

Child Disability Allowance

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POLICY DISCUSSION PAPER NO 2

*This paper was prepared in the Social Policy Division,
Department of Social Security by*

Susan Thomson

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CHILD DISABILITY ALLOWANCE

INTRODUCTION

This paper looks at the history of the social security provision of assistance for children with a disability and the problems in determining which children should receive assistance. It examines the purpose of child disability allowance (CDA) and possible directions for reform.

BACKGROUND

Handicapped Child's Allowance

The payment precursor to CDA, handicapped child's allowance (HCA), was introduced in November 1974 as one of a number of measures directed towards the welfare of handicapped children. It was paid to a parent or guardian who had the custody, care and control of a severely physically or mentally handicapped child who was likely to need constant care and attention permanently or for an extended period. HCA was paid in addition to child endowment for families with a disabled child and was free of income test.

In 1977, a second level of qualification for HCA was introduced for children who were not *severely* handicapped but who were *substantially* handicapped, in recognition of the needs of low income families caring for a child whose handicap, while not severe enough to satisfy the original medical criteria, imposed a significant financial burden. Payment was made on the basis of both required care and costs.

Children qualified for this second category if their need for care and attention was only marginally less than the care and attention needed by a severely handicapped child. Payment for this category was subject to a test of financial hardship and was made on the basis of reimbursement of documented extra costs incurred because of the child's disability, up to the maximum rate for a severely handicapped child which was, at that time, \$15 a week.

However, the two-tier structure of HCA resulted in considerable problems of interpretation: when was care and attention constant and when was it marginally less than constant? Because of the lack of understanding of the rationale for the payment there were numerous appeals to the Administrative Appeals Tribunal (AAT). For example, in 1984-85 there were 53 appeals lodged with the AAT with 50 per cent upheld and 50 per cent set aside.

Over the years the AAT interpreted *constant care and attention* in various ways, including:

- . intense or substantial;
- . frequent or recurring on a regular basis;
- . including or wholly comprising vigilance, surveillance or supervision as well as more active care;
- . capable of being provided to a child attending an ordinary or special day school; and
- . preventative as well as addressing the actual symptoms.

Marginally less care and attention could, therefore, include anything between slightly less than constant to more than that required by an average child of the same age.

In 1983, the Commonwealth Government established the Handicapped Programs Review to examine the effectiveness, coverage, administration and future directions of Government programs for people with disabilities, particularly those administered by the Department of Social Security.

New Directions, the report of the Handicapped Programs Review (1985), raised many substantial concerns with HCA. These covered:

- . the inadequacy of the allowance;
- . confusing and inconsistently applied eligibility criteria, particularly the distinction between the *severely* and *substantially* handicapped categories;
- . the treatment of significant extra costs associated with a child's disability;
- . the need for additional incentives to care for disabled children at home; and
- . the complexity of administrative forms and procedures.

The Social Security Review (1986) pointed to the complexities and difficulties in understanding the existing arrangements for determining severe financial hardship in families with a disabled child not defined as *severely* handicapped. It argued that an unnecessary stigma was associated with receipt of HCA for a less than severely disabled child, because of the requirement for the family to declare itself to be in severe financial hardship. The Review also commented on the inadequate level of payment and lack of indexation of the payment.

Other areas of concern included:

- . interpretation of the meaning of *constant*,
- . difficulties in identifying additional costs for the substantially handicapped category, and the possibility of discrimination against people whose incomes were so low as to prohibit extra expenditure on a disabled child; and
- . inequities where differing perceptions of the severity of a disability could result in different levels of assistance for similarly disabled children.

The Social Security Review recommended recognition of the greater needs of families with a disabled child through an increase in HCA and by the amalgamation of the universal and income tested payments into a single level non-income tested child disability allowance without the distinction between severe and substantial disability.

These proposals, based on the principle of horizontal equity, had the long term objective of improving and maintaining the disposable incomes of all families with children with a disability relative to other families with children without a disability and relative to individuals and couples without children.

Child Disability Allowance

Child disability allowance (CDA), a non-means tested, single level payment, replaced handicapped child's allowance in November 1987.

The aims of the new payment were to provide extra financial assistance for children with disabilities where the children needed extra care and to encourage family rather than institutional care of children with disabilities.

Qualification for the payment was to rest solely on the provision of *substantially more care and attention* than was needed by a child of the same age without a disability and did not recognise the additional expenditure arising from disability related costs nor the severity of the disability'. CDA did not attempt to measure the severity of the child's disability and thereby overcame the problems presented by the existence of two categories and determining which category the child best fitted.

CDA also overcame the stigma attached to having to prove financial hardship that was required of families with a *substantially* handicapped child in order to qualify for payment and the need for parents to document the costs incurred as a result of their child's disability.

¹While the aim of the payment was to encourage family rather than institutional care, this factor is not addressed in the eligibility criteria.

In drafting the CDA legislation, efforts were made to emphasise the need for care and attention to be continually recurring; provided every day; significant in nature; and required for an extended period of time.

It was felt that comparing the care and attention required by a child with a disability to that required by a child of the same age without a disability would provide a more objective measure of the need for care. It was not intended that the parents' daily activities must be entirely dominated by providing extra care and attention for the child. However, the extra care and attention the child receives must be provided to meet the needs created by the disability and not that merely provided by a concerned parent.

