MEDICAL PRACTICE

Contemporary Themes

Children's Wheelchair Clinic

K. S. HOLT, H. DARCUS, H. LORNA BRAND

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Summary

During the first year of a children's monthly wheelchair clinic 29 out of 34 chairs supplied in the past were found to be unsatisfactory. The advantages of a central clinic for a region where clinicians and technical officers can meet are emphasized, as is also the need for wider dispersal of knowledge about wheelchairs for disabled children.

Introduction

In our experience many of the wheelchairs supplied to handicapped children are unsatisfactory. The need for a chair is often not realized because the child's parents assume that if a chair is needed the doctor will prescribe one. Unfortunately not all doctors are aware of the possible advantages of wheelchairs (such as enabling the family to be mobile, relieving parents of a carrying burden, giving the child good postural support, and also the pleasure of being able to propel himself in cases where this is possible) and may forget to consider whether a chair is necessary. Even if he realizes the need the doctor may not know which types of chair are available or where to obtain this knowledge and so may prescribe an unsuitable chair. This may precipitate and aggravate deformities, restrict the child's activities, and irritate the child. For example, serious consequences may result from the use of ill-fitting appliances and chairs by children with muscular dystrophy.¹ Furthermore, the need for well planned and correctly adjusted modifications of postural support as growth occurs is frequently forgotten or ignored.

Though a variety of wheelchairs are available for children their design leaves much to be desired. Children seem to be

expected to fit the chairs rather than the chairs being designed to fit the children. Some years ago, when drawing attention to the important general principle that provisions for children should be based on studies of the children themselves, it was pointed out that children's wheelchairs appeared to be scaled down versions of adult chairs, with proportions out of keeping with body size and shape in childhood.² Unfortunately little anthropometric data exist on either normal or handicapped children to permit sensible planning and design.

The despair of seeing children sitting in ill-fitting chairs³ stimulated us to plan a handicapped children's wheelchair clinic. Discussions were held with the department of physical medicine of the Hospital for Sick Children, Great Ormond Street, London, and the local appliances office of the Department of Health and Social Security at Euston Road, and as a result a wheelchair clinic was begun at the Wolfson Centre in December 1970. The experience during the first year is reviewed below.

The Clinic

The clinic is held at the Wolfson Centre as part of its services as a regional assessment centre for handicapped children. The centre is linked with the Hospital for Sick Children, Great Ormond Street, and appropriate staff of the hospital collaborate with the staff of the centre in running the clinic.

A half-day session is held each month. Children are referred by consultant staff of the centre and Hospital. Attending the clinic are physiotherapists, occupational therapists, technical officers from the local appliances department of the Department of Health, and a paediatric physical medicine specialist. A paediatrician is available for consultation. The children's needs are discussed by the group, the children try several of the chairs which are kept on the spot, decisions are made about the prescription of the chairs and modifications,* the chair prescribed

The Wolfson Centre, London WC1N 2AP

K. S. HOLT, M.D., F.R.C.P., Director

H. DARCUS, B.M. B.Sc., Physical Medicine Specialist

H. LORNA BRAND, M.C.S.P. Physiotherapist.

*"Modification" means a structural alteration of the chair. The addition of simple accessories such as trays and weather protection is not dealt with separately.

for the child is then delivered to the centre, and the child and his parents attend again to be shown its use and maintenance.

The Children and their Requirements

Thirty-three children (18 girls, 15 boys) aged from 16 months to 14 years were seen on 52 occasions. Twenty suffered from cerebral palsy, 4 from spina bifida, and 9 from miscellaneous conditions, such as spinal atrophy and mental retardation. When first seen in the clinic one child did not have a chair but the other 32 children had 34 chairs between them; 25 had one chair, two sets of handicapped twins shared one chair each, and one had three chairs (Table I). Of the 34 existing chairs 29 were found to be inadequate or unsatisfactory, and 24 of these had to be discontinued (Fig. 1). To try to give some indication of the

