT, are funded via a central appliance budget following authorisation by either the child's consultant or the Superintendent Paediatric Physiotherapist[18]. During the financial year 1999 – 2000, a minimum of £80,136 was spent from this budget on children's equipment mostly on specialised seating (39%), standers (27%), sleepsystems (13%) and walking aids (12%)[19].

The Education Department in Cornwall works to a policy of inclusive education thus the vast majority of children with complex needs, specifically of a physical nature, are educated within mainstream school settings[20]. If a child needs specialised equipment to access the national curriculum, it is recommended by either a special needs advisory teacher or therapist (NHS or SSD) following assessment. Once received by the Special Education Branch, the recommendation is discussed at a panel where a decision is made as to provision. Non-educational provision such as mobility equipment is accessed through the Health Service.

During the financial year 1999-2000, £70,000 was spent on "special equipment" mostly on specialised seating (44%), and computers (42%), together with toileting and communication systems.

3.12 Understanding concerns

A second key output was the identification of the limitations pertaining within the existing system. Some of these found an echo across agency boundaries.

A first common concern was the lack of robust IT management information. This has numerous attendant costs. Staff from all agencies highlighted the lack of, or the deficiencies surrounding, any centralised method of organising equipment provision. It is then difficult to know what is being used at any one time, staff have to spend significant time organising and tracking down equipment and recycling of equipment tends to be minimal, with most items being purchased new[21]. In Health teams working in the community such as CLIC and Diana, for instance, each team may have access to its own small range of equipment but individual stock is not common knowledge and thus not available in an emergency. Social Services staff are similarly often unaware of items being held in stock centrally and so request new purchases. There may also be many items of equipment "lost" in the community which may not be being serviced / maintained. An allied concern voiced by NHS staff was the lack

[18] RCHT paediatric staff having agreed criteria as to the prescription of such items.

[19] This figure does not include footwear, orthoses or devices such as nebulisers and suction machines. Nor does it include expenditure by the other Trusts. PHT physiotherapists alone, for instance, reportedly have a caseload of approximately 100 Cornish children. Again exact figures were difficult to ascertain due to limited IT management systems and items being purchased from a variety of different sources on a one-off basis.

[20] There are however 3 special schools in the county for children with severe learning disabilities and these hold a slice of the special equipment budget to purchase equipment for their students. As noted above, links have now been made with another HAZ funded project which aims to foster an inter-agency approach to children in special schools. This was another "Early Result" area – but was subject to a delayed start.

[21] With no method of transportation between schools recycling can also become very expensive.

of a formal recall system, so that staff spend considerable time trying to get saturation monitors and suction machines back when they are no longer being used.

A second common theme was confusion and at times duplication of roles and responsibilities, with concern surrounding assessment, funding and provision. Inadequate communication, inconsistent geographical boundaries, organisational remits and the increasing versatility/multi-functional nature of some equipment all contributed to the confusion. There is no clear policy, for instance, as to who should fund different items of medical equipment, leading to inconsistency in provision across the county. Within Health, uncertainty surrounds the recycling policy and within education confusion surrounds responsibility for the assessment of items such as specialised seating.

Staff from Health and Social Services, i.e. the two key providing agencies both highlighted concerns that too much emphasis was placed on equipment provision rather than on therapeutic intervention or treatment. Some clients were therefore felt to be at risk of becoming dependent on equipment rather than learning independence.

They also pointed to a lack of available resources. At the time of consultation the stock at Social Services central stores, for instance, was limited - mainly to recycled items which were often unsuitable and, despite requests, there was no buffer system of the kind in operation for the adult stock thus everything was processed as an interim order involving extra paperwork and time delays[22]. Similarly, in Health, children are on occasion being discharged home with ward equipment owing to a lack of availability of equipment in the community. This can potentially deplete ward stock but there are few other options unless discharge is delayed.

Such problems are compounded by a lack of budgetary provision. Health staff providing services in the community have, for example, limited or non-existent budgets for small items of regularly used stock whilst delays in obtaining equipment from Social Services mean that some referrals from Health therapists are not placed and requests are diverted through for trust funding. The Health Authority has meanwhile not specifically included any provision for children's equipment within its contracts with service providers. This is a problem that is compounded, as staff from education note, by high expectations, with everyone wanting the "Rolls Royce" of equipment. This is a feature that appears to be exploited by manufacturers, who change styles, colours and prices regularly.

Staff in these two agencies were also concerned about a lack of guidance and policy. The lack of agreed multi-agency guidelines for the provision of specific items of children's equipment, coupled with a lack of clarity as to individual roles and responsibilities, produced what was described as a "woolly" system with provision varying according where children live[23]. Health staff highlighted, for example, the lack of any policy regarding the provision and funding of augmentative communication devices. Education or charities are the main providers at present but again funding is limited.

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[22] A buffer system has now been introduced for Paediatric OTs – as a direct response to staff requests.

[23] RCH therapists are the only practitioners with agreed, written guidelines for the provision of specific items of children's equipment. These guidelines however, are only used in the managed area of RCHT and confusion still occurs regarding agency responsibility for items such as seating. Wide ranging inconsistency in provision is apparent across the county.

