

# **Impact of Medical and Technological Advances on Survival Rates of People with Disabilities**

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## **ABSTRACT**

In recent times, the life expectancy of people with disabilities has increased in Australia; however, it is important to ensure that these added years of life are accompanied with improvements in health related quality of life. Medical and technological advances can also benefit people with disabilities and improve their survival and quality of life. To enable people with disabilities to fully utilise the benefits of the advances in medicine and technology, societal attitudes towards people with disabilities needs to change with more equitable medical treatment of people with disabilities. In addition, coordination of health care for people with disabilities is essential to provide appropriate and timely health services. Medical and technological advances in diagnostics and prognostics, surgical intervention, pharmacotherapy and general technology have played an important role in improving the health and quality of life for people with disabilities. Future medical and technological advances hold great promise and are expected to unfold in the next several decades. This report highlights several key issues for people with disabilities in relation to their health and wellbeing, major medical and technological advances that could benefit people with disabilities, ethical considerations in the use of these advances as well as future advances in medicine and technology.

## **1. INTRODUCTION**

In Australia, in recent decades there have been increases in life expectancy for people with disabilities, as well as, for the general population (AIHW, 2007). The expected life with disability has increased from 14.7 years in 1988 to 18.6 years in 2003 for males and from 16.0 years to 20.7 years for females (AIHW, 2006a).

Several studies have identified major risk factors that predict decreased life expectancy of people with disabilities including immobility (Eyman et al., 1990; Hutton & Pharoah, 2006; Plioplys, 2003), assisted feeding (Eyman et al., 1993; Plioplys, 2003), severity of intellectual disability (Bittles et al., 2002; Shavelle et al., 2001), and secondary diseases, disabilities or infections, including heart defects, blindness and epilepsy (Day et al., 2005; Hayes et al., 1997; Hutton, 2006; Patja et al., 2000). In addition, the presence of multiple risk factors increases the overall risk of mortality (Hutton, 2006). Therefore, it is likely that advances that decrease the severity or incidence of these predictors are likely to increase the survivability and life expectancy of people with disabilities.

Advances in medical technology which encompasses all aspects of medicine including devices, pharmaceuticals, surgery and the organisation of medical practice itself has improved the lives of people with disabilities. These advances have added years to life, however, it is important that these added years of life should be accompanied with improvements in health-related quality of life. The World Health Organization (1998) noted that 'adding years to life' is an empty victory without 'adding life to years'. Advances in technology have improved people's independence and social participation. For example, better assistive technologies and advances in electronic and information technology have improved accessibility which has been liberating for many people with disabilities.

## Purpose

The purpose of this report is to explore the impact of medical and technological advances that have made a beneficial contribution to the life expectancy and quality of life of people with disabilities. This report focuses on disabilities with aetiology during early and mid lifespan and includes cerebral palsy, multiple sclerosis, epilepsy, Autism Spectrum Disorders, spina bifida and Down syndrome. Key issues and trends contributing to increased life expectancy are presented in this report. The major medical and technological areas covered in this report include advances in: diagnostics and prognostics; surgical interventions; pharmacotherapy; and general technology. In addition, ethical considerations in the use of technology and medical advances along with medical and technological developments that hold promise for the future are discussed.

## 2. KEY TRENDS AND ISSUES

In Western Australia, 68,409 people reported a need for core activity assistance (ABS, 2007). Of these, 31,664 (46%) were 64 years and under and 36,745 (54%) were 65 years and over. The life expectancy of Western Australians with disabilities has increased and with increases in life expectancy and an ageing population, the number and types of health services required will be affected placing high demands for health care.

### 2.1 Increase in life expectancy of people with disabilities

Studies on life expectancy for people with disabilities in Australia showed gains in life expectancy were accompanied by an increase in expected years of life with disability or a severe or profound limitation (AIHW, 2006b). The expected life with disability for males increased from 14.7 years in 1988 to 18.6 years in 2003 and from 16.0 years to 20.7 years for females. Furthermore, the expected years of life with severe or profound core activity limitation increased from 3.2 years to 5.4 years for males and from 6.0 years to 8.3 years for females as illustrated in Figures 1 and 2 below (AIHW, 2006b).