TABLE I—Distribution of Chairs among the 33 Children

	No Chair	Share of Chair	1 Chair	2 or More Chairs	Total
Originally ..	1	4	25	3	33
Finally ..	0	4	19	10	33

FIG. 1—Assessment of existing chairs and provision of new ones. (Does not include new chair supplied to child who did not have one previously.)

nature and frequency of the reasons for changing chairs the foremost reason in each case was used in the following analysis:

Existing chairs do not give postural support	..	..	..	10
Child has outgrown chair	..	..	..	6
Child cannot propel chair	..	..	..	6
Need for double chair to share with sibling	..	..	..	7

As a result of attending the clinic the child without a chair was given a new one with modifications. Four chairs regarded as satisfactory were continued unchanged, and another satisfactory one was supplemented with an additional new modified chair. Four unsatisfactory chairs were modified and then continued in use, and another chair dealt with in this way was supplemented with an additional new modified chair. Twenty-three chairs were so unsatisfactory that they were discontinued and replaced by 28 new chairs, of which 16 were modified, and one unsatisfactory chair was discontinued and not replaced.

The following selected case histories further illustrate some of the problems encountered.

NEED FOR CORRECT POSTURAL SUPPORT

A girl of 6 years with a progressive degenerative condition needed a wheelchair in which she could sit correctly for long periods despite a poor sitting balance. She had used a baby buggy but in this her back

was rounded and she could not hold up her head; also she had outgrown it so that her feet dangled off the footrest. A model 8C (Fig. 2) was ordered with the following modifications: the seat size to be adjusted to fit the child, the back rest to be made 4 in (10 cm) higher to support her head, and a shoulder harness, detachable tray, and weather protection to be provided.

FIG. 2—Basic model 8C open (overall width 51 cm) and folded (25.5 cm).

Three months later the child's condition deteriorated rapidly and she was admitted to hospital. The chair had not arrived so the order was cancelled pending the outcome. One month later she was unable to hold up her head even in an upright position. Further modifications were ordered: the back rest to be inclined 15° backwards in order to support her floppy head and the seat width to be narrowed by two 2 in (5 cm) lateral seat supports. Five months later after much agitation the chair was delivered. When tried in the chair the child sat well and comfortably with her head and trunk supported. A 2 in (5 cm) backrest cushion was ordered to shorten the seat depth; a commercial (Mothercare) harness was ordered to replace the large, clumsy, stiff leather one supplied with the chair; and the tray which had not been delivered was reordered. The chair went home with the child. The tray, harness, and backrest cushion were delivered to the home six weeks later.

This shows the type of modifications to an available standard model which were required to give postural support, the frequency with which changes may be necessary when the child's condition alters, and the problems resulting from slow delivery.

NEED FOR CHILD TO PROPEL OWN CHAIR

A boy of 8½ years with athetosis needed a wheelchair in which he was adequately supported and able to propel himself. He attended the clinic in his model 8LV, which is a "light-weight" model weighing 35 lb (16 kg). His head extended over the top of the backrest and he could control neither his head nor the bizarre movements of his limbs which this extension provoked. The seat was too wide and too deep to stabilize his pelvis adequately. His feet did not reach the footrest. His family had fitted groin straps and a high trunk strap to ensure his safety.

The family, living outside the region covered by our local appliances office, had been repeatedly told that the child was allowed only one wheelchair, so that the chair had to be taken from home to the day centre with the child. This involved the mother loading the chair on to the hospital car, which was driven by elderly volunteer women; travelling to the day centre with the child in order to hold him on her lap, since he could not sit alone; and unloading the chair when they arrived. The return journey at the end of the day was similarly arduous.

Modifications to the existing chair were ordered to be carried out in the child's home area so that he would not be without his chair. The footrest to be raised 2 in (5 cm) and replaced by a detachable footboard, and to be fitted with a check-strap at the back. A car-type detachable headrest, a 2 in (5 cm) thick backrest cushion, and a shoulder harness to be provided. The parents agreed to make lateral seat supports. If these modifications were satisfactory a duplicate chair was to be ordered and the child would be trained to propel the chair.

