Down Syndrome Needs Opinions Wishes Study Report
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Preface

by Fiona Stanley, Patron DSAWA

The Telethon Institute for Child Health Research (TICHR) aims to improve and to promote the health and well-being of all children through the unique application of multidisciplinary research. Its areas of research include birth defects, intellectual disability, autism and other neurodevelopmental disorders. Down syndrome is the most common known cause of intellectual disability with up to 30 babies being born in WA each year. Over the last 20 years, there has been a significant improvement in survival and life expectancy of these infants, which corresponds with an increasing need for medical and support services.

This report translates the information collected through the Down syndrome NOW study in 2004 from over 350 families throughout WA with a child with Down syndrome. It reflects the current needs and status of these children and young adults and their families. Such information is important for support agencies, medical and therapy providers, educational services, early intervention programmes and most importantly, families caring for children and adults with Down syndrome.

We are grateful that this report has been made possible through a Strategic Plan Implementation Grant from the Disability Services Commission. In conjunction with the Down Syndrome Association of Western Australia, the TICHR is delighted to release the findings from the study in this report, which will be distributed both to relevant stakeholders, medical practitioners and participating families. The involvement of families through focus groups, which identified key issues, has provided information that makes the report relevant and a truly collaborative effort.

Professor Fiona Stanley AC
Director, Telethon Institute for Child Health Research
Professor of Paediatrics
The University of Western Australia
Preface

by Jan Gothard

This work encapsulates the points of view and experiences of more than 300 families of children and young people with Down syndrome across Western Australia. Based initially on questionnaire responses, the material presented here was further shaped and moulded by parent focus groups working in conjunction with the Telethon Institute for Child Health Research. The resulting publication documents the experiences, hopes and expectations of a significant portion of a particular Western Australian community group: people who live with Down syndrome.

Focusing on three parameters - the individual, the family, and the community - the data and statistics give an invaluable and previously undocumented insight into some of those aspects of life which can be quantified. Health and medical conditions, weight and diet, social and recreational activities, employment and post school options and strategies are just some of the areas surveyed. The study also addresses the significant issue of community engagement and support through factors such as education, therapy, and government and non-government services. The statistical data is clearly and accessibly presented and is a wonderful resource for anyone seeking concrete data on Down syndrome.

Combined with evocative comments from parents and caregivers, all of which add colour and flesh to the data, the report is, however, even more than a compilation of valuable statistics. As a parent, I found the comments confirmed my awareness that some social, physical and emotional characteristics are often shared by people with Down syndrome, whereas others reminded me that we all experience aspects of disability in unique ways. The use made of personal commentary reinforces the value of the statistics.

This is a wonderful resource for anyone interested in disability today, but particularly so for parents, families and carers of people with Down syndrome, who will find this publication helpful, reassuring and extremely informative.

Jan Gothard
Down Syndrome Association of Western Australia (Inc.)
Introduction

Down syndrome is the most common known cause of intellectual disability, accounting for 12-15% of the population with intellectual disabilities in developed countries.\textsuperscript{1-3} The prevalence of Down syndrome varies throughout the world and is changing with time. In 2000 it was reported that approximately one in 900 children was born with Down syndrome each year in Western Australia (WA).\textsuperscript{4}

Down syndrome was first described in 1866 by an English doctor, Dr John Langdon Down. He recognised a common group of physical characteristics in these children, along with varying degrees of intellectual disability. In 94% of cases Down syndrome is associated with an extra copy of chromosome 21 and is known as Trisomy 21. Chromosomal translocation and mosaicism are responsible for the remaining six per cent of genetic abnormalities.\textsuperscript{5}

In 2004, the Telethon Institute for Child Health Research (TICHR) in Perth, WA conducted an important population-based study on the health, needs and functioning of children and young adults with Down syndrome. The study aimed to collect information from families regarding a range of issues and challenges faced by themselves and their children with Down syndrome. It focused on gathering data related to medical, educational, social and functional aspects of their child’s or young adult’s life, along with the effects and impact on the family of having a family member with Down syndrome.

An important purpose of this study was to compare the health, functioning and educational experiences of school-aged children with Down syndrome in 2004 with their counterparts of seven years previously, when a similar study had been undertaken.\textsuperscript{6, 7} It also provided the opportunity to follow the original cohort over time. Furthermore, families were invited to comment on their satisfaction and access to a range of services such as therapy, employment and recreation.

Five-hundred families with children or young adults aged up to 25 years living in WA were asked to complete a comprehensive questionnaire. A total of 363 families completed the questionnaire, a response of 73%. Almost three quarters (72%, $n = 259$) of those who filled out the questionnaire were mothers of children and young people with Down syndrome; in 17% ($n = 61$) it was filled out by both natural parents, in 5% ($n = 16$) by adoptive parents and in 5% ($n = 16$) by fathers.
This study has gathered substantial information about individuals with Down syndrome and their families living in WA.

In February 2007, focus groups were held with families of children and young adults with Down syndrome and with service providers to determine what areas they thought were most important to include in this report.

The identified priority areas are the focus of this report and will be highlighted in three sections:

- The Individual with Down Syndrome;
- The Family;
- Community and Support Services.
The Individual with Down Syndrome

‘He is a fun guy, very caring, very excitable...loves a bit of drama, but will put his arms around someone who is hurting’ (Age 24 years)

‘J has won two gold medals at the national Rowing Championships in Victoria and Tasmania and for the past two years he is WADSA Powerlifting State Champion which has given him a lot of respect and credibility in the community. He is often asked to give talks to schools and other groups about living with Down syndrome...this is a great way to educate the masses...straight from the ‘horse’s mouth’ and I know he has helped change the image of disabled people amongst the general public’ (Age 23 years)

‘She brings happiness and is caring...she has always been friendly and loving person to others...it has been said on many occasions that if someone in the group is feeling down or sad, E can bring them up feeling good again by just being around them’ (Age 22 years)

‘Whole hearted enthusiasm...helping to educate and inform broader community that people with disabilities have abilities too’ (Age 19 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
This section of the report focuses on key findings related to the children and young adults with Down syndrome. It includes discussion of medical issues, functional abilities, puberty and social relationships.

Seventy-five per cent (n = 273) of the individuals described in this report lived in the Perth metropolitan area, with 25% (n = 90) residing in country Western Australia (WA). Almost all were born in WA (87%, n = 311), with the remainder born in other states of Australia (8%) or overseas (4%).

There were slightly more males (57%, n = 205) than females (43%, n = 158). The average age of the individuals was 12 years, with the youngest being less than 12 months old and the oldest 25 years. Just over half (58%, n = 208) were of school age and 26% (n = 96) were young adults aged 18 years and over (Figure 1).

![Figure 1: Distribution of individuals with Down syndrome according to age group.](image-url)
Medical Issues

Children born with Down syndrome in developed countries were reported in 2002 to have a life expectancy of 58.6 years; for males this is greater than females by 3.3 years. Life expectancy has increased dramatically in the last 50 to 60 years, primarily due to improvements in cardiac surgery and technology, the use of antibiotics and primary prevention techniques such as immunization.

Sixty years ago, less than 50% of babies with Down syndrome survived the first year of life; today infants born with Down syndrome in developed countries of the world have a 94% chance of surviving to one year of age. For babies born with a congenital heart defect the chance of surviving the first year of life was reported as 88% in 2000. Unfortunately, survival rates are significantly lower in Aboriginal children born with Down syndrome and this discrepancy is similar to that reported for African American infants compared to white Americans.

Medical Conditions

Children born with Down syndrome may have a range of medical conditions; those most commonly reported include heart, gastrointestinal, respiratory, orthopaedic and sensory problems. Children with Down syndrome are also at increased risk of developing leukaemia. Recent research has highlighted that Alzheimer’s disease is believed to develop in about 3% of adults with Down syndrome by the age of 40 years, increasing to 40% before the age of 60 years.

Families participating in the survey were asked to describe whether their son or daughter had ever had a range of different medical conditions.

Forty-five per cent of individuals (n = 160) were described as having had a heart condition, with just over one-third of these defects being a ventricular septal defect (n = 54). The dramatic improvements in cardiac surgery and survival rates in recent years in children with Down syndrome is repeatedly highlighted in the research literature, and this is reflected in the small numbers (5%, n = 17) of children who were reported by families to have an ongoing or current heart problem (Figure 3).
Figure 2: Number of individuals who had ever had a particular type of medical condition.

Figure 3: Number of individuals who have a particular ongoing medical condition.
Eye and ear problems were the most common ongoing medical conditions in children and young adults with Down syndrome. Other ongoing conditions reported by families were thyroid problems (13%), flat feet (12%), constipation (13%), atlantoaxial instability (4%), leukaemia (2%), epilepsy (2%) and asthma (6%).

Fifty-six per cent of the 203 individuals who had had an ear condition had ongoing problems and this was particularly true for the young and those in the primary school years (Figure 4). Males (65%) were more likely than females (51%) to have been reported to have ever had an ear condition, although this gender difference was much less marked for ongoing ear problems (56% and 50% respectively). Just under half (n = 159) of the parents reported their children had been fitted with grommets, and for some children this had occurred on more than one occasion. Fifty-four children and young adults (15%) were reported to have a significant and ongoing hearing loss.

Figure 4: Individuals with ongoing ear problems according to age group.

Surgical treatment has been found to be beneficial in reversing some of the conductive hearing loss related to chronic otitis in Down syndrome. However, individuals with Down syndrome do not appear to improve as much as others after myringotomy, adenoidectomy and removal of cholesteatoma, and this is thought to be due to abnormal ear structure.