The care and attention must be required permanently or for an extended period. If care and attention of the degree required to qualify for CDA will not be needed for longer than 12 months, the child is not generally considered as meeting the definition of a *disabled child* (permanently or for an extended period) and CDA is not payable.

CDA is payable in respect of a child under the age of 16 years and for dependent full time students aged 16 to 24. Children attracting CDA may qualify for disability support pension once they turn 16. Data have not been kept on the number of children qualifying for CDA who subsequently claim disability support pension². This is due to the fact that the CDA payment is made to the parent while disability support pension is paid to the person with a disability. As at June 1993 some 1 290 children over the age of 16 qualified for CDA.

ISSUES

1. TRENDS

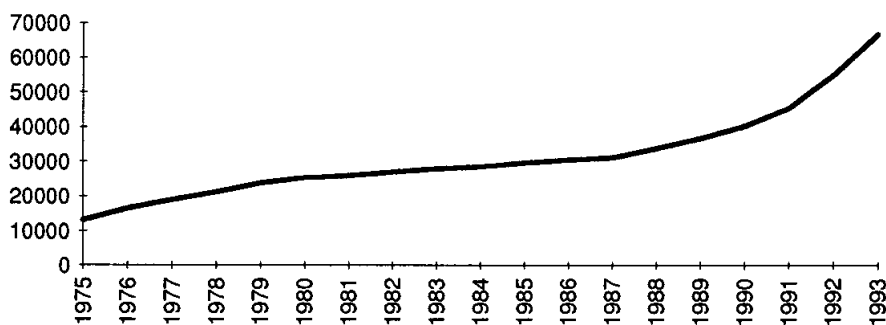
There has been a number of trends over the last decade which raise important questions about the nature of the payment. These include increasing numbers, growth in expenditure, variations in take-up across regions and a shift in medical conditions attracting payment. The following sections explore these trends and their implications.

Increasing numbers

The number of children qualifying for HCA or CDA has grown strongly from 13 040 in 1975 to 66 800 in June 1993. This represents an increase of over 400 per cent since the introduction of HCA in 1975.

² However, research is currently underway in DSS to track a group of CDA recipients turning 16.

**FIGURE 1 - HANDICAPPED CHILD'S ALLOWANCE AND
CHILD DISABILITY ALLOWANCE
TOTAL NUMBER
1975 - 1993**



DSS Quarterly Family Allowance Survey.

As shown in Figure 1, the rate of growth has increased even more in recent years, with the introduction of CDA and its new eligibility criteria, including the removal of means testing, and associated publicity material. There has been a 97 per cent increase in the number of qualifying children since June 1988.

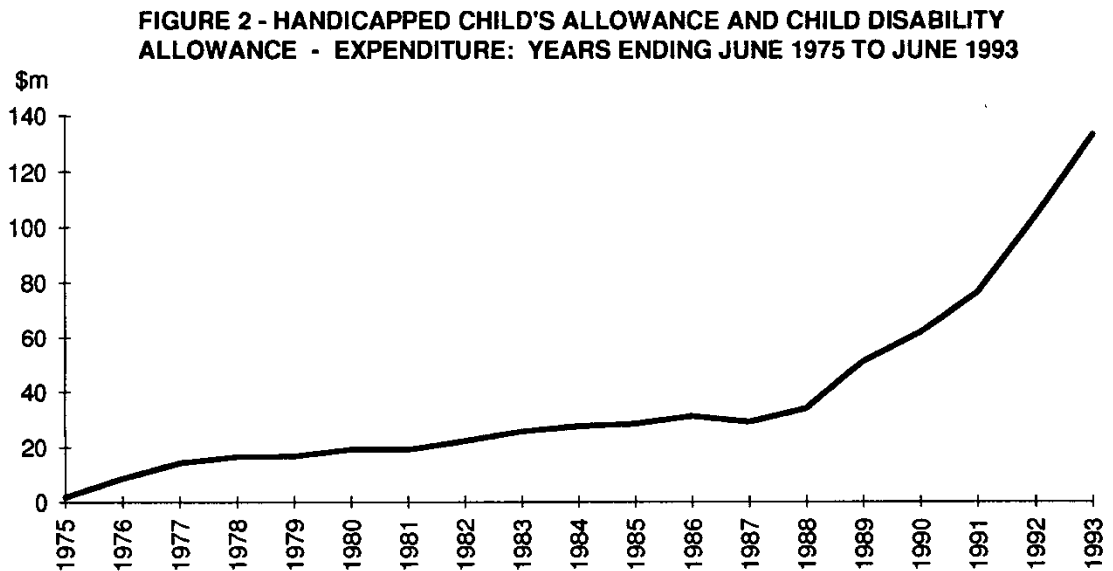
The rapid increase since 1991 has resulted from an increasing awareness in the community of the availability of CDA. This growing awareness can be attributed to publicity surrounding successful appeals; networking of parents of children with particular medical conditions through self help organisations; successful, although limited, publicity campaigns and outreach conducted by the Department; and more general practitioners and specialists advising their patients of the payment.

