

# Evaluation of the PATCH nursing service: partnership and training supporting children with complex needs at home

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The PATCH project was an intersectoral initiative between health, social and education services in Lanarkshire, Scotland which provided support at home from two experienced children's nurses for parents of children with complex disability. The project was funded by the Scottish Executive Health Department Innovations Fund for Children's Services for two years from April 2000. This article reports results of an external independent evaluation of parents' and agency members' perceptions of the PATCH service. Audiorecorded interviews were obtained from members of eight families and eight agencies. Issues related to the two key aspects of support addressed in the project, carer training and partnership working, are presented. The skilled approach to training adopted was successful in creating a network of carers, both lay and professional, which resulted in improved respite and rest for parents. Effective partnership working resulted in improved communication, the development of an innovative child record, effective help in crises and improved service co-ordination. Together, the training and partnership elements of the PATCH service addressed practical, emotional and social difficulties experienced by families. The freedom to work flexibly and to approach agencies directly and the ability to cut across established organizational structures were significant factors in improving support for families. A number of key aspects of nursing expertise and possible outcome indicators for such a service are presented.

**Key words:** carer training; children's nursing; children with complex needs; partnership working

## Introduction

Caring for a child with special and complex health needs presents enormous challenges for families, often throughout 24 hours. Increasing numbers of preterm infants, and children with congenital impairments and chronic illness now survive, a subset of whom are technology dependent (Kingdom and Mayfield 2001; Kirk, 1999). With the emphasis now on community care, parents of children with special needs must organize compli-

cated care regimes, use increasingly sophisticated life-sustaining equipment and negotiate their way through a maze of service provision.

The PATCH project – partnership and training supporting children at home – was an intersector initiative between health, social services and education in Lanarkshire, a central Scotland region (population 562 000). The project aimed to provide support for parents of children with complex disability by training family members and carers from health, social work, education or voluntary agencies, to undertake necessary tasks to a standard which would allow parents to have confidence in those carers' contributions to a child's care. The project, led by health, was funded by the Scottish Executive Health Department Innovations Fund for Children's Services for a two-year period from

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April 2000. An estimated 500 families in Lanarkshire were caring for a child with complex needs at that time (Lanarkshire Health Board, 1999). The PATCH service was designed and introduced by two children's nurses, supported by an intersectoral steering group; the nurses were highly experienced in acute children's nursing, but neither had a community nursing qualification. This article reports the findings of the external, independent evaluation of family and agency members' perceptions of the PATCH service and its two key concepts – partnership and training (Runciman and McIntosh, 2002). The internal evaluation report is available from Lanarkshire NHS Board (Tonner and McGunnigal, 2002).

### **Caring for the child with special needs**

Social, emotional and financial effects of caring have been reported (Kirk, 1998; 1999; Murphy, 2001a; Sadler, 1995). Social effects include isolation, restriction to family activities from lack of time and lack of babysitters and skilled carers, medicalization of the home environment and lack of privacy from intrusion of many visits from health professionals. Financial effects from loss of earnings, particularly women's earnings have been cited (Murphy, 2001a). Emotional effects include depression, sleep deprivation, prolonged grieving, stress, exhaustion, the need to be on the alert for crises, uncertainty about a child's development and education and fear of the future and of the child dying (Reeve and Miers, 1994; Sadler, 1995). Performing unpleasant procedures that carry risks of causing pain and distress (Procter *et al.*, 1998) and acting as advocate for a child, in asserting a child's rights to receive appropriate care, have been noted as stressful (Kirk, 1998). Parents cite anxieties about the risk of neglecting siblings and about pressures on siblings from assumption of caring responsibilities beyond age and abilities (Murphy, 2001a). Parental relationships may also be vulnerable; however, the assumption that children with special needs irreparably harm marriages has been questioned (Eddy and Walker, 1999).

Flexible respite support is one of the most consistently cited family needs (Murphy, 2001b). Finding competent carers in whom parents have confidence and who are able to offer support over 24 hours or during evenings, at night and at week-

ends may be a problem (Kirk, 1998). An evaluation of a nurse-led own-home respite support service for parents of children with complex needs ( $n = 17$  families) found that some parents lost faith in the service on the grounds of its lack of flexibility (Olsen and Maslin-Prothero, 2001). A survey of paediatric home care teams in England ( $n = 109$ ) revealed 32% offering a service at weekends and bank holidays, 18% providing an evening service and 6% providing a night service; only a minority offered on-call support (While and Dyson, 2000). For families who depend upon skilled child care in order to get respite support, carer training is therefore an important issue.