Fig 1: Life expectancy with disability

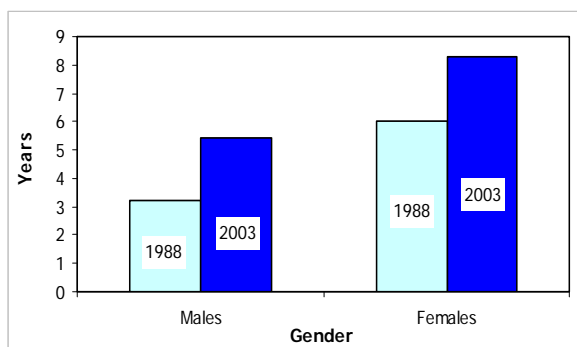
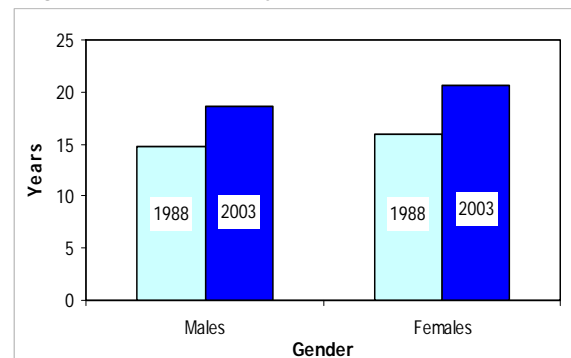


Fig 2: Life expectancy with severe or profound limitation



The changing survival of children with Down syndrome over the past 50 years presents a good example of the increase in life expectancy for people with Down syndrome. Glasson et al. (2002) found that the life expectancy of 1,332 people with Down syndrome in Western Australia between 1953 and 2000 was 58.6 years and 25% lived to 62.9 years. In other words, the past 50 years the life expectancy of people with

Down syndrome has increased by 0.94 life years per calendar year to a median life expectancy of 60 years compared with an increase of 0.22 life years per calendar year in the general population of Australia during the same period (Bittles & Glasson, 2004). The increase in survival indicates that the life expectancy of people with Down syndrome is approaching that of the general population (Glasson et al., 2002). Furthermore, it has been studied that survival rates for the first year of life have improved from below 60% in 1940-1950 birth cohorts, up to 80% in 1950-1970 birth cohorts, and over 90% in 1980 birth cohorts (Bell et al., 1989; Fabia & Drolette, 1970; McGrother & Marshall, 1990; Thase, 1982). Strauss et al. (2007) found that children with severe disabilities and in adults requiring gastrostomy feeding, mortality rates fell 3.4% per year for the 20 years between 1983 and 2002. This upward trend in life expectancy is noted for cerebral palsy, spina bifida, intellectual disability and neurological diseases (Hemming et al., 2006; Oakeshott & Hunt, 2003; Patja et al., 2000; Plioplys, 2003).

Technological and medical advances have resulted in increased survival of people with disabilities. However, in some cases, these advances have led to increased rates of disability. For example, advances in perinatal care have resulted in increased survival rates for extremely low birth weight infants. Associated with improved survival rates for immature infants could result in increased rates of disability and poor quality of life for the survivors (Wilson-Costello, 2007) which need to be addressed.

## **2.2 Ageing of people with disabilities**

In Australia, the proportion of people ageing with a lifelong disability is rapidly increasing (Bigby, 2002; AIHW, 2006a). The number of people over the age of 60 years with lifelong developmental delays is expected to double by 2030 (cited in Barnhart & Connolly, 2007). The beginning of ageing for some people with disabilities is earlier than the general population. Studies in the US have shown that the beginning of ageing for people with developmental disability takes places when the individual is in the mid – to late 40 years or early to mid-50 years of age (Janicki & Wisniewski, 1995, cited in AIHW, 2000). Premature ageing has been consistently reported in people with Down syndrome and intellectual disability resulting from other chromosomal causes (Janicki & Wisniewski, 1995 and Suttie, 1995, cited in AIHW, 2000). Ageing people with Down syndrome are more likely to have hearing and vision impairments, hypothyroidism, musculoskeletal problems and congenital heart disease (AIHW, 2006a). Health care systems need to be capable of responding to the changing needs of this population as it ages. Gaps in policy and provision of service across sectors such as aged care and disability need to be filled and resourcing should be geared to facility ageing in place (Bigby, 2002).

### **2.3 Earlier onset of disease**

There is evidence to show that there is earlier onset and higher incidence of disease for some people with disabilities. For example, studies have shown earlier onset and higher incidence of Alzheimer's disease in people with Down syndrome (Bigby, 1998). Likewise, it was noted that some people with intellectual disability may acquire dementia much earlier in life at round 50 years. Glasson et al. (2002) noted that the increase in survival is accompanied by significant mid-life health problems. Between 38 – 78% of people with Down syndrome have hearing loss and the identification and treatment of hearing loss is a major part of medical management of people with Down syndrome (Roizen et al., 1993; Dahle & McCollister, 1988; Balkany et al., 1979).

### **2.4 Cultural shifts and changes in medical practice**

Advances in medicine and technology over the decades can benefit people with disabilities. For example, increased access to surgical methods for repairing congenital heart defects in children with Down syndrome has occurred in recent decades, resulting in improved survival rates (Leonard et al., 2000). To enable people with disabilities to have access to advances in medicine and technology, a shift in social attitudes towards equitable medical treatment of people with disabilities and overcoming access barriers are important. In addition, changes in medical practice and attitudes are essential for advances in medicine and technology to have maximum impact on people with disabilities. Woolf et al. (2007) noted that it is these social and cultural shifts that drive both the development and accessibility of advanced medical care.

### **2.5 Medical training and best-practice medicine**

Health care practitioners are often ill informed about the health care needs of people with disabilities, and the health related challenges faced by people with disabilities. As a result, people with disabilities do not receive the best treatment available. Furthermore, information about disability medicine and disability should be taught at an undergraduate level to medical and allied health students (Iacono et al., 2004). Best practice guidelines based on trials for various conditions are effective ways of ensuring that the best methods for treatment are kept up to date and individuals have the best chance of receiving the best care available (Myers & Johnson, 2007; White et al., 2007). Evidence-based medicine also serves to focus advances in medical technology via governing medical bodies selectively endorsing those advances and practices that are safe and effective, increasing the chances of maximising benefit and minimising risk to the patient and to re-focus efforts on prevention (Fleisher et al., 1998). A good example of this is the promotion of folate and its fortification in foods. Bower et al. (2007) showed a decline in neural tube defects, anencephaly and spina bifida from 1980 to 2006 in Western Australia (Table 1) which is thought to be due to increased intake of maternal periconceptional folic acid supplements and in foods fortified with folic acid.

Table 1: Numbers and proportions of cases of birth defects by year of birth.

| Defect              | 1980-84<br>Number<br>Proportion* | 1985-89<br>Number<br>Proportion* | 1990-94<br>Number<br>Proportion* | 1995-99<br>Number<br>Proportion* | 2000-04<br>Number<br>Proportion* | 2005<br>Number<br>Proportion* | 2006<br>Number<br>Proportion* |
|---------------------|----------------------------------|----------------------------------|----------------------------------|----------------------------------|----------------------------------|-------------------------------|-------------------------------|
| Neural Tube Defects | 207<br>1.9                       | 238<br>1.9                       | 252<br>2.0                       | 203<br>1.6                       | 182<br>1.5                       | 44<br>1.6                     | 34<br>1.2                     |
| Anencephalus        | 92<br>0.8                        | 111<br>0.9                       | 110<br>0.9                       | 91<br>0.7                        | 79<br>0.6                        | 16<br>0.6                     | 10                            |
| Spina Bifida        | 96<br>0.9                        | 106<br>0.9                       | 116<br>0.9                       | 96<br>0.8                        | 89<br>0.7                        | 23<br>0.9                     | 21<br>0.7                     |

\* Proportions are per 1,000 births and are only calculated if number of cases is greater than 13.

## 2.6 Coordination of health care

There is a need for health services to continue the shift from episodic care targeting acute symptoms to care management over the lifespan of the person with a disability as well as coordination of health care from various health providers. For example, in the case of spina bifida, many medical disciplines are involved in the care of an individual (Dunleavy, 2007). With advances in diagnostics, chronic care of spina bifida can begin prenatally and continue through the lifespan. Early intervention and sustained care can prevent disease sequelae such as kidney failure common if not treated in people with spina bifida (Ahmad & Granitsiotis, 2007; Dik et al., 2006). Sustained care can be further enhanced by multidisciplinary teams, which include generalists, such as a nurse coordinators (Dunleavy, 2007). The coordination of care can also improve the quality of life and experience of care for people with disabilities.

