SUPPORT AND SERVICES ACROSS THE LIFESPAN FOR INDIVIDUALS WITH VISUAL IMPAIRMENTS IN THE UNITED STATES, AUSTRALIA, AND SWEDEN: A COMPARATIVE ANALYSIS

by

KATHERINE A. TAYLOR

(Under the Direction of DAVID L. GAST)

ABSTRACT

People with visual impairment may face severely limited opportunities for employment, independent living, and social/community involvement. This paper investigates the policies, procedures, and legislation within the United States, Australia, and Sweden that impact their citizens with visual impairments, to determine how these measures affect this population in terms of educational, vocational, medical, social, and emotional well-being. These countries' practices are then compared and contrasted with each other, so that the more successful measures may be identified and considered for implementation on a wider scale. This could lead to an improved quality of life for people with visual impairments, as well as help to reduce the widespread fear and misunderstanding (and the resultant discriminatory practices and attitudes) that this population continues to experience.

INDEX WORDS: United States/America(n), U.S., Australia(n), Sweden/Swedish, disability/disabilities, policy/policies, vision/visual impairments, agency/agencies, legislation, support(s), and service(s).

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DEDICATION

I wish to dedicate this thesis to my parents, Ron and Maril Yeske, for their tireless support and encouragement. They have always urged me to pursue my goals, no matter how lofty they seemed to anyone else, and never let me use my visual impairment as an excuse to get out of working hard. The high work ethic and belief in myself that they instilled in me are gifts that I know will continue to help me for the rest of my life. Words cannot adequately express my love and gratitude.

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CHAPTER 1

INTRODUCTION

Research has indicated that for the general public in the United States (U.S.), loss of vision trails only cancer and AIDS on the list of most-feared medical conditions (National Federation of the Blind, 2011a). This dread and misunderstanding is not limited to this country, however, which has led to needless neglect and suffering for this population worldwide: as of 2002, the World Health Organization estimated that only 5 to 10 percent of the people with visual impairments worldwide ever access disability support or services (Pollard, Simpson, Lamoureux, & Keeffe, 2003).

However, certain countries have implemented extensive support and services to help people with visual impairment live productive lives as fully participating members of society, while simultaneously helping the general public gain a better understanding of this disability. This paper provides an overview of the assistance and opportunities offered to individuals of all ages with visual impairments in three politically, geographically, and socially diverse nations: the U.S., Australia, and Sweden. This overview compares and contrasts each country's varied policies and procedures in terms of how these measures affect citizens with visual disabilities' educational, vocational, medical, social, and emotional well-being.

Unless otherwise specified, the described supports and services are available to all persons with disabilities in each country; consequently, the terms "disability policy" and "people with a disability" are used unless a specific reference to "visual impairment" is made. Additionally, for the sake of brevity, this paper most often refers to "visual impairments," which covers the entire spectrum of legal blindness (as defined by each country, as outlined in the following chapters), and which refers to conditions that cannot be corrected to the point where they are no longer considered disabling. Individuals who are legally blind may actually have a fairly wide range of visual acuity, from varying degrees of "low vision" through "blindness," where there is no measurable vision at all.

United States

As a superpower, the U.S. holds a unique position, in terms of its ability to influence other countries' social policies. As Koh (2003) argues,

> "the most important respect in which the United States has been genuinely exceptional…[is] in its *exceptional global leadership and activism*. To this day, the United States remains the only superpower capable, and at times willing, to commit real resources and make real sacrifices to build, sustain, and drive an international system committed to international law, democracy, and the promotion of human rights. Experience teaches that when the United States leads on human rights, from Nuremberg to Kosovo, other countries follow" (p. 1487).

Further, according to Nye (2009), the U.S.'s actions toward its citizens, especially those who are more vulnerable, constitute a "soft power" that can influence the ways in which other countries approach solutions to their own social issues. Nye defines a country's "soft power" (as opposed to "hard power" such as military action) as "its culture (when it is pleasing to others), its values (when they are attractive and consistently practiced), and its policies (when they are seen as inclusive and legitimate" (Nye, "Combining Hard and Soft Power," para. 5, 2009). This paper investigates whether or not U.S. policies and procedures indicate that such high standards are truly applicable to U.S. citizens who are visually impaired, especially because even the

Americans with Disabilities Act (1990), one of the country’s most important pieces of disability legislation, expresses doubt about good outcomes for people with disabilities, even as it confirms the national sense of worldwide leadership and influence:

> “[C]ensus data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally… [T]he continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous…” (Section 12101).