### **Carer training**

Many carers, including parents and close family members, will be involved in supporting a child with complex health needs and, as care needs change over time, the network of carers who require foundation competence and skill update may expand. Several concerns related to training have been reported. Finding and recruiting volunteers willing to care may be difficult, particularly where a child is technology dependent (Murphy, 2001b; Townsley and Robinson, 1999). Parents themselves often feel inadequately prepared to use equipment and perform highly technical procedures (Kirk, 1998; 1999). Before discharge from hospital, the mother may be the only person within a family who is taught a procedure and instruction may be given by nurses who cannot interpret caregiving for the home environment (Glass *et al.*, 1996). Parents have reported tensions in relationships with professionals who fail to recognize and respect parental expertise when it exists (Coyne, 1995; Herrington *et al.*, 2001; Kirk, 1999). As parents become experts, they in turn express anxiety about health professionals whom they perceive as lacking in essential knowledge and skill (Ford and Turner, 2001).

Difficulties related to lack of training are summarized in Townsley and Robinson's (1999) review of enteral tube feeding for disabled children. They report instances of children being fed orally rather than enterally, as recommended, during short-term residential care. Disputes over the definition of enteral care as a nursing or a social care issue also occur with health authority and

social services being unwilling to rethink definitions or reach compromise. Lack of clear policy within services about lay carers and their training and uncertainties about accountability, legal liability and insurance for both lay and professional carers have limited the development of training and the provision of effective respite support.

Townsley and Robinson (1999) and Lightfoot *et al.* (2001) also note a history of poor co-ordination between health and education and a lack of clear policy and practice guidelines for education authorities regarding inclusion of children with special needs. School staff may be unsure of who to contact in the NHS for advice about a child and they require an informed lead health professional and a mechanism for systematic communication about a child's health needs.

### Partnership and service co-ordination

National policy directives stress the importance of partnerships and of interagency working at strategic planning, service commissioning and service provision levels (Department of Health, 1998; The Scottish Office Department of Health, 1998). Partnership has been described as an elusive concept (Lee, 1999), that defies succinct definition. Literature suggests that partnership working, with families and between agencies, involves processes of negotiation, consultation, collaboration and joint decision making (Mitchell and Sloper, 2001). There would be expectations of family involvement in planning, delivery and evaluation of services, and a need for professional sensitivity towards the balance of power and control in relationships and to the balance of enabling versus doing within the nurse role (Bond *et al.*, 1994; Gibson, 1995; Kawik, 1996).

A national survey (Beresford, 1995) of parents caring for a severely disabled child ( $n = 1100$ ) revealed worrying concerns about the experience of being a service user, for example, a sense of isolation and conflict with professionals, delays in service provision, inadequate information and poor communication. Parents of children with the highest levels of special care needs were the most dissatisfied with services. For many parents in the survey, dealing with services was the most stressful part of caring. Within children's nursing, partnership working appears to present particular chal-

lenges to power sharing and to respecting parents' knowledge and experiences of agencies and services (Gould, 1996; Haas *et al.*, 1992).

On balance, literature focuses more on partnership issues between nurses and families in the hospital (Casey, 1995; Coyne, 1995), rather than in the community setting, and on partnership issues with family members than with multisectoral agencies. Evidence to date suggests, however, that partnership working in children's nursing may be more readily achieved in the community than in the hospital environment (Taylor, 2000).

This brief review of literature related to carer training and to partnership and service co-ordination suggests a number of problem areas for families of children with special needs. The independent evaluation, undertaken by invitation of the PATCH intersectoral steering group, provided the opportunity to examine whether such problems could be resolved.

### Evaluation aims and design

The aim of the evaluation was to provide case studies ( $n = 10$ ) of families' and their key supporting agency members' perceptions/experiences of the PATCH service.

### Sample selection and recruitment

#### Families

From a matrix of information about the range of interventions and the level of input to each of 54 families recruited to the project by September 2001, a purposive sample of 10 families was selected, three having received low input, three medium input and four high input. The PATCH team confirmed that the full range of their work was reflected in the sample, and that to their knowledge, there was no reason at that time to exclude any of the 10 selected families. Eight of the 10 families agreed to participate in a home-based audiorecorded interview (Table 1). One was unable to take part because of family circumstances at the time; the other because of the death of their child.