Recent research has found that inner ear abnormalities are much more common in Down syndrome than previously reported; with inner ear structures uniformly small compared to the general population.
Almost 60% (n = 215) of parents reported their son or daughter as having ongoing vision problems. No real gender difference was found. In all but the youngest age group ongoing eye problems were reported for between 70 to 80% of individuals (Figure 5). Forty-three per cent (n = 159) of the children and young adults described in this report wear glasses for a range of vision problems, including long (hypermetropia) and short (myopia) sightedness and astigmatism.

Common abnormalities of the ear, nose and throat in children with Down syndrome include malformation of the eustachian tube, shortened palate and narrowing of the oropharynx and nasopharynx. In combination with systemic hypotonia, these abnormalities underlie the high incidence of recurrent otitis media and obstructive sleep apnoea seen in children with Down syndrome. For the individuals in this survey, 51 (14%) families indicated their child suffered from sleep apnoea, however only nine (3%) reported it as an ongoing problem. A recent study to determine the incidence of obstructive sleep apnoea syndrome (OSAS) in young children with Down syndrome found that 57% of the children had abnormal results on an overnight polysomnography and showed evidence of OSAS. In the light of the recent research findings, families in WA may be underestimating this condition in their children.

Families were asked a number of questions related to their son’s or daughter’s dental health. Almost 30% (n = 107) of individuals had had fillings, 35% (n = 127) had had teeth extracted, and 16% (n = 57) of children and young adults had bleeding gums on a regular basis. Low muscle tone, the facial features and jawline of individuals with Down syndrome, and difficulties with the functional task of cleaning teeth all place this group at higher risk of oral health problems than the general population.
Medications

The majority (88%, n = 321) of individuals with Down syndrome were reported to be taking some form of medication on a regular basis. The most commonly used medications were nutritional supplements, thyroxin, and treatment for constipation and asthma prevention. There was some variation in medication use according to age group, with those in the five to nine age group having the largest proportion of children reporting not being on any medication, compared to young adults where most were reported to be taking some form of medication.

Use of Medical Services

Eighty-eight per cent (n = 319) of families reported their child or young adult saw a general practitioner in the previous 12 months. The average number of visits to a general practitioner was approximately five for the period. Use of specialist services was variable, with the most commonly visited specialists being related to the dominance of eye and ear problems in children and young adults with Down syndrome (Figure 6). Fifty-six per cent (n = 201) of individuals also made at least one visit to the dentist during the 12 month period of interest.

Families of 55 (16%) children reported that their son or daughter had had to stay overnight in hospital during the previous 12 months, with the two most common reasons being a respiratory infection or ear infections and/or related surgery. To date there has been little quantitative research comparing the health service use of children with intellectual disability and particular conditions such as Down syndrome. However one record linkage study examining hospitalisations in the first five years of life found that children with a medically diagnosed intellectual disability (a high proportion of which would be Down syndrome) were twice as likely as children without an intellectual disability to have been admitted to hospital, and that they were likely to have had more admissions and longer hospital stays. Further research in this area using population-based linkage studies is needed.

![Figure 6: Use of medical services according to type of medical specialist.](image-url)
**Body Weight**

Families were asked to provide the height and weight of their child or young adult with Down syndrome. These were used to calculate the Body Mass Index (BMI) for each individual.

The BMI has been shown to be a reliable indicator of body weight for most children and adolescents. Specific age and gender BMI growth charts are used in children and adolescents to determine the relative position of the child's BMI among children and teenagers of the same sex and age.

For families that described their son's or daughter's weight and height in this report, these charts were used to interpret the degree to which this group were of a healthy weight, underweight or overweight.

Down syndrome specific charts have been published but were not available for this report, however they may be used in future publications.

One-quarter of individuals had BMI scores that indicated they were either underweight or a healthy weight, with the remainder of the group (75%) recording scores that indicated they were overweight or obese. Girls tended to be more overweight than boys, and this gender difference seemed to be particularly true for children aged between five and nine years. Almost 40% of parents (n = 141) said their son or daughter had a weight management problem. The proportion of parents indicating their child or young adult had a weight problem increased with the child's age, with almost 60% of young adults 18 years and older being reported to have a weight problem, compared to just over 20% of children in the youngest age group (Figure 7). Weight management problems were more commonly reported for daughters than sons (Figure 8).

![Figure 7: Proportion of individuals being reported as having a weight management problem according to age group.](image-url)
For parents reporting their son or daughter had a weight management problem, their comments reflected common themes of overeating, poor food choices, and lack of exercise and motivation. They also reflected the diligence and hard work required by parents to try to maintain a healthy weight in their child.

‘B lives in a hostel where it appears they take no responsibility to provide adequate diet...they serve whatever is cheapest (i.e. a lot of carbohydrate) and residents can choose what they eat...despite many requests and meeting with management, this remains a problem. B’s weight is now a serious medical concern’ (Age 24 years)

‘Is unable to regulate own diet and exercise routine...he is dependent on parents to maintain healthy diet and organise regular exercise sessions’ (Age 23 years)

‘His mother watches his food intake...left alone he would be 100kgs’ (Age 21 years)

‘She eats reasonably healthy...but keeping weight in check has been a huge problem since puberty’ (Age 20 years)

‘Lack of exercise...if I try to reduce any unhealthy food habits he will often refuse to eat at all until I give in...his mood will become very unpleasant for us’ (Age 19 years)

‘I think it is a case of sluggish metabolism...she does lots of activity, albeit fairly slowly...but however hard we try her weight continues to rise...I fear that she will really get obese as time goes on...her thyroid function is within normal limits so it is not that...if I had an answer I would be happy for her’ (Age 18 years)

‘Lack of exercise is an issue...is not keen on physical exertion...she is quite happy to watch TV and snack’ (Age 12 years)

‘Slow metabolism, muscle tone...unable to sustain long periods of exertion’ (Age 7 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
A number of recent studies have expressed concerns regarding the high prevalence of obesity in individuals with Down syndrome, with research highlighting concerns of obesity elevating risk factors for cardiovascular disease, diabetes and associated mortality in those with intellectual disabilities.\textsuperscript{19-21}

Several factors are thought to contribute to the development of weight problems, including ongoing medical issues, dietary problems and choice of sedentary activity such as watching television. It is thought that both physiological and motivational factors are important when engaging individuals with Down syndrome in physical activity.\textsuperscript{22}

The high numbers of individuals reported by families to be overweight or obese in this survey further highlight the need for specialised, targeted intervention programmes in WA to break the cycle of contributing factors and assist in community engagement and participation.
Functional Abilities

Families with a child with Down syndrome aged over two years were asked to describe their son’s or daughter’s ability on a range of functional tasks related to self care, sphincter control, communication, transfers, mobility, communication and social cognition.

The findings in this section were from parent’s reports of function, as determined by completing a section of the questionnaire known as the Functional Independence Measure for Children (WeeFIM). This evaluative measure has been validated across a range of children, including those with disabilities, and aims to describe consistent, basic performance in daily routines in a common language.23

It has been used previously to assess the function of children and adolescents with Down syndrome in the United States 24 and by the TCHR in WA in 2002.7

In response to our focus groups, we made it a priority to describe in detail the variability in functioning of individuals with Down syndrome within and across age groups.*

Self Care Skills

Self care skills include activities such as dressing of upper and lower body, toileting, eating, grooming and bathing.

Bathing

The majority of individuals (71%, n = 213) were able to safely get into and out of the bath or shower, although nine per cent (n = 27) were described as independent but carers were concerned for their safety.

Approximately half of children and adolescents (52% and 54% respectively) aged between 10 and 17 were independent in the self care activity of bathing; the remainder still requiring either supervision or help to complete this task successfully (Figure 9).

*For each of the areas of the WeeFIM there was some variation in the number of families who answered each question. The percentages reported related to total number of families who answered each question, rather than the total number participating in the study.
The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.

Figure 9: Amount of help required with bathing according to age group.

‘She doesn’t like turning taps on and off...she gets confused about hot and cold’ (Age 18 years)

‘My child began showering independently at the age of 16’ (Age 19 years)

‘Supervision required at all times for safety’ (Age 16 years)

‘He can perform most of the tasks but definitely needs supervision to hurry him along...he would spend hours ...until hot water ran out...in the shower without being reminded to go on to the next task’ (Age 14 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
**Grooming**

Families were asked to comment on their son’s or daughter’s ability to perform activities such as brushing teeth, washing face and hands, and combing or brushing hair.

As expected, for most individuals with Down syndrome it appears their independence in grooming improves as they get older. However, tasks such as cleaning teeth properly, shampooing hair and shaving remain a consistent challenge, requiring supervision and help well into adulthood (Figure 10).

![Figure 10: Amount of help required with grooming according to age group.](image)

‘Only needs prompting to brush teeth properly, all else OK’ (Age 22 years)

‘Needs reminding and only 50/50 does things properly...cannot do some tasks by herself like brushing hair etc’ (Age 18 years)

‘She needs reminding to do these tasks and someone to quality control or she gets slack. For example she developed gum disease because we had stopped checking to make sure that she was doing more than just a cursory flick’ (Age 18 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
**Dressing**

Fairly similar challenges were reported by families whether dressing waist up or waist down, although dressing waist up seems a little easier for most individuals with Down syndrome than dressing waist down. Half of the children aged 10 to 13 years were reported to be independent in putting on a shirt, jacket, dress, jumper or hat.

Although independence increases with age, there remains a small proportion of adolescents and young adults who always require help when dressing. For many families, their child was reported as achieving independence in their dressing waist down skills during their teenage years, however the majority used clothing adaptors such as velcro fastening for shoes and elastic waist bands. For most, the challenges of tying shoelaces and manipulating zips and small buttons on jeans remain too difficult and are not often achieved.