Unfortunately, despite being founded on such conceptions of equality and freedom for all citizens, discrimination and devaluation toward people with disabilities have been the norm in the U.S. for much of its history. The first U.S. social policies aimed at helping people with disabilities were instituted during the Industrial Revolution of the mid nineteenth century; this was when the importance of education for everyone, not just the economically advantaged, was being realized; however, at this stage, it was still the case that any child who had a visual impairment or other issue preventing him or her from learning in the same way as the majority was considered “feebleminded,” regardless of the nature of the limiting condition (Pfeiffer, 1993, p. 724). In response, children with disabilities were almost always placed in special boarding schools: even as recently as 1970, only 1 in 5 children with disabilities were educated in “mainstream” U.S. schools (U.S. Office of Special Education Programs, 2005). Children with visual impairments were taught to do simple manual tasks such as broom-making and other tedious employment “skills,” and when they reached the age of majority, they were usually shifted to large, government-run institutions for adults, where they were essentially condemned to lives of isolation and deprivation (U.S. Office of Special Education Programs, 2005). This woeful situation endured well into the twentieth century, though there were occasional bursts of progress; for instance, Pfeiffer (1993) described how World War II veterans who had become disabled strongly objected to being relegated to such a marginal position in society, and how their grassroots activism and increasing public awareness led to the foundation of such national advocacy organizations as the National Federation of the Blind (established in 1940) (National Federation of the Blind, 2011b). Finally, in the 1960s, deinstitutionalization became the new trend (National Council on Independent Living, 2006), and by the 1970s, the first legislation intended to eradicate discriminatory and isolating practices against people with disabilities were promulgated (notably, the Vocational Rehabilitation Act of 1973, as well as the Education for All Handicapped Children Act of 1975, which was later codified as the Individuals with Disabilities Education Act); these laws, and other landmark legislation, will be described in more detail in the following chapters.

In a detailed 2007 report, Prevent Blindness America, the largest nonprofit organization dedicated to raising awareness about vision loss in the U.S., conducted an economic impact study in which it found that "The annual cost of adult vision problems in the U.S. comes to approximately $51.4 billion," composed of the following estimated costs: Direct medical costs ($16.2 million), other direct costs ($11.2 million), lost productivity ($8.0 million), medical care expenditures ($5.12 million), informal care costs ($360,000), and health utility costs ($10.5 million) (Prevent Blindness America, 2007, p. 3). In fact, visual impairments are so common in the U.S. (though most may be corrected with contact lenses or eyeglasses, or through surgery) that more than 150 million U.S. residents are estimated to spend more than $15 billion annually to purchase corrective eyewear (Prevent Blindness America, 2008). Unfortunately, there are still many visual impairments that are not amenable to such correction, so there is still a great need for continued research to help these individuals to receive the kind of “human rights” that the U.S. claims to offer all of its citizens and which, per above, are additionally meant to positively influence other nations’ policies and procedures.

Australia

Like the U.S., Australia is a Westernized nation (Word IQ, 2010) with a predominantly English-speaking population (English Speaking Countries.org, n.d.). Another similarity between the U.S. and Australia is their geographic size: According to The Encyclopedia of the Nations (2011a), Australia encompasses 2,967,892 square miles, and is approximately the same size as the continental U.S. (though the total U.S. geographic size, at 3,537, 438 square miles, is much larger than Australia) (U.S. Census Bureau, 2011b). However, Australia’s estimated population of 22,447,400 (Australian Bureau of Statistics, 2011b) is much lower than that of the U.S., which was estimated at 307,006,550 in 2009, the latest year for which census data were available (U.S. Census Bureau, 2009). Australia’s vast size, combined with its much lower population, engenders unique questions about the availability and efficacy of service delivery to its citizens with visual impairments. According to the Australian Institute of Health and Welfare (2011), a national agency within the Australian government, 260,326 Australians (under 65 years old) utilized disability support services in 2008-9; of these, 162,513 were residents of major cities, with the other 97,813 recipients living in regional, remote, or unknown areas, where presumably public transportation and access to supports and services is either unavailable or less accessible than in the major cities. Therefore, investigating the Australian model for providing assistance and services to non-city dwelling residents with disabilities may offer valuable guidance about incorporating effective delivery methods for people with visual impairments who reside in rural or remote areas in other nations.