This increase in numbers has occurred mostly among children with certain conditions. DSS surveys of medical conditions of children qualifying for CDA conducted in 1982 and 1992 show that, as a proportion of the total primary medical conditions represented, asthma increased from 1.3 per cent to 26.8 per cent and developmental delays from 1.2 per cent to 13.4 per cent over the last 10 years. Considering the increasing incidence and diagnosis of these conditions in the community, it is expected that grants of CDA for children with these conditions will continue to increase and that they could remain the dominant medical conditions qualifying for payment.

It is important to consider whether this growth in numbers is consistent with the aims of the program or if the program has become too broadly based. Also at issue is whether the growth in numbers is consistent across the potentially eligible population.

Growth in expenditure

At the same time, the amount paid out for HCA and CDA has grown from \$8.5 million in 1975-76 (the first full year of HCA) to \$133.2 million in 1992-93. This growth is presented in Figure 2.



Expenditure has quadrupled since 1987-88. This rapid growth can be attributed to the increase in the rate of the payment (from \$92 a month for HCA in October 1987 to \$67 a fortnight in October 1993) and the increase in numbers that accompanied the introduction of CDA.

Similarly, the more rapid increase in outlays since June 1991 reflects an increased growth in numbers receiving CDA, partly attributable to the extension of health care cards from November 1991, the introduction of indexation and an increase in the payment of \$4.30 a fortnight which took place in January 1992.

Expenditure grew by 36.1 per cent and 28.3 per cent in 1991-92 and 1992-93, respectively. This growth in expenditure can be expected to continue unless there is some change in the eligibility criteria.

There is a need to consider whether this rate of growth is sustainable or even desirable.

Take-up

Allsopp, in her 1991 case study of CDA, attempted to estimate its take-up. She compared the total number of children aged 5 to 15 attracting CDA with various estimates from the ABS Survey of Disability and Aging conducted in 1988. She assumed that the differences in definition between the ABS survey and CDA eligibility meant that children with only one severe handicap would not be eligible for CDA but that those with two or more severe handicaps would be eligible.

Allsopp concluded that the available evidence indicated that the take-up of CDA was likely to be between 50 and 75 per cent. Her conclusions were supported by her pilot publicity campaign which generated a large number of inquiries and claims from potentially eligible parents. Similarly, her survey indicated a low level of awareness of CDA.

Allsopp's research indicated several barriers to the take-up of CDA including:

- . lack of awareness of the payment;
- . difficulties faced by parents with gaining access to information about the payment and in determining whether the payment was applicable to their situation; and
- . difficulties in completing the claim process.

DSS research undertaken in 1992 found differences in the level of receipt of CDA between the States. CDA approvals in New South Wales were found to be consistently lower than other States, with take-up in Tasmania being higher than, or equal to, the national average in all regional offices. Part of this difference can be attributed to the high incidence of asthma in Tasmania.

The higher level of receipt in Tasmania was also found to correlate with lower socio-economic status. Families with low incomes have greater health problems. They also have a greater incentive to apply for all possible benefits, particularly where there are additional disability related costs. Families already receiving income support or family payments, and thus in contact with the Department, are more likely to be aware of other entitlements.

The level of CDA receipt, like the level of receipt of other social security payments, declines as the distance between the client's residence and the capital cities increases. Thus the level of receipt of CDA in rural and remote regions is lower than in metropolitan regions. CDA grants, as a percentage of basic family payment grants, varied from 0.9 per cent in Area North Australia to 2.1 per cent in Queensland Area South. The ratio of the grant of these payments is as low as 0.2 per cent in Alice Springs Remote Region, 0.5 per cent in Cairns Remote Region and 0.6 per cent in Katherine Remote Region.

Allsopp and others have examined reasons for the variation in the level of receipt of CDA between regions. Some of the factors believed to have been responsible are:

- . different regional health patterns, which, in turn, are affected by the impact of family lifestyles and environmental factors such as climate and pollution levels;
- . migration of families with disabled children from rural areas to larger population centres with better medical facilities or specialised facilities for children with disabilities;
- . the subjective interpretations of the CDA guidelines at the regional level;
- . access to information about CDA within communities and amongst health professionals;
- . the relative impact of outreach and publicity campaigns conducted by the Department;
- . the greater general awareness of entitlements in urban areas;
- . the socio-economic status of the region; and
- . varying community attitudes towards disabilities and the receipt of social security assistance.

While there has been considerable growth in the overall numbers of children qualifying for CDA, the payment has major take-up problems among certain groups such as families living in rural and remote areas, particularly Aboriginal families. This suggests a need to ensure that reforms to CDA should take account of the factors outlined above in order to remove the current regional differences, as far as possible, in the take-up of the payment.