Education and Social Services both highlighted the lack of a formal review system with teachers or parents expected to notice, for instance, when an item is getting too small. This tends to lead to crisis rather than preventative work. They also drew attention to the lack of storage space with individual schools having to store unused equipment on the premises, increasing the dangers of it being damaged or forgotten. There was also a common concern from Health and Education about the lack of cleaning facilities with staff reportedly often undertaking this job themselves.

3.13 Defining what is required.

A third very important product of this consultation process was a broad consensus as to what was required:

> "Everybody was saying the same thing, they basically wanted a one stop shop whereby they could make one phone call to a central store to order and arrange delivery of all the items the child required - an integrated Health, Social Services and Education equipment store."

Within this scenario certain items of equipment were repeatedly highlighted as problematic. These appeared to be the most time consuming to organise, involved the greatest confusion over service responsibility for provision or were inconsistently provided by agencies. Items mentioned most frequently[24] in this respect were seating, wheelchairs and buggies, communication equipment, beds and cot sides, suction machines, saturation monitors and car seat.

More specifically, those interviewed expressed the need to work towards:

- a "joined up" service for children with complex needs
- the development of clear, agreed criteria as to who does what, when and how they can be contacted
- a "centralized" system whereby all equipment is held in one place, managed by knowledgeable staff and can be accessed readily over the telephone by relevant staff
- a joint agency approach to ordering, delivery, cleaning, maintenance and recycling
- an equipment amnesty to retrieve equipment not being used
- a computer system that allows comprehensive tracking and recording of equipment, incorporating barcodes on larger items of equipment
- clear guidelines for provision of specific items of equipment to ensure equity.
- clear procedures identifying items of equipment agencies would not usually provide and an indicator as to other sources of funding.
- a formalized review / monitoring system
- the development of "trial" equipment stock, which could be provided on a short-term loan basis to ensure it meets needs prior to formal provision
- and teams to hold a small stock of frequently used "consumable" items of equipment (Clapperton, 2000).

A corollary of this agenda was the widespread realisation that in order for these changes in service delivery to be made changes in attitude and approach needed also to occur. All agencies needed to be committed to change and agreement needed to be from the top down, greater interagency collaboration was also essential

[24] On more than 5 occasions.

if roles and responsibilities were to be streamlined. Clarity of agreement and clear policies and procedures needed to accompany the changes and decisions needed to be guided throughout by the requirement to improve the efficiency of the services in meeting children's needs. Concerns were voiced, for instance, about developing a system entailing excessive paperwork or one which used a committee to decide upon provision as it was felt these could cause further delays.

This consultation process has proved to be not only an important fact-finding activity but also an aid in itself to more effective partnership. It identified the many people who provide equipment and, by virtue of detailed consultation, not only established their role in the system and their reservations concerning the system of which they were a part but also helped them understand the role of their partners. It was thus a first important step towards better inter-agency working.

"It was clear from the start that each agency held perceptions, accurate or not, about the other agencies' abilities to provide equipment, therefore the draft document was written to establish a common understanding of the current situation at all levels. I don't think that people, aside from those practitioners involved in equipment provision on a daily basis, were fully aware of how big this issue was for children and practitioners."

The consultation process was also critical in prompting another re-assessment of the remit of the project.

"After saying that the project had to be extended to cover equipment for all children with complex needs the remit of the project grew daily. People were asking if I would look at the provision of wheelchairs and incontinence aids as well as all the other items and it was just not possible to cover them all."

The Project Lead, in consultation with her Line Manager, had then to decide to concentrate "quite strongly" on therapeutic equipment, specialised medical items used in the home such as suction machines, ADL equipment and specialised items used in schools.

3.2 The View from the Schools

Specialist equipment is often a key factor in ensuring that children with complex needs are able to make the most of their education. Representatives from education were included in the consultation process described above. However, the education department within Cornwall works to a policy of inclusive education so the vast majority of children with complex needs, particularly those of a physical nature, are educated within mainstream school settings. If such a child is identified as needing specialised equipment to access the national curriculum, an assessment may be carried out by a number of different practitioners including the Advisory Teacher for Physical Disability, a Health Physiotherapist / Occupational Therapist or a Social Services Occupational Therapist (Clapperton 2000, p7).

Initial discussions suggested that the provision of specialised equipment for use in mainstream schools is a source of confusion and could be significantly improved. A short postal questionnaire was thus designed to assess Head-teachers satisfaction with different aspects of current service provision (including delivery times,

demonstration and assessment) and to collect suggestions as to how the service could be improved. This was sent to all comprehensive schools and a one-fifth[25] of all primary schools in the County. From the 81 questionnaires distributed 72% were returned. This, as with the willingness of stakeholders to be interviewed (above), suggests a high level of interest in the topic. Significantly, given that it focuses on one of the key locations where specialist equipment is used, it also provides a first input from a user's perspective.

Over half of Primary Schools (53%) with experience of equipment provision, but less than one-third (31%) of Comprehensive Schools, were satisfied with the service provided. The main causes of dissatisfaction in both instances related to delays in gaining an assessment of need, or in the supply of the equipment following assessment.

