

*family*

A D V O C A C Y

PO Box 502  
Epping NSW 1710

305/16-18 Cambridge St  
Epping NSW 2121

Phone: (02) 9869 0866  
Facsimile: (02) 9869 0722

Record

219

File Number

10194

Author: Unknown

Title: Report on workshops: Extra costs of disability

Original source: -

Resource type: Written

Publication Date: 01/10/87

Publisher Info: Commonwealth Office of Disability

### Abstract

In 1987 the Office of Disability invited people with disabilities, their advocates and families to participate in meetings held in four Australian States in order to obtain their ideas about the range of costs issues which affect their day-to-day lives, and the best way to gain this information. This report provides feedback to the participants and community agencies involved and some information to Commonwealth and State Government departments. **Keyword: Families**

# REPORT ON WORKSHOPS

## EXTRA COSTS OF DISABILITY

OFFICE OF DISABILITY  
OCTOBER

# 1987

## EXTRA COSTS OF DISABILITY

### 1. INTRODUCTION

1.1 The Office of Disability has a role to provide policy and planning advice to the Commonwealth Government, through the Minister for Community Services and Health. In order to perform this role, the Office has to be able to provide up-to-date and reliable information. During 1986, the extra and unavoidable direct and indirect costs of disability emerged as a major concern to consumers and appeared to be an important component of any specific issue identified by the Office as part of its work in the policy area.

1.2 In June 1987, the Office of Disability invited people with a disability, advocates and families to participate in meetings held in four States in order to get their ideas about:

- the range of costs issues experienced by individuals and their families:
- the costs issues most pertinent to research into the extra and unavoidable direct and indirect costs:
- the most appropriate ways of gaining this information from individuals and families.

1.3 Consequently, the workshops enabled consumers to provide information about the costs, which affect their everyday lives. The Office of Disability considers that this approach will lead to policy and planning decisions, which are more relevant to the needs of people with disabilities and their families.

### 2. AIMS OF REPORT

2.1 This report is not intended to repeat the issues with which participants of the workshops are already familiar. Specifically, the report will:

- provide feedback and a progress report to participants who attended workshops, and to community agencies in the four States visited:
- provide information about the workshops to groups and individuals in the States which were not involved:
- provide some information (identified as extra costs) to Commonwealth and State Government Departments, and community agencies:

### 3. BACKGROUND

3.1 The Office of Disability conducted twenty-one workshops between 1 June and 19 June, involving 336 participants. Six meetings were held in both Western Australia and Queensland, five in South Australia and four in Tasmania. Eight meetings each were held for adults with a disability and eight for parents of children while five "general" meetings held included adults, parents of adults with a disability, and spouses, carers and advocates.

3.2 The workshops were, in general, well attended and broadly representative. Only very few had limited attendance.

3.3 People attended the meetings held specifically for adults with an intellectual, physical or multiple disability as well as people with a visual or hearing impairment. The general meetings and those for parents were similarly represented and included advocates of people with a psychiatric disability.

3.4 The meetings followed a similar pattern each time, and were structured to:

- Illicit the key costs information:
- First, participants identified the range of specific costs related matters which directly or indirectly affected their day-to-day living.

- Deal with as many cost issues as possible in detail:
- During this stage, participants focussed on cost areas in detail. In some meetings a couple of issues were dealt with while in others as many as half a dozen were discussed. The number of issues covered in detail was governed by the complexity of its costs related aspects.
- Find out consumer views about the feasibility and possibility of research into the extra and unavoidable direct and indirect costs of disability:
- Participants suggested that this was an important area for research but they also acknowledged the complexities of such a task.
- During this discussion suggestions about the various ways in which costs of disability research could be arranged and structured in each State were made.
- Find out preliminary information on services/benefits which were available in each State aimed at offsetting costs:
- advice to the Social Security Review in order to raise sensitivity to the broad range of costs experienced by people with a disability and/or families:
- advice to the Australian Caption Centre stating the comments and concerns of people with a hearing impairment about access to education and information television programs:
- response to the Australian Consumer Affairs Council accepting an invitation to discussions about areas of disadvantage to people with a disability.

The Office of Disability would like to thank all those who attended the workshops for their valuable participation and will keep you informed of developments.

Participants were asked to identify any allowances, benefits, services or programs that were available in their State and what different methods would be effective in offsetting some of the extra costs of disability in the future.

