*Marty, Stuart, Peter, Lenny Lamb, Aryne.**

UNCLE BOB'S CLUB CHILD DEVELOPMENT CENTRE

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The Uncle Bobs Club Child Development Centre, situated at 56 Chapman Street, North Melbourne, is part of this unit.

INTRODUCTION

In this International Year of the Disabled Person, the needs of all persons with a disability are being look at more critically, but perhaps the general public is more aware of adults with a disability, than of young children. Young children with disabilities are not a vocal group as such, although their parents are becoming increasingly vocal and banding together into effective Action Groups. Young children with disabilities may be thought to be "cute", and the general public is relieved that they have parents who are responsible for them. But those same children experience acute frustrations, and their parents experience chronic grief because *their child is unable to lead a normal* life. Many find it necessary to expend a tremendous amount of time and emotional effort on the physical care and intellectual stimulation of their child, and in many cases, the increased financial demands can be critical for the *family budget.*

Professionals involved with young children with disabilities have long been aware how important it is to provide appropriate treatment and stimulation for the child, and support for parents, at an early age, if the child is to develop to the limit of his potential and achieve the maximal quality of life.

Studies have shown that manyparents do not receive the understanding and support they need, particularly during the period of diagnosis when the extent of the disability is uncertain. This is a shattering time for parents, and professionals are constantly looking at ways of improving the quality of service at this stage. The Uncle Bobs Club

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**Photographs used with permission of the parents of the children.*

Child Development Centre, through its Play Groups, aims to help some families at this stage. However, the Centre is primarily concerned with children of kindergarten age. The program of therapy, kindergarten, and ongoing assessment for each child, as well as parent counselling and support at various levels, is all directed towards helping each child reach his potential, improving the quality of both his life, and that of his family, and helping him to participate in the community, in a meaningful way.

DESCRIPTION

Uncle Bobs Club Child Development Centre is part of the Department of Developmental Paediatrics, at the Royal Children's Hospital, Melbourne. It has operated in its present home since March 1979. The unit was previously known as the Handicapped Children's Centre, operating within the main hospital building. The move to a splendid old Victorian house in Chapman Street, North Melbourne, followed months of alterations, made possible by a substantial donation from the Uncle Bobs Club. There was considerable anxiety among both staff and parents concerning the move, from the security of the hospital building, to an "old house across the road", and the changes in organisation which this involved. All responded very quickly to the relaxed atmosphere of the new surroundings, and the cohesiveness of the unit increased, because of its physical separation from the hospital.

The centre has bright, spacious kindergarten rooms, rooms for therapy and activities, and a large room for parent meetings and playgroups. There is a garden and well equipped playground for outside play.

The centre provides a program for about twenty five children, between three and six years of age, in two kindergarten groups. The division between the younger and older group is related to developmental as well as chronological age. Children attend for two or three days a week from 9.30 a.m to 3.00 p.m. and transport is usually provided by Red Cross Society free of charge. Children come from all parts of Melbourne but there are obvious disadvantages if the time and distance involved in travelling is considerable.

Two playgroups provide a program for about twelve children aged from nought to three years, who attend weekly with their mothers.

This program needs a large staff. The salaries of three full time kindergarten teachers, one part time teacher and two assistants are funded by the Division of Pre-School Child Development of the Health Commission. The hospital provides allied health professional staff on a part time basis. These include physio-therapists, occupational therapists, speech pathologists, psychologists and social workers.

Doctors are involved in reviews and planning and are always available for consultation. Two full time ward assistants help with the physical care of the children.

There is close co-operation between staff members at all levels and the multidisciplinary approach is of great value in making the centre a cohesive unit and developing good individual programs for each child.

The centre exists as part of, yet separate from the hospital setting and has a medical basis because all children attending have some disability. Physiotherapists, occupational therapists and speech pathologists work within this medical framework. However, the kindergarten teacher and playroom form the keystone of each child's program, and the kindergarten directress co-ordiantes all activities within the centre. All staff are involved with ongoing assessment of each child, but many are seen by the psychologist for a more formal intellectual and emotional assessment, which may lead to referral for full psychiatric assessment.