## 2.7 Awareness and accessibility of medical and technological advances

Many people with disabilities may not be aware of medical and technological advances that could help them to live more meaningful lives. In addition, they may not be able to afford to purchase equipment or avail surgery or pharmaceutical advances. For example, assistive technology, particularly the high tech ones are expensive (Shaughnessy et al., cited in Columbus, 2006). Kapperman et al. (2002; cited in Columbus 2006) noted that many students who could potentially benefit from assistive technology were not receiving them. This was mainly attributed to funding, competition and the conservative nature of education (Tinker, 2001 cited in Columbus, 2006).

## 2.8 Specific needs of women with disabilities

Women with disabilities are more likely to develop secondary conditions such as obesity, heart disease, hypertension, type II diabetes, osteoporosis and depression (Piotrowski and Snell, 2007). These women are likely to require the same or more intensive screening protocols as women in the general population. Women with disabilities who are in a wheel chair require special mammography equipment that is not universally available. The barrier of 'invisibility' of health care for women with disabilities needs to be overcome including appropriate support for transition points in the lifespan such as menopause that should not be ignored or de-emphasised in women with disabilities (Piotrowski and Snell, 2007).

## **2.9 Indigenous people with disabilities**

In Western Australia, 2,277 Indigenous Western Australians (4% of Indigenous Western Australians population) reported a need for core activity assistance (ABS, 2007). The life expectancy of Indigenous people in Western Australia is still 16 years less than non-Indigenous people. Indigenous people are known to have less access to services and advances in medicine and technology. The geographic dispersion of the Indigenous population is an important fact in delaying or limiting access to services. Many Indigenous people also experience extreme socio-economic disadvantages that impact on their health and wellbeing. Indigenous people have significantly lower incomes, higher unemployment rates and poorer educational outcomes. There is a need to improve access to services for Indigenous people.

## **2.10 Impact of economic rationalism and decision-making**

Over recent decades, economic rationalist principles have increasingly been applied by successive Australian governments to the health sector and impacted on decision making in terms of service rationing and provision (Germov, 2005). A central tenant of economic rationalist theory is the linkage of limited resources with their most effective utilisation and, market forces can dictate how limited resources will benefit the most people (Walker, 2003). Komesaroff (1999) noted that economic rationalism has seen the shift in decision-making from strategic long term goals to increasing reliance on the market to guide health sector development that is expected to put downward pressure on health costs and shift power balance from providers (doctors) to consumers (patients). The imperative of economic rationalism has been to 'do more with less' which raises concerns of equity and accessibility of service delivery (Leeder, 2003). Competition and economic incentives can lead to over servicing in some areas and under servicing in others (Komesaroff, 1999). The encroachment of commercial interests as a result of privatisation runs the risk that high return services are prioritised over looking after the needs of the elderly, chronically ill and people with disabilities (Brooks, 1999).

## **3. MEDICAL AND TECHNOLOGICAL ADVANCES**

Medical technology can be regarded as the techniques, equipment, drugs, and procedures used by health professionals and the systems in which they are delivered to individuals requiring care (Fleisher et al., 1998; Mechanic, 2002). Technological advances have benefited care and outcomes by improving our understanding of disease mechanisms and the ability to improve diagnostic and therapeutic success (Lundberg & Alexanderson, 2007). These advances also serve to increase the availability of effective therapeutic strategies and even provide cures to ailments that reduce life expectancy or quality of life.



### 3.1 Diagnostics and prognostics

Advances in diagnostics and prognostics are very important in increasing survivability and quality of life of people with disabilities (Cormack et al., 2007). Diagnostics and prognostics increase the chances of early detection of potential conditions that lead to disability and enable preparation both medically and in terms of adjustment for the family for the future needs of the child (Leonard et al., 2000; Strauss et al., 1997). For example, the 'triple screen test' can identify more than three quarters of spina bifida-complicated pregnancies at 16 weeks gestation (Northrup & Volcik, 2000). Maternal serum screening for neural tube defects and foetal aneuploidy (a change in the regular number of chromosomes as in the case of Down syndrome) has become a part of established medical practice and most recent advances have enabled screening to occur in the first trimester rather than later trimesters (Driscoll & Gross, 2008). Positive results of serum tests may recommend subsequent amniocentesis and ultrasonography to confirm diagnosis. Effective and early prenatal diagnosis of complications associated with neural tube defects can dramatically improve life expectancy and quality of life (Northrup & Volcik, 2000). More recently, 4-dimensional imaging using magnetic resonance imaging (MRI) can detect fetal complications such as ventriculomegaly (dilated ventricles) and suggest the need for intrauterine surgery (Hedrick et al., 2003; Lingman, 2005).