Two months later he was seen again and none of the modifications had been carried out. The lateral seat supports had been made by the occupational therapist at the day centre. The father had again asked the local technical officer about a second chair and was told that the head appliance office at Blackpool has refused to authorize it. The mother reported that the child had made several successful attempts to propel the chair, so a capstan handrim was fitted and lent from the clinic in order to make it even easier for him. Capstan handrims were ordered to be fitted to both wheels of the chair (Fig. 3).

FIG. 3—Patient in chair with capstan handrail fitted.

No reply was given to several telephone calls and letters to the local technical officer asking that the modifications be embarked on and that a duplicate chair be provided until three months later, when we heard from the family that a new chair with all the requested modifications had just been delivered, that it was satisfactory except for the harness, and that the other chair had been taken for modification.

This case illustrates how a severely handicapped child can be helped to achieve some independence. It also highlights the difficulties of dealing with children living outside the local catchment area.

NEED FOR CHAIR TO SHARE WITH SIBLING

Two siblings with spinal atrophy, one of 4 years, the other of 3 years, needed a chair which they could also share with a younger, non-handicapped but prewalking sibling. The two handicapped children previously had shared a model 8C wheelchair which was now too small for them.

A model 13J chair was ordered to be adapted to seat two children at the back and one child at the front. Another requirement was that the chair should fold small enough to fit into the back of a Mini Traveller. Less than two months later the chair was delivered. The children sat comfortably in the chair and the mother found it easy to manoeuvre but heavy to push when the children were in it. It folded just small enough to fit into the van but the fixed footrest prevented it from being levered into the van, so this heavy chair had to be lifted in.

Each time the chair was folded and unfolded the front of the canvas tore away. There was no weather protection. The mother was so pleased to have one chair for all three children that she took it immediately for a trial period, and it was arranged for a contractor to visit the home to make further modifications.

Four months later the contractor repaired the canvas and made the footrest foldable. A specially designed hood to cover the front seat as well as the back seat was provided and a Perspex window was put in the back of the hood, which was attached by butterfly nuts so that it could easily be removed when not in use; this was necessary because it was so cumbersome. No apron was provided so the children were not protected from driving rain (Figs. 4 and 5).

FIG. 4—Chair for three children, hood raised.

FIG. 5—Chair for three children, hood removed.

Six months later the mother reported that she was still pleased with the chair but had had to replace her small van with a larger one and needed help to load and unload the chair. She found the chair most useful to push the children around locally and used it a lot in the summer. Its use with the van was limited by the effort needed for loading and unloading.

We were satisfied with this modification but subsequent "double" chair modifications have not been so satisfactory. They have had to be returned to the contractors on numerous occasions, and the delivery time has been much more than the two months recorded above.

Discussion

Five aspects of wheelchair provision appeared particularly important from the year's experiences. Firstly, to have correctly fitting chairs modifications were often required. Of the 31 new chairs ordered 19 required modification. This implies unsuitability of currently available models. Secondly, long delays in the delivery of chairs created additional problems as a result of growth of the child, possible changes in the disorder, and intense parental anxieties. Delivery times are analysed in Table II.

FIG. 6—Routes of communication.

Only nine of the 36 chairs were delivered in less than three months, and eight took longer than six months to arrive. Seven of the 12 unmodified chairs took three to six months to arrive, and all of these were commercial wheelchairs. It appears that communications between the independent firms and the Department of Health and Social Security do not always result in a prompt service. The need for modifications undoubtedly delayed delivery in some cases. The chain of communication for processing the orders is fairly complicated, especially in the case of children living outside the region covered by our local appliances office (Fig. 6). In such cases, which occur frequently in a referral

TABLE II—Delivery Times of the 36 Chairs

	1 Month	3 Months	6 Months	12 Months	Over 12 Months	Total
New chair, no modifications	2 (1)	3 (2)	7 (7)			12 (10)
New chair with modifications		4 (1)	7 (0)	5 (0)	3 (0)	19 (1)
Existing chair with modifications			5 (2)			5 (2)

Figures in parentheses refer to number of commercial chairs.

centre like London, the orders for new chairs have to go from Euston Road to the appliances office in the child's home area. If structural modifications to the chair are required the order must then be forwarded to the central office in Blackpool before being referred to the chair manufacturers for these alterations. Additional minor modifications, if required, are carried out by local private contractors.