The social worker takes an overall view of the child as a member of a family group and the community and endeavours to keep all factors in perspective. She assesses and interprets family dynamics and her role also includes that of family advocate within the hospital and community; providing information regarding entitlements and facilities and making appropriate referrals; crisis intervention; as well as ongoing counselling and support to parents The social worker is also involved in staff counselling and support in relation to parents' attitudes and needs.

REFERRAL AND ADMISSION

Admission to the centre is via the Department of Developmental Paediatrics. Referral is made to the Medical Director of the department and is generally made by a doctor, but may come from other professional sources, either within the hospital or from the community. A parent or relative may also initiate referral, and the social worker is available for personal or telephone discussion regarding the appropriate course of action. All referrals are discussed at weekly intake meetings and if appropriate, an appointment is made with a departmental doctor. Only a small proportion of children who are referred to the department enter the Uncle Bobs Club Child Development Centre, but if this is considered a possibility, the child and his parents are seen by a multidisciplinary assessment team, including at least some staff members from the Uncle Bobs Club Centre. If it is then considered that the centre will best meet the needs of the child and his family, they are introduced to the centre, and offered enrolment in either a playgroup or the kindergarten, depending on age and emotional maturity.

The kindergarten program at the centre is most relevant for children with severe multiple disabilities who require intensive therapy and a kindergarten program combined with ongoing assessment. Their disabilities make it difficult for them to attend a local kindergarten and have the therapy they need. Many have cerebral palsy and disabilities may include visual, hearing, and speech problems as well as difficulties with mobility and delayed development. Assessment of the child's intellectual ability is difficult and may take many months if many problems are combined, particularly if speech is affected, and if there are significant emotional problems but assessment is necessary if staff are to develop and provide an appropriate program, and for long term planning and placement. It is also most important for the parents to have a realistic understanding of their child's problems and intellectual ability, so that they can relate to him and handle him appropriately. There is an understandable tendency for parents to be overprotective, and because their child is so very dependent, continue to treat him as a baby.

Children with lesser disabilities also attend, either for some of the above reasons, or for help with a specific problem (e.g. toilet training or behaviour problem), for a limited period of further assessment, for social reasons, or because there is no vacancy in an appropriate centre closer to home.

The program is also relevant for children whose parents have established trust within the hospital but who have not yet accepted that their child has a long term disability. It may be threatening to the parents and damaging to the child's progress to refer those children to another centre or kindergarten and break the continuity of therapy or professional contacts at this stage.

PROGRAM

The program is centred around the kindergarten room. The children arrive around 9.30 a.m. and spend the first hour in the kindergarten playroom concentrating on pre-school activities. At 10.45 a.m. they have a snack followed by toiletting, and as many of the children have difficulty with feeding or toilet training, this is an important part of the

The author (on right), staff and children at the Centre. "Therapy is integrated with a childs play program."

training program. After this, there is free play (indoors or outdoors depending on the weather) when physical and social development are encouraged. Before lunch, there is music group, and after lunch a rest period with intensive individual physiotherapy for those who need it. Stories, music and free play complete the program before the children go home about 3.00 p.m. Throughout the day therapists join the kindergarten teachers, and integrate therapy with a child's play program. Therapists also work with individual children in the therapy rooms when necessary.

Because each child's program is centred around the kindergarten room, his closest relationship is generally formed with his teacher. One of the most valuable aspects of the centre is the multidisciplinary approach and the very close co-operation of all team members. If a child has difficulty settling and relating to new adults, therapist and psychologist will usually observe and work with the child in the playroom initially, only removing the child to another room and a one-to-one relationship, when he is emotionally ready. By working in the playroom, therapists have a very positive influence by imparting therapeutic techniques to the room staff. Two therapists may work together with a child, especially when there is a very severe disability, e.g. when correct trunk support is necessary before the child can use his hands effectively.

Because many of our children have such severe disabilities, the staff are constantly meeting challenges, especially in the area of communicating with children who are physically unable to speak, and of improving the mobility and independence of children who are completely physically dependent. Our therapists and teachers have been active in pioneering new methods in non vocal communication, in mobility aids and aids to daily living.

An individual program is planned for each child and the initial assessment prior to admission to the centre provides the basis for this program. Goals are set and are usually very limited in the early stages while child and staff are getting to know each other. Progress is plotted on standard charts. Every child is reviewed each term at weekly staff meetings regarding his medical, physical, emotional, social and intellectual status. Possible changes to his program are considered, either within the hospital (e.g. extra therapy) or in the community (attendance at a local kindergarten or centre). After these review meetings, an appointment is made for the parents to discuss the results with a departmental doctor and discuss any concerns they may have about their child.

There are also frequent formal and informal discussions among staff regarding both the children, and organisation within the Centre. Naturally many major or minor problems arise which need rapid solutions, and the mutual support of team members is invaluable to staff morale as well as to the well being of the children.

We have a specialised and intensive program for children with disabilities, but one of our constant goals is to "normalise" our children as much as possible in line with current trends in education and general care, and this is an important goal of International Year of the Disabled Person, with its motto "Break Down the Barriers".

Excursions play an important part in our program, and some of the more important are the most mundane, e.g. tram and train rides, visits to the local milk bar and supermarket where each child chooses his own ice cream etc. — experiences most children take for gran-

The Child Development Centre.

ted but out "special" children are sometimes denied because it is "too hard" for mother. Each week a group of children is taken swimming. The Halliwick method is used which is a physiotherapy based method of movement. Parents are encouraged to use the Noah's Ark Toy Library for Handicapped Children. The library van visits the centre monthly and parents may borrow toys that are appropriate to their child's developmental level, at nominal cost. Parents may also visit the library at its headquarters, or other monthly van visiting sites.

This year we have three neighbourhood children without disabilities attending our four year group several times weekly and this has been most successful. They provide valuable language stimulation and normal peer interchange and rivalry which our children need and respond to positively. If a child with disabilities wants a toy and an active child gets it first; what better motivation for crawling to it quickly? The neighbourhood children and their mothers are also enjoying the experience and have not ' "caught" grotesque habits from associating with "monsters"!! '

Increased numbers of children with special needs, and more children with severe disabilities are now attending local kindergartens, and a number of our children attend our centre say two days and a local kinder two days weekly. This provides a combination of individual work and therapy and normal peer stimulation but it is important to choose the kindergarten carefully, regarding physical accessibility and teacher acceptance and experience. The child's developmental level must also be considered and a four year old child functioning at a three year level, should attend a three year kinder group. Our staff liaise with the local kindergarten and reciprocal visits are arranged, and in some instances a regular special visiting teacher is organised. Intellectual ability and emotional stability are more important for successful integration than physical competence.

The period each child attends the centre varies considerably, from one term to three years and is according to his needs and the availability of another suitable program accessible to the home.

All our children are referred to Counselling, Guidance and Clinical Services of the Education Department, when they approach school age. A guidance officer assesses the child in his kindergarten, and consults with his teacher, before discussing plans with his parents. Many of our children proceed to special schools for physically disabled children, but some go to Spastic Centres, Special Developmental Schools or Day Training Centres; or they may transfer to another special kindergarten (e.g. Yooralla kindergarten) or local ("normal") kindergarten.

PLAYGROUPS

We have two playgroups operating weekly for young children with disabilities and their mothers. Both groups have up to six children with physical disability and/or intellectual delay. One group is for very young children, from babies up to about two years, and the other for two and three year olds, or until time of entry into a kindergarten program. The groups are run by a kindergarten teacher and social worker, and admission is via the Department of Developmental Paediatrics.

These play groups have three major aims:—

1. To provide the child with suitable play activities and foster the mother's enjoyment of her child through playing with him.
2. To help parents work through the grieving process by giving them the opportunity to express feelings, share experiences, and help each other in a controlled setting.
3. To further assess the child and the mother/child relationship and so assist in formulating an ongoing program.

The groups also help mothers to set limits and commence the separation process and the social worker provides information regarding facilities and when necessary, gives individual counselling outside the group situation.

The program is levelled towards the individual needs of the child, and for part of the session, mothers are encouraged to play with their own child and recognise appropriate play materials. Activities include table work, messy play and floor play. The one formal group activity, music, is aimed at encouraging listening skills, concentration and group participation, as well as enjoyment.

The organisation of both groups at any one time varies according to the developmental level, disabilities and emotional status of the children, and the emotional status and needs of their mothers.

Our playgroups seem particularly suitable for children who already have considerable involvement at this hospital, where staff communication is important and where Playgroup can assist in the child's assessment. It is particularly appropriate if, in addition, the mother is expressing considerable anger and denial concerning the diagnosis. For children who are expected to proceed to the Uncle Bobs Club Child Development Centre's full program, it has proved an invaluable introduction, minimising anxiety and separation problems for both mother and child. If the child does not enter the kinder program, plans are made for him to transfer to another playgroup, kindergarten or day centre.

Mothers develop close relationships with the other mothers and children within the playgroup setting and come to realise that although their children have widely differing disabilities, they all have the common bond and sadness of a child with special needs.

PARENTS

I have already referred to "parents" and "family" in relation to the child, but I cannot stress too much that every child is a member of a family, and he will not gain full benefit from a program unless the family accepts and is able to co-operate with it. Discussions concerning a child's progress and future plans include parent attitudes, wishes and capabilities, interpreted by the social worker and other team members, and no significant change is made to the program without consultation with parents.

Parent involvement in the centre varies considerably, depending on cultural, intellectual, emotional, geographical and economic factors, the needs of other young children, and support from extended family. Some mothers rarely visit the centre, and a few attend each session with their child for weeks or months. Parents are encouraged to visit regularly but one of the goals of our centre is to encourage emontional and physical independence in the children, and severe separation problems are handled sympathetically and with much sensitivity by all members of the team.

The stresses caused by the acceptance and care of a child with a long term disability are tremendous, and the rate of marriage breakdowns in such families is high. In many families an interdependence between mother and child develops which can have an adverse effect on other family relationships. Fathers can unwittingly be "shut out", when mother most needs his support, and siblings find it hard to understand why mother has to spend so much time with the disabled child. Many mothers are quickly able to accept that their child is happy attending our (or another) centre, that trained staff are able to care for him nearly as well as herself and that he can cope emotionally without her. The child is then able to develop an individual personality and mother is able to consider her own needs, and to give more time to other family members and household tasks, thus improving family relationships. Other mothers find it very difficult to separate, especially if there are not other children requiring attention, and the process is slow and painful for both mother and child.

Help available to parents includes formal counselling sessions with social worker or psychologist, informal input from other staff members, informal discussions with other parents (generally over a cup of coffee in the kitchen) who may have progressed further in the painful process of acceptance of the disability and separation, and formal parent groups.

We have monthly Mothers Club meetings, generally with a topic suggested by the mothers, and an outside speaker. The topics are mostly information oriented but discussion frequently progresses to "feelings" and family relationships. Fathers are welcome and sometimes attend these meetings, and we also hold infrequent Parent Meetings in the evening. Significantly, the most regular attenders are parents of younger playgroup children.

We encourage participation by other family members, especially brothers, sisters and grandparents, and there is a "family week" when they are invited to visit the centre. Grandparents frequently have even more difficult than parents in accepting a disability in a member of the family, and because of this are unable to give parents the support they need. Some grandparents attend Mothers' or Parents' meetings and are always welcome. Parents who must devote extra time, including many hospital visits, to a child with disabilities may find it hard to meet the needs of other children, and visits by the siblings to the kindergarten or playgroup on suitable occasions, can help greatly, by giving meaning to the visits and helping the siblings understand the program.

CONCLUSION

The Uncle Bobs Club Child Development Centre aims to improve the quality of life of a comparatively small number of children with disabilities and their families. However, through teaching at both undergraduate and postgraduate level, and the interchange of ideas with people at all levels working in the community with young children with disabilities, we aim to help a much wider group.

Our children develop at different speeds and parents move through the stages of acceptance of disability in different ways, but most of our families are happy in the centre and are helped by our program in its widest sense.

I would finally like to pay a tribute to the parents who entrust their children to our care. The centre staff care for them a few hours a week – parents care for them the rest of the time. Centre staff go home at the end of the day – parents basically care for them twenty four hours a day, seven days a week, fifty two weeks a year. Tremendous love, devotion and wearing physical effort is involved, and expectations of normal parent rewards must be modified.

Nothing can remove the grief of parents and the difficulties for children with disabilities, but professionals can help to lighten the load, by personal contact and by developing appropriate programs.