Choosing clothes that were appropriate for the weather conditions was also reported as difficult for some individuals, with parents often being required to ensure suitable clothes choices.

**Eating**

Two-thirds of parents reported their child as being safe, independent eaters (n = 218). Those children who required help were mostly in the younger age groups, although 44 (13%) individuals spread across all age groups were reported as requiring supervision when eating. This was primarily in terms of guiding food choice, controlling overeating, providing assistance in cutting some foods and concern regarding a tendency to choke.
Toileting

Parents were asked to indicate how much help their son or daughter required with toileting, that is, help with wiping after urinating and bowel movement and pulling pants up and down.

For those in the youngest age group under five years only eight families answered this question, so their results were not included.

Approximately half of the children were reported to be independent in toileting in their middle primary school years, however a small proportion of adolescents and young adults appear not to have achieved independence in the functional skill of toileting (Figure 11).

![Figure 11: Amount of help required with toileting according to age group.](image)

By the age of 13 years, two-thirds of individuals were reported to be completely independent in their bladder management. Parents described most ‘accidents’ as being related to times of excitement, resulting in forgetting or waiting too long to go the toilet, and also as a precursor or indicator that the child was becoming unwell. A small proportion of adolescents and young adults were reported as not achieving independence in this particular area of self care (Figure 12).
Just under two-thirds of children aged 10 to 13 years were reported as being independent in bowel management. Some parents reported their child used medication to manage constipation which sometimes resulted in bowel accidents. It was also frequently reported that help was required with wiping after a bowel motion.

‘He rarely has bowel accidents, but isn’t very skilled with toilet paper, in spite of our perseverance. He doesn’t want our interference we respect that...’ (Age 19 years)

‘Needs constant reminding and coaxing and is toilet timed not trained... toileting is my biggest bug bear” (Age 9 years)

‘Completes toileting himself’ (Age 15 years)

‘Help is only very rarely needed...accidents are extremely rare’ (Age 11 years)

‘100% for bladder, 75% for bowel... not good at using toilet paper and flushing’ (Age 10 years)

‘Toileting is a BIG part of our son’s life...because of soiling pants help is needed to clean body and toilet after use...we spend a lot of time in the toilet’ (Age 23 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Social Cognition

Social cognition included aspects of functioning such as social interaction, behaviour, problem solving and memory.

Behaviour

Overall, for those families answering this question, 55% (n = 178) described their child as able to control their behaviour independently most of the time, 23% (n = 74) need supervision to do so in unfamiliar or stressful circumstances, and 22% (n = 71) of individuals were described as always needing help to control behaviour. Behaviour appeared to be most challenging in the five to nine year age group and again in the adolescent years (Figure 13). Behaviour problems most commonly described were connected with aggression and frustration, sometimes through obvious triggers and at other times for no apparent reason.

![Figure 13: Amount of help required to control behaviour according to age group.](image)

‘At school when angry or frustrated he will yell and scream, throw things and try to hit teachers. This happens mostly at school but he does act out when asked to do tasks by his sisters and other adults...rarely throws a tantrum for Mum and Dad’ (Age 13 years)

‘Our son has a variety of behavioural problems biting, attention seeking, self harm, throwing objects, running away etc etc’ (Age 11 years)

‘Wish my other four were as well behaved’ (Age 19 years)

‘I have never seen her angry...stubborn though’ (Age 16 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Social Interaction

Parents were asked to comment on how appropriately their son or daughter deals with everyday social interactions, including taking turns in conversation, playing games by the rules and showing consideration to others.

This particular area of functioning appears to be quite challenging for many individuals with Down syndrome, with just under one-quarter being described by their parents as achieving independent and appropriate social interaction skills.

While these skills appear to improve as an individual grows older, just over 60% of young adults were described as being independent in their social interaction skills (Figure 14).

![Figure 14: Amount of help required with social interaction according to age group.](image)
**Problem Solving**

Parents were asked to indicate how their child dealt with problem solving in everyday life, that is, recognising a problem (e.g. cannot find a particular object) and taking action to try to solve the problem.

Twenty-six per cent (n = 83) of individuals were described as requiring no assistance to adequately solve a problem encountered in their everyday life, 20% (n = 65) require supervision and the remainder were reported as always requiring help (54%, n = 172) (Figure 15).

Parent’s comments related to their son’s or daughter’s problem solving abilities were variable, highlighting the competency of their children in many situations and also the frustration some experience when not being able to sort out a problem or situation.

![Figure 15: Amount of help required with problem solving according to age group.](image)

‘Gives up easily...doesn’t believe he’s capable, needs reassurance or direction’ (Age 23 years)

‘Needs help to deal with problems...likes things to be exactly right and doesn’t like variations’ (Age 19 years)

‘No trouble with remote controls for plasma, DVD, TV, foxtel and playstation...motivation is the key...I can’t watch foxtel if he’s not here’ (Age 19 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Memory

Families were asked to indicate how well their son or daughter remembered recent events, for example, what they did yesterday, a birthday party or holiday.

Forty-three per cent (n = 134) were described as remembering events most of the time, 19% (n = 59) require prompting or reminding to recall a situation and 38% (n = 117) need help all the time to remember or may not recall the event at all (Figure 16).

Parent's comments indicated that it was often difficult to assess their child's memory skills due to their limited verbal communication. In addition, several families commented that they thought their son's or daughter's long term memory was quite good, but that they had difficulties with remembering short term or recent events.

'It's hard to know what is memory and what is difficulty in communication, but will often just say 'yes' to whatever question is asked' (Age 8 years)

'It appears to be very orientated in the immediate present situation, though retains lessons learnt from past experience' (Age 4 years)

'Remembers events but doesn't remember lessons at school i.e. can't read or write or do maths but can cook you eggs on toast from scratch...go figure!' (Age 13 years)

'Has a good long term memory but doesn't understand time...1 week or 1 day' (Age 23 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child's age has been provided.
**New Skills**

Families described how easy it was for their child to learn new skills or routines. Like other areas classified as social cognition functions, families reported at least one-third of adolescents and young adults still required help when learning a new task (Figure 17). Many families described one of the key factors in acquiring a new skill being the individual’s motivation to want to achieve that particular task.

![Figure 17: Amount of help required to learn new skills according to age group.](image)

‘He likes his routine. If it’s a fun thing no problem...if it’s making his bed he protests and tries to walk off or sit down on the job’ (Age 17 years)

‘She continually requires guidance and supervision to learn a new skill’ (Age 14 years)

‘S is not as quick as other kids to pick up new things...she needs things explained more often and more thoroughly or needs more time to practice...there may be some skills she will never pick up...others she will learn eventually’ (Age 12 years)

‘Learning new skills depends on the time you give to teach the task and more importantly whether he wants to learn it. If it is a task he is interested in you have a chance in teaching it but if it is something where there is no initial interest it is really hard’ (Age 11 years)

‘This depends very much on what the skill is and if he is motivated e.g. cannot tie shoelaces despite years of practice but can ride a motorbike change gears’ (Age 20 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Communication

Families were asked to describe how well their son or daughter understands both verbal or non-verbal communication and how well they use expressive language.

Overall, approximately half of the individuals were reported to be independent in their comprehension and expressive communication skills. As expected, the proportion of children and young adults who understood most everyday conversation increased with age, reaching the highest proportions for those aged fourteen years and over, with approximately 60% achieving this maximum level of comprehension (Figure 18). Although an individual’s ability to express themselves improved with age, it was in the high school years where this ability seemed to substantially increase, with 60% (n = 44) of adolescents aged 14 to 17 years being independently able to express their needs (Figure 19).

Development of expressive language appeared to mirror comprehension abilities, although this was not reflected in parents’ qualitative comments, where families reported a general trend for their child to understand more than they are able to express. Similarly, research related to communication abilities in Down syndrome has reported stronger receptive language skills compared to expressive language.7, 25, 26

Figure 18: Amount of help required with comprehension according to age group.

Figure 19: Amount of help required with expressive language according to age group.
**The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.**

‘Limited understandable verbal language but high level of comprehension...dyspraxia is the reason for poor verbal expression...within family and regular contacts expressive language is understood 80% of the time, however, within the community this drops significantly as does confidence’ (Age 23 years)

‘Speech is not clear and often unable to understand’ (Age 19 years)

‘Level of understanding and also desire to communicate is greater than his capacity to do so’ (Age 11 years)

‘S has always had good communication skills...if ever there is an issue with us understanding her it is usually because she speaks too quickly and runs words into each other’ (Age 12 years)

‘He would not understand a deep abstract talk on the radio or at home...things are understood better when broken down into simpler words but his comprehension is better than his expressive language’ (Age 19 years)
Mobility

With regard to the questions asking parents how well their son or daughter was able to walk, crawl, transfer from chair to standing and manage stairs, the majority reported their children were independent in these skills.

Ninety per cent of individuals were described as being able to walk safely and independently, with the only area of concern for some families being that their child required some assistance to negotiate stairs safely.

Other Functional Tasks

Families with a son or daughter aged 12 years or older were asked to comment on their child’s abilities related to a range of other functions, including using the telephone, using public transport, dealing with a range of domestic type duties and managing money.

Using the Telephone

Parents were asked whether their adolescent or young adult could answer the telephone and make telephone calls to both familiar and unfamiliar people. One-third (n = 60) of individuals were described as being able to use the telephone successfully most of the time, 22% (n = 41) needed supervision to use the telephone successfully with unfamiliar people, and 45% (n = 82) needed significant help to use the telephone or did not use it at all (Figure 20).

Figure 20: Amount of help required to use the telephone according to age group.
Parents made a number of comments related to the use of the telephone that repeatedly highlighted similar themes; the limitation that language difficulties places on their child using the telephone, that their son or daughter is likely to answer the telephone but has difficulty making calls, and that many of the adolescents and young adults don’t particularly like using the telephone.

‘His language is a barrier to his using a telephone...although he knows how to dial a number and get his basic message across to family and friends’ (Age 23 years)

‘My daughter loves to use the phone and uses it more than I do...she now wants a mobile phone’ (Age 18 years)

‘Answers phone with no problem but cannot dial numbers to make calls...will talk to friends or family confidently’ (Age 14 years)

‘Our son can answer the phone effectively 100% of the time...he needs verbal prompts to make outgoing calls’ (Age 14 years)

‘She answers phone calls in the correct manner...although most people cannot understand her...she cannot make phone calls’ (Age 11 years)

‘Until recently has refused to use the phone...we have encouraged using the speaker phone and also when family members are away from home we ask to talk to him and he will answer questions...will not initiate conversation, make calls or answer the phone’ (Age 20 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Using Public Transport

Most parents reported their son or daughter required significant help, and had had limited opportunity, to use public transport (Figure 21). For those living in the country, the majority reported there was little public transport available.

However, for families living in the metropolitan area who had a child old enough to use public transport, safety and vulnerability issues were consistently raised as reasons why their son or daughter did not use public transport. Families of some young adults reported their son or daughter successfully used familiar routes on trains or buses after training, but expressed concern about their ability to do so safely in an unfamiliar situation.

Figure 21: Amount of help required to use public transport according to age group.

‘Does not use public transport unless with a friend or family member...safety issues are a concern...use private transport when needed’ (Age 23 years)

‘My daughter goes to work on a train and bus and the same home...she knows the way and doesn’t have any trouble because she has trained to do this...she would have a lot of trouble if there was a strike or breakdown and she had to choose an alternative route home’ (Age 24 years)

‘I am concerned for his safety using public transport because of his friendliness’ (Age 22 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Money and Managing Finances

It appears that managing money and finances is a significant challenge for adolescents and young adults with Down syndrome (Figure 22). The majority were reported as not being able to achieve this task, and parents expressed concern regarding the lack of assistance and training available in this area to both themselves and their young adults.

![Figure 22: Amount of help required with managing money according to age group.](image)

‘Has little concept of the value of money or amounts required for any unfamiliar expense’ (Age 23 years)

‘If given large amounts of money she will spend it unwisely...if given small amounts of money that she knows has to last her then she budgets more wisely’ (Age 20 years)

‘schools program is very frustrating... very dated
...school right in city has no shopping skills offered
...every Wednesday does deposit banking with aid upon my request’ (Age 16 years)

‘Vulnerable to exploitation and cannot save money
...burns a hole in her pocket’ (Age 14 years)

‘Our child has no comprehension of money
...only that you can buy things with money’ (Age 13 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
There is a large body of research that has focused on particular aspects of development in children with Down syndrome, particularly those under five years of age.

There has been less examination of the functional abilities across all ages from a more holistic viewpoint. However a previous TICHR study[7] and one from the US[24] did find children with Down syndrome to be most independent in their mobility and locomotion, and to require most assistance in communication, higher cognitive functions and more complex self care tasks.

One recent report[27] has also described and summarised a range of findings related to functions of memory, motor skills, social development and communication in the early years of life and how they may influence the emergence and development of skills in the adolescent and young adult years.

Families and service providers are referred to this excellent article for suggestions related to areas of focus for intervention and a range of functional outcomes across key areas of development.
Social Relationships and Activities

Families who had children aged four years or older were asked to answer a series of questions related to their child’s friendships and participation in social activities.

Friendships

Recent research has indicated that children and adolescents with Down syndrome are able to form relationships with peers that meet expected criteria for true friendships. In this survey, more than two-thirds of families (n = 265) commented that they felt having Down syndrome had adversely affected the number and quality of the friendships their child has been able to establish. Twenty-eight per cent of families (n = 100) reported that their child had no close friends. There was little difference in the friendship patterns reported for individuals with Down syndrome according to whether they lived in the Perth metropolitan area or rural WA, although girls seemed more likely than boys to have close friends.

![Figure 23: Number of close friends reported for the individual with Down syndrome according to age group.](image)

When looking at the number of friendships reported by families for their son or daughter, children and adolescents in middle primary school and high school seem to struggle the most in terms of having any friendships of substance (Figure 23).

It appears that although adolescents may experience a drop off in friendships upon leaving school, as they move into their early adult years the number of friendships increase, with the pattern changing towards more friendships with other young people with disabilities.

These themes were reinforced by the comments made by families about their child’s friendships.
‘Although he went to a regular school (ESU) and the other boys loved him, he never made any friends who would ring him up and ask if he’d like to go out for a pizza then catch a movie sort of thing. All his social engagements are still organised by me ...as you would do for a young child’ (Age 23 years)

‘Friends disappear as the child gets older because of the intellectual/emotional/social differences. The gap gets bigger as the Down syndrome child gets older’ (Age 20 years)

‘Most of her friends are people who also have a disability, and her capacity to mix with regular girls of her age is impacted by her limited hearing, social development and independence’ (Age 18 years)

‘Although my daughter is very social she doesn’t have any close friends. She has never had friends in her age group except when she was in lower primary when they all just played together...I’m hoping that as she becomes an adult she will make friends. I think the teenage years are a very difficult time for children with Down syndrome’ (Age 18 years)

‘Initiating conversation and interaction and appropriate topics of conversation makes it very difficult for them to interact outside of their familiar or comfort zone. This is definitely an area that should be introduced into all school programs’ (Age 16 years)

‘My son’s friends are mostly other people with Down syndrome now...there has been a gradual shift over the years from having a few friends without Down syndrome to this... later primary school years were particularly difficult as the gap widened. Now he is happiest having fun with others like himself’ (Age 14 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Activities

Families were asked to indicate the amount of time their child spends in a typical week engaged in certain kinds of activities, such as watching TV, reading, using a computer and playing outside games that result in their child sweating.

Watching TV or a video/DVD was the activity that children and young people with Down syndrome would be most likely to spend their time doing in a typical week (Figure 24).

A recent Australian survey found that children aged five to fourteen years spent more time watching television, videos or DVD’s than any other activity; spending an average of twenty hours in the two week reference period engaged in this activity. This is a similar finding for children and adolescents with Down syndrome.

![Figure 24: Amount of time spent in a typical week according to a particular type of activity.](image-url)
Puberty

Studies of adolescent development indicate that children with Down syndrome mature at the same rate and in the same sequence as children without Down syndrome.\textsuperscript{30-32}

For individuals with Down syndrome who were 12 years or older, parents reported that 92% ($n = 157$) had begun to show signs of puberty. The average age that changes were reported to occur was twelve years, with the youngest being eight years and the oldest sixteen years. For the 76 females aged 12 years or older, most (83%) had started having menstrual periods, with the average age of menarche being 12 years. This is similar to the average age of menarche (12 to 13 years) in the general population in developed countries.\textsuperscript{33}

Just over half (57%) of the parents reported that their daughter had problems related to her menstrual cycle and one-third were on medication to help manage their periods. Most of the problems reported by parents that related to their daughter's menstrual periods were described as difficulties with hygiene management, an understanding of what menarche involved and the regularity of managing monthly bleeding.

When parents were asked if they thought there was anything unusual about their child’s sexual development, most (78%) thought this was not the case. However, half of the parents described their son’s or daughter's social or emotional development during puberty as unusual and not what they would have expected (Figure 25).

Reported differences were not more common for one particular gender compared to the other. The types of social and emotional changes related to parents’ perceptions of excessive mood swings, inappropriate sexual behaviour, lack of emotional maturity to manage the physical changes occurring during puberty and their increased vulnerability to sexual abuse.

While some families noted the ‘People First’ program as being of some assistance in helping their child to understand aspects of sexuality and relationships, most commented on the need for more support and information for themselves to assist their teenage son or daughter adequately through this period.

![Figure 25: Reported unusual development during puberty.](image-url)
Key Findings

Some of the key findings from this study related to medical issues, functional abilities, puberty and social relationships include:

- About half of the children in the Down syndrome population were born with congenital heart disease but early surgical intervention means that few children (5%) have ongoing cardiac problems.

- Eye and ear problems were the most common ongoing medical issues, with nearly a third having ongoing ear problems and 60% have ongoing visual problems. The majority of these were not severe but 15% did have ongoing and significant hearing loss.

- Other reported medical conditions affecting a small proportion were thyroid problems (13%), constipation (13%), atlantoaxial instability (4%), leukaemia (2%), epilepsy (2%) and asthma (6%).

- Almost 40% of parents said their son or daughter had a weight management problem and this was more prevalent in young adults 18 years and older. As with the general population, obesity is becoming an increasing issue for individuals with Down syndrome.

- Children and young adults in this study were functionally most independent in their mobility and locomotion, and required the greatest assistance in communication, higher cognitive functions and more complex self care tasks. In addition, families described their adolescents and young adults as having particular challenges in managing money, using public transport and using the telephone.

- The ability to perform functional tasks for this group of individuals with Down syndrome revealed the variation in skill levels across this type of disability. However, it is important to note that while most skills appeared to improve as children got older, a proportion of adolescents and young adults had not achieved independence in a range of self care, cognitive and social interaction abilities. This has significant, and sometimes overlooked, implications for service providers and policy makers.
The quotes are by parents reflecting comments on their child with Down syndrome. The child's age has been provided.

I don’t know that she brings any benefit to the groups that she belongs to anymore than the next participant...but when the Belly dance group perform for the public I believe that she shows the public at large how able a person with Down syndrome can perform next to an average person of her age’ (Age 18 years)

‘One day I will write a book! He contributes to each person’s life to which he comes in contact...tolerance, patience, inspiration to name a few’ (Age 16 years)

‘Educates other children in awareness of special needs children. He is a joy to watch playing soccer and basketball in a normal team like any other child’ (Age 13 years)

‘He helps to make people in the community see that people with Down syndrome are individuals...they can be energetic and they feel and express a range of emotions...his presence helps to dismantle some of the stereotypes’ (Age 9 years)

‘The motorcycle clubs don’t have any other members with disabilities...I has created a positive awareness and respect by his determination and perseverance to achieve. Despite it being much harder for him to learn he has won his division two years running...the members join in his delight in his successes’ (Age 20 years)
The Family

‘It is a long-term, life-long commitment. The future is uncertain as we do not know if he will ever have independence or move away from home. Our life seems to revolve around our child...we must always consider him. In some ways it has made us stronger and more caring as individuals and closer as a family unit. I worry about the long-term prospects and the responsibility his sibling will have when I am no longer here’ (Age 23 years)

“Having a child with a disability has definitely changed the way we live in many ways. We most certainly would have lived a different life, had our daughter been normal. We may have travelled more...I may have entered the workforce...we really don't know. But we are not unhappy with how our life has panned out with our daughter. She is, in fact, a source of great joy to us’ (Age 20 years)

‘Overall, she has enriched and added immensely to our family and we couldn't do without her. Problems to overcome...Yes...but plenty of love, fun, wit, enthusiasm for life, happy anticipation of events and thoughtful helpfulness to share. Many wonderful people we've met in life's journey since our Down syndrome daughter arrived...achievements previously taken for granted are now greatly appreciated’ (Age 19 years)

‘It has made our life a whole lot more interesting. I have experienced pain and grief I didn't know it was possible to bear, yet parts of me have been opened up to surprising and unexpected joy. The people we have met in this journey have been such an inspiration. My faith in God has grown and deepened’ (Age 4 years)

‘Sadness, grief, joy, many mixed emotions...look for blame but no one to blame...no answers, just that this happens...we are proud...we waited for years to have another baby and love the one we've been given’ (Age 6 months)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
This section will give a brief overview of some general demographic characteristics of families completing the questionnaire, findings related to informal supports and health of parents, and the sibling experience.

### Demographic Information

The majority (91%) of families taking part in the study were two-parent families, with nine per cent (lower than the 15% in the WA population overall\(^3^4\)) describing themselves as single-parent families.

Approximately 90% of parents (\(n = 328\)), a slightly higher proportion compared with the WA population overall,\(^3^4\) reported their first language as English, the remaining 10% of families being very culturally diverse, describing first languages spoken at home as Vietnamese, Mandarin, Italian and Macedonian. Ninety per cent of families (\(n = 328\)) reported that their son or daughter with Down syndrome had a health care card. Just over half (\(n = 204\)), a similar proportion to the Australian population overall\(^2^9\), reported they have private health insurance for their child or young adult.

### Work Status

Seventy-nine per cent (\(n = 288\)) of fathers were reported as working either full or part-time with only one per cent (\(n = 4\)) reporting they were not working due to their child’s disability. Forty-seven per cent (\(n = 169\)) of mothers reported they worked either full or part-time, one third described themselves as full-time homemakers (\(n = 114\)) and three per cent (\(n = 10\)) said they were not working due to their child’s disability. The remaining proportions of mothers and fathers were not working for other reasons. Employment levels of fathers and mothers in this study were slightly lower than that for the general population (91% and 62% respectively).\(^2^9\) Not surprisingly, the proportions of women reporting they were in paid employment increased incrementally with the age of their child with Down syndrome (Figure 26).

![Figure 26: Proportions of women reporting working either full or part time according to age group of child with Down syndrome.](image-url)
**Mother's Age at Birth**

The average age of mothers at the time of birth of their child with Down syndrome was 31 years. Two-thirds of women (n = 246) reported being aged under 35 years when they had their child with Down syndrome, with only 10% (n = 36) being 40 years or older (Figure 27). Similar patterns of age of mothers at time of birth of a child with Down syndrome have been reported in recently published data from England and Wales, where 68% of mothers were aged under 35 years and 10% were 40 years or older.35 Previous research describing maternal age distribution in infants born with Down syndrome in WA between 1980 and 1996, showed significant changes in mother’s age at birth over this period, with an increasing proportion of mothers aged 30-34 years and 40 years and older, and a decrease in the proportions aged 25-29 and 35-39 years.4 Further research relating to the impact of pre-natal maternal screening on the birth prevalence of Down syndrome will be important.9

![Figure 27: Average age of mothers at time of birth of their child with Down syndrome.](image)
Family Supports and Health of Parents

Families were asked to indicate how helpful informal support networks had been to their family during the previous three to six months.

For the primary caregivers who answered this section of the questionnaire, their spouse, other children and parents provided them with the most help in caring for their child with Down syndrome. For most families, friends and the larger extended family were not a great source of help on which they could regularly call (Figure 28).

![Figure 28: Parents reports of helpfulness of informal support networks in caring for their child with Down syndrome.](image)

Two of the sections in the survey asked parents to complete a series of questions involving a self-assessment of their mood on a day-to-day basis, and a brief self-assessment of their physical and mental health.

As the majority of parents completing the questionnaire were mothers, it is appropriate to assume that, in essence, these questions and outcomes apply primarily to mothers who have a son or daughter with Down syndrome.

The self-assessment of mood involved the use of the Depression Anxiety Stress Scale (DASS). The DASS is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress.

Parents rated the extent to which they have experienced each state, over the previous week, by using a four point scale.

The scores for each scale depression, anxiety and stress are calculated by summing the scores for the relevant items with higher scores indicating greater depression, anxiety and stress.
Overall, parents of a child with Down syndrome in this study did not report any particular problems with depression, anxiety or stress, with the average scores being well within what is considered to be normal for the general population (Table 1). A small proportion of parents (7%, n = 20), however, indicated severe anxiety, stress levels and depression as determined by the DASS.

However, using the SF-12 Health Survey, which measures the physical and mental health of populations, it was found that mothers described their physical health as better than their mental health.

The average physical health score was similar to the Australian average, but the average mental health score was significantly lower. It appears the mother’s mental health was strongly influenced by child behaviour and caregiving demands.

Mothers caring for children with significant behaviour challenges were more likely to experience higher levels of mental stress, as were mothers who have a child or young adult who requires ongoing help with aspects of everyday functioning and self care (for example, dressing, using the telephone, and social skills and interactions).

These findings are similar to that of other disability research that indicates that the more challenging behaviours that are present and the more dependent the child, the greater the stress levels of the mother.

**Siblings**

Most study families (82%, n = 298) reported having other children in addition to their child with Down syndrome. Nearly three quarters of families (74%, n = 268) thought there have been benefits to their other children because they have a sibling with Down syndrome.

Commonly, parents reported siblings to be more understanding, compassionate, patient and tolerant of difference as a result of living with their brother or sister with a disability.

*Definitely the girls have grown up with an amazing awareness of people less fortunate than themselves...compassion, empathy and understanding’*

*‘They are both very caring individuals who have a lot of patience when dealing with children...they have both learned that if you want to do something you just keep on trying until you get there’*

*‘Not yet...at this time the boys are asking me questions ...why can’t E talk properly, why does E always get her own way etc...in later years I hope they will learn to respect and appreciate all kinds of people, whether they have a disability or not’*

*‘Tolerance, understanding, more appreciative of the gifts that they have been blessed with...our other children are very talented and capable young ladies and I feel that having a sister with Down syndrome has meant that they are less arrogant than they may otherwise have been ...they have a better sense of how it might be for others who are not so blessed as they’*

*‘Open to differences and diversity without judging...capacity to be unselfish and other-orientated...more accepting of our faults and failings...understand unconditional love’*

*The quotes are by parents reflecting comments on siblings of their child with Down syndrome.*
Many families (61%, n = 221) also commented on the disadvantages to siblings in living with a brother or sister with Down syndrome. Themes of receiving less time and attention from parents, having to assume increased responsibilities at an early age, a sense of embarrassment related to their sibling’s behaviour and missing out on usual family holiday time were repeatedly highlighted by parents.

“They have probably had to grow up and be far more responsible than others the same age because they always looked out for her...life was a lot more serious for them...although you want to treat each of your children equally, giving them the same amount of time was impossible...this must have an impact on them”

“No ‘normal’ family time...outings, holidays, parties, normal stuff!!!...too much time spent on my daughter with Down syndrome in comparison to them”

“Less time, money, attention from their parents...embarrassed as 12-13 year olds...have been expected to be responsible for their sister by others...mostly within the school system”

“Holidays were not appropriate...due to routines...sometimes embarrassed when sister’s behaviour was bad in public...as teenagers wouldn’t let friends call at our house”

“Our daughter who is closest in age to our son with Down syndrome has perhaps had to grow up a little too quickly, in that she took on a lot of responsibility for him and felt it was her ‘job’ to protect and look after him”

Contemporary service delivery models in disability are changing and now attempt to address the needs of the whole family. Reflecting this trend, in the last twenty years there has been a number of studies focusing on the impact on siblings of living with a brother or sister with a disability.

Many national and international studies have reported both positive and negative effects on siblings; positive effects being increased compassion, tolerance and understanding for others, while negative effects include increased responsibilities, reduced family recreation and socialisation, restricted time with parents and feelings of embarrassment in front of peers.42-47

Families in WA in 2004 who have a child with Down syndrome have reflected these research findings in their descriptions of the effects on their other children of living with a sibling with a disability.