Thirdly, many of the accessories supplied with standard chairs are unsatisfactory. For example, harnesses were cumbersome, too large, and inefficient. Commercially available harnesses were substituted in many cases with good results. The hood and apron weather protection adds unnecessary weight and gives the chair a grotesque appearance. Certain types of commercially available weather protection are more efficient, cheaper, and pleasing to look at.

Fourthly, there were many problems of transportation. Hospital-provided transport frequently would not co-operate in bringing the wheelchair with the child to and from the clinic. We informed the service if a chair was to be included and whether or not it would fold but our requests were not always met, and some families were delayed many hours because of this. Transportation of the wheelchair by bus or family car was also difficult, and very few wheelchair models are of a size and weight to allow family travel without elaborate and discouragingly difficult preparations.

Fifthly, there was a need for double wheelchairs for the large minority group of handicapped twins, handicapped siblings, and handicapped children with prewalking siblings. Such chairs do not exist at present apart from a double "buggy." Single wheelchairs are sometimes modified, but this is false economy because of the expense in time and money. These "double" chairs are usually used principally as transit chairs. The children do not sit in them at home and in many cases it is not even possible to get the chair through the front door. There is therefore an urgent need for the production of a light-weight, easily foldable compact, double wheelchair which will provide good postural support for short periods and is easy to manoeuvre and pleasing to look at.

Finally, we were impressed by the little consideration given to the needs of the attendant. For example, brake levers were often difficult to reach and the provision of shopping trays was either ignored or made impossible by the structure of the chair.

Our experiences during the first year of this wheelchair clinic reinforce our anxieties about wheelchairs supplied to children. Even accepting that the children referred to the clinic were selected to some extent as being those especially in need of help, the fact that 29 out of 34 chairs supplied to these children were unsuitable is most unsatisfactory. In many cases the original wheelchair prescriptions had been made with insufficient knowledge of wheelchairs and consideration of the children's needs. Differentiation between chairs for transit and those for prolonged and functional sitting was seldom made.

These deficiencies could be overcome in two ways. Firstly, by ensuring that everyone working with handicapped children is fully aware of the indications for wheelchairs and the types and modifications available. Some of this information is available already, but we had to spend a long time collecting it together and filling all the gaps. Comprehensive information about wheelchairs for children should be more widely and readily available from central information bureaux for the disabled, Department of Health appliances offices, and wheelchair clinics in hospitals and assessment centres. Dissemination of this information would occur if doctors, therapists, and technical officers were encouraged to work more closely together and if the Department of Health in conjunction with interested clinical units were to promote short training demonstrations, distribution of explanatory pamphlets, and production of tape and slide teaching aids.*

Secondly, it must be realized and accepted that the prescription of wheelchairs and training in their use is no simple matter to be solved by a quick signature on a form or delegation to the most junior person available. There is confusion at present about who prescribes what. Sometimes a chair prescribed for home use is not or cannot be used in school because the school chair and the home chair are prescribed by different authorities. This confusion requires resolution. Those undertaking this

*The National Fund for Research into Crippling Diseases will soon be publishing some of this information in a special wheelchair supplement of "Equipment for the Disabled."

work require knowledge and experience of the following: (a) the children's needs as growing and developing children, (b) the disorders from which the children suffer, (c) the home and family situation, (d) the range of chairs and modifications which are available, (e) contact with other workers who are able to implement all the recommendations promptly and efficiently, and (f) the opportunity to refer to a central clinic.