> "We have been trying to have a specific laptop for one child that can be used as he moves through to the comp. School. Social Services are now trying to see if they can provide one for this child – we have had no luck with other agencies & resources are limited."

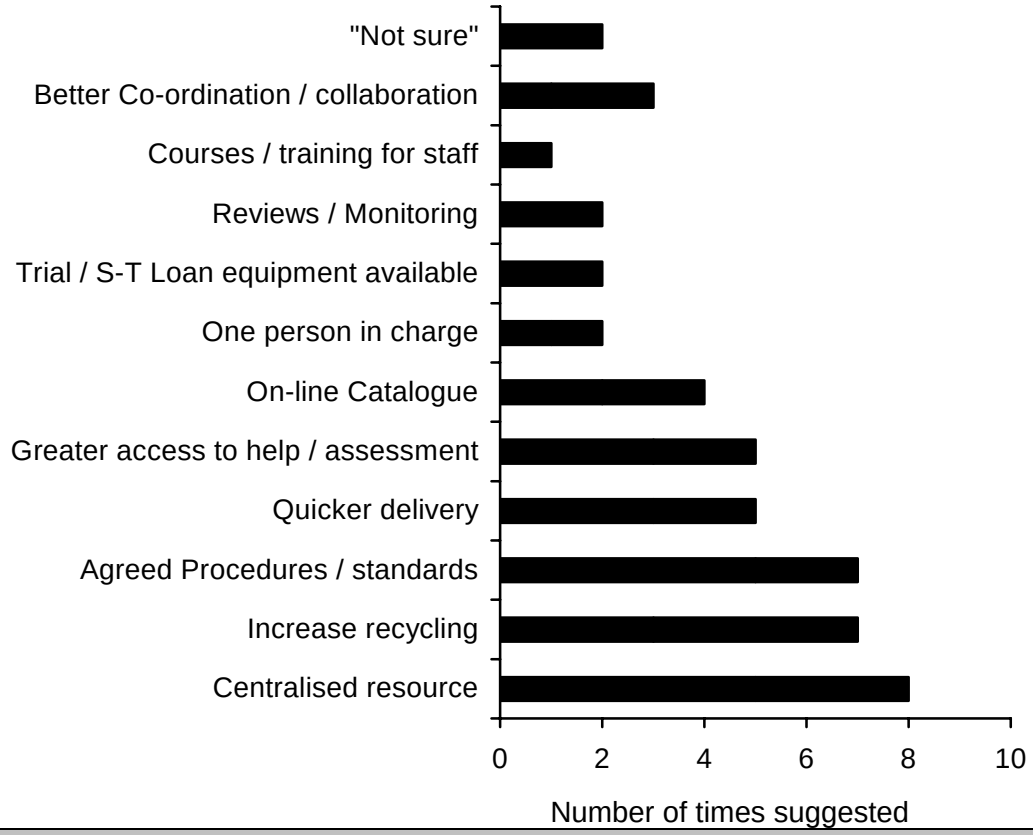
Other concerns included a lack of resources, confusion over who should fund equipment, insufficient numbers of support staff to update software and difficulties arranging the collection of unused items. Differences in satisfaction, whether with assessment & delivery or demonstration varied with the origin of the service, but no consistent patterns emerged, suggesting a more complex explanation than agency responsibility alone. A minority of schools (13%) also held unused equipment and one, concerned with the lack of demonstration suggested:

> "There are so many people to deal with, it means that the equipment has <u>never</u> been used."

Many schools (72%) expressed ideas for improving the provision of specialised equipment with the majority reinforcing the need for a centralised resource capable of efficient delivery, collection and re-cycling (Figure 1).

Figure 1: Head-teachers' suggestions for improvement

[25] 50/240 Primary Schools.



"In the past we have had children who needed very specialised equipment which was provided by various agencies. It would have been much more efficient and easier to access if there had been one centralised body responsible for the equipment. The main problem is knowing where to go!" "The grey area between health/education somehow clarified….it is confusing."

Two schools however, were more than satisfied with current provision stating; "We are happy with the service provided" and "It's very good at present".

3.3 The Users' Viewpoint

More than 400 children living in Cornwall, were provided with specialised equipment from the statutory agencies during 1999-2000. In the first phase of the project it proved difficult to sample parent's view adequately. Some of the problems here too stemmed from the identified need to revise the original remit. Intensive research had already (Nash, 1998) been undertaken with parents of children with severe complex needs, that is with those who essentially formed the focus of the Diana Project and would have formed the focus of the Special Equipment project as originally conceived, and a review was planned for 2000. Both the researcher responsible for the review and the Project Lead for this project were only too aware of the dangers of further burdening these parents.

"We felt that the potential for duplication of questions and saturation of the families was too great, especially given the many commitments and appointments these families already have. From my past experience working as a paediatric

OT, families have often commented that there are too many people involved and they are tired of continuously answering the same questions."