* The quotes are by parents reflecting comments on siblings of their child with Down syndrome.
**Key Findings**

In terms of their cultural diversity and use of private health insurance families with a child with Down syndrome appear to be similar to most Western Australian families. However fewer mothers and fathers with a child with Down syndrome were in paid employment. There were also less one-parent families in the Down syndrome group than in the general population, although a few parents made poignant comments related to their marriage breakdown as a result of parenting their child with a disability.

Key findings in this section on families include:

- The average age of mothers at the time of birth of their child with Down syndrome was 31 years. Two-thirds of women reported being aged under 35 years when they had their child with Down syndrome, with only 10% being 40 years or older. These findings are similar to those in other developed countries.

- For most parents, the main sources of help and support were their spouse, their other children and their parents. Friends and other members of the extended family were reported to be of little support and assistance on a regular basis.

- Families with a child with Down syndrome described both advantages (reported by 74% of parents) and disadvantages (reported by 61% of parents) for their other children as a result of living with a brother or sister with a disability. Positive effects were reported as increased compassion, tolerance and understanding for others, and negative effects included increased responsibilities, reduced family recreation and socialisation and restricted time with parents.

- Mental but not physical health was poorer in mothers of children with Down syndrome than in the general population. It appeared that mothers of children with significant behaviour challenges were particularly prone to poorer mental health as were mothers of young people who required ongoing help with aspects of everyday functioning and self care. The proportion of mothers with significant anxiety or depression was however low.
‘We designed family home around our disabled daughter’s needs...impacted on lives of her siblings...stress on marriage...socially difficult to entertain in our home...Christmas... rest of our family doesn’t want disabled daughter there...our family feels isolated’ (Age 14 years)

‘Having a child with Down syndrome means we have to make some sacrifices and accommodate S’s special needs. However, all of our children are different and all have their own demands. S probably requires more time and attention than our other children, but not a substantial amount. She is a great person and her contribution to our family is overwhelmingly positive’ (Age 12 years)

‘I feel like I am on the outside looking in...I love her very much but at my age now (50) I would like some time to myself’ (Age 19 years)

‘My life has been affected to the point of despair...my life changed the moment he was born...of course I loved him unconditionally...his birth father didn’t, so we separated when my son was 14 months old. I am finding life harder to cope with as my child gets older and more challenging to care for behaviour-wise. I am scared for the future...I have to accept that I am a carer for the rest of my life’ (Age 8 years)

‘T is a well loved family member, but to be honest life is very stressful’ (Age 8 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
This section of the report focuses on the services available and accessed by families with a child or young adult with Down syndrome, and includes findings related to parents’ impressions and descriptions of school, employment, therapy and respite services, and community recreation. It also highlights parents’ level of satisfaction with medical and therapy services.

**At School**

In WA, families with a child with a disability are entitled to send their child to mainstream school, within either the public or private educational system. Many schools have a special education unit or centre, in which children with a disability may spend part or all of their school day. In addition, there is a small number of publicly funded schools, Education Support Schools, which provide educational opportunities exclusively to children who have a disability.

Of the 363 families participating in the survey, nearly two-thirds (n = 225) reported that their child was attending kindergarten, pre-school or school. Just over three-quarters (n = 172) of these were attending mainstream schools (approximately half attend a special education unit within a mainstream school), 19% (n = 43) were attending education support schools and a few were home-schooled.

Families were asked to indicate what they saw as the benefits and drawbacks of mainstream schooling for children and adolescents with Down syndrome. Common themes emerged that described the benefits in terms of socialisation opportunities for the individual with Down syndrome (particularly in the early primary school years); an opportunity for them to be part of their local community and attend school with their siblings; and the education of peers and the general school community in issues related to disability.

‘Helps most of the mainstream children to be more aware
...open...accepting’ (Age 16 years)

‘Children are with their siblings
...they establish themselves in their community’ (Age 13 years)

‘Socially beneficial for both children with disabilities and without
...learn from their peers’ (Age 9 years)

‘My child is behind academically however is ‘normal’ in other areas...social skills, ability to participate in class activities...she wouldn’t cope at a special school...other children learn so much from having disabled children in their everyday environment, not the least, tolerance’ (Age 6 years)

‘Very good in early years up to mid-primary
...with good support, good teachers, positive attitudes it can be an affirming experience with lots of good modelling and learning’ (Age 14 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Although 72% (n = 163) of families reported that, in general, they thought their son’s or daughter’s educational needs were being met, many families expressed frustration in the inclusive schooling process and described a number of drawbacks to mainstream schooling. By far the most common concern expressed was the lack of knowledge by teachers related to educating children with special needs in a mainstream school, and lack of tolerance and understanding of inclusive policies by educators. In addition, families commented on the tendency for their child to be bullied, isolated and lonely in the mainstream setting particularly in the upper primary and high school years.

A number of families mentioned that the inclusive schooling experience had been a positive one for them, only because they chose a private school rather than a public school for their son’s or daughter’s education.

‘Difficult to maintain as ‘gap’ gets larger in late childhood...emotionally and physically draining for parents if they have to educate and support teachers’ (Age 17 years)

‘Negativity of some principals and lack of enthusiasm by classroom teachers...some regard children with disabilities as ‘too hard’ (Age 14 years)

‘Bullying/ridiculing...little contact with other children with disabilities for long term friendship...peer friendships may not last’ (Age 13 years)

‘The teachers take on a huge extra workload and the classes are not necessarily reduced in size to accommodate special needs children ...this is a systemic issue rather than school based issue but unless addressed seriously there will be much more teacher burn out in the future especially as many schools have special needs students in mainstream’ (Age 11 years)

‘Inclusivity is as good as each individual teacher and the whole school benefits...can be successful...can be disgraceful’ (Age 10 years)

‘Without proper support, good teachers and the right attitude it can be disastrous...even in a very good setting the gap widens from about 10/11 years of age’ (Age 16 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
No Longer at School

Ninety-five (26%) adolescents and young adults were no longer at school. Of these, almost two-thirds (n = 58) were engaged in regular day activities outside of the home that did not include paid employment. These activities were described as attendance at TAFE and being involved in crafts, outings, cooking and bowling as part of Post School Options (PSO) or Alternatives to Employment program*. Just over two-thirds of parents thought their son’s or daughter’s needs were being met under the current day activity arrangements.

‘He loves going to the disco and enjoys the social environment...he looks forward to these activities all week’ (Age 24 years)

‘Current needs being met...but once TAFE is finished for the year then my daughter has a lot of spare time. She will, however, return to TAFE next year’ (Age 20 years)

For the one-third of families who thought their young adult’s needs were not being met, there were common themes of difficulties being engaged in meaningful activity, rather than just ‘babysitting’, and lack of physical activity options.

‘This activity is a blessing but cannot replace meaningful work placement which is not available...frustration at not finding some meaningful work placement is a source of ongoing problems at present’ (Age 23 years)

‘We feel that he needs more physical activity and dietary education’ (Age 20 years)

‘PSO is good if the right person can be found...some carers are happy to take easy options which doesn’t help the person they are supposed to be helping. Often I find my daughter is spending unnecessary money on food and rubbish instead of doing interesting, low cost activities...we need more guidelines...I feel the money each person is granted for PSO could be spent much more wisely’ (Age 20 years)

*Alternatives to employment and post school options programs are funded by the Disability Services Commission in WA and aim to ensure that people with disabilities with high support needs, who require an alternative to paid employment, have access to a range of opportunities to participate in their community.

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Families were asked whether their son or daughter had been in paid employment in the previous 12 months and approximately 70% (n = 65) of individuals were reported as being engaged in some work.

Forty per cent (n = 27) of these young adults had obtained work through employment agencies that specialise in finding work for people with disabilities. A similar number had gained their employment through a school work experience placement and the remainder through family and friends.

Approximately two-thirds of parents reported that their son’s or daughter’s employment needs were being met. However, many parents felt their child’s skills were being underutilised, despite the fact that the individual was happy in the employment placement.

‘He loves going to work and doesn’t enjoy weekends as he can’t work on weekends’ (Age 24 years)

‘My daughter feels very important in her job and customers are continually giving her positive feedback and this makes her feel her role is very worthwhile’ (Age 24 years)

‘Can’t say for sure... feel social interaction she receives at workshop is more than she can expect elsewhere... they at least understand and accept each other without expectations... not my perceived ideal situation but she’s happy there’ (Age 19 years)

‘E is in a business industry (what used to be called a sheltered workshop) and although she enjoys being with the people there she has skills that are not being used... she is underemployed’ (Age 18 years)

For the one-third (n = 21) of parents who felt their young adult’s employment needs were not being met, the key concerns were the limited number of hours available to their son or daughter in open employment, together with long delays in being given the opportunity to try a particular work placement.

‘I works 4 hours a week for job 1... 8 hours a fortnight for job 2... she would love more hours... her employment agency is ineffective and not helpful’ (Age 24 years)

‘Unsure... she seems fairly content but it is frustrating when there is no work on some days and they do nothing... hard to explain to her at times’ (Age 19 years)

‘She is with an employment agency... she studied to be a kitchen hand for three months... it is now nearly six months and they have not offered any work... I have heard that this happens to others’ (Age 20 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Respite Services

Respite services are designed to provide temporary care for individuals with a disability to provide families with a break from the physical and emotional demands of care giving. In WA, there are a number of private and government-funded organisations that provide respite care to families. For the families who answered questions related to respite services, 46% (n = 159) of families indicated that they had received respite care, with only a small proportion (7%, n = 24) indicating they had sought such care but not received a service. The remaining 160 families indicated they had never requested any respite care for their son or daughter. Similar proportions of families reported using in-home respite services and overnight respite placements for their child or young adult (Figure 29).