#### Agencies

Each family nominated an agency member whose support had been significant for the family and whose knowledge of PATCH contact with them would be

**Table 1** Profile of the families interviewed

Family	Interviewees	Age of child	Child's diagnosis	Child's condition
1	Mother + aunt	9 years	Cerebral palsy	Relatively stable
2	Mother	5 years	Lissencephaly	Fragile with crises
3	Mother	13 years	Sanfillipo syndrome	Crises, deteriorating
4	Mother + father	5 months	Cleft palate	Changeable with crises
5	Mother + father	1 year	Necrotising enterocolitis	Relatively stable
6	Mother + father	3 years	Spina bifida, epilepsy	Relatively stable
7	Mother	2 years	Cerebral palsy	Changeable with crises
8	Father	5 years	Bilateral duplex kidneys	Relatively stable

helpful for the evaluation. All eight agency members agreed to take part by audiorecorded telephone interview. Health, social work, education and voluntary sectors were represented (Table 2).

### The semi-structured interviews

Before a family interview, the relevant PATCH nurse provided an outline of the child's history, the reason for PATCH referral and the family's current circumstances. Similar areas of content were covered in interviews with family and agency members (Figure 1).

Interview processes differed markedly. Family interviews lasted from 25 to 45 minutes with only minimal interviewer questioning, and were dominated by the need of family members to tell their story. Agency members interviews were shorter and interviewer led. They lasted from 12 to 20 minutes, and were more tightly structured around the scheduled questions.

### Data analysis

Audiorecordings of interviews were transcribed in full, and independently analysed by both mem-

Perceptions of the impact of the PATCH service in relation to:

- crisis situations
- a family's ability to get enough help of the right kind when needed
- proactive strengthening of support before problems arise or reach crisis point
- consultation with families and assessment of their needs for care and support
- direct care provision by the PATCH team
- training and support for family and agency members to undertake key procedures and provide care for the child
- improving families' confidence in the skills of others to care appropriately for their child
- improving service co-ordination
- preventing hospital admission and/or facilitating earlier discharge
- changes in family life in terms of abilities to manage/cope, anxiety/stress levels, time for siblings/each other, access to respite care.

**Figure 1** Semi-structured interviews: topics covered with family and agency members

*Primary Health Care Research and Development* 2003; 4: 307–318

**Table 2** Agency member nominated by each family

Family	Agency	Post held
1	NHS child health services	Locum consultant paediatrician
2	Voluntary sector, special needs school	Team leader, nursing
3	NHS health centre	Treatment room nurse
4	Social services	Registered child minder
5	NHS primary care trust	Speech and language therapist
6	Social services, shared care scheme <sup>a</sup>	Resource worker
7	Education, nursery	Head of nursery
8	Education, primary school	Head teacher

<sup>a</sup>Shared Care Scheme is a scheme in which a family is recruited by social work to share the care with a disabled child's own family.

bers of the evaluation team. Significant sections of text were highlighted and analytical comment noted in transcript margins. Key concepts were then identified and discussed. As the findings were strongly positive, the database was carefully examined for negative instances. There was a high degree of agreement between the two analysts regarding emergent themes, particularly in relation to the context of caring for a child with complex needs and to the concept of training, which families described clearly. Family members used the word 'training' and talked about it in some detail. In contrast, families did not in conversation use the word 'partnership', talking rather about a wide range of forms of support provided by the PATCH team. Partnership may be a more abstract, complex concept and a word more readily used in professional than in lay discourse. Partnership, however, was clearly illustrated throughout the family and agency data, and agreement about the issues within the concept of partnership was reached following discussion.

### Ethical approval

Ethical approval was obtained from Lanarkshire NHS Research Ethics Committee. Families had provided the PATCH team with written consent to the use of anonymized information for audit purposes and to disclosure of information about their child to named professionals and carers. Of concern in the evaluation, however, was the possibility that the uniquely distinguishing features of a child's condition and/or family circumstances might preclude guarantees of anonymity. Families were therefore given a copy of their interview transcript, with identifying names removed. Participant

release was sought and obtained for the use of quotations for publications and presentations.

