CHILD WELFARE AND THE DISABLED — IS THE BATTLE FOR JUSTICE REALLY BEING FOUGHT?

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ABSTRACT

This paper is based on the latest findings of the Children's Bureau of Australia recently released study entitled *Particular Care Reconsidered* by Barbara Szwarc. The Study, being a follow-up to the 1979 Report by N.J. Smith and G. Gregory entitled *Particular Care* was based on an Australia wide survey conducted in June 1984 on all children living in Non-Government Childrens Homes and Foster Care. Particular concentration in the study has been given to children in disadvantageous positions.

Also referred to in this paper is another report by Barbara Swarcz on *A Study Into The Victorian Children's Aid Society Respite Care Program During the 1985-86 Holiday Period.* This report was based primarily on the perceptions of parents of the children who used the program.

Of particular concern in this paper is the amount of undue injustice and inequality that such children and their families suffer just because their children are disabled.

FOREWORD

Many disturbing features were revealed in the 1979 Children's Bureau Study of children in substitute care in Non-Government Organizations.

One of the primary aims of this new study was to give a comprehensive account of changes which have taken place in the field of substitute care over the subsequent five years – particularly examining the following two crucial questions:–

(a) had the impact of the de-institutionalization movement and the philosophy of creating out of home care as close as possible to ordinary home life really made any difference in the actual provision of substitute care? and

(b) what was the impact of changes in government policy and practice in respect to preventing so many children from entering substitute care?

This paper concentrates on a group of children of particular concern, these being children with disabilities. It examines the above-mentioned questions in respect to these children, reflecting on certain findings of the Study which are highlighted in this paper.

DISABLED CHILDREN IN SUBSTITUTE CARE IN NON-GOVERNMENT ORGANIZATIONS – RESEARCH FINDINGS

I General characteristics

* More than one quarter of the children in care had some sort of disability. Of these, more than half had intellectual disabilities; one quarter had multiple disabilities; whilst one eighth had physical disabilities.

* One fifth of all children in care had disabilities which were considered to be of either a moderate or severe nature.

* Disabled children represented one fifth of all the children in care who were State Wards in the care of Non-Government Organizations.

II Age

* Associations were found between the ages of children in care and whether or not they had any disability. Younger children in care appeared far less likely to have any disability than children of an older age grouping. About one-fifth of the children who were less than seven years of age had a disability, in comparison to three-tenths of those in care who were seven years of age or older.

* Children who had multiple disabilities were much more likely to have been admitted into care at an earlier age than other children. Nearly half of the children with multiple disabilities were admitted into care before they reached the age of seven years, whereas only one quarter of the children in other categories were already in care at such an early age. Similarly nearly half of those with severe disabilities were in care before they reached the age of seven years.

* Whilst only one-eighth of the children without disabilities had already been in care for five years or more, in contrast more than quarter of the children with disabilities had already been in care for at least this amount of time. Hence, disabled children were more likely than other children to have been in care for a long period of time – in fact nearly half of the children with severe disabilities had been in care for at least five years.

* Additionally, results appear to indicate that, as the length of time increases, the greater the proportion of disabled children in the population of children in care – for example, disabled children represented 17.9% of the children who had been in care for up to one year; 30.1% of those who had already been in care for a period of between one and four years; and 42.0% of those who had been in care for at least five years.

III Family Circumstances

* When considering the prime reason for the child's admission into care, results show that a far higher proportion of children with either intellectual or multiple disabilities than other children were admitted into care primarily because of their parents' inability to cope with them. In fact, more than half of those with either intellectual or multiple disabilities were admitted into care primarily because of this reason, in contrast to one quarter of those with physical disabilities and one third of those without any disabilities.

* A far higher proportion of children in care with disabilities than those without disabilities were referred into care by the child's parents themselves – in fact it was three times that of children without disabilities who were referred by their own parents. (25.7% compared to 8.9% respectively).

* More than half of the children with disabilities were still under the legal guardianship of their parents. In contrast, just over one third of those without disabilities were still under parental guardianship. Furthermore, just over one third of the children with disabilities were State Wards – in contrast to more than half of those without disabilities. These results indicate that children with disabilities are more likely than those without disabilities to remain under the legal guardianship of their parents.

* Nearly half of children with disabilities had lived with both their natural parents before entering substitute care. In comparison, only about one quarter of the children without disabilities had lived with both natural parents before the child entered care. On the other hand, a much greater proportion of children without disabilities when compared to those with disabilities came from single parent situations when the child last lived at home – one third of those without disabilities in comparison to one fifth of those with disabilities came from lone parent families.

IV Substitute Care Provision for Disabled Children

- Nearly six out of every ten children in congregate care facilities had some sort of disability – this being either an intellectual or multiple disability. In contrast, only one fifth of those in family group homes and one eighth of those in foster care had some sort of disability. Overall results appear to indicate that larger type facilities are more likely to contain a high proportion of disabled children, whilst the more community-based smaller types of care, are likely to have only a smaller proportion of disabled children.
- Nearly one third of the children with intellectual disabilities and more than one quarter of those with multiple disabilities were still living in large congregate care facilities. This contrasts strongly with the finding that only 7.0% of the children without disabilities were still living in such facilities. Physically disabled children were an exception here, with only 4.5% still living in such facilities.
- When comparing the proportion of disabled children in foster care with children without disabilities in this form of substitute care, further marked differences arose. Whilst nearly one quarter of those without disabilities were in foster care the propotion of intellectually and multiple disabled children in foster care drops to only one tenth. Hence, such children are far less likely than other children to be in foster care. Overall, the results indicate that the more severe the disability is, then the greater the likelihood that the child will be placed in a larger type facility.

V Summary Profile

The disabled child in substitute care is most likely to be intellectually or multiply disabled, he is far more likely to have been admitted into care at a much younger age than other children and is far more likely to have been in care for at least five years.

When compared to other childre, the intellectually and multiply disabled child in care is far more likely to have been admitted into care because his parents were unable to cope with him – but *not* because of his parents *unwillingness* to cope with him. It is more likely that he was referred voluntarily into care by his parents themselves and it is most likely that his parents have still remained his legal guardian. It was also far more likely that he was living with both his natural parents before entering care and less likely than non-disabled children to have come from a re-constructed family or lone parent situation. In contrast, the physically disabled child in care is far more likely than others to have come from a family comprising of at least two other siblings.

Once in care, the intellectually or multiply disabled child is far more likely than other children in care to have been placed in a congregate care facility and is very unlikely to be placed in foster care.

IMPLICATIONS

In respect to the study's first concern as to the impact of the normalization and de-institutionalisation trend and its effects on the provision of services for children requiring substitute care, of great concern is the fact that when a child comes into care primarily because he needs a family, we now tend to place him in a family group home or in foster care. *However* when a child comes into care primarily because he has a moderate or severe disability but is nevertheless still in need of a family, he still faces a high possibility of being placed in an institution. The results found in *Particular Care Reconsidered* show that although some changes are evident, intellectually and multiply disabled children are still largely excluded from generic types of care and hence have not benefited as much as others from some of the progressive developments in planning and caring for children separated from their families. As least one third of those children are still consigned to large group care, congregate care establishments or hospitals and therefore may face a bleak future of never ending institutional care.

Hence, in answer to the question of whether the impact of the de-institutionalization movement and the philosophy of creating out of home care as close as possible to ordinary home life has really made any difference in the actual provision of substitute care, results are still most disturbing in respect to disabled children, strongly indicating that they have still not benefited as much as others from some of the progressive developments which have taken place over the five year period.

In respect to the second issue of examining the impact of changes in government policy and practice preventing so many children from entering substitute care, it is alarming to find that not only are disabled children highly over-represented in the population of children in care, but that more than half of these children were put into care primarily because their parents could not cope w'th them. Futhermore, one quarter of such children in care were put into care by their parents themselves. *Yet hardly any were in care because of their parents unwillingness to cope with them!* One must question how many of these families reached the point of needing to place their child because of inadequate respite facilities; lack of support, help or other resources necessary in their own homes to prevent such a high number of disabled children having to live away from their own families.

The findings of the *Study into The Holiday Respite Care Programme Run by The Victorian Children's Aid Society during 1985-86 Holiday Period* which was based on parents perceptions of the programme clearly demonstrates that there is a serious dearth in the provision of support services for families with disabled children liing at home. Information was obtained via a mailed questionnaire sent to the 23 families who participated in the holiday respite care programme run by VCAS during the 1985-86 school holiday period.