It was thus decided that the original researcher would also speak to parents specifically around specialist equipment needs. Unfortunately, the funding for that evaluation was curtailed so the review did not take place. At the same time, the extension of the specialist equipment project meant there was now a requirement to speak to a far wider range of families. Again linkages between HAZ projects proved useful with the Project Lead linking into the advisory group of parents/carers of children with complex needs established as part of the HAZ funded Joint Agency Strategy for children with complex needs. This enabled the Project Lead to speak to a group of some 30 parents. Unfortunately, the majority of these children had purely learning difficulties and their parents reported little experience of specialised equipment provision.

A first project-specific insight into the perceptions and experiences of users is thus only available from seven parents who completed an initial questionnaire. Even with this small base several pertinent themes emerged pointing to a lack of satisfaction with the current service. None of the parents / carers felt they were given sufficient information at the assessment stage as to the type of equipment available before a decision was made as to which item would be provided for their child and most felt a wider range of equipment should be provided. There was evident dissatisfaction with the time taken between assessment and provision and also with the time taken to obtain an assessment in the first place.

"Parents do not know to whom they should speak initially (school phsio, social workers, teachers, OT)."

The majority of parents also felt insufficient time had been spent showing them how to use the equipment once it was provided (with potential implications for the correct usage of equipment and the safety of the child). Finally most parents had experienced confusion over which agency should pay for an item of equipment for their child.

A second, much larger consultation exercise is now underway with a questionnaire being despatched to the family of each child identified as receiving specialist equipment in the last financial year from RCHT and Social Services. This was finally despatched to 208 families. However, again what should be a simple logistical process has had its complications.

"Data protection issues had to be resolved before names and addresses could be provided to me and Social Services had to request and co-ordinate individual responses from each local office as each holds its own records rather than them being held centrally."

3.4 Costing the Service

A second arm of the scoping survey was to investigate how individual budgets were spent in order that an expenditure profile could be drawn and areas of duplication or potential efficiency savings be identified. This was again not a simple procedure because not all items were fully described on the data sheets available and equipment may also be purchased under other budgets. However, data for 1999-

2000 was obtained from RCH appliances, SSD stores and Special Education, providing a first estimate from the three key agencies. A minimum figure of £215,000 was identified for 1999-2000 which did not include specialised medical equipment such as portable nebulisers, orthotics, wheelchairs and equipment purchased by Devon Hospital Trusts.

A number of costs were found to attach to the present system, some of which could be reduced. It was apparent, for instance, that all agencies order the vast majority of children's equipment on an individual item rather than bulk purchase basis with the three main agencies tending to use the same range of companies and often buying the same products. One company, for instance, received 86 individual orders worth £42,000 from Cornwall, equating to 20% of the total expenditure during 1999-2000 yet no bulk purchase discounts appear to have been made. This same recourse to individual orders[26] also has a high administrative cost, whilst delivery can take 4-6 weeks following receipt of an official order. Yet none of the three agencies have a fully comprehensive IT system designed to provide management information regarding the effectiveness or "real cost" of equipment supply, capable, for instance, of identifying trends, the individual ordering habits of practitioners or accurately tracking items throughout their usage.

In some instances orders were also found to have been made for items of equipment which were actually already available in the County. Thus Education and Health each purchased 3 "Symmetrikit" chairs costing on average £1,200 per chair, yet during the same period, Social Services had the equivalent number of these chairs available in their central Truro store. Furthermore, under current VAT arrangements, Local Authorities can reclaim VAT on children's equipment whereas NHS Trusts cannot so the 3 Symmetrikit chairs purchased by Health cost an additional £630 in VAT compared to those purchased by Education / SSD.

A corollary of the lack of integrated purchasing is limited recycling. Social Services is the only agency with a formal storage, delivery and re-cycling facility. However, owing to the revolving door nature of current service provision whereby cases are shut once individual episodes of intervention are completed, equipment is not routinely subject to formal review following initial delivery. This has potential implications for usage, continued suitability to the child's need, maintenance, safety and liability issues.

3.5 A View from around the Country

The sections above have described the considerable effort that went into understanding how the service is configured locally, how both providers and users feel about the system and where changes should be made. A questionnaire was also sent to a sample of twenty-five Social Service Departments and twenty-five Health Trusts on a national basis. The aim of this exercise was to learn more about the administrative arrangements that guide equipment provision elsewhere. Whether guidelines for provision exist, for instance, and whether these are agreed on a multi-agency basis, whether agency funding responsibility has been determined and whether the majority of items are funded jointly, who takes lead purchasing and assessment responsibility and whether there is a joint equipment store for children's equipment.

[26] a minimum of 418 across the 3 agencies orders to ISG for Computer Equipment or items purchased through NHS Supplies.

Again a significant response (70%) was received reinforcing the impression already given as to the widespread interest in and relevance of this project. In line with the Audit Commission Report "Fully Equipped" (Audit Commission, 1999) there were evident geographical variations but the majority of departments (65%) were found to have guidelines for the provision of equipment although fewer than one-third had guidelines agreed on a multi-agency basis. Similarly the majority (72%) had an agreed policy as to which agency had funding responsibility for different items of children's equipment. However, the nature of this agreement (historical/verbal/formal) was not quantified and most (79%) departments went on to report that the majority of equipment remained funded on an individual agency basis with historical definitions of responsibility, based upon therapeutic or social need, still appearing to underpin the majority of equipment supply. More than two-fifths also had a joint equipment store although the main partners were Health and Social Services. Indeed, few respondents had any formal tripartite agreements involving Health, Social Services and Education. All but one of the departments also claimed to recycle equipment as a general rule although inefficient tracking and collection systems were identified as reducing effectiveness and the ability to recycle is compromised by the specialist nature of many items of children's' equipment coupled with an ever-changing market and growing expectations.