### Evaluation findings

Parents and agency members greatly appreciated the work of the PATCH nurses and were strongly in favour of the continuation of the PATCH service. It was described as 'excellent', 'totally invaluable', 'a godsend' and 'an inspiration'.

Parents had experienced many social and emotional pressures, particularly exhaustion, anxiety and isolation.

T was critically ill in a coma for 10 days, by the grace of God he came home but nobody was willing to help. I couldn't get washed, dressed or eat until my husband came home at night. It was T and I constantly . . . I was changing T two hourly . . . I was turning his position two hourly during the night. His MR10 (apnoea monitor) was going crazy during the night. I had to make sure the oxygen wasn't running out . . . T at that point was stopping breathing continually. So I'm doing two hourly obs and everything during the night. I'm also with him during the day. I lost nearly a stone in weight. *Mother 2*

Parents also expressed frustration and disappointment with support services associated with poor co-ordination and frequent changes of personnel.

I sometimes felt that I had to do everything myself, I was co-ordinating everything . . . I

really did feel on my own, very isolated when B was very young. I felt I was cut off from (the hospital) and I was really quite disappointed in the after-service there. *Mother 7*

Interviews revealed a number of ways in which the PATCH nurses were able to provide support for families and for agency members through training and partnership.

## Training

Table 3 shows the content of training necessary for the eight families and the wide range of carers in receipt of training.

The challenges of dealing with the procedures and equipment essential for a child's survival and treatment were perceived as 'frightening'. Pre-PATCH, parents were unable or reluctant to trust others to care for their child. Even fathers and close family members 'wouldn't touch' the child. Training provided in hospital had been limited, particularly in relation to interpreting how to cope with the child's care and equipment in the home and community setting. A mother and father talked of being 'stuck in' and 'sitting in the house taking shots each at going out' because they did not know 'how to go mobile' with their baby and her feeding pump. Nasogastric and gastrostomy feeding were

particularly problematical. The pattern of recurring and new problems as a child's condition changed was stressful; for example, seizures worsened and medication needed review. Parents talked of repeatedly contacting GPs whom they perceived as lacking the necessary knowledge and as able only to refer families back to specialist care.

## The training approach adopted

It was evident from parents and agency members that training was sensitively introduced and was in line with key educational principles:

- learning needs of carers were assessed
- demonstration of techniques and skills was offered by PATCH nurses in partnership with parents; opportunities were given over several sessions, for repeated practice of skills under supervision until confident and practice sessions were well paced and unhurried. Training sessions might last from 20 minutes to 2½ hours and training could continue for up to eight weeks
- reasons for action and ways of undertaking care were explained and questions were answered; feedback on performance was given
- level of information and training was appropriately pitched; written information was provided in various forms to support demonstration and explanation and trainers were contactable if carers were uncertain or problems arose.

**Table 3** Trainees and content of training

	NG feed	Gast feed	Shunt	Seiz	Ox/suct	Neb	MR10	Meds	Catheter
Parent(s)	✓	✓	✓	✓				✓	✓
Siblings				✓					
Aunts	✓	✓							
Grandparents	✓	✓							
Respite care day		✓							
Respite care night		✓							
Shared carers			✓	✓	✓	✓		✓	✓
Drivers/escorts		✓			✓	✓	✓		
School staff		✓							
School nurse		✓						✓	
Other nurses				✓				✓	
Nursery staff				✓				✓	
Residential school		✓						✓	
Child minder	✓								

NG feed, nasogastric feeding/tube insertion; Gast feed, gastrostomy feeding and care; Shunt, shunt management; Seiz, seizure management/administration of rectal Diazepam/intrabuccal Midazolam; Ox/suc, administration of oxygen and use of suction; Neb, nebuliser use; MR10, use of apnoea monitor; Meds, administration of medication; Catheter, intermittent bladder catheterization.

Mothers particularly appreciated the PATCH nurses' thoroughness, their willingness to consult and involve mothers and their concern to follow the mother's way of looking after the child.

