

FOR DEBATE

Tertiary paediatrics needs a disability model

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Background

Many of the children coming to a specialist children's hospital or unit, particularly inpatients, are "disabled". Disabled in this context means that the children have medium or long term limitations to their mobility and ability to care for themselves. Their problems and needs are complex and multiple. They require a multidisciplinary team to assess and manage problems. These problems often have a serious impact on their own and their family's lives. Families may be disadvantaged potentially by both the process of coping with disability and the difficulties of obtaining medical care. It is likely that any single specialist group within the hospital will not identify all of the problems that are experienced by families.

International perspective on disability

The United Nations General Assembly agreed on 24 December 1993 (Resolution 48/96) some standard rules for the equalisation of opportunities for persons with disabilities. The document published in 1994 gives a straightforward account of the rules.¹ To convey a flavour of these, rules 2 and 3 on medical care and rehabilitation are reproduced as an appendix, but the whole document is relevant.

The European Community Guidelines on disability services clearly follow those of the United Nations. A major theme to the relationship between medicine and disabled people internationally is that it is a partnership between those involved. This is based on the following premises.

- (1) Many of the needs of disabled people and their families are not medical but social, educational, and financial. Prioritisation of these needs requires input from the client group, and hospitals need to be fully aware of these multiagency issues.
- (2) The medical issues may be framed by doctors in terms of specific medical problems rather than problems as they affect families. In this context, voluntary organisations have had an increasing impact on medical practice. For example, specific disease/syndrome groups have identified characteristic behaviours in their children and asked that medical professionals consider these because they are their priorities.² These initiatives have set the agenda for much current research.
- (3) Many medical advances in treatment produce greater degrees of dependency, which, although hopefully transient, cre-

ate disability. We need insight into these problems from carers and patients.

- (4) Medical assessment and treatments are becoming increasingly complex and sophisticated, and this level of specialisation has absorbed much of the resources of medicine. Medical organisations may be ill equipped to manage the inevitable non-medical problems that children and carers bring with them to the hospital. Nevertheless, home and community factors may determine the long term outcome of medical intervention—for example, the use of multilevel orthopaedic surgery in the cerebral palsies.³
- (5) Most of the life and care of the children and families takes place away from a tertiary hospital, and guidelines and liaison services need to make sense of all these factors.
- (6) It is a basic human right that, when loss of control over one's body occurs, this is handled in a way that gives the client and carers maximum ability to influence decisions about how these matters are handled.

There are important lessons to be learned from the provision of rehabilitation services to people with disability in developing countries. Full participation by the community served, particularly including users—that is, parents and children—in planning and implementation of such a programme is regarded as mandatory in this setting.⁴ There seems to be no difference in principle about the style of service required in the United Kingdom.

The myth of the acute hospital

There may be a lingering view that the main role of a specialist paediatric hospital is to provide a single decisive medical or surgical intervention that cures the patient. Many of the children attending are disabled by anyone's definition. They have a range of motor, cognitive, psychiatric, and behavioural problems, whatever the specific reason for coming to us. However, much of medicine today involves participation in a long term "contract" with the family in the management of their child's oncological, metabolic, cardiac, renal, orthopaedic, psychiatric, etc problem. It is a disability model with acute episodes. The practice of many units and support services recognises these issues, but the overall organisation of the hospital may not. It is proposed therefore that a specialist children's hospital should be

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Accepted 7 March 2000

primarily geared to provide appropriate support for disabled people and that this will create a more appropriate, friendly, and responsive service for all clients. This would also structure the approach of all staff.

What would such an approach mean?

- (1) Travel and access would be investigated and proposals made to provide cheap and readily available transport. This may create the need for a wider range of family accommodation and for minibus services, as well as appropriate car parking. If examined nationally, there may well be issues about the costs of public transportation, which should be dealt with.
- (2) Units should survey and analyse the needs of families looking at the distances, the reasons, the practical difficulties, the financial impact, and emotional issues involved.
- (3) There would need to be direct involvement of families in the development of services in the hospital in order to: (a) help in the training of all members of staff; (b) advise over the timing and organisation of clinics; (c) assist with communication; (d) advise on the physical facilities and equipment within the hospital; (e) assist with retail and other service provision on the site; (f) advise about restaurants etc; (g) advise on parent accommodation; (h) maintain a system that keeps the hospital informed on these issues by providing continuing feedback from parents.

Using national parent support organisations, systems need to be developed that provide truly representative parental views.

- (4) Our pattern of outreach and shared care work should be based on the assumption of disability being an important factor and developed on the basis of partnership as outlined above. Thus an important aim of outreach is to ensure equity of access to services.
- (5) Any negotiation required with the local authority—for example, with respect to the need for car parking—will be on the basis of the agreed needs of disabled people. Specialist hospitals would create a disability forum, in which the definition of disability is widened to include those with short and medium term impairments through illness, and this forum would include organisations concerned with disability.

The way forward

Professionals, units, and hospitals concerned with specialist children's services do their best to take account of these issues, but the systems for developing multiagency, parental, and community involvement are not in place. It is inappropriate and inefficient to have to create systems and working parties to deal with multiagency issues in modern hospitals. These systems with parental and community involvement should be an integral part of the structure.

Appendix

The United Nations General Assembly agreed on 24 December 1993 (Resolution 48/96) some standard rules for the equalisation of opportunities for persons with disabilities.

RULE 2—MEDICAL CARE

States should ensure the provision of effective medical care to persons with disabilities.