Clearly we support the establishment of similar clinics to serve regions of suitable size. We are impressed by the advantages of technical officers and clinicians working together, especially when the same group of people are present at each clinic. Similarly, we do not support the fragmentation of arrangements for the supply of chairs to children.

Delay in the delivery of chairs is a major problem. Why cannot chairs be available almost immediately? Modifications cause delay, most of which occurs at the chair manufacturers, but need this be as long as it is? Long delays are very troublesome and inhibit the prescription of modifications, which results in the child being given the most readily available chair and a blind eye being turned to the deficiencies. Attention should be given to finding means of quicker communication and also ways to make it easier for technical officers to contact and select contractors carrying out modifications to chairs.

As a result of our experiences during this year we feel justified in recommending the continuation of the clinic, its extension to other children in the area, and its replication elsewhere. Regional clinics would circumvent many delays. Whereas in the past one half-day a month was devoted to the work we plan to increase this to a whole day each month to allow more time for training the child and his parents in the use and maintenance of the chair. An outline of the wheelchair training programme which we follow is shown in Appendix.

We are grateful to all our colleagues at the Hospital for Sick Children, Great Ormond Street, and the Euston Road appliance office who collaborated in this work.

References

- ¹ Dubowitz, V., *Clinical Pediatrics*, 1964, 3, 323.
- ² Holt, K. S., *Proceedings of the Royal Society of Medicine*, 1966, 59, 135.
- ³ Holt, K. S., *British Medical Journal*, 1970, 4, 430.

Appendix

OUTLINE OF WHEELCHAIR TRAINING PROGRAMME

This outline is designed to help children achieve independence with their wheelchairs, to guide attendants and children to know when assistance is needed, and to aid attendants of totally dependent children. Each programme is tailored to suit the individual needs of each child and family, but all instruction follows the main outlines of safety, methods of transfer, mobility, and management of the wheelchair as described below.

Safety.—Brakes on before attempting any transfers. Use of safety strap. Optimum positioning of the chair for transfers.

Methods of Transfer.—To and from bed, toilet, bath, another chair, floor, car.

Mobility (see Check List).—Child's ability to adjust own position in the chair. How to propel the chair forwards and backwards, turn, manoeuvre around furniture and through doorways, get up and down curbs and ramps. Instruction is also given for attendant-operated chairs.

Management of Wheelchair.—How to fold chair. How to fit and remove accessories. Simple maintenance—for example, cleaning, tightening loose nuts, care of pneumatic tyres, etc. Some of these points are now covered in the "Hints on the Use of your Wheelchair" handbooks recently issued with chairs provided by the Department of Health. Inform family that the chair can be exchanged when no longer suitable.

Wheelchair Training Programme: Check List

Name:

Age:

Date:

	Item	Ability	Comment
Safety	1. Lock brakes		
	2. Unlock brakes		
	3. Fasten safety strap		
	4. Unfasten safety strap		
	5. Raise foot rest		
	6. Lower foot rest		
	7. Position of chair for transfers		
Transfers	8. Wheelchair to bed		
	9. Bed to wheelchair		
	10. Wheelchair to toilet		
	11. Toilet to wheelchair		
	12. Wheelchair to bath		
	13. Bath to wheelchair		
	14. Wheelchair to other chair		
	15. Other chair to wheelchair		
	16. Wheelchair to floor		
	17. Floor to wheelchair		
	18. Wheelchair to car		
	19. Car to wheelchair		
Mobility	20. Adjust own position in chair		
	21. Propel chair forwards		
	22. Propel chair backwards		
	23. Stop chair		
	24. Manoeuvre around furniture		
	25. Open doors		
	26. Through doorways		
	27. Up curb		
	28. Down curb		
	29. Up ramp or incline		
	30. Down ramp or incline		

■ Can do independently. ■ Can do with assistance. □ Cannot do.

Examiner: