

COMMUNITY SUPPORT: CHILDREN AND DISABILITY

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What is Community Support?

Is it support *from* the community to the family?

This could be construed as voluntary support, possibly emphasising the "charitable model" whereby the more able and financially independent people in the community assist those less able and more disadvantaged.

I prefer to see community support as high quality, low cost services provided by governments (local, state and federal) to enable the child with disabilities to remain with the natural family and be an integrated member of the community.

And what if this support is not enough? If, for some reason — severity of disability, difficulty in adjusting too and coping with the effects of the disability, illness of other family members, financial difficulties — it becomes impossible for the child to remain with the natural family, what then?

It has been suggested in the fairly recent past that "total family breakdown" should occur before permanent out-of-home care is considered for a child with disabilities, and a disregard for the well-being of the *total* family. Would support be available to the family when the child with disabilities is no longer "at home", and if so, from whom?

The reasons for seeking out-of-home care for a child with disabilities differ (in general) from the reasons for seeking this care for a child who is not disabled.

The level of love is rarely in question. Reasons for seeking out-of-home care are more likely to be the severity of disability, and the detrimental effects on other members of the family resultant from enormous pressures. We are in fact not talking about 'normal' families but an abnormal family situation because of the disability factors mentioned.

This indicates that:

- (a) Maximum supports must be provided in an attempt to prevent family breakdown.

(b) When the first signs of breakdown become apparent increased support must be offered including a high level of in-home care and out-of-home respite care.

(c) If the family is still unable to cope, the child may need to be cared for away from, but as close to as possible, the family home *before* total breakdown occurs. Parents should be given the option of continuing to take full responsibility for all decisions made with respect to the child's care, development and future. On-going support must be provided to the family to assist them in dealing with the trauma and possible guilt experienced when the child is placed outside the natural family environment.

All persons involved with the family must have specialist skills and be non-judgemental. They must have a total understanding of the individual needs of the family. Too often inaccurate judgements are made about a family's lifestyle, ability to cope and emotional involvement and this not only increases the pressures on the family but results in inappropriate decisions being made both on behalf of the child with disabilities and on behalf of the family.

Governments are expounding some very sound philosophies in relation to services for people with disabilities and they are developing innovative policies for development and implementation. But how realistic and practical are these policies? They have frequently been developed in isolation from the actual needs of children with disabilities and their families. The Community Services Victoria, office of Intellectual Disability Services "Ten Year Plan for the Redevelopment of Intellectual Disability Services" (Interim Report, June 1987) states "Such early intervention programmes should serve to reduce the need for services to the intellectually disabled after early childhood" and "... to ensure that the number of persons dependent on the special services of OIDS are kept to a minimum...". Does this suggest that intellectual disability is 'curable'? What consideration is made for the fact that many young children who have Down Syndrome have fewer 'disability' problems than children who have Down Syndrome and who have reached puberty? Is the government more concerned with reducing services (and

therefore reducing costs) at the expense of children who have intellectual disabilities and whose needs will change and *may increase* with time? What provision will be made for support to the families both now and in the future? To what extent has the total client group been considered, and what provision will be made for the profoundly, multiply disabled children and their families?

The following provides a brief overview of service needs and short falls in relation to today's situations.

In-Home Support

The level of in-home support required is dependent not only on the severity and type of disability but also on family structure, cultural background, religious and ethical issues, individual personalities, stamina and health of all family members, stability of the marital relationship, financial situation, suitability of environment (particularly where there is also an element of physical disability) and access to support from immediate family and friends.

The range of in-home supports which must be available include:

- Child-care to enable parents to participate in social and recreational activities, day or night.
- Child-care for the working parents, including after school and school holiday care.
- Emergency/crisis care.
- Assistance with household tasks.
- Care for the siblings when the parents accompany the child with a disability to medical appointments or school/pre-school excursions.
- Overnight (short-term and long-term) care for those families who prefer this option for respite care.

Services ideally should be low-cost, high quality and non-judgemental.

The Specific Home Help Service which is available through most municipal councils has the potential to provide the above support. Unfortunately few councils provide more than a limited child-care service and minimal assistance with house work.

Respite and Long-Term Residential Care

It is essential that a *range of options* for both short-term (respite) and long-term residential care is available. Each family and each child with disabilities is

individual and the specific needs must be respected. One family may feel more comfortable with a trained and experienced carer living in the family home and caring for the child with disabilities while the parents and siblings have a vacation. Another family may feel more confident if the child with disabilities is cared for in a facility (dare I say "hostel") which has trained staff persons caring for a number of other children with similar needs.

Who are we to judge what is right, what is most appropriate and what is most beneficial? The options available today for respite/long term care include:

- Specific Home Help (limited usually to a few hours each week).
- Interchange (child spends approximately one weekend each month with a family in the community. Limited by funding and availability of host families).
- Foster care (care arranged with a family in the community and according to need. Not available in all regions and limited by availability of host families).
- Community Residential Units and family group homes (care arranged according to need. Limited by scarcity of resources, cost to parents in some regions, lack of staff training and inappropriate staff employment).
- Hostels/nursing homes, Institutions. Unacceptable to many families and seen as inappropriate by most referral persons. Limited placement.

I would highlight transport/accessibility to services as a separate issue.

Q. How do families reach the service?

Q. Does every family have a telephone?

In summary, although there appears to be an adequate range of options available the limitations are severe and many families are unable to obtain the level of support they require. A further restriction is placed on those families who have no means of transporting their child with disabilities and the respite option cannot be reached by Public Transport.

EDUCATIONAL SERVICES

Today's government has stated quite clearly that it sees the integration of children with disabilities into regular schools as a priority, while continuing to provide for those children who remain in segregated settings.

This is, of course philosophically sound, if somewhat unrealistic given the economic constraints of the present day.

To effectively maintain a dual system and ensure that the educational, physical and emotion need of all children with disabilities are met to enable them to achieve their maximum potential requires adequate and appropriate support and

services in all environments.

I have no desire to debate the pros and cons of integration or segregation. Where I come from both have a place. I am in the business of supporting families not policies.

The major difficulties being experienced at present are outlined below. The resolution of these difficulties is, I feel, a long way off.

- Lack of understanding of disability and the effects of disability by regular school communities resulting in:
 - (1) resistance to integration.
 - (2) inadequate provision of resources or over resourcing or inappropriate resourcing.
- insufficient funds provided by today's government to provide for successful integration where a high level of resources is essential.
- lack of in-service and pre-service teacher training.
- employment of unsuitable persons as integration aides and integration teachers.
- lack of information dissemination to parents of children with disabilities.
- absence of transport for integration resulting in children who could benefit from integration being forced to remain in the segregated environment.
- lack of curriculum development and support in regular schools.
- resistance of some special schools to integration for fear of being closed.
- inadequate resources to special schools which have transferred from Health Department / Community Services.
- lack of educational development in special schools.

OTHER ESSENTIAL SUPPORTS

Financial

All the love in the world and the best of intentions do not pay the bills.

Regardless of the effects and the severity of the disability increased costs are incurred when a child with disabilities comes into the family home. Travel to medical appointments, special food and clothing, increased child-care and respite care costs, appliances and equipment, and increased health problems of other family members all take their toll at some time. As a parent of a child with disabilities I could have stocked both a toy shop and a clothing shop at times with items I had purchased in good faith only to find they were of no use.

Although the Handicapped Child's Allowance and government appliances schemes provide some assistance it rarely even meets half the additional costs incurred.

Emotional and Developmental

Parents need to have the opportunity of receiving counselling to assist them in coping with disability. This type of support must never be forced on a family but must be available and must be strictly confidential and provided in a non-judgemental, non-threatening manner.

Behavior management courses must be available to assist families in caring for their child with disabilities if they so desire.

Early Childhood Services

When a child with disabilities comes into the family one of the effects may well be a feeling of isolation. Disability can be totally overwhelming, all consuming and confining. The family feels that its "differentness" must keep it apart from the rest of the community.

It is essential that a range of early childhood services are made known to the family and that they are able to choose the services which most suit their needs as well as being most beneficial for the child with disabilities.

This range of services should include in-home and out-of-home services, segregated and integrated services encompassing playgroups, early intervention programs, pre-schools, kindergartens, to libraries, music groups etc.

Sibling Support.

For many years it was not taken into account that the siblings are quite often severely affected when a child with disabilities is present. Fortunately this issue is now being addressed and support for siblings is available through a number of channels. It is important that this support is continued and increased.

I would like to conclude by addressing some of the major concerns that I have with recent developments. My intention is to be cautionary rather than over-critical.

If we are aware of the possible effects the implementation of some recommendations may have then perhaps a change in direction can be encouraged without jeopardising the sound philosophy.

Non-Categorization

No-one likes to be labelled but sometimes labels are helpful. If the total needs of a family and of a child with disabilities are to be met then those needs need to be defined.

Labels, categories or diagnoses can give us direction, if nothing else. A child with Down Syndrome obviously has Down Syndrome and when the parents are armed with this information they are able to obtain information and support that will be of benefit to them. The future is perhaps not quite so daunting if some idea of prognosis is known.

Our children *do* have disabilities, they *do* have special and unique needs and certainly each child should be looked at as an individual. But it is sometimes comforting to know that you are part of a group and to be proud to belong to that group. Our children must also learn to stand up for themselves and to do so they must understand why they are different because they have "impaired gross and fine motor function, perceptual difficulties, lack of co-ordination, muscular rigidity, delayed development and . . .". My own daughter sorted her problems out fairly early. When questioned why she could or could not do something she would reply, "It's the cerebral Palsy!".

Another danger of non-categorization is that it could lead to the provision of inappropriate services. We must be very careful that our tippy-toeing around the actual issues and our over-sensitivity to labels does not lead us into an "Irish stew" of under-servicing, over-servicing or inappropriate servicing.

Parent participation

There can be no dispute that parent participation in the planning and development of services is essential. Parent participation is also essential for effective monitoring and evaluation of service provision.

Unfortunately with the integration of children with disabilities into regular schools and community-based services increased pressures are being placed on parents. In many instances parents are expected to find their own support services, provide transport, be available at any time of the day and encourage their children to do an increased amount of work at home. In addition, parents must be available to attend meetings, fill out questionnaires, be involved in workshops and seminars and respond to written documents if they want services which meet the needs of their whole family.

With these expectations placed on parents as well as the age-old financial, emotional and physical strains associated with caring for a child with disabilities it is understandable that some parents give up and opt for a segregated environment for their child's development. And what of the situation where the lone parent or both parents work full time?

Not only is integration creating these increased pressures. It seems that with any service provision (including hospital care) maximum parental involvement is expected. Parents must have total decision-making responsibility and they should be given every opportunity to participate in drawing up service plans and programs. Parents must also be given the opportunity to participate, at whatever level they are able, in service provision! An increasing number of parents are, however, finding it impossible to meet the expectations of today's "society".

In-Home Services for The Early Childhood Age-Group

There seems to be an assumption that it is preferable to provide services in the family home to the very young child to alleviate need for parents to continually run backwards and forwards seeking services for their child. This is commendable philosophy but parents also need to meet other parents in similar situations! Children need to interact with other children and adults.

It is important that a balanced and supportive program is offered to ensure that in-home services are provided where necessary but that parents are also given the opportunity of meeting other parents to form support networks and increase their knowledge of their child's disability and of the services available to them.

Community-Based Accomodation

The Community Services Vic., Office of Intellectual Disability Services "Ten Year Plan for the Re-development of Intellectual Disability Services" (Interim Report, June 1987) provides for no residential options (for children) except the natural family, adoption or foster care and states that "... Foster Families need to be adequately reimbursed for the care and support they provide and children in their care need funding to obtain supporting services and assistance" (Part 1, page 59).

What implications does this have for the natural family who has been unable to provide continuing care for their child with disabilities? To see another family in the community provided with additional support services and funds to care for a child they love dearly but could not cope with because of lack of support and financial disadvantage would tear them apart.

Maximum support – financial, emotional and physical – must be provided to the natural family and only then, if the family is still unable to care for the child with a disability should an alternative family be "reimbursed". One must first determine why the family is unable to care for the child with a disability (and of course there will be cases where the child is, perhaps, unwanted) and whether or not it is realistic to expect another family to care for the child. One must also consider very carefully why an alternative family is prepared to care for the child and ensure that it is not for possible financial gain.

There is no argument that family care is *the* most acceptable form of care for any child, but at what cost and at whose expense? Perhaps at the expense of the child's well-being?

Integration onto the Community

With all the positive outcomes of integration (not just for education? but in general) and assuming that in the future sufficient support services *will* be available

for successful integration it should be hard to find any reasons to feel even slightly apprehensive.

There is perhaps one small area that has not received much consideration. We all need peer-group support and interaction. Where children with disabilities are spread throughout regular environments there may be little opportunity for them to associate with other children with disabilities. Some families may not see this as important. Other families may experience feelings of isolation from their peer group.

This is being addressed by the Ministry of Education in some regions and support groups or families of children with disabilities who are integrated into regular schools are being formed. Other regions should be encouraged to provide similar opportunities.

Finally, by totally depressing the audience and presenting what appears to be an extremely negative view of some positive and innovative philosophies and policies one could be forgiven for assuming that I support segregation and de-institutionalisation. Not so!

I do, however, feel very strongly that low-cost, high quality, non-judgemental services must be provided at a level sufficient to ensure successful implementation of those policies. I also feel very strongly that a *range* of service options must be available to meet the individual needs of children with disabilities and their families. Experienced and specialist trained staff are essential for advice, guidance and appropriate (hands-on) service provision.

If we work through all the issues I have outlined and turn them into positive outcomes then our children with disabilities will have a meaningful and worthwhile future that we can all be proud to be part of.

**The Bureau
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check about
membership**



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