![Figure 29: Proportion of families reporting using respite services according to type of respite services.](image)

![Figure 30: Proportion of families reporting using respite services according to age group.](image)
The most common sources of in-home respite services were family and friends (26%), followed by a number of different government-funded respite organisations. Similarly, for families reporting using overnight respite services, family and friends (38%) were the most commonly cited source of this service. The largest proportion of families using respite services were those with a son or daughter aged 18 years or older (Figure 30). Approximately two-thirds of families using any form of respite service indicated they contributed to the financial cost of this service.

For families who made comments related to respite services, common themes were the high cost of some respite services; the lack of availability of respite places, particularly if their son or daughter had additional health or behaviour problems; and the sense that their child was not ‘disabled enough’ to justify their use of such a service.

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.

‘Would like to use some respite care...been told difficult to get and Hirschsprung’s makes this more difficult’ (Age 25 years)

‘Don’t feel our need is great enough to request respite even though we may have needed time out’ (Age 23 years)

‘I talked to another mother who receives respite every school holidays from the same organisation...you wonder what you have to do to get the same service’ (Age 17 years)

‘Commonwealth funding withdrawn from local organisation...rates have risen rapidly...no one can afford this new rate!’ (Age 14 years)
Therapy Services

In WA, disability professional services (including physiotherapy, occupational therapy and speech pathology) are provided to children and adolescents with Down syndrome by a number of government-funded agencies. Families can also pay for therapy services by accessing private therapy services throughout the state.

Therapy Services at School

Families were asked whether their child had had therapy at school in the last year. One hundred and twenty-four children and young adults did not attend school. Of the 197 individuals attending school, 147 (75%) were receiving therapy at school. Proportionally, slightly more children living in the Perth metropolitan area (78%) were receiving therapy at school than children living in country areas of WA (65%).

Therapy appears to be more likely to be provided to children with Down syndrome at school in their primary school years. For families who reported that their child received therapy at school, the amount of therapy dropped off significantly during the high school years (Figure 31).

While a few families reported they paid for a therapy service at school, most indicated that the services were provided free by government-funded agencies. However, therapy services were not necessarily provided by a therapist, in fact, more commonly they were provided by a therapy or teacher’s assistant who was implementing a program devised by a therapist.

![Figure 31: Proportion of children receiving therapy at school according to age group.](image)
Speech pathology was the most common type of therapy received followed by occupational therapy and physiotherapy. Children in pre-school, tended to receive therapy from all disciplines. This dropped off dramatically as the children moved through primary school and high school particularly for physiotherapy (Figure 32). Speech pathology was reported to be received throughout most of the primary and high school years.

Most families considered the amount of therapy available for their child to be very inadequate. This was particularly true for families with a child in a mainstream school rather than an education support school.
"M needed more speech therapy...I couldn’t afford private therapy...not enough speech therapists, did the best we could with 1 visit a term" (Age 18 years)

"Thin on the ground...too little to make a difference" (Age 16 years)

"I am so frustrated with therapy services...almost non-existent...my child has had one assessment and a follow up report for the school to refer to...the school is expected to implement any suggestions which is unrealistic" (Age 14 years)

"Therapy services at mainstream school are lacking greatly...if you are lucky you see a therapist once a year" (Age 13 years)

"Generally happy about therapy being included into school classwork and being incorporated into all learning areas...I do believe however that my son needs one on one speech therapy as he is unable to speak and he gets very frustrated with his inability to communicate effectively with people...there is very little feedback from therapists and no follow up programs offered to parents to reinforce skills that are being taught during therapy sessions" (Age 11 years)

"My son is at high school...there is very limited therapy interventions available...It’s pretty hopeless" (Age 14 years)

"The lack of therapy services when your child reaches school age matched my expectations based on other parents experience...haven’t had any physiotherapy for years!" (Age 10 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Therapy Outside of School

Families were asked whether their child had had therapy outside of school in the last year. Of the 335 families who answered this question, 118 (35%) were receiving therapy in the community. Unlike that reported for therapy received in the school setting, similar proportions of children living in the Perth metropolitan area and country WA were receiving therapy in the community.

By far the greatest proportion of children using services in the community were those aged five years or less, and the majority appear to be receiving this service free, either as a home-based service or by attending a hospital outpatient department. The number of families and children accessing community-based services dropped off dramatically as the children moved through school, and this was most noticeable from the middle primary years into adulthood (Figure 33).

Unlike those services received in the school, most families indicated community services were delivered by a trained therapist rather than a therapy or teacher’s assistant. The most common type of therapy received in the community was speech pathology, followed by physiotherapy and occupational therapy.

While there were relatively small numbers of children and young adults over the age of five years accessing community services, the pattern of service usage was quite different for the different age groups.

Figure 33: Proportion of children receiving therapy outside of school according to age group.
Speech pathology tended to be accessed by those using services throughout much of the school years, until dropping off quite dramatically in young adulthood.

In contrast, both physiotherapy and occupational therapy tended to be used less during the middle primary and high school years, but showed a slight increase in usage again during young adulthood (Figure 34).

Figure 34: Proportion of children receiving a particular type of therapy outside of school according to age group.

‘It’s available but at high cost. I am currently working which has enabled me to afford a higher HBF table and as well go to private as TF have nothing for high schoolers at all!!!!!!’ (Age 16 years)

‘We only attend until our HBF rebate runs out...usually after about 6 months for both speech and OT’ (Age 11 years)

‘Therapy sessions/home visits are invaluable at this early stage for my son as progress is constantly monitored and assessed’ (Age 1 year)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Community Recreational Activities

Eighty per cent (n = 236) of families who responded to this question indicated that their child regularly took part in community activities that were not conducted by, or involved contact with, a health professional.

The most common activity was swimming, with approximately one-third (n = 80) of children and young people being involved in this activity. Visits to the park, tenpin bowling, ball sports and dancing were other examples of the more frequently reported community recreational activities. As would be expected, those very young children aged five years and under participated in less community recreational activities than older children and young adults.

The majority of families assisted their child to engage in community activities. While many families were happy with the recreational opportunities available to their son or daughter, some families highlighted ‘barriers’; such as access to transport, the requirement of a carer to assist their child to participate in an activity, and the hesitancy of some mainstream sporting clubs to include people with disability.

Some families also mentioned that, while there were activities for young children and adults, there were significant gaps in availability of recreational activities for young adolescents and older teenagers (Figure 35).

![Figure 35: Proportion of families reporting whether their child's recreational needs are being met according to age group.](image-url)
‘Swimming and gym have been a great source of enjoyment for my daughter. It helps her health and fitness, gives her social contact and the chance to meet friends...and gives her ‘outings’ that she can always look forward to’ (Age 19 years)

‘Bowling and indoor soccer are held at community venues and are groups set up by parents because of the need for activities...swimming is fully integrated into a regular squad...this activity was totally arranged by us and supported by us through involvement in the club and regular discussions with coaching staff’ (Age 14 years)

‘Used a lot of local community mainstream recreation as a young child...but as a young man, as the intellectual and physical gap grew between his peers, it has become more difficult to enter mainstream activities and we now access specialist services’ (Age 17 years)

‘As a young teenager my son is finding it increasingly difficult to be as competitive as his peers. He no longer plays in a basketball team...the basketball association registers whole teams and my son doesn’t have the social network to get together his own team...nor does any group invite him to join a team’ (Age 14 years)

‘To find appropriate and ‘non-transient’ consistent carers are the biggest problem. C needs to become confident and secure with a regular and caring person’ (Age 16 years)

‘Acceptable for inclusion if he has an assistant’ (Age 11 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Parents’ Perceptions of Medical and Therapy Services

Families were asked to evaluate the care they receive from medical practitioners and therapists by answering 20 questions that make up a particular instrument called the ‘Measure of Processes of Care’ (MPOC).47

This evaluation of services measure was developed by researchers from McMaster University in Canada, following extensive consultation and input from parents of children with disabilities, and is based on aspects of care that parents view as important.

It aims to determine how satisfied parents are in relation to five key areas: how they feel about the extent to which they are treated respectfully, treated as partners by health professionals in the care of their child, how co-ordinated the services are they receive, and how satisfied they are with the specific and general information provided to them about their child with a disability.

Families rate each question on a scale from 1-7 to indicate a behaviour occurred to a ‘very great extent’ (7) or ‘not at all’ (1).

The average scores for the five key areas of the MPOC are detailed in Table 2 for both medical and therapy services. Families tended to rate the area of respectful and supportive care the highest, and the provision of general information the lowest.

Overall, families in WA reported being reasonably satisfied with both the medical and therapy services provided to their son or daughter with Down syndrome. Aside from the area of ‘enabling and partnership’, families were more satisfied with therapy services than medical services, with statistically significant differences in average scores across four of the five areas. Interestingly the pattern of overall responses provided by these WA families was similar to that found in other national and international research focusing on parents’ perceptions of services provided to their child with a disability.48-50

Table 2: Average scores for families’ satisfaction within the five areas of the MPOC for medical and therapy services.

<table>
<thead>
<tr>
<th></th>
<th>Medical Services</th>
<th>Therapy Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respectful and supportive care</td>
<td>4.93</td>
<td>5.16</td>
</tr>
<tr>
<td>Enabling and partnership</td>
<td>4.84</td>
<td>4.67</td>
</tr>
<tr>
<td>Co-ordinated care</td>
<td>4.45</td>
<td>4.90</td>
</tr>
<tr>
<td>Provided with specific information</td>
<td>4.01</td>
<td>4.73</td>
</tr>
<tr>
<td>Provided with general information</td>
<td>3.54</td>
<td>3.94</td>
</tr>
</tbody>
</table>
Medical Services

On average, approximately 90 families (25%) did not answer the questions related to satisfaction with medical services, presumably because in the previous 12 months they had not made use of or accessed any medical care for their son or daughter.