4 Developing a Model

As a result of the consultations undertaken in the first phase of the project three models were then devised and taken to the Children's Planning Steering Group for consideration. It is worth noting briefly at this juncture the role of this group.

HAZ funding was not dependent on the establishment of an executive body with responsibility for the oversight of the project. The Project Lead in this instance reports to a Line Manager in Child Health but, despite the multi-agency remit, there is no multi-agency dimension to this steer. Meanwhile, at the strategic level there has been a long-standing lack not just of a multi-agency Steering Group but also of any Steering Group at all. The Children's Planning Steering Group is an informal sub-group of the Children's Services Planning Group[27] and assumed responsibility for overseeing two key HAZ projects. This project drew briefly on this group too but found managerial time essentially too stretched to assume yet another responsibility and also reservations about the appropriateness of a reference group which still did not include Child Health or a representative from Social Services with responsibility for children with complex needs. Nevertheless, it was able to obtain an opinion from this Group as to which of the three models, outlined below, represented the preferred option for developing specialist equipment provision.

OPTION 1 **- Remain the same but responsibilities for the provision of specific items of equipment are clearly agreed on a multi-agency basis.**

- This option would involve the least amount of change. Agency responsibilities for all items would have to be clearly determined but individual ordering/ recording systems would continue.
- Clarified roles and responsibilities would reduce duplication of effort whilst the development of guidelines for provision of specific items of equipment would increase service users awareness of what is and is not available.

[27] The accountable group, inter alia, for the HAZ Children & Young People's Work Programme

- The difficulties and confusion caused by changing professional roles and by increasingly multi-purpose equipment would not be resolved, nor would it address the key issues of recycling, long delays between assessment & delivery or lack of storage. Equity in provision across the county would not be ensured as Trusts may work to different criteria and the efficiency savings afforded by joining forces would not apply.

Example – Lincolnshire
This system pertains in Lincolnshire where agencies work to specific guidelines for the provision of children's equipment and an unwritten agreement as to the funding responsibility for individual items. Short-term equipment for use at home is funded by Health, whilst long-term is funded by the by SSD and equipment for use at school is funded by Education. Seating is often jointly assessed by Health / SSD practitioners with equipment ordered & stored by individual agencies.

OPTION 2 **- Agencies retain individual responsibility for the majority of items but establish a pooled budget for identified "grey area" equipment.**

- This option would resolve the confusion as to agency responsibility. However, with equipment increasingly having dual function, it is anticipated that the range of "grey area" equipment would continuously expand. Regular review of the range of items available from the pooled budget would be necessary and procedures established to manage overspends.
- Agreed multi-agency procedures / protocols would be required in order to access the pooled budget. Consideration would also have to be given to the need for a multi-agency decision making panel and for one agency to take the lead role in ordering stock from this budget in order to promote efficiency.
- Careful consideration would also be required to ensure this option was compatible with Care Management and operational management systems.
- With widely circulated guidelines, this option would reduce confusion and duplication of effort but would not address the storage and recycling issues for Health / Education nor speed up provision significantly.
- Potential savings may be reduced depending on which items are purchased via the pooled budget. For example, it was noted above that one supplier currently receives £42,000 worth of orders for both specialised seating & standing frames. If seating is identified as a "grey area" whilst standing frames are considered a Health responsibility, the combined purchasing power would drop substantially.

Example – Norfolk
In Norfolk equipment that is clearly the responsibility of one agency is paid for by them whilst equipment that has dual purpose is requested via a multi-agency panel for joint funding (seating, communication aids, etc.) Meetings are held bi-monthly although the frequency can be increased according to demand. A Senior Manager in the SSD holds the pooled budget and SSD takes responsibility for ordering, delivery, etc with equipment being reviewed every 12 months. The initial capital in the pooled budget has had to be increased owing to the growing demands on this resource.

OPTION 3 **- "Whole systems approach" incorporating a pooling of budgets and resources for all but the most specialised of items.**

- This option would involve the pooling of all resources into one centralized facility from which all aspects of equipment provision, including recycling & maintenance, would be undertaken to achieve optimum use of resources and purchasing power.

- The only items not included, depending on the contribution of each agency, would be the very specialised medical items or possibly computers / software used in school.
- Practitioners, suitably qualified to assess for individual items of equipment, could access it directly following identification of need rather than having to refer on to another agency. Duplication of effort, the number of professionals involved with the child and the time taken between assessment and delivery would therefore be significantly reduced leading to improved service quality and user satisfaction.
- Jointly agreed criteria for provision of specific items of equipment would be necessary to ensure equity across the county whilst equipment lines could be standardized to achieve discounts based on economy of scale / bulk purchasing.
- Gathering all unused stock into one centralized facility would not only free up vital storage space but would ensure optimum levels of recycling, again potentially speeding up delivery times and reducing the proportion of new stock purchased.
- Comprehensive and accurate management information could be gathered regarding operational costs, trends and outcomes to inform budgetary decisions and performance indicators.
- Unless contracted out to an independent company having it's own facilities or integrated into a "Community Equipment Store", this option would involve a substantial initial layout by all agencies to purchase a suitable site, install a comprehensive IT support package, employ staff and establish a countywide delivery service.