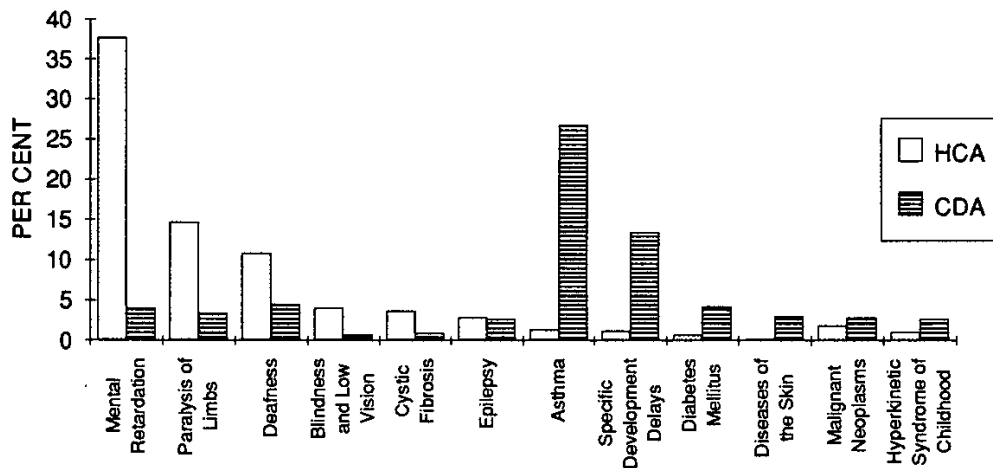
Shift in medical conditions

Medical conditions were not recorded centrally in DSS on the masterfile for HCA. However, a Departmental survey of medical conditions of children attracting HCA conducted in March 1982 found that mental retardation (coded according to the International Classification of Diseases) was the most frequently occurring primary medical condition, accounting for 37.7 per cent of the children. Other frequently occurring conditions were: paralysis of the limbs (14.6 per cent); deafness (10.8 per cent); low vision (4.0 per cent); and cystic fibrosis (3.6 per cent).

As was the case with HCA, the medical conditions of children attracting CDA are not recorded on the DSS masterfile. In order to establish the predominating medical conditions covered by the allowance, in September 1992 the Department conducted a file survey of 426 records in eight regional offices. The survey found

that asthma was the most frequently occurring primary medical condition, accounting for 26.8 per cent of the children. Other frequently occurring conditions were: specific delays in development, including attention deficit disorder and developmental delays (13.4 per cent); deafness (4.5 per cent); diabetes mellitus (4.2 per cent); and mental retardation (4.0 per cent).

FIGURE 3 - COMPARISON OF PRIMARY MEDICAL CONDITIONS OF CHILDREN QUALIFYING FOR HCA AND CDA



Survey of Morbidity Characteristics of Children Receiving Handicapped Child's Allowance, December 1988 and DSS research undertaken in 1992.

As shown in Figure 3, the medical conditions of children qualifying for CDA have changed dramatically in the 10 years from 1982. Broadly speaking, there has been a shift away from severe physical and intellectual disabilities towards health and behavioural problems.

This shift reflects the change in eligibility criteria from those applying to HCA to those applying to CDA: a move from establishing the existence of a severe or substantial disability to establishing the amount of care and attention provided by the parent. The type of medical conditions currently attracting CDA reflect the high time and effort requirements on the part of the parent.

Consideration needs to be given to determining which children should be given assistance. This raises a number of important questions.

. Does this shift in medical conditions appropriately reflect the aim of the program?

- . Is the payment heading in the direction it was intended?
- . Should the payment be made only to families with children with a severe disability or to a wider group which includes children with a wider range of medical conditions?

The issues raised in these sections beg the question: what is the purpose of the payment?

2. PURPOSE OF ASSISTANCE FOR CHILDREN WITH DISABILITIES

Clearly, the purpose of CDA needs to be clarified. Is it to compensate parents for:

- . the extra time and effort they spend on their child;
- . the additional costs resulting from the child's disability;
- . having a child with a severe disability;
- . or to encourage family rather than institutional care?

Options previously canvassed in relation to HCA included:

- focusing eligibility on
 - the amount of care and attention required by the child;
 - the amount of time spent caring for the child;
 - the costs associated with the child's disability; or
 - the child's level of impairment;
- . treating the payment as compensation for the parents' loss of opportunities for workforce participation;
- . restricting eligibility to situations requiring a degree of care for which the only alternative is institutionalisation; or
- . increasing the rate and reducing the number of eligible clients by restricting payment to those providing care similar to that provided by carer pensioners.

These different options would effectively select a different group of qualifying children, varying from those with high time and effort needs to those with high levels of impairment to those with both. Some of the options would target less severe conditions while others would include very severe conditions only, such as those that require the parent to provide constant care and attention.

Outlined below are several different approaches to providing assistance for children with a disability.

Compensation for parents' extra time and effort

If the purpose of the payment should be to compensate for the parents' time and/or effort, then the current eligibility criteria should probably continue.

However, the problems outlined above, as they currently apply to CDA, would continue; in particular the difficulties with determining appropriate levels and type of care for non-disabled children and disabled children and when the care for a disabled child is substantially more than for a non-disabled child of the same age. Parents would continue to be paid for the care they provide and be discouraged from handing the responsibility for the care over to the child.

One way of assisting determining officers could be to develop detailed care profiles which outline the necessary levels of care required by children with specific medical conditions at particular ages.

Consideration would need to be given as to whether preventive care should form part of the care regime.

The issue of the amount of time and effort parents are able to expend on their child would continue. As long as the payment is based on this premise, it will disadvantage those parents with limited time to commit to their child. On the other hand, it discriminates against those families who encourage the child to manage his/her own condition.

Assistance with the costs of the child's disability

If the purpose should be to assist parents with the costs of the child's disability, then some measure of what such costs are, and which children incur them, would need to be developed.