Improved diagnostics allow the detection of previously unknown or underlying impairments that would otherwise go untreated and provide the opportunity for developing more appropriate and comprehensive treatment strategies. For example, the aetiology of Autism Spectrum Disorders is poorly understood and diagnosis typically depends on identifying the presence of clinical symptoms such as language difficulties. Electrophysiological assessment (detecting brainwave behaviour in response to target stimuli) in children with Autism Spectrum Disorders can detect problems in central auditory processing that may contribute to language disorders often seen in Autism Spectrum Disorders (Kwon et al., 2007). Interventions that better target underlying problems in central auditory processing stand a good chance at improving language development outcomes. Improved communication skills can have positive outcomes for later life span development (Turner et al., 2006). In another example, patients with autoimmune disease often suffer from interstitial lung disease associated with increased mortality (Fathi et al., 2004). Advances in high-resolution computer topography (CT) have increased the sensitivity of detecting interstitial lung disease over conventional chest radiography (Mayberry et al., 2000) and in clinical practice, CT is important in evaluating the success or otherwise of therapeutic efforts (Wilkes et al., 2005).

The use of MRI permits the detection of brain lesions associated with multiple sclerosis much earlier than in the past and has proven to be a reliable and reproducible technique for studying the disease mechanisms of multiple sclerosis (Arnold & Matthews, 2002; Banwell et al., 2007; Triulzi, 2004). Further advances in MRI techniques such as magnetic resonance spectroscopy can provide information about chemical changes in addition to the structural changes available using conventional MRI (Banwell et al., 2007; Traboulsee, 2004). Given that treatments of multiple sclerosis include immunomodulating or immunosuppressive agents with strong side effects (Prosser et al., 2004), using advanced methods of MRI to monitor treatment response is important for optimising outcome (Arnold & Matthews, 2002; Rovaris & Filippi, 2005). Effective use of MRI reduces the need for repeated invasive biopsies (Lundberg & Alexanderson, 2007). In addition to being non-invasive, MRI provides the added advantage of being able to scan larger areas, whereas biopsies tend to be localised.

Other advantages of advances in prognostics include awareness of vulnerability to secondary diseases and impairments and implementing early screening to avoid development of long-term sequelae of disease progression (Venail et al., 2004). For example, at birth Down syndrome is associated with increased vulnerability to cardiac, gastrointestinal, immunological, respiratory, sensory and orthopaedic problems that can greatly decrease life expectancy and quality of life if not identified and treated (Bittles & Glasson, 2004; Bittles et al., 2007). In 2% of cases, children with Down syndrome have immune system deficiencies leading to diseases that can lead to a host of complications such as laryngitis and bronchitis which can be ameliorated by establishing regular clinical examinations every few months to manage and control infections (Venail et al., 2004).

### **3.2 Surgical Interventions**

Surgical interventions typically use operative manual and instrumental techniques on a patient to investigate and/or treat a pathological condition such as disease or injury, or to help improve bodily function or appearance by invasive means. Many advances in surgical procedures have improved functioning and life expectancies of people with disabilities. There are many examples of surgical procedures that have benefited from medical advances in imaging, techniques and knowledge. Image guided and surgical navigation systems, robotic assistive devices and surgical simulators are all examples of advances that can improve surgical practice and patient outcomes (Chen et al., 2005; DiGioia et al., 1998).

Early childhood survival of people with Down syndrome has shown major improvements mainly due to medical advancement in cardiac surgery, as well as, in general health management (Glasson et al., 2002). Approximately half of the children with Down syndrome are born with congenital heart disease which is now repairable as a result of advances in medical technology. Children with neurological impairments often experience severe feeding problems which can lead to malnutrition and developmental delays (Vernon-Roberts & Sullivan, 2007). The placement of a gastrostomy feeding tube is a preferred method of providing long term sustenance to children when other nutritional therapies have failed and can lead to significant improvements in life expectancy and improved quality of life (Smith et al., 1999). Evidence suggests that gastrostomy tube feeding increases life expectancy over other forms of tube feeding such as nasogastric tube feeding (Plioplys, 2003). One possible reason for this is that nasogastric tube feeding can cause or exacerbate gastroesophageal reflux (GER) more often than gastrostomies (Plioplys, 2003; Vernon-Roberts & Sullivan, 2007). A surgical procedure known as Nissen fundoplication can be used to help young children recover from GER (Hassall, 2005) and there is evidence to show that long-term outcomes can be positive both to the patient and their family (Bourne et al., 2003; Lafullarde et al., 2001). The above example explains how medical advances have increased surgical options for providing assisted feeding and for correcting any negative side-effects such as GER.

Approximately 85% of infants born with spina bifida develop hydrocephalus which is a life threatening condition in which intracranial pressure increases to the point where it can cause brain injury if left untreated (Northrup & Volcik, 2000). Hydrocephalus is treated by insertion of a shunt (a small flexible tube) to provide drainage to the blocked ventricles. Prior to effective shunting for hydrocephalus, the estimated chance of a

child with spina bifida surviving to 12 years was 29%, with most deaths occurring in the first 4 years (Steinbok et al., 1992). In young adult patients with spina bifida and abnormal intracranial pressure, shunt placement can improve neuropsychological functioning, especially verbal and visual memory and attention and cognitive flexibility (Mataró et al., 2000). Advances in intrauterine surgery can close the spina bifida defect while the fetus is still in the womb and reduce the incidence of shunt-dependency (Bruner & Tulipan, 2005; Bruner et al., 2004; Hedrick et al., 2003). Finally, people with disabilities can also benefit from advances in minimally invasive surgical techniques, like treating incontinence (Lorenzo et al., 2007) which can dramatically improve quality of life.

### **3.3 Pharmacotherapy**

Advances in medications that alter biology or functioning have had many beneficial effects on life expectancy and quality of life in people with disabilities. Prenatal steroids have been used in premature deliveries to enhance lung maturity and possibly vascular stability in the brain, reducing the incidence of cerebral palsy as well as avoiding other complications associated with cerebral palsy (Ronan & Gold, 2007). Antispasmodic medications such as diazepam can be used to modulate tone and provide pain relief in children with cerebral palsy (Verrotti et al., 2006). Other medications useful in reducing tone include baclofen, tiagabine, GABA agonists, which inhibit synaptic reflexes of the muscles and can improve range of motion, positioning and quality of life (Chu & Sala, 2006; Verrotti et al., 2006).

Natalizumab, a new class of drugs is recommended for the treatment of multiple sclerosis which has proven to be particularly difficult to treat (Rudick et al., 2007) resulting in improved health related quality of life (Rudick et al., 2007). Older immunosuppressants such as azathioprine continue to be used to slow progression of multiple sclerosis, although adverse events are common and need to be carefully managed when used (La Mantia et al., 2007). Research has also shown that high doses of cyclophosphamide in severe refractory cases of multiple sclerosis can result in disease stabilisation, improved functionality and improved quality of life (Gladstone et al., 2006). Another medication, interferon beta-1a, can improve cognitive function of people with multiple sclerosis as well as reducing relapse rates (Flechter et al., 2007). Finally, injections of botulinum (commonly referred to as botox) can be effective in treating bladder symptoms often common in multiple sclerosis (Kalsi et al., 2007). Botulinum also appears to have utility in treating muscle tone in people with cerebral palsy and produces some benefits in the long term (Ronan & Gold, 2007; Sättilä et al., 2006).

Pharmaceuticals are reported to have some success in treating symptom clusters that appear with many disabilities such as Autism Spectrum Disorders in which case the focus is not on cure but on ameliorating maladaptive behaviours (Erickson et al., 2007; McCarthy, 2007; Palermo & Curatolo, 2004). For example, psychostimulants can be effective in treating hyperactivity and inattention disorders and can assist non-pharmacological interventions such as specialised education (Erickson et al., 2007; Handen et al., 2000). Antipsychotics such as risperidone have also been used to reduce aggression, agitation and repetitive behaviours in children with Autism Spectrum Disorders (McDougle et al., 1998). Serotonin reuptake inhibitors such as fluoxetine and clomipramine are known to reduce repetitive and stereotypic behaviours (McDougle et

al., 2000). In these drugs, the focus is on controlling specific problem behaviours rather than underlying causes or social impairment. One possible exception is donepezil, a drug that has some evidence to suggest that it can improve receptive and expressive language scores and cognitive functioning (Yoo et al., 2007).

### **3.4 General technology**

Advances in general technology can assist people with disabilities by addressing functional limitations that might otherwise reduce or restrict social participation. A range of assistive technologies are available for controlling devices such as television, video and digital video disc (DVD), telephones, doors, lights, appliances and page turners. Access methods include voice control, big buttons, switches and scanning. The robotic assistive wheelchair is an example of assistive technology for people with disability, which is equipped with sensors to detect obstacles and measure the distance to the closest object (Nuttin & Claes, 2007). The Eyegaze system, a direct-select vision-controlled communication and control system, is another example of assistive technology which can perform speech synthesis, lights and appliances control, typing, operating a television and using the mouse and keyboard-controlled computer applications (LC Technologies Inc, 2005) and is useful for people with disabilities.

Assistive technology can also enable people with disabilities to live more independently and to undertake activities of daily life (Yeager et al., 2006) thereby improving their quality of life. Assistive technology is also important in removing barriers to employment and to enable people with disabilities to work more productively (Yeager et al., 2006). Adapted telephone, wheelchairs, magnifiers and adapted computer equipment used by people with disabilities to perform their tasks in the workforce have been shown to improve their productivity and self-esteem (Yeager et al., 2006). For children, assistive devices can improve development, academic performance, quality of life (Henderson et al., 2008) and address specific developmental issues (Jump et al., cited in Rudolph, et al., 2003).

Orthotics have been used for children with cerebral palsy for more than 50 years. Originally they were intended to simply provide antigravity support to weakened extremities and correct posture. Advances in design and studies have led to the understanding that orthotics can also directly modify tone and reflexes, prevent deformities and change resistance to passive stretch (Ronan & Gold, 2007). Prescription of orthotics can lead to significant improvements in gait and reduced energy expenditure, thereby increasing mobility (Balaban et al., 2007; Radtka et al., 2005; White et al., 2002). For example, the use of the myoelectric hand could substitute for the loss of the hand (Jump et al., cited in Rudolph et al., 2003).

## **4. ETHICS AND THE USE OF MEDICAL AND TECHNOLOGICAL ADVANCES**

During the 19<sup>th</sup> and 20<sup>th</sup> centuries, many people with disability were thought to be genetically 'unfit' as they would pass on their 'defects' to future generations and many people with intellectual disabilities were subject to forced sterilisation. These decisions were made not for the best interest of the person concerned but on the perceived interest of parents, carers or society (Gunther & Diekema, 2006). In examining the value and ethics in the use of technology and medical advances, it is important to consider any improved quality of life that will result from these technologies for the person with the disability, their families and carers, as well as, the benefits of these

advances, the potential harm and risks for the person with the disability. Decisions to use technology and medical advances such as genetic screening, hysterectomy, attenuation of growth and cosmetic surgery for people with disabilities should be made after taking into account the ethical considerations.

Predictive genetic testing or genetic screening which involves the use of genetic tests in asymptomatic individuals to determine the risk of developing genetic disorder in the future raises a number of ethical issues for people with disabilities, physicians and policy makers. Ethical questions arise in relation to the process of research, development and marketing of genetic screening tests; use and interpretation by physicians and patients and the use of these results in public health and other policy contexts. Other issues include stigmatisation of individuals and groups, as well as, the potential for genetic discrimination. Discrimination by health insurers is likely wherein the use of predictive genetic testing in setting premiums for life insurance could occur resulting in a 'genetic underclass' (King, 2007).

Sterilisation refers to surgical intervention resulting in the termination of an individual's capacity to reproduce and when performed without the consent of the individual who undergoes the procedure it is referred to as forced sterilisation (Frohman, 2007). Forced sterilisation of people with intellectual disability can be considered as an infringement on human rights as it effectively denies the person present and future enjoyment of their human rights (Frohman, 2007). However, it is important to also consider the potential benefits and risks of this procedure for the person with a disability, as well as, for the family before consenting to the procedure. The example of an 18 year old woman with autism and mild to moderate intellectual disability with severe depression related to menstruation highlights ethical issues that need to be considered in relation to hysterectomy in people with disabilities, particularly young people. In this situation, the severity of the patient's depression, limitations of pharmacological management, inability to medically manage the menstrual bleeding, impact of the patient's behaviour on the care givers, likelihood of pregnancy and inability to raise a family as well as the severe autism were taken into consideration while considering hysterectomy. In general, the management of menstrual problems in people with intellectual disability rarely requires hysterectomy (Skinner et al., 2005).