Example - Somerset
In Somerset a joint equipment store is scheduled to commence in October 2001, the partner agencies being Health, Education and SSD. This will involve the pooling of budgets and will ultimately incorporate equipment for people of all ages living in the community. A "standard" range of 150 items of equipment (including children's) has been established and written guidelines for the provision of specific items to ensure equity are underway. The service is to be contracted out to an independent supplier and practitioners will have individual PIN numbers that will allow access to specific items. All current stores will be closed down and systems merged. Area based SSD technicians are to be employed by the company gaining the contract and will provide a "man with a van" type service. They will deliver, fit and give basic instruction in the use of the equipment and a pooled fund manager will be employed to oversee the store operation and undertake audits / spot checks.

The Children's Planning Steering Group agreed that Option 3 was the most appropriate, particularly given the awareness that the Department of Health was planning to undertake a whole scale modernisation of Community Equipment Services in the near future. Prior to the DoH intervention, the intention had then been to consult with Stakeholders about which option seemed most appropriate to ensure all were signed up to the agenda for change. However, the Department of Health guidance published in March 2001 provided prescriptive guidelines promoting a whole system approach as in option 3 and this was no longer felt to be necessary.

This HAZ funded project was therefore in the strong position of being in advance of national thinking. The next section evaluates the Phase One activities that placed it there but significantly it also acknowledges that these national guidelines, with their wider emphasis on all community equipment, may also effect the degree to which the project is now able to continue towards its Phase Two aim of developing a streamlined, easily understood method of specialised equipment provision for *children*.

5 Evaluation of Phase One Activities

5.1 A Difficult Operational Context

The project had its origins in a difficult operational context. As both section 2 and section 3.1 note the provision of specialist equipment is currently the responsibility of a variety of agencies. Services have largely been developed in isolation and whilst examples of good practice are apparent there has been an evident lack of multi-disciplinary working and communication. Working practices, organisational ethos and the availability of resources vary, for instance, on an inter-agency basis and moves towards joint working therefore carry perceived threats as well as opportunities.

Within agencies there are similarly many different professionals with responsibility for specialist equipment. The prospect of change may again be associated with threat. This may be particularly so when key groups within the process already feel themselves undervalued. In such circumstances it is not surprising that:

> "Initially people were wary of the project as there were concerns that provision could potentially be made worse rather than better. Over time though I think things have slowly changed and the potential benefits of integrating provision are being realised."

Section 2.4 also described the lack of a multi-agency disabled children's register within the County[28]. Again this had ramifications for the Project, not least because (once it's remit started to widen) it had in effect to define its own client group because strategic decisions have not yet been taken as to who constitutes a child with a complex need. This hints at a fundamental tension in organisational dynamics, whereby scarce resources are focused on service delivery rather than released for operational support or policy development and communication is accorded insufficient priority. This suggestion is reinforced, for example, by the lack of centralised methods of recording equipment provision (section 3.12) despite the cost to staff in terms of time spent organising and tracking down equipment and the constraints it imposes on recycling, review and maintenance.

The existence of significant problems such as these were clear right from the initial conception of the project, indeed, they formed the rationale for funding. In such a context the achievements of the project should not be underestimated.

5.2 An Enabling Context

At the same time changes, largely in the national agenda, have provided what is, in many ways an increasingly empowering context for the project. Quality Protects, for instance, will from 2001/2 to 2003/4 bring a cash injection for the development of support services for disabled children and their families, whilst the White Paper (Valuing People: a new strategy for learning disability for the 21st Century) published earlier this year raises the profile of services for this group and provides access to

[28] Many people have been militating for this development, not least a number of HAZ projects and significantly the project which addresses children in special schools now intends using part of its funding for this purpose.

funds. Significantly, there will need to be effective links in place between Health and Social Services in order to make optimum use of the these resources, so agencies have to sit down together and work in partnership. A similar emphasis on partnership working also permeates the area-based initiatives which can be expected to have an impact on children with complex needs such as the Children's Fund and Sure Start and again initiatives developed under these auspices will be expected to demonstrate joint working.

The publication of the DoH Guide to Integrated Community Equipment Services earlier this year provided, in many ways, the most tangible contextual support possible for the project. Basically this promotes the development of an integrated equipment store in all areas of the country, funded on an inter-agency basis with a common method of ordering, recycling and delivery. As the Project Lead explained:

> "The guidance re-iterates all of the project's findings and the consensus of stakeholders' opinion which was great news. It also seems likely that although only classified as guidance there will be little choice and integrated equipment stores will[29] happen. Health and Social Services Departments across the country will have to work towards an integrated store whether they like it or not and the project findings will help reinforce the need from a local perspective."