It would not be desirable to return to the problems experienced with HCA where parents were required to document their additional disability related expenditure. Measuring the level of costs is difficult because they are integrally tied to ability to spend: the more money a family has the more it can spend on disability related needs.

Different conditions require different medications, special equipment, treatments, etc with varying costs. Some items that are needed for some conditions are also used by the general public, for example air conditioning units, computers, etc. Would these items be classified as disability related expenses or not?

Disability related costs have been shown to vary considerably according to the level of functional handicap (Wightman and Foreman, 1991). The functional handicaps used in the study included self care (need for help or supervision with showering, bathing, personal hygiene, dressing or eating a meal), mobility (need for help or supervision with moving around the house, moving around familiar places and using public transport) and communication (need for help or supervision to be understood by, or to understand, people).

If payments were to be targeted to those with a severe functional handicap, such as a mobility handicap, some measure of functional handicap would need to be developed.

Recognition of the child's disability and its impact on the family

If the purpose of the payment should be recognition of the child's disability and its impact on the family, then some way of determining the severity of the disability would be required.

One way to arrive at such a measure would be to develop appropriate impairment tables for children along the lines used for disability support pension.

This option would determine the level of severity of the child's disability. It would not attempt to measure the input from the parent or that of specialists, nor would it attempt to measure the costs arising from the child's disability. Nevertheless, increasing level of impairment is also a good indicator of increasing level of both required care, associated costs and the impact on the family.

Under this option, the child's disability would not be determined by his/her age nor the parent's care and attention as is currently the case. Parents would no longer be discouraged from passing the management of the condition over to the child as s/he becomes older.

Encouragement of family rather than institutional care

If the purpose of the payment should be to encourage family rather than institutional care, then the eligibility criteria would need to reflect this intention.

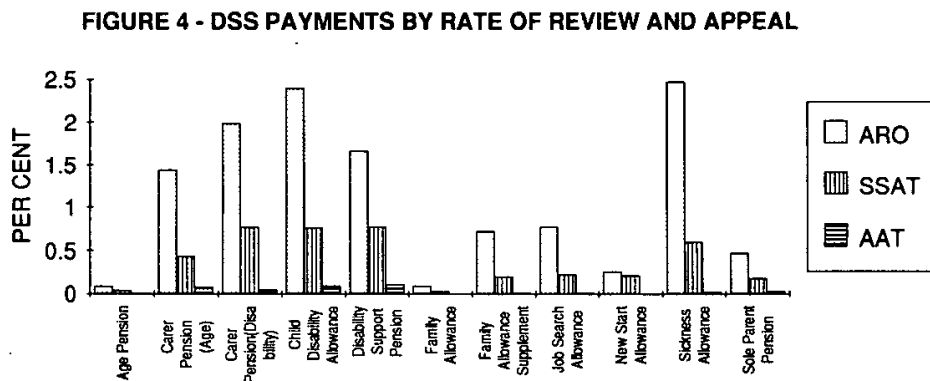
Currently, many of the medical conditions attracting CDA would not, even without CDA assistance, result in the institutionalisation of the child. A means of determining the conditions which are likely to result in institutionalisation (without the payment) would need to be developed. This would be difficult as attitudes towards the institutionalisation of children have changed over time. Today, the institutionalisation of children with disabilities is very rare; even children with very severe disabilities are cared for in the family home, for example children with Down's Syndrome.

Restricting the purpose of the payment to encouraging family rather than institutional care would be less relevant today than when HCA was first introduced.

Basing the payment on this criterion alone would be very restrictive and would dramatically reduce the number of qualifying children.

3. ADMINISTRATIVE ISSUES

While it is essential to address the purpose of the payment before examining the form of assistance, it is also important to look closely at how the current arrangements do or do not work in practice. With HCA, the major challenge was the difficulty in determining whether the child was *severely* handicapped or *substantially* handicapped. This problem of interpretation has continued with CDA with the problem shifting (because of the new eligibility criteria) to determining whether the level of care and attention is *substantially* more than for a child of the same age without a disability. It is reflected in the high incidence of review activity and appeals generated by CDA.



Based on yearly average number of grants derived from DSS four weekly currents, number of reviews conducted by Authorised Review Officers (ARO) and appeals to the Social Security Appeals Tribunal (SSAT) and the Administrative Appeals Tribunal (AAT).

The point clearly made by these statistics is that the current determination process leaves a lot open for interpretation. How this has come about is illustrated in the following sections.

Level of care required

The amount of care provided by parents for their non-disabled children varies enormously, and may depend on the parents' financial resources, time constraints, level of education, personal values and so on. Similarly, the amount of care and attention parents provide a disabled child will vary and what parents may view as necessary for their disabled child's needs will also vary.

Allsopp found that parents have difficulties in assessing how much extra care and attention a child with a disability needs, particularly parents of new babies and first time parents. This indicates how difficult it can be to determine whether a parent is carrying out preventive action or being over-protective.

Although the treating doctor can be expected to have a knowledge of the child's medical conditions s/he may have a limited knowledge of the child's required care, including preventive care. Allsopp found that the family GP may not have a good understanding of a child's disability and its effect on the family.

Children whose conditions are **not** well controlled may qualify for CDA, whereas children whose conditions are well controlled by preventive care may not. This issue particularly relates to asthma cases which can result in hospitalisation if preventive action is not undertaken.