Growth can be arrested significantly by the use of high-dose estrogen at an early age. This growth-attenuation therapy has been used as a therapeutic option for children with profound developmental disabilities. The potential benefits of this therapy are that it makes it easier for caring for the child as it is easier to move and transfer a smaller person from place to place. This could be argued as an advantage for the carer rather than the child. However, there are several benefits to the child including, the fact that a child who is easier to move will be moved more frequently, receive more stimulation, have fewer medical complications, be taken on family activities and outings, and enjoy more social interaction. Furthermore, there will likely to be more direct and personal contact between the parent and the child without the need for hoisting apparatus and other devices. Growth attenuation could offer parents the opportunity to extend the time they can care for their child at home rather than place them in an institution (Gunther & Diekema, 2006). The only risk identified with this therapy is the risk of thrombosis which does not appear to be excessive. Therefore, it can be argued that growth attenuation in a nonambulatory child with severe developmental disability could benefit the child and the carer. However, in considering the use of growth-attenuation

therapy, it is important to look at the benefits to the child and also the harm it could cause.

Plastic surgery is used to improve facial appearance and also social acceptance of people with Down syndrome. The majority of children with Down syndrome have extra skin at the inner corners of the eyelids, slanting eye openings and a flattened nasal bridge. In other cases, flattened mid-facial region and a downturned lower lip along with a protruding tongue with an open mouth are common. Studies by Olbrisch (1985) have indicated that parents of 300 children who received plastic and aesthetic corrections have indicated a satisfaction of 95% and the children's situation has improved including being less stigmatised and improved social integration. Although this technology has been around for over twenty years, there is not a lot of evidence in favour of the use of plastic surgery with Down syndrome (Leshin, 2000). The procedure involves major surgeries using general anesthesia and long periods of recuperation. The ethical consideration of subjecting a child to cosmetic surgery with no medical benefit before they are able to provide or withhold consent is an important issue to be taken into account while considering cosmetic surgery for children.

## **5. FUTURE ADVANCES**

Several medical and technological developments are expected to unfold in the next several decades to enable people with disabilities to lead more fulfilling lives. Research into the understanding of disease mechanisms is fundamental to developing cures as well as pharmaceuticals.

Research on key molecules associated with neural development during optic nerve regeneration holds promise for guiding the development of future therapies that can restore nerve damage and functional connections in the visual pathway by, amongst other things, increasing plasticity of adult neurons or by recreating developmental expression patterns (Rodger et al., 2006; Symonds et al., 2007; Thomas et al., 2007).

Stem cell research and cell therapy have potential for providing effective new treatments for a wide range of disorders including epilepsy, neurodegenerative disorders and autoimmune conditions such as multiple sclerosis (Goldman & Windrem, 2006; Shetty & Hattiangady, 2007). The potential lies in the ability for regenerative medicine and tissue repair, potentially overcoming the inability of humans to naturally heal the nervous system. There have been some early successes in the use of cell therapy wherein people who have received cell therapy show modest improvement (Walczak & Bulte, 2007) and in the case of a patient with spinal cord injury, some improvements in sensation and movement was observed (Kang et al., 2005). However, it is not clear if these improvements were spontaneous recovery and, therefore, more research is needed to determine this. Controlling or inhibiting gene expression is another technique with promise as it can be used to target genes responsible for the appearance and progression of specific diseases, in this way the genetic expression of diseases would be prevented, effectively masking the disease (Kofschoten & Regazzi, 2007).

Other advances with potential include various methods of stimulation such as electrical and magnetic of the central and peripheral nervous systems to ameliorate symptoms

and improve functional performance (Fregni & Pascual-Leone, 2007; Glinsky et al., 2007; Normann, 2007).

## **6. CONCLUSION**

Medical advances have resulted in increased survival of people who in the past would have had an increase probability of dying. Advances in one field often improve health advances in other areas. For example, improved diagnostics has the flow on benefit of identifying the needs of a person with disability and guiding treatment strategies that are optimal for the individual. The improved care and increasing life span witnessed in the absence (or rarity) of curative treatments subsequently means that for many people, living with a disability is a long term prospect. Social and health systems need to cater for people with disabilities and be sensitive to their long term needs and take into account patient care and long term outcomes. The benefits of medical and technological advances for the person with the disability, as well as, the potential harm and risks should be considered in examining the value and ethics in the use of these advances. Action is required to reduce the inequalities in accessing service for people with disabilities. Improvements of databases and registries are important to monitor and evaluate progress or the lack thereof. Furthermore, research on understanding disabilities and disorders, as well as, future advances in medicine and technology hold great promise for improving the quality of life and survival of people with disabilities.

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