Again there are certain conditions attached with money only released to Health if there is a joint plan[30]. Yet, ironically, this development also poses a threat to the Project as currently constituted for the second stage of the project, where the information gathered to date would be used to develop a new method of equipment provision, has in effect been put on hold firstly awaiting the issue of these key guidelines and now latterly because developments are seen as being played out on a different stage, with different players and in response to a script written by central government rather than by local authors.

It is important that the impetus gained in this area via HAZ funding is consolidated rather than placed to one side. The achievements of the project to date suggest both that the information gathered and the contribution that the project lead can make should be seen as a resource for the new store and a cornerstone from which to take developments forward. This would demonstrate that the HAZ philosophy of learning from change has really been recognised in the wider policy arena.

5.3 Project-specific Achievements

5.31 Clarity of purpose

A first major achievement of the project was a critical consideration of the remit. At the outset the project was focused solely on those children with the most severe needs. Shortly after appointment however, the project lead made the decision that not only would it be inappropriate to focus solely on such a small group of children, ignoring the system pertaining for their less severely disabled peers and potentially compounding existing inefficiencies by imposing a duality of provision, but also that the wider system of provision urgently needed to be addressed. The report has already described the knock-on effects of this decision in terms of defining the new target group and the clarity of purpose that was then required to ensure that project efforts were not then dissipated by trying to respond to an ever-widening agenda

[29] Original emphasis.
[30] Social Services already having received their allocation in their PPS settlement.

In retrospect the Project Lead still feels that:

> "it would have helped if maybe there had been more time given to deciding exactly what the remit of the project was, where were we starting, where were we finishing, what exactly was intended. This would have resulted in clearer guidelines and definitions being set as to the remit of the project."

Indeed, as Section 2.1 outlined, the original bid did not clearly state that the project was expected to do any more than scope the requirement for change and make recommendations as to how this change could be achieved.

The requirement to evaluate the project helped in that it encouraged the project lead to clarify the aims of the project, address the kind of activities that were needed in order to meet these aims and explore the assumptions that lay behind these aims. This is one area where capacity funded centrally by the HAZ has also proved to be worthwhile.

5.32 Defining need

A second considerable achievement of the project to date has been the comprehensive research conducted into the configuration of the system locally, the establishment of current shortcomings and the synthesis of requirements into three models for potential development. This analysis has also been informed by systems operating in other parts of the country. A shortcoming of the process to date has been the limited input from users of the service but this has already been identified by the Project itself and an extensive consultation process is again underway to make sure that the voices of the service users are also heard.

Achieving clarity of purpose and ensuring the necessary information is available for project development, (including establishing supporting networks and developing trust), are extremely time consuming processes. This is particularly the case when, as in this project, a multi-agency solution is sought and yet there is a limited history of joint working on which to build. This point is developed further below but it is important to note here that the time frame for project-specific achievements can be compromised if funding is allocated to under-developed bids and that time invested pre-bid submission in such a context is time well spent.

5.33 Communicating and establishing trust

Section 3.1 demonstrated how the consultation process initiated by the Project proved a first important step towards better inter-agency working. It allowed individuals the opportunity to voice their concerns and inform the process of change, it developed an understanding of the role of others and the constraints under which they operated and it revealed a widespread consensus as to what was actually required to improve the system. The project lead recognised that there were initial concerns that any change might compromise the delivery of the service and therefore used feedback mechanisms such as the draft report to keep stakeholders informed and involved with the process and has now established focus groups and reference groups for practitioners and managers respectively, drawing again on links with the Joint Agency Strategy.

There is a suggestion here therefore that organisational ethos is slowly changing and that value is being accorded to communication and the exchange of information but this challenge has to be more actively embraced and institutionalised.

"Owing to the high demand on certain services, the pressure is on practitioners and managers to keep the waiting lists down and see as many clients as possible. In my opinion, whilst all this is going on, communication is the first thing to suffer. There just isn't enough time to speak to everybody you would plan to and attendance at meetings is affected. Really it's false economy as everybody starts working in isolation. If, for instance, the Paediatric OTs from Health and Social Services met formally every few months, issues around duplication of roles, who should be doing what and why children may have more than one OT could be quickly resolved."

However, there is also evidence that organisational barriers continue to pose problems at strategic threshold points. The project lead suggests "we would have got there" but that the advent of national guidelines has strengthened the chances of delivering the proposed model of change in this area. But tellingly, there was also a strong suggestion that the national imperative had avoided the requirement for many difficult project-specific discussions locally "it appears that there is no choice". It should be stressed again, therefore, that for significant change to occur then the willingness to act in partnership has to extend to senior levels of management.

5.34 Building networks

The project has also proved able to establish useful and effective networks with other projects concerned to improve services for children with complex needs. The HAZ had an initially central facilitating role here in bringing project leads from the Children and Young People's Work Programme together for quarterly meetings. Relationships forged with the HAZ funded Joint Agency Strategy have been particularly productive enabling, for instance, the two Project Leads to combine resources in order to develop a common definition of children with complex needs and also to share meetings thus reducing consultation overload.