Because of the difficulties in determining what constitutes *substantially* more care and attention, the Department of Social Security sought legal advice from the Attorney-General's Department in 1989. The advice was that the phrase was of *wide and ambiguous application* and that any one of the following three interpretations could be accepted as satisfying the requirements of the legislation.

1. A specific ratio of additional support (*ratio interpretation*) based on the **amount of care needed** by a normal child of a particular age, against which the care required by a disabled child of the same age could be measured.
2. Some more or less fixed amount of additional care (*quantum interpretation*). This involves determining the **amount of time taken** in caring for a disabled child compared to a *normal* child of the same age and quantifying the additional amount of time which would qualify for the payment.
3. The nature and intensity of the support (*quality interpretation*). This involves identifying the **type of additional support needed** by the disabled child over and above that needed by a non-disabled child of the same age.

Type of care

Payment of CDA is also dependent on the child receiving the required care and attention from the claimant on a daily basis. The nature of this care will, of course, vary according to the medical condition of the child. The types of care recognised by the Tribunals for the grant of payment have included:

- . an hour of the mother's time spent each day to build the self confidence of a 13 year old with enuresis (bed wetting);
- . emotional support provided by the mother over the telephone to her child, who was deaf since birth, during his first year at university;

- . purchase and preparation of gluten-free foods;
- . supervision to ensure the child, a 4 year child with coeliac disease, did not eat the wrong foods and visits to the dietitian and paediatrician; and
- . insulin injections, supervision of diet and eating times, regular visits to medical practitioners and foot care in the case of a 16 year with diabetes.

Examples of the types of care **not** recognised as qualifying for CDA have included:

- . care and attention provided to ensure that a 5 year old with mild to moderate asthma was warm, adequately rested and received regular medication;
- . the help provided to an 18 year old with enuresis as it comprised the kind of help, love, care and attention that every child needs; and
- . the extra attention provided to a 12 year old with learning problems as it was determined to constitute *assistance* rather than *care and attention*.

These findings reflect the individual nature of each case and how what may appear to constitute substantially more care and attention in one case may not in another.

Definition of disability

The *Social Security Act 1991* defines a child as disabled if s/he:

- . has a physical, intellectual or psychiatric disability;
- . needs care and attention from another person on a daily basis; and
- . the care and attention needed is substantially more than that needed by a person of the same age who does not have a physical, intellectual or psychiatric disability.

While the care and attention required for the management of the condition may not alter as the child grows older, the fact that the condition can be self managed rather than managed by the parent is the determining factor for the payment of CDA. Similarly, some conditions are considered manifest only until a certain age whereupon the payment is reviewed, for example diabetes mellitus under six years, phenylketonuria (a congenital disorder resulting in brain damage without dietary restriction of particular proteins) under 10 years. A child who has a condition which can be managed by him/herself, for example asthma, diabetes, below the knee amputation with a prosthesis, etc is not considered to be a disabled child. Similarly, a child who is assessed as disabled when young and becomes more able to cope with the disability when older may subsequently be assessed as not disabled.

Costs of disability

The perception of most parents receiving CDA is that the payment is to assist with the extra costs associated with the child's disability. However, the costs incurred as a result of the child's medical condition are not taken into consideration when determining the level of care provided for the child.

Nonetheless, the costs of disability are perceived by the community to be an important factor in determining the level of care that parents can afford to provide for a child with a disability and both parents and DSS staff believe they should be considered when assessing eligibility for CDA.

DIRECTIONS FOR REFORM

Purpose of the payment

To pay CDA in recognition of a child's disability and its impact on the family, rather than the level of care provided by his/her parents, would ensure that assistance is determined by the severity of the child's medical condition rather than the level of time and effort parents can expend or afford. Basing qualification on the child's level of disability would remove the discretionary and intrusive nature and uncertainty that surrounds the current payment. It would also recognise the level of care and costs associated with the child's disability while removing the uncertainty as to whether to assess the level of care that is provided or the level that is needed.

Payment of CDA in recognition of the child's disability recognises the considerable physical and emotional needs of such children and their families. Some of these needs include:

- . additional care requirements such as supervised meals, medication, exercises;
- . additional costs relating to medical treatment and therapy, medications, aids and appliances, special diets and clothing;
- . family stresses, ranging from parents being able to spend less time with the child's siblings through to marriage breakdown; and
- . additional support and care, particularly if the child is in pain or is severely restricted from participating in normal childhood activities.

CDA and DSP

The Disability Reform Package recognised that people with disabilities want to play a greater role in the workforce and the community. It contained many measures to improve the participation of adults with disabilities in labour market activities.

However, it did not address the needs of children with a disability as they approach working age. Currently, there is no link between CDA and disability support pension (DSP) because they are paid for different purposes. Paying CDA in recognition of the child's disability rather than paying the parents for their time and effort or, alternatively, their financial outlays would be a first step in developing such a nexus.

The second step would be to assess CDA in a similar manner to DSP assessment, that is based on a minimum level of impairment. Relating assistance to the child's disability, determined by his/her level of impairment, would result in a change in the pattern of conditions currently occurring amongst CDA children to reflect more severe medical conditions rather than health and behavioural problems. These children are more likely to qualify subsequently for DSP. Basing payment on the child's level of impairment would compensate for parental effort and additional costs as these increase with greater levels of impairment. It would also assist in helping families with children who would otherwise be institutionalised.