In this way the workshops were designed to add to the information already available about extra costs and to provide information for future work in this area.

#### 4. COSTS IDENTIFIED FROM THE WORKSHOPS

4.1 There are four attachments to this report.

A: Attachment A is a completed list of the costs issues generated from all the workshops. The list is separated into those identified by adults, and those identified by parents. Under each heading are the areas people said represented extra and unavoidable costs.

B: The specific cost areas, which were given detailed discussion during the meetings, is appended as Attachment B.

C: A summary of the ten costs items participants ticked off as priorities for themselves personally or for their families is appended as Attachment C. Some common themes have emerged from this and they do not differ a great deal among the States the Office visited. There are differences, however, between issues identified by adults with a disability, and those identified by families, as would be expected.

D: Attachment D is a short resume of some of the information the office of Disability has discovered from visits to States Governments. Members of the Office visited some State Government Departments in Tasmania, Queensland and Western Australia, as well as holding some initial discussions with the Premier's Advisor on Disability in South Australia. These meetings were held to find out about allowances and programs particularly for people with a disability and families, which offset the extra costs of disability in those States. The resume lists some of these, as well as similar developments of which the Office is aware in other States. Contact names and addresses have been included if more information about these is sought.

## 5. UTILISATION OF THE INFORMATION GATHERED FROM THE WORKSHOPS

The Office of Disability has already used some of the information gathered from participants of the workshops, and anticipates that opportunities to feed into policy development and planning decisions in this way will continue. The Office's work to date has included:

### ATTACHMENT A (i)

#### EXTRA DIRECT AND INDIRECT COSTS OF DISABILITY AS IDENTIFIED IN THE WORKSHOPS FOR ADULTS WITH A DISABILITY

---

##### Access

- to public transport
- to buildings
- restricted hours of services

##### Accommodation

- housing
- private board, nursing home fees
- purchase of special house
- support
- effects location e.g. where one lives
- cost of being placed in 'alternative' residentials

##### Attendant Care

##### Child Care

##### Clothing

- special
- cleaning
- special designs
- wear out more quickly
- shoes

##### Communications

- need for an interpreter in an emergency

### Community Attitudes

- stigma
- lack of recognition, worth
- trades/sales persons take advantage

### Costs of Caring

- cost of caring for a spouse

### Costs in Terms of Family Relationships

- motional costs of family separation
- costs of other children because of teasing
- added strain
- emotional, physical and financial costs to families
- emotional strain
- cost of being a single mother with a disability

### Costs in Terms of Social Relationships

- added strain
- skills for participation
- loss of community participation
- seen as second class citizen or not seen at all
- social cost of lack of access
- cut off from information
- loss of social opportunities, friends and neighbours
- disruption of social networks
- isolation
- prejudice

### Deprivation/Doing Without

- restrictions
- information
- limitations because of income
- sexual relationships
- loss or lack of security
- loss of privacy



## Drugs

- medicines
- pharmaceuticals

## Education

- no support in high schools
- not being able to write
- lack of time for ongoing education
- education after 18 years
- disability affects the type of training one can get after leaving school
- lack of access lack of reading and writing skills
- Braille books
- lack of access to adult education
- job training

## Electricity/Gas/Heating

- power bills
- home heating
- home air-conditioning

## Embarrassment

### Emotional Costs

- fight to get services
- costs time and energy
- leads to frustration
- because of lack of information
- because of misunderstanding by others in community

### Equipment Aids

- government taxes
- prostheses
- initial costs
- maintenance costs
- wheelchairs
- hearing aids
- baby cry alarms
- flashing alarm clock

- doorbell (flashing)
- shoes
- typewriters
- tape recorders
- special beds
- goosenecks
- glasses
- callipers
- TV set and antennae
- video
- decoder
- batteries

#### Food

- special diets
- diabetic food
- preparing meals
- extra food for seeing eye dog

#### Fees

- nursing home
- respite
- child care
- home help
- community nursing
- reading for people with a visual disability

#### Frustration

#### Health Costs to Family Members

- fear of the future
- fear of the unknown
- emotional stress and strain
- frustration
- marriage breakdown

#### Health Costs to Self

- stress
- frustration

### Health Insurance

- needing top cover

### Holidays

- limited options
- lack of access, hotels, etc
- rooms might cost more

### Home Help

### Home Modifications

- extensions
- modifications.

### House Maintenance

- cleaning
- gardening
- handyman tasks

### Insurance Premium Loadings

- fire
- health

### Isolation

- social
- educational
- recreational

### Lack of-Savings

- no low interest loans

### Leisure Equipment

### Loss of Employment Opportunities

- loss of earnings for family members
- loss of career opportunities

### Loss of Income/Income Foregone

- it costs extra to work

- it costs to look for work
- loss of benefits
- inadequate income
- financial stress
- lack of access to superannuation
- loss of or lack of promotion opportunities
- lack of ability to earn an income
- loss/decrease in income

#### Loss of Recreational Opportunities

- entertainment
- social activities
- sport
- limits to recreation, entertainment

#### Loss of Self Esteem

- vulnerability in financial dealings

#### Lost Independence

- lack of private life of one's own: always being noticed
- lack of control

#### Medical

- special dental services
- specialists
- bandages
- first aid

#### Paramedical

- therapy (particularly rural)

#### Personal Hygiene Items

- toiletries

#### Regular Household Items

- suitable furniture

#### Respite Care

#### Rural/Remote

- relocation costs to get services

#### Telecommunications

- telephone - cost of installation and rent
- telephones
- telephone extensions necessary
- captioning telephones
- computers
- flashing lights, loud bells
- TTY's (no public TTY's)
- supertext decoder
- use of 013
- postage
- missed opportunities

#### Time

- in getting to specialist services
- frustrations and time to find out what is available
- attending meetings
- attending appointments

#### Transport/Travel

- having to buy a private car
- sales tax
- mobility allowance eligibility
- car parking
- cost of second or special car
- needing two seats for travel
- licence
- needing assistance
- having to keep lots of appointments
- taxis
- modifications to cars

ATTACHMENT A (ii)

### EXTRA DIRECT AND INDIRECT COSTS OF DISABILITY AS IDENTIFIED IN WORKSHOPS FOR PARENTS WITH A SON/DAUGHTER WITH A DISABILITY

---

### Accommodation

- running 2 homes e.g. need to run farm and maintain city home in order to get services.
- residential services (lack of)
- cost of nursing homes
- away from home costs e.g. board, washing and ironing
- parents with an adult son/daughter with a disability have limited options about where they live after retirement

### Clothing

- clothes wear out more quickly
- orthopaedic boots and shoes
- clothing which is stained through dribbling does not last as long - have to buy more and better quality
- extra nappies, sheets and mattresses
- constant replacement of lost clothing for child who lives away from home
- necessity for 2 sets of everything
- specially made clothing

### Cost in terms of family relationships

- no time for family relationships
- no choice about what you do
- marriage breakdown
- extra stress on mother if having another child e.g. attitude of others may be abortion

### Damage to House

- Maintenance costs and replacement costs of carpets, wallpaper, paint, breakage's

### Drugs

- Pharmaceutical costs

### Education

- fees at kindergartens which will meet needs
- fees for early intervention
- education ends earlier (15 years)
- fees of vocational training
- costs of tutors, equipment e.g. computers, TTY's

- costs of private schools
- costs of 'integration' aide
- toys and equipment
- lack of time for on-going education for carers

#### Electricity/Gas

- extra equipment and costs of heating and cooling
- extra cost of increased use of hot water

#### Equipment/Aids

- purchase of wheelchairs, splints, waterbeds, incontinence aids
- loss and damage e.g. to wheelchairs and glasses

#### Food

- special diets e.g. allergies

#### Health costs

- lack of being able to retire as a parent
- anxiety
- fear (of unknown future)
- exhaustion
- stress on parents and other family members
- need to support family members to cope e.g. grandparents
- development of self opportunities all foregone
- maturity to plan own future

#### Holidays

- extra cost of accommodation because people with disabilities must always go with parents
- limited opportunities to take holidays

#### Home care

- cost of help in house

#### Home modifications

- extensions
- extra room
- access
- special equipment
- building for security and protection (fences., locks)

### Hospital stays

- separation from parents and other children

### Income foregone

- superannuation and other benefits
- family life disrupted

### Insurance and Superannuation

- higher premiums on life insurance
- clauses which lessen insurance pay-outs

### Lack of security

- assets test: can't "will" money to son/daughter because they will lose their pension
- pension eligibility stopped because of increasing skills

### Laundry or Dry cleaning

- greater cost due to incontinence
- necessity to buy more soap powders
- wear and tear on washing machines