For the 20 questions that make up the five key areas of the MPOC, there was a consistent tendency for families with a child in the two oldest age groups (14 to 17 years, and 18 years and older) to rate the way medical practitioners treated them more highly than families who had a child in the younger age groups (Figure 36). For some questions, families living in country areas of WA rated medical services more highly than families living in the Perth metropolitan area (Figure 37).

Figure 36: Responses of families to the question ‘treat you as equal’ according to age group.

Figure 37: Responses of families to the question ‘provide a caring atmosphere rather than just give you information’ according to location in WA.
Parents did not rate the area of co-ordinated and comprehensive care as highly as the areas of respectful care and enabling and partnership. For example, two thirds of the families indicated the needs of their whole child were only looked at to a small or moderate extent (Figure 38).

Figure 38: Responses of families to the question ‘looks at the needs of your whole child’.

Approximately one-third of families consistently used the ‘to a small extent’ category for questions that asked if they were provided with information about the types of services in the community; if there was information available to them in various forms, such as booklets; and if they were given information and advice on how to contact other families. This was also the case for whether families were provided with information about their son’s or daughter’s disability, and this was particularly true for parents with a child in the younger age groups (Figure 39).

Figure 39: Responses of families to the question ‘have information about your child’s disability’ according to age group.
When families were asked to express opinions on doctors, some felt this section was not particularly relevant as they had had little need for medical services in recent years due to the good health of their child or young adult.

For those that did express an opinion on services there appeared to be no middle ground; families were either very happy with services and the way they and their child were treated or extremely dissatisfied.

‘Not really relevant to our family, as C has very little medical intervention now that is not typical for others her age. ‘Doctors are very good treating her as a typical young adult’ (Age 21 years)

‘Currently the majority of services I receive are good...earlier I did not have as much confidence in all aspects of my child’s treatment...people dealing with my child did not have much practical experience’ (Age 13 years)

‘Unchanged ...always feel isolated’ (Age 13 years)

‘I have chosen medical professionals who only give good service...if they don’t I move to another one’ (Age 9 years)

‘Mum has had to help other parents! Organisations don’t help...not much information given...no change in my opinions of medical care’ (Age 7 years)

‘I sometimes feel specialists are not familiar with general medical problems of children with Down syndrome and that some of their views are dated’ (Age 9 months)

‘I find I always do the enquiring/searching for a better quality of life for my daughter, but I am totally alone in my search for names, facilities, and services...the medical profession only provide the referral’ (Age 16 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Therapy Services

Between 40 to 50 per cent of the families participating in the survey did not answer the questions related to satisfaction with therapy services, presumably because in the previous 12 months they had not received or accessed any therapy services for their son or daughter. Most of the families who did not complete this section had children in the 14 to 17 years age group and 18 years and older age group.

For the 20 questions that make up the five key areas of the MPOC, there was a tendency for families with a child in the youngest age group and the oldest age group (less than 5 years and 18 years and older) to rate the way therapists treated them more highly than families who had a child in the other age groups (Figure 40). In general, there was little difference in responses of parents in regard to satisfaction with therapy services according to whether they lived in the Perth metropolitan area or country WA.

Questions in the area of the MPOC that focused on whether parents felt the therapy care of their son or daughter was co-ordinated and comprehensive, generally indicated that they thought this occurs to a moderate to great extent.

The exception was the question related to whether therapists make sure that at least one team member is someone who works with your family over a long period of time. Twenty-seven per cent (n = 56) of families indicated this did not occur at all or did to a small extent, with only 40% (n = 81) commenting that consistency in therapists occurs to a great extent (Figure 41).
Figure 41: Responses of families to the question ‘make sure that at least one team member is someone who works with you and your family over a long period of time’.

Consistently, approximately one-quarter of families used the ‘to a small extent’ category for questions that asked if they were provided with information about their son’s or daughter’s disability; if they were provided with information about the types of services in the community; if there was information available to them in various forms, such as booklets; and if they were given information and advice on how to contact other families. While the pattern of parents with a child in the youngest and oldest age groups being more satisfied with therapy services than families with children in the other age groups was also apparent in this area, the differences between the groups was much less marked than in the other four areas of the MPOC evaluation tool.

Figure 42: Responses of families to the question ‘have information available about your son or daughter’s disability’ according to age group.
Parents’ comments related to therapy services, like medical services, were polarised to those expressing significant satisfaction with services to those expressing extreme dissatisfaction. Most parents who reported being happy with services were receiving early intervention services or private therapy services. The recurring themes related to parent dissatisfaction were the inconsistency and high turnover of therapy staff and the under-resourcing and lack of therapy available, particularly to school-age children and young adults.

‘Overall, lack of funding to provide services especially as the child gets older his needs are seen as less urgent than those with multiple disabilities or those who are younger’ (Age 16 years)

‘We have a fantastic group of people who work closely with S and our family, informing us of absolutely everything as we go’ (Age 7 months)

‘Therapists are great...unfortunately too many kids not enough therapists...this will never change as no government will put enough money into rural WA’ (Age 3 years)

‘If one doesn’t ask one doesn’t receive...how can one ask if one does not know what is needed or available’ (Age 4 years)

‘Very dissatisfied with therapists...but don’t want to say anything for fear of reducing the hours received to nothing’ (Age 4 years)

‘Speech therapy has been our main therapy...we’ve been happy with that...we pay privately and the therapist comes to the school’ (Age 12 years)

‘I have found over the years finding information about services is like a lottery...good luck if you manage to get it’ (Age 22 years)

‘With TF I go to the assessments, as I’m told my child won’t get services if I don’t...I don’t hear from them for the rest of the year’ (Age 17 years)

* The quotes are by parents reflecting comments on their child with Down syndrome. The child’s age has been provided.
Key Findings

Families with a child with Down syndrome appear to have somewhat of a ‘roller coaster’ ride as they access and negotiate community and support services. While policies of inclusion are theoretically in place for children with a disability in WA, in practice, it appears that the ability to access mainstream school placements and the levels of support available vary greatly from school to school. It would also appear that upon leaving school, access to suitable open employment options for young adults is limited. In all aspects of accessing community services, for parents there is a sense of always having to advocate on behalf of their child to achieve the best possible services and options, and a constant feeling of ‘battling the system’. Key findings related to school, employment, therapy and medical services, respite services and community recreation were:

- Three quarters of children with Down syndrome of school age were attending a mainstream school, with approximately half being part of a special education unit within the mainstream school.

- The inclusive school experience for the child with Down syndrome in WA and their family appears to be dependent on the particular school and their willingness to embrace and support a child with a disability. The mainstream school experience can be particularly challenging for children in their upper primary and high school years.

- Two thirds of families with young adults with Down syndrome who were engaged in day activities, rather than paid employment, indicated they thought their son’s or daughter’s needs were being met. For the one-third of families who thought their young adult’s needs were not being met, concerns were related to being engaged in meaningful activity and lack of physical activity options.
• For those young adults engaged in paid employment, two-thirds were said to be satisfied with their options, despite some parents reporting they thought their son’s or daughter’s skills were being underutilised. For the one-third of parents who felt their young adult’s employment needs were not being met, the key issues were the limited number of hours available to their son or daughter in open employment, together with long delays in being given the opportunity to try a particular work placement.

• Just under half of the families participating in the study had made use of respite services, with use of respite care increasing as the child gets older. Access to services was more difficult for families with a child with additional medical needs or challenging behaviours.

• For families receiving therapy services, concerns regarding the limited access to therapy during the school years, particularly the high school years, were repeatedly highlighted.

• The majority of families assisted their son or daughter to engage in community recreational activities, and this was true for both children and young adults. Barriers to accessing community activities included transport, the requirement of a carer to assist their child to participate, and the hesitancy of some mainstream sporting clubs to include people with disability. There appears to be significant gaps in availability of recreational activities for young adolescents and older teenagers.

• Parents reported being reasonably satisfied with the way medical and therapy professionals treated them in relation to respectful and supportive care, however, reported significant frustrations with the lack of information that they received in relation to their child’s specific disability, community supports and parent networking.
‘He has taught us that people with disabilities are just the same as everyone else inside’
(Age 14 years)

“There have been lots of costs...overall, we are a much better family for having J...he may be something of a burden but I don’t think deep down we really see him that way...he is sort of essential to us being who we are...the heart of our family’ (Age 11 years)

‘I think it has affected our philosophy on life...she sets such a good example when it comes to ‘stopping to smell the roses’ (Age 4 years)
References


**Glossary**

Adenoidectomy: is the surgical removal of the adenoids. They may be removed for several reasons, including impaired breathing through the nose and chronic infections or earaches.

Atlantoaxial instability: is characterized by excessive movement at the junction between the atlas (C1) and axis (C2) due to either a bony or ligamentous abnormality.

Cholesteatoma: is a skin growth that occurs in an abnormal location, such as the middle ear behind the eardrum. It is usually due to repeated infection, which causes an ingrowth of the skin of the eardrum.

Eustachian tube: is a tube that links the pharynx to the middle ear.

Hirschsprung’s disease: is a congenital disorder of the colon in which certain nerve cells, known as ganglion cells, are absent, causing chronic constipation.

Hypotonia: is a condition of abnormally low muscle tone.

Myringotomy: is a surgical procedure in which a tiny incision is created in the eardrum, so as to relieve pressure caused by the excessive buildup of fluid, or to drain pus. Myringotomy is often performed as a treatment for otitis media.

Nasopharynx: is the part of the throat that lies behind the nose.

Obstructive sleep apnoea: a sleep disorder characterized by pauses in breathing during sleep.

Oropharynx: is the area of the throat that is at the back of the mouth.

Otitis media: is inflammation of the middle ear, the small space between the ear drum and the inner ear.