I knew that it had been a thorough going-over of all the different points, the pump, the hygiene bit . . . everything I would have done was covered you know the way I did it . . . She just didn't come and take over . . . but very much involved me . . . So I knew that when I left (the trained carers) at home they would be doing exactly what I did so you know that was quite reassuring to me to know that I am confident in leaving them and they won't be cutting corners or doing things differently. *Mother 7*

A clear description of the overall approach of the PATCH nurses to training was given by a resource worker for the Shared Care scheme in relation to supporting a couple, selected to care for a child with epilepsy, hydrocephaly and spina bifida. Training in seizure and medication management, shunt management and intermittent bladder catheterization was necessary. First, the PATCH nurse, the resource worker for the Shared Care scheme and the child's own parents met to identify precisely the child's current condition and care needs and to establish the parents' views about the nature of the support that the new carers would require. A meeting was then held with the new carers to discuss the child's needs and to explore how confident they felt. Finally, an appropriate training programme was designed and set up.

They (the new carers) were very apprehensive about the epilepsy seizures because L was taking fairly major ones at that point and was quite unwell. They were also happening quite rapidly . . . The PATCH nurse went out and did the initial stuff with them about how the seizures were, how they would use rectal Diazepam and then went back out again to revisit it all with them and then was available when L stayed for her first overnight with the family . . . Shortly after that L did have a seizure while staying there and (the PATCH nurse) was on phone call support to them at that point, she gave them her mobile number which they used . . . I think they felt that the training was very much pitched at their level. *Resource Worker, Shared Care scheme*

In comparison to other training resources available to agencies, PATCH training was better in certain key respects. As a 'one-stop' service, it reduced fragmentation and the need to approach several different agencies to teach the full range of topics/skills necessary for any one family. PATCH training was also based on comprehensive knowledge of the child and family and was therefore entirely relevant and focussed holistically on the needs of the individual child and family.

### Policy-related restrictions

A major source of frustration for mothers was the apparent restriction imposed on social services carers regarding the type of care they were allowed to provide for a child. It seemed puzzling that PATCH nurses could train a wide range of carers in NHS and private health care sectors and lay carers such as friends, family or neighbours but they could not train social services carers, who might already know a child well and be trusted by the mother. Restrictions to care became particularly frustrating when a child's condition deteriorated and care needs changed. The result for parents might be disruption to continuity of care where a carer of longstanding could not be trained in new techniques, or duplication of effort where a trained nurse had to be present in addition to a social services carer.

J needs nursing care now which is good in one way but it's cut down my services, because the Social Work Department won't let any of their workers who are extremely good and confident with J, be trained up for like suctioning and giving him medication, which the PATCH nurses would be able to do . . . they go in and train carers but the Social Work Department won't let that happen. *Mother 3*

### Partnership

Evidence of the PATCH nurses' ability to work successfully in partnership with parents and agencies was clearly evident, reflected in phrases such as 'we worked together', 'they involved everyone', 'she sat down with me' and 'she was there with us'. The following exemplify this mode of working.

### Constructing the PATCH record

The PATCH child record, assembled by parents and the PATCH nurse working together, was highly valued. The record, in a loose-leaf folder, provided a detailed picture of the child's daily life, care requirements, behaviour, likes and dislikes and was designed to accompany the child, for example, to school, respite care or relatives' homes. Mothers particularly welcomed clear descriptions of what to do in the event of problems or crises, for example, in seizure management or choking, or if a child was restless or agitated. Mothers also talked of the significance of the record in relation to addressing the difficult issue of end-of-life decisions and of communicating such decisions to others.

We had to make a decision whether we wanted to put him on a ventilator . . . It was quite a hard decision . . . Now all that has been written up and it's in his book, everybody knows . . . I am just glad that's done . . . They supported me throughout that while we went and signed everything . . . That's all been part and parcel of this book and it's taken away a lot of the pressure of having to make that decision again. *Mother 3*

### Providing help in crisis

Crisis intervention took several forms: rapid assessment of a child's clinical condition with medical referral; provision of on-the-spot care for the child to allow the mother to get out of the house for a break; accompanying anxious parents during stressful points at home or in hospital; and arranging short hospital admission for respite.

One mother (family 1) described concern when her child's condition changed markedly, with frequent retching and excessive sleepiness. Through assessment, the PATCH nurse identified a problem with anticonvulsant medication. The value of the PATCH nurse's knowledge and experience in exercising clinical judgement in this situation was confirmed by the consultant paediatrician.

The willingness of the PATCH nurses to step in and look after a child when a mother was at breaking point was greatly appreciated. The significance of this help was evident as a topic mentioned at interview within the first minutes of mothers' conversations. Fears were particularly acute where

parents were coping with a first baby with new problems and an uncertain future.