Latterly this has extended to other projects under the HAZ umbrella with a focus on children with complex needs[31] and interestingly not only does this group now meet as a recognised sub-group within the quarterly pro-forma meetings, providing a focused point for discussion and problems sharing but it is also planning a seminar for strategic managers in September to look at the means by which this group of projects can ensure access to decision-makers at the senior level and address the ways in which these initiatives can be sustained beyond the lifetime of HAZ.

From an evaluation point of view this is a very interesting development. It has come about because of a problem common to many projects – the lack of a fully representative multi-agency steering group with the ability to take strategic decisions about the development of services for children with complex needs. This project has therefore struggled to define and gain access to a suitable executive and found itself by default competing with numerous other projects for access to individual strategic decision makers; a process wasteful of both managerial and practitioner time and hardly conducive to an appreciation of linkages. On the one hand the joint seminar demonstrates the ability of related projects to define a common need and take collective action to remedy it and is a clear achievement again in terms of joint working. However, it needs also be acknowledged that this action had to be taken not only because the importance of effective line-management and access to an

[31] Including children in special schools and voice output devices.

executive body was insufficiently appreciated at the outset but also because raising the need through other forums proved ineffectual. “It’s clear that we have to take this forward ourselves by getting all the key managers into one room, presenting the need and hopefully initiating a productive discussion”.

5.4 Emerging Lessons

Many of the lessons to emerge from this project to date find echoes in earlier reports. Section five above has already stressed the importance of an appreciation of context (and hence of locally-sensitive responses[32]), the need for clarity of purpose, the significance that attaches to consultation, the importance of communication in establishing trust and understanding, and the tangible results that can attach to effective networking. It has demonstrated how time-consuming this process typically is and has shown how HAZ funding, by supporting dedicated staff time, can make a real difference to the ability to actually take work forward. Here it is suggested that the project lead represents a real local resource whose experience should be harnessed in the development of integrated community equipment stores.

It has also shown again the need for central support for individual projects. Unfortunately the HAZ support structure has not yet been able to facilitate a multi-agency steering group to oversee all projects relating to children with complex needs, carrying representation of all the relevant statutory agencies and capable of making formal decisions and financial commitments.

It is probably significant here that within Social Services provision for children with complex needs is assumed by community care rather than by children’s services, as there was concern that disabled children’s issues would be lost in the emphasis on child protection. In contrast, Social Services very significant contribution to both the Children’s Services Planning Group (which steers the CYP Programme) and the Children’s Planning Steering Group (which oversees a number of HAZ Projects) has come from children’s services and strategic interagency links to community services regarding children with complex needs remain far less developed.

However, this suggestion has now been placed before the HAZ Steering Group whilst the Children’s Services Planning Group is in the process of considering changes in structure and function. It will be interesting to see how this develops.

An allied lesson is the need for multi-agency commitment to be secured at all levels. The introduction to this report shows that this project had its origins in a tripartite proposal and it was therefore always unclear exactly which agencies were signed up to which parts of the bid. Indeed, there is some uncertainty, despite the multi-agency origins of the bid on paper, as to the degree of consultation and agreement that had occurred before bid submission. It has been suggested that if, for instance, strategic planners from more than one agency had actually to sign that they were in agreement with the proposal then responsibility for the success of the project would be more firmly institutionalised.

Nor should the significance of small but incremental improvements be overlooked. Following the concerns of local service providers (see section 3.1), for instance, a short-term contract is being arranged to collect, clean and store more than 50 items of equipment, the ward stock used in the community by the CLIC team has been

[32] It will be interesting as this project progresses to get a greater feel for any geographical differences.

identified and the process of identifying unused health equipment in therapy settings has also been initiated.

6. Conclusion

The future of the project is beset by some uncertainty. As this report was in preparation a meeting was planned to look at how the different agencies could combine to move towards an integrated community equipment store as required by the Department of Health. The Project Lead has been asked to consider undertaking the joint project manager's role for the Integrated Community Equipment Store in Cornwall because of the expertise built up in the course of this project. There is evidence therefore of a willingness to learn from change and potentially institutionalise the learning from this project.

Indeed, the Project lead continues to be committed to sharing the learning both locally, via for instance talks to the Diana Steering Group and Plymouth Health/SSD Paediatric Occupational Therapists and nationally via the National Association of Paediatric Occupational Therapists' Journal, the National Association of Equipment Providers' Annual Conference and the National Association of Paediatric Occupational Therapists' Annual Conference.

In the short-term two areas where it is expected that further project-specific progress will be made is in the production of agreed multi-agency guidelines for the provision of specialist equipment for children and in the clarification of individual practitioner roles and responsibilities.

Again, encouragingly, this produces more than the immediately obvious outcome, because:

> "As long as there is a clear purpose, the more people sit down and talk the greater the impact on service provision for children and their families. The need for greater communication cannot be underestimated, for instance, if people are more aware of what other people are doing and why they are doing it then the need and the duplication reduces."

Much has been achieved in terms both information and raised awareness as to the need for inter-agency working. Yet the relief that the national imperative moves the project from a negotiable suggestion to a statutory requirement suggests that much hard work remains in order to ensure that innovatory ideas are able to secure the high-level commitment needed to put them into practice and secure real change.

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