### Loss in terms of social relationships

- loss of community involvement
- loss of opportunities for relationships with other children
- problems with neighbours
- costs extra to take child out

### Loss of employment opportunities

- loss of further study opportunities
- lack of child care, babysitting for carer and/or spouse
- for person with a disability (who goes on to IP)
- extended time out of the workforce
- choices cut off for mother
- unable to give time and commitment to career leading to loss of promotions not
- practical to relocate



### Loss of recreational opportunities

- lack of community understanding isolates family and its problems

### Medical

- extra specialist advice and treatment

### Modifications to vehicles

- cars have to be more suitable, larger than normal
- cars need modification

### Paramedical

- cost of therapy

### Personal care

- costs of carers who are not the usual unpaid family members

### Regular Household items

- detergents
- adaptations (of TV for captions)
- extra linen
- buying two sets of kids equipment

### Relocation expenses

- in order to get services e.g. move from country to city

### Respite

- family allowance is stopped for a child who is in respite and for any other children in the family. Repayments of FA for the other children may take several months
- HCA and 28 days respite is totally insufficient
- paying for sitters
- charges for respite by agencies are average of \$10 per day

### Telecommunications

- Baby cry alarms
- Telephone Typewriters

### Transport

- taxi-fares
- need for second car
- need for larger car

- cost of petrol, mileage
- airfares e.g. to see medical specialists

#### Toys/Leisure Equipment

- need for toys which will last

## ATTACHMENT B

### COSTS ITEMS FOR WHICH SPECIFIC RESEARCH QUESTIONS WERE GENERATED

---

#### ADULTS

Transport costs  
 Costs of equipment/aids  
 Health costs to family members  
 Costs to family relationships  
 Costs to home help  
 Costs of personal care  
 Respite costs  
 Costs of telecommunication/communication  
 Stress  
 Costs of quality of life  
 Costs of earning and income  
 Clothing costs  
 Costs of modifications  
 Loss of employment opportunities  
 Costs of independence/dependence  
 Costs of access to appropriate training  
 Costs to/of social relationships  
 Costs of adult education  
 Costs of living in rural areas

#### FAMILIES

Accommodation costs  
 Respite costs

Loss of income/income foregone/employment opportunities  
Costs of education  
Stress  
Costs of rehabilitation  
Costs of/to social relationships  
Clothing costs  
Transport and travel costs  
Costs of stays in hospital  
Costs of therapy  
Costs of household wear and tear  
Cost of household items  
Equipment/aids costs  
Community attitude costs  
Costs of access  
1599A

ATTACHMENT C (i)

**COSTS IDENTIFIED AS PRIORITIES IN GENERAL WORKSHOPS FOR  
ADULTS WITH A DISABILITY AND FAMILIES**

---

COSTS IDENTIFIED IN GENERAL WORKSHOPS FOR ADULTS WITH  
A DISABILITY AND FAMILIES

QUEENSLAND	TASMANIA	SOUTH AUSTRALIA	WESTERN AUSTRALIA
Costs of Accommodation	Transport Costs	Transport Costs	Transport Costs
Costs: Family Relationships	Costs of Aids/Equipment	Costs: Family Relationships	Costs: Family Relationships
Costs: Social Relationships	Costs: Social Relationships	Costs: Social Relationships	Costs of Holidays
Transport Costs	Costs of Caring	Medical Costs	Costs: Recreational Opportunities
Respite Costs	Costs of Telecommunications	Accommodation Costs	Costs: Social Relationships
Home Modification Costs	Loss: Employment Opportunities	Costs of Aids/Equipment	Education Costs
Costs of Holidays	Costs: Family Relationships	Costs: Recreational Opportunities	Costs of Aids/Equipment
Loss: Employment Opportunities	Respite Costs	Health Costs: Family Members	Loss: Employment Opportunities
Costs of Aids/Equipment	Laundry/Dry Cleaning Costs	Attendant Care Costs	Respite Costs
Loss of Income/Income Foregone	Health Costs: Family Members	Costs of Deprivation	Loss of Income/Income Foregone.
Costs of Aids/Equipment	Costs of Telecommunications	Transport Costs	Transport Costs
Transport Costs	Costs of Aids/Equipment	Costs: Family Relationships	Loss: Employment Opportunities
Costs: Family Relationships	Transport Costs	Loss: Employment Opportunities	Home Modification Costs
Loss:	Loss:	Costs:	Costs of