He had stopped breathing through the night and we couldn't get him going and we had to get an ambulance out . . . We really couldn't have managed this last few weeks without her (the PATCH nurse) . . . we reached breaking point about three weeks ago and she met us at (the hospital) and she was there with us from about 9 till about 11 o'clock at night. *Mother 4*

Mother 4 also valued the PATCH nurse's ability to arrange quickly a weekend hospital admission for her child. This respite break came at a time when she and her husband were 'just dead on our feet basically getting up through the night with him'.

### Service provision and service co-ordination

Key features of service-related support included improving access to treatment, providing information and advice, liaising with agencies and organizing and attending multidisciplinary meetings.

Problems with nasogastric and gastrostomy feeding, with stoma site overgranulation and with recurrent infections of stoma sites, eyes or skin were of major concern to parents. Particularly appreciated was the PATCH nurses' ability to get infections diagnosed and treated more quickly than through normal general practitioner channels. Dealing with problems from the home base reduced the number of visits to GPs and to hospitals. The ability of the PATCH nurses to 'cut out the middlemen' was important where a child's condition was unstable and deteriorating; for example, they could negotiate direct entry to a hospital ward, bypassing Accident and Emergency. Working to reduce the need for hospital admission was also important where hospital-acquired infection had caused serious problems in the past and parents preferred their child to be treated at home.

Novice and experienced parents and agency members appreciated the range of practical advice and information that PATCH nurses were able to give. As a result of their ability to interpret, explain clearly 'in layman's terms' and advise, parents and agency members felt more knowledgeable, reassured and confident.

We had been told so many things about P you kind of looked on him as a wee bit freaky at times . . . (the PATCH nurse) came along and got us looking at him in a completely different way again, so it's given us an awful lot more confidence with him and I think we are a lot more positive about the future as well. *Mother 4*

The PATCH nurses had assumed joint responsibility for contacting agencies and had become a 'first point of contact' for families. Mother 3, who had many years' experience of service provision summarized the picture.

For new families, I feel that it is indispensable, it will take away the strain of them having to chase somebody up by phone or just to know where to go. A lot of times, I didn't know where to go and I was phoning other people and you get passed on. 'Oh, it's not my problem' and all the rest of it. I feel it's a really good service, it's going to be good for the future. *Mother 3*

Where relationships with agencies, particularly social work, had been poor, PATCH nurses had acted as 'peacekeeper'. Their persistence in seeking improvement was particularly valued.

She's trying to bring all the parents in from the cold . . . She's trying to bring us all in together, it's like in a circle, with her arms around us protecting us from the eejits (idiots) as we call them . . . I don't have very much respect in the system and the girls are changing my mind very slowly on that. *Mother 2*

Parents and agency members referred to helpful work by PATCH nurses in organizing and attending meetings with or on behalf of parents. This appeared to improve communication.

There was a bit of confusion so we actually had a team meeting . . . (the PATCH nurse) was part of that team with the community medical officer, myself, the parents, the dietician, so we all actually worked as a partnership . . . we all discussed the problems that we found with this young boy with his eating and his feeding and we managed to agree on the proper way to progress a care plan. *Nursing Team Leader, Special Needs School*

The contribution of the PATCH nurses at pre-school assessment meetings was noted positively in relation to preventing social exclusion of children with special needs from nursery and school provision. The head teacher of a primary school was honest in her report of initial reluctance to accept a special needs child. Not only was she anxious about risks for the child, but there were uncertainties about the adequacy of staff skills and of the school environment.

I think if we hadn't met with the PATCH nurses . . . he'd have been treated with kid gloves. I was very reluctant to let him out to the playground . . . to let him take part in PE, to climb on climbing frames and the box, there was no way I was going to have that . . . D would have missed out on an awful lot if we hadn't been so well informed. *Head Teacher, Primary School*

Accepting this little boy with bilateral duplex kidneys who was gastrostomy fed, had two major outcomes for the school, both of which supported social inclusion; the building of a disabled toilet for the child's use and the employment of an auxiliary staff member to accompany and support the child.

## Conclusion

There has been little research in the UK exploring parents' experiences of caring at home for children with complex health needs (Kirk, 2001). This small evaluation study therefore makes an important contribution to knowledge of parents' perceptions of the impact of the innovative nurse-led support service for families of such children. The sample in the external evaluation was small. However, the key issues reported here are reflected in the internal evaluation (Tonner and McGunnigal, 2002), and in the findings of other pre-PATCH studies noted in this article, strengthening confidence in their validity.