The fact that three quarters of those who had used the respite care programme run by the Agency had used other forms of care as well for their child throughout the year (in 6 cases, the families had used *at least* two other respite facilities) highlights the serious lack of availability of such services for those in dire need. Hence families in need are forced to use a fragmented range of respite services rather than using one place only – with which children can familiarize themselves.

The findings of this survey particularly highlight the fact that the majority of families are in a desperate position when it comes to getting some breaks from the constant and exhausting demands for caring for their disabled child – especially during the school holidays – when the children are at home with them all day. As one mother put it "Ive done the rounds many times" and hence "I don't know what I would do without the programme".

The abnormality of family life which so often exists when constantly caring for a disabled child was highlighted by the fact that some families also mentioned that it provided a desperately needed opportunity for "the rest of the family to spend time together to pursue activities that Joey is unable to participate in". In many cases the physical strain becomes overbearing and hence the break enabled the mother to rest from the physical strain as well.

Although all the families expressed gratefulness with the service, most felt that the amount and nature of the respite care they were able to receive was far from satisfying their needs for respite.

All of the families felt that there was some sort of limitation in the programme. In nearly all these cases, the nature of the limitations mentioned highlighted the enormous lack of resources available in the community for these families as well as their desperate need for respite. Five families felt that the two week period was too short.

Also, in 5 cases, a need was expressed to operate the programme during the May and September school holidays as well. Additionally 3 families "were desperate for weekend relief". The urgent need to have a place available to care for their children "when an emergency arises" was also mentioned by 2 families. Furthermore, the difficulties encountered in "booking their children early enough due to there being not enough places to accommodate such children" was mentioned by 5 families. "If you don't book ahead, you miss out."

Parents were also asked whether they felt it was more difficult or less difficult to obtain respite care than it was twelve months ago. Only 3 of those families who responded to the questionnaire felt that it was "less difficult" to obtain respite care now than twelve months ago, while 4 felt that there was "no difference". Of the remainder, 5 families stated that they felt that it was definitely "more difficult".

Generally the findings of *Particular Care Reconsidered* do show that the proportion of children with moderate or severe disabilities in care has halved over the five year period from four out of every ten in 1979 to two out of every ten in 1984.

Looking at this result from a one-eyed point of view, this decline appears to indicate that some preventative measures introduced over the five year period seem to have had some positive impact. However interpretation of this result as totally positive must be made with great caution. In examining factors responsible for this decline one must question whether there has been an actual increase of support and provision of help to these families; or is the decline due to lack of availability of substitute care services for children in families at the point of breakdown or in danger of reaching such a point?

There is a strong possibility that the decrease in the number of disabled children in substitute care facilities may not be a totally positive indication of preventative measures having an impact but rather of lack of provision of range of services for those in need.

CONCLUSIONS

We have a responsibility to ensure that the provision of an adequate and accessible range of services is available to all families, particularly those who cannot fight for themselves.

The examples cited in this paper are only a few indications of the desperate position many families of disabled children are in. Many are fighting desperately to keep their child at home. However in order to prevent such families from breaking down, the lack of any type of respite facilities, let alone ones particularly suited to the needs of each child and their family, must be acted upon.

Evidence clearly indicates that the scope and availability of such programmes is far from meeting the requirements of these families and hence is considered grossly inadequate.

If we are attempting to provide maximum opportunity for the disabled child to remain at home, where appropriate evidence from *Particular Care Reconsidered* and *A Study into the Holiday Respite Care Programme run by the Victorian Children's Aid Society during the 1985-86 Holiday Period* indicates that far more energy and resources must be invested in providing adequate supports within the community.

Providing adequate respite care facilities should be seen as a vital aspect of this support, along with the development of home-based support services and early intervention programmes.

In many cases, the availability of regular relief accommodation for the child may be responsible for the difference between having the child at home and needing to place him in permanent care.

For those who are unable to keep their child at home, there needs to be a range of services developed for their children ranging from part-time residential care to *foster care or full-time residential care in a* small family-like setting in the community, which have the needs of the child as well as of his family as paramount importance. Unlike the other categories of children in substitute care, the finding that a disturbing proportion of at least one third of the children with moderate or severe disabilities are still consigned to institutions are facts which cannot be ignored.

High priority must be given to the implementation of fully co-ordinated and monitored services which meet individual needs of the families as well as their children.

REFERENCES

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