Eligibility criteria

Some means of measuring the severity of the child's disability would be required in order to be able to assist a family with a child with a severe disability. The severity of the child's disability could, most appropriately, be measured by assessing his/her level of impairment.

DSP eligibility is determined by assessment of the claimant's impairment and work incapacity. Introducing an impairment based assessment process for CDA would provide a stronger link between CDA and DSP.

Assessment tables developed for determining DSP eligibility consist of system based tables that assign impairment ratings in proportion to the severity of the condition and their impact on normal function. Tables appropriate for children at varying ages would need to be developed in conjunction with medical specialists and, perhaps, community organisations. There may be some difficulty in assessing infants. Review periods would need to be set for each child as s/he grows older.

Measuring the child's impairment could mean that the assessment process would largely be undertaken by the CMO by way of a medical examination.

The greatest difficulty with using an impairment based approach is determining the minimum level for qualifying the child for payment. It could, for example, be set at 20 per cent, the same as disability support pension. Of particular concern is which disabilities and medical conditions should be considered severe enough to warrant payment.

Alternatively, eligibility could be determined by an extended list of manifest conditions which could include all medical conditions that would constitute a

severe disability. The size of such a list would be enormous and extremely complicated as it would need to include a vast range of medical conditions and syndromes together with some measure of the level of severity that would constitute a manifest condition. While this approach would preclude the need for a CMO medical assessment of each child it would require extensive knowledge on the part of regional office staff to be able to determine whether a child's condition was manifest. Even with the current list of only 13 manifest conditions there is often not enough information provided by the treating doctor for staff to determine whether the condition is manifest. These cases are referred to the CMO for advice. This process would need to continue and would probably mean most claims would need a CMO opinion.

Notwithstanding these issues, there would be merit in expanding the current list of manifest conditions as one way of reducing the number of medical examinations.

Basing eligibility on the child's disability, rather than the level of care provided by the parent, would overcome the need to address concerns expressed within DSS over whether a child is eligible if care is provided outside the home by service providers such as schools and child care centres. It would also allow payment for new born babies who have not left hospital because of their medical condition or children newly diagnosed and recently hospitalised.

Rate of payment

While it may be simpler to have a single rate of payment, it may be fairer and more publicly acceptable to have a range of levels of assistance according to the level of impairment. Consideration could also be given to extending the health care card for children whose impairment rating falls just short of the minimum level for attracting payment. This might reduce concern about failing to access CDA. However, families who receive full additional family payment already receive the health care card and the Pharmaceutical Benefits Scheme safety net exists for all other families (currently \$312.30 a year but due to rise to \$400 a year from 1994).

If the purpose of the payment were recognition of the child's disability, then it may be considered justifiable for families with more than one child with a disability with impairment levels just below the minimum to qualify for payment in recognition of their additional needs.

Provision of a two tier payment structure could be seen to be reverting back to a HCA style payment. It would also generate a high rate of appeals from claimants wanting to test their eligibility for the higher rate. A single rate of payment would be far simpler to administer and result in fewer appeals.

Provision of a health care card for children with a 10-20 per cent impairment level would provide assistance with the extra costs generated by these children. It would also assist in maintaining horizontal equity with other families. However, it would increase the number of claims and their costs as all claims would require a

CMO assessment. Having two entry points for assistance, that is one for the health care card and one for payment of CDA, would increase appeals from those who just failed to meet the eligibility criteria.

Restricting payment to under 16 years

If CDA is based on a level of impairment similar to that required for DSP, there would be little reason for continuing payment for children over the age of 16 years as those with severe disabilities can qualify for DSP once they turn 16. Once the child receives DSP, the parent may qualify for carer pension if s/he is required to provide constant care for the child.

Ceasing eligibility at 16 years could encourage more children to claim DSP in their own right. Many parents are currently reluctant for their children to claim DSP as they believe that receiving a pension means a lifetime on income support for their children with no likelihood of them ever entering the labour force. However, the introduction of the Disability Reform Package encourages DSP recipients to participate in rehabilitation, education, training and employment opportunities which will assist young people with disabilities to participate in community life as they grow older. There are an estimated 1 300 children over the age of 16 who attract CDA each year.

Payment of carer pension

In some cases, a child with a disability requires constant care from one or both parents. This level of care may be required in order to keep the child at home as opposed to placing him/her in an institution or alternative residential care (such as fostering arrangements).

Restricting CDA to children with a minimum impairment rating the same as that required for DSP provides a case for qualifying a parent for carer pension if s/he has to give up work to care for the child at home. Parents providing frequent care in connection with the child's bodily functions or constant supervision to prevent injury to the child should probably be able to qualify for carer pension, subject to meeting the usual income and assets tests.

Eligibility for carer pension in the case of a child could be inferred, as it could be argued that all carers of young children have to provide frequent care and constant supervision. It could, for example, be restricted to those caring for a child qualifying for CDA with an impairment rating of more than 40 per cent.

Parents of children without disabilities can place their children in day care and school while they work. However, these may not be options for parents of children with severe disabilities, particularly infants. There could be difficulties with inferring the level of care required, as suggested above, as some children with severe disabilities, including manifest conditions, attend day care and school while their parents work.