Employment Opportunities Costs of Telecommunications Home Modification Costs Loss of Income/Income Foregone Costs of Deprivation Costs of Holidays Costs of Education	Employment Opportunities Education Costs Costs Recreational Opportunities Costs of Regular Household Items Home Modification Costs Costs of Gas/Electricity Costs: Social Relationships	Recreational Opportunities Costs of Aids/Equipment Costs of Holidays Costs of Deprivation Costs of Accommodation Costs: Social Relationships Loss of Income/Income Foregone	Holidays Costs: Family Relationships Costs of Aids/Equipment Home Care Costs Costs: Recreational Opportunities Costs of Education Costs of Deprivation
---	--	---	--

ATTACHMENT C (iii)

COSTS IDENTIFIED AS PRIORITIES IN WORKSHOPS FOR ADULTS WITH A DISABILITY

Queensland	Tasmania	South Australia	Western Australia
Loss: Employment Opportunities Transport Costs	Costs of Home Care Costs of Food	Costs of Education Transport Costs	Costs: Family Relationships Costs of Education Transport Costs
Costs of Education Respite Costs	Loss: Employment Opportunities Costs: Recreational Opportunities Costs: Toys/Leisure Equipment	Costs: Family Relationships Loss of Income/Income Foregone Costs of Accommodation	Transport Costs Loss: Employment Opportunities Costs: Holidays

Costs: Family Relationships	Costs of Clothing	Loss: Employment Opportunities	Costs of Caring
Costs: Social Relationships	Costs of Caring	Costs: Recreational Opportunities	Costs: Recreational Opportunities
Costs of Home Care	Costs of Accommodation	Health Costs: Family Members	Costs of Clothing
Costs of Caring	Medical Costs	Costs of Caring	Loss of Income/Income Forgone

### STATE GOVERNMENT DEVELOPMENTS

In each State, members of the Office of Disability held discussions with some state government departments.

In these early discussions the Office discovered some important new developments taking place which will be of assistance to people with a disability and their families. For example in: -

Tasmania, the Transport and Parking Concessions Scheme for people with severe disabilities, introduced in July 1985, has been reviewed. A number of recommendations have been made about eligibility criteria among other areas and further information is available from:

Ms Ruth Streets  
 Disabled Persons Services Unit  
 12 Murray Street  
 HOBART TAS 7000  
 Phone (002) 302973

South Australia, an interesting initiative has been taken in setting up the Disability Services Co-ordination project. Ms Rosemary Wighton, Deputy Director General, Department for Community welfare heads up the project and is responsible for establishing mechanisms to improve the planning and provision of services to people with a disability and the co-ordination of these services between government and non-government agencies and between State and Commonwealth. An important aspect of

this project is a clear definition of the State's role in Human Services provision to people with a disability.

Contact: -

Mr Randall Barry  
Disability Services Co-ordination Project  
PO Box 39  
Rundle Mall  
ADELAIDE SA 5000  
Phone (08) 2133441

Western Australia, the State Housing Office, HOMEWEST, has developed policy which establishes a framework for the provision of public housing services that are responsive to the needs of people with disabilities. The policy document is available from:

Ms Ann Hartree  
HOMEWEST Centre  
99 Plain Street  
EAST PERTH WA 6000  
Phone (09) 3230171 (x420)

A Taxi subsidy Scheme has been proposed to the West Australian Government.

New South Wales, the Housing Department has established a Disability Housing Unit, and has endorsed a policy, which contains a set of Principles and Objectives. In recognition that there is an extra cost of disability, \$40 per week is added to the eligibility criteria. For further information:

Ms Cath MacKenzie  
Disability Housing Unit  
PO Box K100  
HAYMARKET 2000  
Phone (02) 2827459

Queensland, the Transport Department introduced a subsidised taxi scheme in July this year. The scheme is a 50% subsidy operating on a voucher system. Books of vouchers and membership cards are issued to

people with a disability themselves. The scheme commenced in Brisbane will extend to Mackay and the Gold Coast within the next few months and other areas after that. For further information, contact: -

Mr Jim Archibald  
Transport House  
The Valley Centre  
230 Brunswick Street  
FORTITUDE VALLEY QLD 4006  
Phone (07) 2534700

(Taxi subsidy schemes are also in operation in:

Darwin  
Sydney  
Canberra)

These do not, of course, represent the total range of services in these States but have been selected as developments, which may be of interest to people who receive this report.