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Abstract

STAR, a Victorian family support group, produced a questionnaire for parents regarding the support parents have experienced and what they thought was needed instead or additionally. This paper lists the questions and responses. While it doesn't go into detail it provides helpful information on how other parents found help and where. **Keyword: Families**

PARENTS AND COMMUNITY TOGETHER

PARENT QUESTIONNAIRE

1. TYPES OF DISABILITY

89 parents responded to the Parent Questionnaire. They had 92 sons/daughters with the following disabilities:

Intellectual Disability (non specific)	41
Down's Syndrome	18
Rare syndromes/conditions	9
Developmental Delay	7
Autistic	4
Macro/Microcephalic	4
Viral Encephalitis	3
Cerebral Palsy	3
Hydrocephalus	1
Behavioural Disability	1
Not Specified	1

Some children also had additional/multiple disabilities. These were as follows:

Cerebral Palsy	15
Physical	4
Hearing	4
Visual	2
Speech/Language	2
Asthma	1

2. AGE GROUPS

The sons/daughters of the parents responding to the Parent Questionnaire were aged:

0 - 5 years	24
6 - 10 years	17
11 - 15 years	25
16 - 20 years	14
21 - 25 years	7
26 - 30 years	2
31 - 35 years	1
36 - 40 years	1
Not specified	1+rt

3. RESIDENCE OF PARENTS

Parents who responded to the Parent Questionnaire came from the following suburbs:

Abbotsford	1	Healsville	1
Albert Park	1	Kangaroo Flat	1
Ardeer	2	Keilor East	1
Ashburton	1	Kilayth	1
Aspendale	1	Kingsville	1
Bacchus March	1	Lalor	1
Beaumaris	2	Lower Plenty	1
Bendigo	2	Malvern East	2
Bentleigh	1	McKinnon	1
Birregurra	1	Melton South	2
Bon Beach	1	Mildura	1
Braybrook	1	Mitcham	1
Brunswick / East	3	Mont Albert	1
Cantebury	1	Montmorency	1
Caufteld / South	2	Moonee Ponds	1
Chelsea	1	Moorabbin	1
Cheltenham	1	Mt. Waverley	1
Clayton	1	Noble Park	1
Coburg	3	Northern	1
Cohung,	1	Nunawading	2
Cranbourne	1	Pascoe Vale	1
Daylesford	1	Pyramid Hill	1
Deer Yark	1	Seddon	1
Doncaster East	1	South Morang	1
Essendon 1 West	2	St. Albans	6
Fawkner	1	Strathmore Heights	1
Frankston	1	Sunshine North	3
Geelong	2	Sunshine West	3
Glen Waverley	1	Thomastown	2
Greensborough	1	Warrandyte	1
		Watsonia	2
		Winchelsea	

1

INTERSTATE:

NSW - Tamworth	1
WA - Quinns Rocks	1

QUESTION 1

When you found out about your child's disability what did you want to know, about most?

The disability 56 62.9%

Your child's future	56	62.9%
Practical services	42	47.2%
Education for your child	42	47.2%

OTHER

Coping Strategies	5	5.6%
Specific Treatment	4	4.5%
Support From Other Parents of Children With Similar Condition	5	4.5%
Meet Other Children With Similar Condition	1	1.1%
Cause	1	1.1%
Hereditary	1	1.1%

★ A majority of parents gave multiple answers to this question.

QUESTION 2

Was the information easy to find?

Yes	22	24.7%
No	67	75.3%

10 of the parents who responded that information was easy to find had sons/daughters with Down's Syndrome.

The 22 parents who responded "Yes" had sons/daughters aged:

0 - 5 years	7
6 - 10 years	5
11 - 15 years	3
16 - 20 years	6
25 - 30 years	1

The parents who responded "No" included comments such as:

"We had no useful information and relied on our own experience and knowledge."

"Word of mouth from other parents at a playgroup, 18 months later than diagnosis"

'17 years ago in a small country town, there certainly wasn't much information available"

"Very little (information) in 1947 except that the best for us and our 2 other children was institutionalisation"

"At the time (1970) there was none"

"...Through media advertisements, eg. Mike Walsh Show, The Age..."

"...this was only discovered by chance..."

"None was available"

"Very little information available 14 years ago"

"We didn't get any information - after many phone calls on our own initiative, discovered Star, Toy Library, etc"

"We never had any information!!! We asked questions but no one could answer them"

"I had very little information"

"I think the information is available, but speaking as a parent, you don't know what to ask or who"

"...when eventually found"

"No useful information received early..."

"There wasn't any until recently"

"Doctor gave us nothing but his bill"

QUESTION 3

What was the most useful information?

None/very little	14	15.7
Correct diagnosis	11	12.4
Information on disability	11	12.4
Honest prognosis	10	11.2
Available Education	10	11.2
Physiotherapy (referral. & advice)	8	9.0
Information from other parents	5	5.6
Early Intervention programs	5	5.6
Articles & Books	5	5.6
Medical Information/ Referral	4	4.5%

Noah's Ark Toy Library	4	4.5%
STAR: Victorian Action On Intellectual Disability (referral & advice)	4	4.5%
Social Worker (referral & information on services)	3	3.4%
Coping Strategies	3	3.4%
Available services	3	3.4%
Normalization theory & practice	2	2.3%
Information from Teacher/School	2	2.3%
Genetic Counselling	2	2.3%
Epilepsy Foundation (referral & advice)	2	2.3%
Infant Welfare Sister (advice & support)	2	2.3%
Day Training Centre (referral)	2	2.3%
Rejected advice to place child in institution	2	2.3%
Occupational Therapist (advice & support)	1	1.1%
Visiting Teacher (referral)	1	1.1%
Royal Children's Hospital (program & advice)	1	1.1%
Confirmation on Visual impairment	1	1.1%
Sedation for child	1	1.1%
Royal District Nurse (advice & support)	1	1.1%
Speech Therapy (referral)	1	1.1%
Contact with S.P.E.E.C.H.	1	1.1%
Travencore Assessment	1	1.1%
Language Delay Programs (Information & referral)	1	1.1%
Autistic Centre (enrolment)	1	1.1%
Royal Victorian Institute for the Blind (referral)	1	1.1%
Home Help (information)	1	1.1%
Hormone Treatment (advice on)	1	1.1%
Transport (information on Red Cross Society)	1	1.1%
Monnington (information on & referral to)	1	1.1%
Grosvenor Hospital NSW contact with)	1	1.1%
Remedial/Special Teacher help from)	1	1.1%
Down's Syndrome Association	1	1.1%
Mental Retardation Division - H.C.V.	1	1.1%
Hope from another parent	1	1.1%
Understanding what disability		

"physically" meant	1	1.1%
Diagnosis that child would never walk	1	1.1%
Advice on child's future in society	1	1.1%
Empathy & advice from friend & neighbour	1	1.1%

Why?

Most parents answered this part of Question 3 in terms of their being able to:

- * understand the implications of their son/daughter's disability;
- * plan realistically for the future;
- * relief at finding a way to manage the situation;
- * adopt a "positive" attitude;
- * feel they were doing something instead of "sitting back helpless"

Perhaps most responses are summed-up in this parent's answer:

"You no longer need to say -
Why me?
What next?
It gives you a base to work from."

QUESTION 4

What did you want most?

Information	62	66.7%
Support from child's paediatrician	30	33.7%
Support from local doctor	27	30.4%
Support from friend	25	28.1%

OTHER

Empathy/support from family	9	10.1%
To meet other parents of children with similar condition	6	6.7%
Empathy/support from spouse	4	4.5%
Empathy/support from friends	4	4.5%

Practical support (feeding/ sleep disturbance)	4	4.5%
To meet children with similar condition	3	3.4%
Support/feedback from therapists/ teachers	3	3.4%
A break	2	2.3%
Support from Royal Children's Hospital	2	2.3%
Placement	1	1.1%
Treatment information	1	1.1%
Home Help	1	1.1%
Visiting Nurse	1	1.1%
Physiotherapy sessions	1	1.1%
Honesty	1	1.1%
Anything!	1	1.1%

QUESTION 5

Who gave you the most help?

<u>MEDICAL</u>	70	78.7%
Paediatrician	15	16.9%
Royal Children's Hospital	11	12.4%
General practitioner	7	7.9%
Infant Welfare Sister	7	7.9%
Physiotherapist	7	7.9%
Social Worker	6	6.7%
Nurse	3	3.4%
Occupational Therapist	3	3.4%
Psychologist	2	2.3%
Royal District Nurse	2	2.3%
Genetic Counsellor	1	1.1%
Royal Women's Hospital	1	1.1%
Queen Victoria Med. Centre	1	1.1%
Speech Therapist	1	1.1%
C'wlth Acoustic Lab.	1	1.1%
Specialist (not specified)	1	1.1%
Red Cross Society	1	1.1%
<u>RELATIVES & FRIENDS</u>	38	42.7%
Friends	13	14.6%
Family/Relatives	10	11.2%
Other children	5	5.6%
Mother	4	4.5%
Spouse	4	4.5%
Neighbour	2	2.3%

<u>EDUCATIONAL</u>	29	32.6%
Early Intervention Prog'm	7	7.9%
EPIC	4	4.5%
Monnington	3	3.4%
Day Training Centre	3	3.4%
Kalparrin	2	2.3%
Kindergarten Teacher	2	2.3%
Malvern Playgroup	2	2.3%
A.N.S.U.A.	2	2.3%
Teachers (not specified)	1	1.1%
Educational Staff (" ")	1	1.1%
Visiting Teacher	1	1.1%
Integrated School	1	1.1%
<u>SPECIFIC SERVICES</u>	14	15.7%
Noah's Ark Toy Library	5	5.6%
Spastic Centre	4	4.5%
Epilepsy Foundation	2	2.3%
Autistic Centre	1	1.1%
R.V.I.B.	1	1.1%
M.R.D.	1	1.1%
<u>SELF HELP GROUPS</u>	13	14.6%
Other Parents	8	9.0%
STAR/Ethel Temby	4	4.5%
Down's Syndrome Assoc.		11.1%
<u>RESPITE / RESIDENTIAL CARE</u>	6	6.7%
Kew Cottages	4	4.5%
St Nicholas's	1	1.1%
Interchange	1	1.1%
<u>OTHER</u>	5	5.6%
Home Help	4	4.5%
Deaconess (church)	1	1.1%

Question 6

(1) **Where do you think a new parent of a child/children whose disabilities are similar to your child/children's would get the most information?**

Other Parents	17	19.1%
Paediatrician	10	11.2%
Royal Children's Hospital	10	11.2%
M.R.D.	9	10.1%
General practitioner	9	10.1%
Infant Welfare Centre	8	9.0%
Hospital	6	6.7%
Noah's Ark Toy Library	5	5.6%
Early Intervention Centre	4	4.5%

Books/publications	4	4.5%
Epilepsy Foundation	4	4.5%
STAR	4	4.5%
Specific services	3	3.4%
Down's Syndrome Association	3	3.4%
Social Worker	3	3.4%
Specialists (not specified)	3	3.4%
Day Training Centres	3	3.4%
Medical library/journal	3	3.4%
Action Grp. Disabled Child'n	2	2.3%
Therapists (not specified)	2	2.3%
R.V.I.B.	2	2.3%
Autistic Centres	2	2.3%
Monnington	2	2.3%
Physiotherapist	1	1.1%
Special Dev. School		
Disabled Persons		
Information Bureau	1	1.1%
S.P.E.E.C.H.	1	1.1%
Vic. Autistic Child'n Assoc.	1	1.1%
Psychologist	1	1.1%
Biala	1	1.1%
Genetic Counsellor	1	1.1%
Occupational Therapist	1	1.1%
Teacher	1	1.1%
Kindergarten Teacher	1	1.1%
'Good' Assessment Centre	1	1.1%
Community Resources	1	1.1%

ON 6

(ii) Where do you think a new parent of a child/children whose disabilities are similar to your child/children's would get the most support?

Other Parents	36	40.5%
Early Intervention Programs 10	1	1.2%
Family/Relatives	9	10.1%
Friends/Neighbours	8	9.0%
Specific, /local services	6	6.7%
General Practitioner	5	5.6%
Mental Retardation Division	5	5.6%
Infant Welfare Sister	4	4.5%
Paediatrician	4	4.5%
Social Worker	4	4.5%
Noah's Ark Toy Library	4	4.5%
STAR	3	3.4%
Monnington	2	2.3%
Spastic Centres	2	2.3%

Occupational Therapists	2	2.3%
Action Grp. Disabled Child'n	2	2.3%
Home Help	2	2.3%
Interchange/Respite Care	2	2.3%
Epilepsy Foundation	2	2.3%
Day Training Centre	2	2.3%
Royal Children's Hospital	1	1.1%
Kalparrin	1	1.1%
EPIC	1	1.1%
Autistic Family Support Centre	1	1.1%
Biala	1	1.1%
Physiotherapist	1	1.1%
S.P.E.E.C.H.	1	1.1%
Therapists (not specified)	1	1.1%
Down's Syndrome Assoc.	1	1.1%
Diagnostic Groups	1	1.1%
Community Resources	1	1.1%
Special School teachers	1	1.1%
Kindergarten teacher	1	1.1%
Speech therapist	1	1.1%
Hospital	1	1.1%
Kew Cottages/St. Nicholas'		
Parents Association	1	1.1%
Yooralla	1	1.1%

(iii)Where do you think a new parent of a child/children whose disabilities are similar to your child/children's would get the most practical help?

Specific Home Help	29	32.6%
Family/Relatives	12	13.5%
Interchange/Respite Care	9	10.1%
Early Intervention Programs	9	10.1%
Other parents of children with similar disability	8	9.0%
Friends/neighbours	8	9.0%
Local Council- babysitting	7	7.9%

Question 6

(ii)Where do you think a new parent of a child/children whose disabilities are similar to your child/children's would get the most support?

Other Parents	36	40.5%
Early Intervention Programs	10	11.2%
Family/Relatives	9	10.1%

Friends/Neighbours	8	9.0%
Specific, /local services	6	6.7%
General Practitioner	5	5.6%
Mental Retardation Division	5	5.6%
Infant Welfare Sister	4	4.5%
Paediatrician	4	4.5%
Social Worker	4	4.5%
Noah's Ark Toy Library	4	4.5%
STAR	3	3.4%
Monnington	2	2.3%
Spastic Centres	2	2.3%
Occupational Therapists	2	2.3%
Action Grp. Disabled Child'n	2	2.3%
Home Help	2	2.3%
Interchange/Respite Care	2	2.3%
Epilepsy Foundation	2	2.3%
Day Training Centre	2	2.3%
Royal Children's Hospital	1	1.1%
Kalparrin	1	1.1%
EPIC	1	1.1%
Autistic Family Support Centre	1	1.1%
Biala	1	1.1%
Physiotherapist	1	1.1%
S.P.E.E.C.H.	1	1.1%
Therapists (not specified)	1	1.1%
Down's Syndrome Assoc.	1	1.1%
Diagnostic Groups	1	1.1%
Community Resources	1	1.1%
Special School teachers	1	1.1%
Kindergarten teacher	1	1.1%
Speech therapist	1	1.1%
Hospital	1	1.1%
Kew Cottages/St. Nicholas'		
Parents Association	1	1.1%
Yooralla	1	1.1%

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Specific Home Help	29	32.6%
Family/Relatives	12	13.5%
Interchange/Respite Care	9	10.1%
Early Intervention Programs	9	10.1%
Other parents of children with similar disability	8	9.0%
Friends/neighbours	8	9.0%
Local Council- babysitting	7	7.9%
Teachers - Special School	5	5.6%
Noah's Ark Toy Library	4	4.5%

Teachers - Regular School	3	3.4%
Mental Retardation Division	3	3.4%
Physiotherapist	3	3.4%
Spastic Centres	3	3.4%
NONE!	3	3.4%
Infant Welfare Centre	2	2.3%
A.N.S.U,A.	2	2.3%
Paediatrician	2	2.3%
Royal Children's Hospital	2	2.3%
Kalparrin	2	2.3%
Monnington	2	2.3%
General Practitioner	2	2.3%
Day Training Centre	2	2.3%
Occupational therapist	2	2.3%
Norparrin	1	1.1%
Independent Living Centre	1	1.1%
Royal District Nurse	1	1.1%
Kindergarten teacher	1	1.1%
Hospital (not specified)	1	1.1%
Speech therapist	1	1.1%
Special Care Unit	1	1.1%
Visiting Teacher	1	1.1%
Multipurpose Taxi	1	1.1%
Nursing Mothers Association	1	1.1%
Paramedical services	1	1.1%
Yooralla	1	1.1%
Financial assistance - Handicapped Child's Allow.		
Invalid Pension	1	1.1%

QUESTION 7

What would you like to see Included in the Parents' Information Kit?

Information on: -

Specific Home Help	73	82.0%
Self Help Groups	64	71.9%
Resources	63	70.8%
Rights of People with disabilities	61	68.5%
Opportunities for Adults with intellectual disabilities	57	64.0%
Community Residential Units	56	62.9%
Rights of a family with a member with disability	56	62.9%

Behaviour Modification	56	62.9%
Assessment	54	60.7%
Right's of children with disability in hospital	51	57.3%
Regional Teams M.R.D.	51	57.3%
Recreation	50	56.2%

Information on: -

Making wills	48	53.9%
Principals of normalization	45	50.6%
Role of professionals	45	50.6%
Normal growth & development	45	50.6%
Guardianship	44	49.4%
Least Restrictive Alternative	43	48.3%
Advocacy	40	44.9%
Foster care	31	34.8%
Adoption	21	23.6%

OTHER

Local resources	5	5.6%
Allowances & pensions	4	4.5%
Respite care	3	3.4%
Coping techniques	3	3.4%
Toy libraries	3	3.4%
Dealing with doctors	3	3.4%
Selecting BEST treatment	2	2.3%
Pre-schools	2	2.3%
Family Day Care	2	2.3%
P.A.D.P.	2	2.3%
Books/ publications/ libraries/ articles by other parents	2	2.3%
Playgroups	1	1.1%
Lectures/discussion groups	1	1.1%
Aids & Equipment	1	1.1%
Assertiveness training	1	1.1%
Information for fathers	1	1.1%
Role of social workers	1	1.1%
Health Centres	1	1.1%
Hobby groups	1	1.1%
Professional services	1	1.1%
Specialist in field	1	1.1%
Activity Therapy Centres	1	1.1%
Family Counselling Services	1	1.1%
Sibling support	1	1.1%
Lifting techniques	1	1.1%
Physiotherapy	1	1.1%
Workshops	1	1.1%
Speech therapy	1	1.1%

Retirement	1	1.1%
Early intervention	1	1.1%
Adult life	1	1.1%
School years	1	1.1%
Churches	1	1.1%
Early years	1	1.1%
Accepting child as an individual	1	1.1%
Funerals & alternatives	1	1.1%

Information on Education: -

Integration into regular school / Kindergarten	58	65.2%
Special Schools	57	64.0%
Special Developmental School	55	61.8%
Day Training Centres	54	60.7%
Special Education Units	50	56.2%
Vocational Training	50	56.2%
Adult Education	50	56.2%

OTHER

Early intervention	4	4.5%
Other education alternatives	3	3.4%
Homebased services/programs	2	2.3%
Research programs	2	2.3%
Methodology of service /school	2	2.3%
Specific help for integration	1	1.1%
Work options	1	1.1%
Live-in/residential school	1	1.1%
Playgroups	1	1.1%
Funding (e.g. Schools' Commission grants)	1	1.1%
Behaviour modification centres	1	1.1%
Parenting skills	1	1.1%
Pros & cons of alternatives	1	1.1%
Swimming classes	1	1.1%
How to get enrolled	1	1.1%
Disability awareness teaching in regular schools	1	1.1%

Information on Specific Disability:-

Learning disabilities	44	49.4%
Developmental delay	44	49.4%
Non-verbal	43	48.3%
Moderate intellectual disability	43	48.3%

Slow learning	41	46.1%
Epilepsy	40	44.9%
Down's Syndrome	39	43.8%
Mild intellectual disability	37	41.6%
Severe intellectual disability	35	39.3%
Autism	35	39.3%
Cerebral Palsy	30	33.7%
Microcephaly	29	32.6%