Carer pension could be restricted to parents caring for children over the age of five years with medical conditions or disabilities that prevented them from attending school. However, the care required for children with severe disabilities is likely to be even higher for children under the age of five years and many parents who may otherwise have worked during this time in their child's life may be forced to give up work to provide full time care and supervision for their child.

Payment of carer pension to families with children with a high impairment level or a manifest condition would be a more appropriate way of providing additional assistance to families with a child with a severe disability than paying a higher rate of CDA. It would obviate the need for a two tier payment structure.

Other issues

Consideration could also be given to allowing clients the choice of a lump sum payment in advance, similar to that applying for basic family payment (ie a partial six month lump sum) or mobility allowance (a full six month lump sum) to assist with the purchase of major cost items.

Automatic reviews which coincide with developmental milestones should be introduced. Such reviews recognise that the child's level of impairment may change and even improve. They would also signal to parents that entitlement is not automatically permanent. Children currently qualifying for CDA would continue to receive the payment until their allocated review date or until they reach an appropriate developmental milestone. They would then have their impairment assessed. Alternatively, a sunset savings clause could apply whereby all current clients are saved until reviewed. All reviews would need to be completed within a target time frame, for example two years.

Conclusion

This paper has been prepared as the first step in reviewing DSS assistance for children with disabilities.

DSS is seeking the views of interested people on the proposed directions for reform as their experience of the current scheme and their views on how it could be changed for the better will be invaluable in determining the future direction of CDA.

DSS is particularly interested in canvassing people's views on the following:

- . payment in recognition of the child's disability;
- . basing eligibility on a minimum level of impairment;
- . determining the severity of the child's impairment by an impairment assessment

process similar to that operating for DSP;

- . qualification for payment if there are two or more children in the family with a combined impairment level of 20 per cent;
- . provision of a health care card for children with at least a 10 per cent impairment threshold;
- . restricting the payment to children under 16 years;
- . payment of carer pension to parents providing constant care to CDA children; and
- . optional payment of lump sum advance.

Address for comments

Comments can be sent to:

Susan Thomson
Disability Policy Section
Social Policy Division
Department of Social Security
PO Box 7788
Canberra Mail Centre 2610

Phone 06 244 7522
008 026 352

Fax 06 244 7936

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ATTACHMENT A**ASSESSING ELIGIBILITY FOR CDA**

A form called *Child Disability Allowance - Determination of Claim* is required to be completed for each claim or review. This form contains information supplied by both the parent and a qualified medical practitioner. Ideally, this should be the child's treating doctor, but information from a medical specialist is also accepted.

The determining officer is required, in most cases, to obtain the advice of the Commonwealth Medical Officer (CMO). The CMO provides an opinion only and does not determine qualification.

The CMO will take into consideration medical and other evidence provided by the claimant and the doctor supervising the child's treatment. The CMO may also contact the supervising doctor or specialist. A medical interview or examination may be undertaken, but it is not essential.

Some medical conditions are considered to be *manifest* and, therefore, do not require referral to a CMO unless the diagnosis is unclear. Conditions assessed as manifest are regarded as satisfying the care and attention test. Some conditions are regarded as manifest until a certain age, for example diabetes mellitus in children under six years, when they are reviewed. A list of manifest conditions is at **Attachment B**.

If any doubt exists about the child's care and attention requirements, the determining officer seeks the advice of the State Senior Medical Officer (SMO) and personally discusses with the SMO those aspects of the claim that are causing concern. Further clarification may also be sought from the treating doctor and/or the parent.

Either the determining officer or the CMO can request a social worker report. A social worker's interview with the claimant may be used to:

- . determine the level of care and attention the child requires;
- . obtain other relevant details for the assessment of the claim or review; and
- . advise the claimant of support services available in the community.

The determining officer then decides whether the care and attention test is satisfied, based on the information provided by the parent, the treating doctor, the CMO, the social worker and any other relevant sources.

Any client who is dissatisfied with a Departmental decision can ask to have the decision reviewed. The first level of review is carried out by the original Determining Officer. The next level of review is to the Authorised Review Officer located in the Area Office. If not satisfied with this outcome, the client may appeal, initially to the Social Security Appeals Tribunal and then to the Administrative Appeals Tribunal. Appeals may be made on points of law to the Federal or High Courts.

ATTACHMENT B**MEDICAL CONDITIONS ASSESSED AS MANIFEST FOR CDA**

- . Down's Syndrome.
- . Blindness in both eyes.
- . Cystic fibrosis.
- . Duchenne's muscular dystrophy.
- . Haemophilia A with factors V111 deficiency (less than 1%).
- . *Severe or profound* intellectual impairment (10 less than 35).
- . Diabetes mellitus - child under six years.
- . Leukaemias and other malignancies on chemotherapy until chemotherapy ceases.
- . Phenylketonuria (PKU) - child under 10 years.
- . Thalassaemia major - child under 10 years.
- . AIDS and HIV infection - irrespective of whether classified as Group 1, 11, 111 or 1V.
- . Terminal illness.
- . Autism - only when diagnosed by a psychiatrist.

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- 1 Dependency Based Payments: Married Women in the Social Security System by Shirley Douglas, Allan Groth and Jocelyn Pech.*
- 2 Child Disability Allowance by Susan Thomson.*