Overall, the PATCH team engendered trust and parents felt secure in being able to access a practitioner who had comprehensive knowledge of their child and was only a phone call away. In complex and at times troubled care scenarios, the ability of experienced professionals to act effectively as

peacekeepers and middlemen was a considerable strength of the service.

The skilled approach to training was successful in creating a network of competent carers and new opportunities for respite for parents, during day and night. Training also allowed families to access educational facilities and supported inclusion for children with disabilities (The Scottish Office, 1999). It was of interest that no parent or agency member expressed any concern about the quality of the training offered. However, parents were aware of difficulties within agencies relating to accountability and legal liability for training and care provision.

Partnership eased the burden of care for parents and improved communication with agencies. Partnership work was direct and visible to families, expressed through successful joint person-to-person communication. Its success also rested upon complex and less visible behind-the-scenes processes of liaison and negotiation in and across care sectors (Mitchell and Sloper, 2001). Taken together, the partnership and training elements of the PATCH service seem to be targeting effectively the practical, emotional and social difficulties experienced by the families (Murphy, 2001a).

### **Expertise of the PATCH nurses**

Within the descriptions of family and agency members, there was evidence of skilled nursing expertise. The successful contributions of the PATCH nurses rested on a range of abilities that would be expected of an experienced nurse with specialist knowledge and skills:

- appropriate use of knowledge in exercising clinical judgment and decision making
- rapid assessment and ability to offer care in crisis
- a range of direct care giving skills, including technical skills
- effective communication, interpersonal skills and teaching skills
- liaison and referral skills
- proactive interagency working
- ability to work effectively across care settings and agency boundaries
- ability to act as an advocate for parents
- ability to offer emotional support.

Of particular interest, was the ability of the

PATCH nurses to make things happen for parents through action that was reactive, proactive and creative. Knowledge of acute children's health services and of the workings of community agencies allowed the PATCH nurses to work across boundaries (Neill and Muir, 1997; Moyse and Dryden, 1999). The freedom to work flexibly (Olsen and Maslin-Prothero, 2001), to approach agencies directly and the ability to cut across established organizational structures and communication systems were significant factors in achieving success in improving the support for families.

A number of outcome indicators were suggested in the data (Figure 2). These could be refined to provide more precise measurable criteria (Lewis and Utting, 2001).

Finally, the PATCH project raises important issues for service organization and education. The PATCH model provides a useful example of successful joint interagency service commissioning and of relevant, effective family support. Models of service delivery within community children's nursing teams vary considerably (Baxter *et al.*, 1998; Davies and Harding, 2002; Eaton and Thomas, 1998; Eaton, 2000; While and Dyson, 2000). The PATCH project suggests that the balance of acute nursing and community nursing knowledge and skill needs to be carefully considered, if the needs of children with special needs and their families are to be met effectively. Future challenges for PATCH include workload and manpower considerations as the service expands, and ability to continue to provide three key features: (1) rapid response; (2) support in crises whenever needed by families, including out-of-hours work times; and (3) top-up training for families over time and for agencies when staff leave and are replaced. At a time of change and development in community nursing roles, dialogue between educators, managers and practitioners is essential to clarify how best to support such a service through both pre- and post-registration educational provision. Parents' voices need to be heard in this professional debate.

### **Acknowledgements**

The research team gratefully acknowledges the help received from the participating families and agencies and from Lanarkshire NHS Board. The

- enhanced parental knowledge and caring skills;
- an enhanced network of people, lay and professional, competent in the child's care and in whose abilities parents have confidence
- enhanced respite support
- support in crisis
- support with end-of-life decision making
- accessibility – a first point of contact, local, rapid response service; access to up-to-date information about a child
- enhanced, more direct, access to services
- less travelling to distant hospitals and to GPs
- quicker treatment for a child with complex disability
- social inclusion for a child with complex disability
- reduced stress and fear for parents
- more free time and rest for mothers and fathers
- gains in parental time with other children
- enhanced quality of family life.

**Figure 2** Possible outcome indicators for a service supporting families of children with complex health needs

views expressed here are those of the research team and are not necessarily those of the research commissioning and funding bodies.

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