- (1) States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organisations of persons with disabilities at the planning and evaluation level.
- (2) Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.
- (3) States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.
- (4) States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.
- (5) States should ensure that the medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.
- (6) States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

RULE 3—REHABILITATION

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

- (1) States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.
- (2) Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.

- (3) All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.
- (4) Persons with disabilities and their families should be able to participate in the design and organisation of rehabilitation services concerning themselves.
- (5) All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organised, where appropriate, in residential form.
- (6) States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.
- (7) Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

1 United Nations. *The standard rules on the equalisation of opportunities for persons with disabilities*. New York: United Nations, 1994.

2 O'Brien G, Yule W. *Behavioural phenotypes*. London: MacKeith Press, 1995.

3 Gage JR. Postoperative care. In: *Gait analysis in cerebral palsy*. London: MacKeith Press, 1991:173–83.

4 Chaudhury G, Menon-Sen K, Zinkin P. Disability programmes in the community. In: *Disabled children and developing countries*. London: MacKeith Press, 1995:152–82.

Commentary

IS A DISABILITY MODEL THE RIGHT ONE?

The disability model has relevance to the groups of children described by Professor Neville. The model includes the important concepts of patient autonomy, the need for the involvement of patients, parents, carers, and self help organisations in the delivery of care, and the requirement to look at all the needs of the child (medical, emotional, social, and educational) in a holistic way. However, I am not certain that the disability model is the only way at looking at these matters nor that it is necessarily the best.

A disability is defined¹ as “any restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human.” I am not sure that many professionals would agree that all children with complex needs have a disability, even though they have a need for many of the same services.

Neville applies the term disability to children with “long term limitations to their mobility and ability to care for themselves”. This would include children with chronic renal failure requiring dialysis, children with cancer requiring chemotherapy and perhaps home nursing, children with colostomies and endotracheal tubes, and children who are dependent on hospital care for treatment of immunodeficiency.

There will be a significant overlap with the needs of children with disability in the commonly accepted sense, and there will certainly be children with neurodisability among the group attending the specialist children’s hospital. Why then do I feel a certain reservation or inhibition about applying the disability model?

Firstly, because I think it devalues its use in the more restricted sense, and secondly because I think that there is a more comprehensive model that could be applied. For disabled people, presenting a positive image about their condition is a major part of their advocacy; no such need is present for children and their families with chronic illnesses, indeed there is a bias in their favour in the media and among the general public. There is thence perhaps a disadvantage in applying the disability model too widely. Could there be an alternative model?

I would suggest that the approach developed in community paediatrics is ideally suited to the problems described by Neville, and is applicable to the whole of paediatric care, which will increasingly take place outside hospital. A community paediatric approach is required because:

- children spend shorter times in hospital;
- parental expectations for information transfer and involvement in care are greater;
- emotional and social difficulties play a greater part in the spectrum of morbidity;
- the team involved in paediatric care is much broader.

In the United Kingdom, we do not have a satisfactory definition of community paediatrics. In the United States, the American Academy has developed a definition that is worth replicating here: “A commitment to utilise a community’s resources in collaboration with other professionals, agencies and parents to achieve optimal accessibility, appropriateness and quality of services for all children and to advocate especially for those who lack access to care because of social or economic conditions or their special health care needs.”²

The concepts of children’s rights as enshrined in the United Nations Convention of the Rights of the Child are also central to community paediatrics and to the children attending a specialist hospital.³

Community paediatrics could be considered to cover all the aspects that concern Neville, and provides a valid model for specialty care. It does not have to be practised outside hospital only, as the concept is holistic. However, I wonder if the solution to the problems posed by Neville may not be to provide a very good transition from specialist hospital to community services, rather than to radically reform the hospital itself; the child development centre concept could be used as an intermediary, with a multidisciplinary team on site working together to connect the various services needed by the child and parents. It is a very hard task to change the ethos of a large hospital, and I am not sure that there is any group with the motivation to do so, desirable though it is.

What steps need to be taken to move services in the direction urged by Neville?

Many departments are likely to say that they already implement a parent and community oriented approach and may not wish to have their patients labelled as suffering from a disability. However, the culture of acute hospitals in the United Kingdom does not favour consumer involvement, despite management rhetoric. I think that it is only through pressure from parent organisations that this approach is likely to be successful. I wonder if Neville has sounded his ideas out on any parent or self help organisation; I am sure that Action for Sick Children would be interested in making hospitals more family friendly, and it has already published a guide in this field.⁴ I suspect that a disability model may not resound in their minds and that they would conceptualise his views as meeting a family's wider needs.

These ideas are important and should be taken up in future discussions by the College on the development of specialist services.

There could be a benefit from using a disability model if it helps colleagues and managers to understand the depth of the changes necessary, and a partnership with self help groups could be the basis of moving the idea forward. In my view, closer cooperation between community paediatrics and tertiary hospital services is the preferred solution.

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- 1 WHO. *International classification of impairments, disabilities and handicaps*. Geneva: WHO, 1980.
- 2 Tonniges T. Reflection from the department of community paediatrics. *Pediatrics* 1999;**103**:1430-1.
- 3 BACCH. Child health rights. Implementing the UN convention on the rights of the child. In: *The Health Service: a practitioners' guide*. London: British Association for Community Child Health, 1995.
- 4 Action for Sick Children. *Health services for children and young people: a guide for commissioners and providers*. London: ASC, 1996.