As in the U.S., Australian policy initially focused on institutionalizing individuals with disabilities. However, in contrast to the U.S., Australian policy has shunned a “melting pot” philosophy, and has long endorsed multiculturalism instead, even going so far as to affirm that “Australia’s multicultural composition is at the heart of our national identity and is intrinsic to our history and character” (Department of Immigration and Citizenship, 2011, p. 2). It may be argued that this multiculturalism, with its emphasis on accepting differences among diverse populations, may have led to an easier switch to full inclusion in mainstream society for people with disabilities. O’Brien and Dempsey (2004) attribute this national multicultural, inclusive attitude to Australia’s very high rate of immigration throughout its history, and immigration is still a major force in present-day Australia: the Australian Bureau of Statistics (2011a) reported that in 2010, immigration accounted for 53 percent of the country’s total population growth, and 6 million residents (23 percent of the total population) were foreign born. In such a diverse cultural environment, the majority population cannot completely dominate, and the large number of different groups necessitates accommodation more than assimilation. Also, as in the U.S., the end of World War II provided a catalyst for change, when veterans with disabilities demanded to be included in mainstream Australian society. This resulted in serious examinations of what protections and policies were needed to ensure that all residents would be given equal opportunities to lead productive lives. Of particular note in this time period was the passage of the Social Security Act of 1947, Part VIII of which mandated that veterans with disabilities must receive housing, unemployment, and health benefits, as needed (Parliamentary Library, 2011). This paved the way for all people with disabilities to demand equal treatment, so that by the end of the 1960s, deinstitutionalization for this entire population was underway (Darcy & Taylor, 2009). Specific legislative support for people with disabilities arrived in 1986 with the Disability Services Act (currently known under the 2009 reauthorized title, "National Disability Agreement") and the 1992 Disability Discrimination Act, among others (which will be discussed in the following chapters).

The economic impact on Australia from visual impairments is significant: Taylor, Pezzullo, and Keeffe (2006), citing a study by Vision Australia, a major national non-profit advocacy organization, found that visual impairments cost Australia A$9.85 billion in 2004 (U.S.$10,824,165,000; XE Currency Converter, 2011; note that all further currency conversions use this source). This estimate was calculated both in terms of actual medical costs as well as estimates of "loss of wellbeing" (Taylor, 2006, p. 272). By 2009, another major study (conducted by Access Economics, a leading Australian economic consulting firm) also included both medical and well-being criteria, and found that the cost had risen to A$16.6 billion (U.S.$18,241,740,000) in 2009, a "massive" amount that the authors found "staggering" (Access Economics, 2010, p. 6). As a result, efforts to formulate and implement viable policies regarding visual impairments are now starting to assume a much more prominent place in the Australian government's priorities.

Sweden

While relatively small in terms of estimated population – 9,422,661 as of February 28, 2011 (Statistics Sweden, 2011) and geography (173,731 square miles, per The Encyclopedia of the Nations, 2011b), Sweden "is widely regarded as the most successful Nordic welfare state and its citizens enjoy one of the highest standards of living in the world" (O'Brien & Dempsey, 2004, p. 129).

Sweden has long been prominent in the disability rights movement. Although Sweden has not felt the impact of immigration like the U.S. and Australia – as of 2010, only 14.1 percent of Sweden’s total population was foreign-born (U.S. Department of State, 2011) – this country still has a relatively long history of understanding and acceptance of people who are different from the majority population, such as people with disabilities. In contrast to the U.S. and Australia, Sweden was neutral during both World War I and II, so veterans with disabilities did not play a role in the Swedish disability rights movement. Instead, Sweden’s welfare state, with its ideals of equality for all citizens, has resulted in a large number of well-organized disability groups and associations. Most prominent of all is the highly influential Swedish Disability Federation (*Handikappförbundens samarbetsorgan*, or “HSO”) a federation of autonomous disability advocacy organizations (as of 2011, there are 39 member organizations) that has successfully lobbied for inclusive policies since its inception in 1942 (Swedish Disability Federation, 2011; Swedish Institute, 2011b). While Sweden did institutionalize people with disabilities for much of its history, by the 1950s, Swedish policy had changed to allow people with milder disabilities to live and work in the mainstream society (Guerts, 2011). In 1969, Dr. Bengt Nirje of the Swedish Association for Retarded Children published a groundbreaking article in which he espoused the “normalization principle,” which he defined as “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1969, p. 181). This advocacy for giving people with disabilities the same rights – and responsibilities – as everyone else was a radical concept at the time, and his article quickly garnered worldwide attention. Although his article only specified people with cognitive impairments, it still has become a touchstone for progressive and fair policy formulation for all people with disabilities (Perrin, 1999). As normalization's birthplace, Sweden has embraced its egalitarian ideology, perhaps more so than anywhere else in the world. In recent years, the Social Services Act of 1982 (reauthorized in 2001), the Discrimination Act of 2008 (which combined seven previous laws), and other legislation have had particular impact on the rights and responsibilities of people with disabilities, as will be discussed in the following chapters. This paper examines the services and supports available to Swedish citizens with visual impairments, to determine if there is sufficient evidence to support Sweden's reputation as a world leader in disability rights, and whether or not similar measures should be recommended for implementation elsewhere.

It is difficult to calculate the economic impact of visual impairments on Sweden because such statistics have not been released. However, being a socialistic society with a universal welfare system, Swedish policy endorses "a politics of redistribution," which is "considered absolutely necessary to make parity of participation possible for people with visual impairments" (Hugemark & Roman, 2007, p. 31). To that end, the National Board of Health and Welfare (2009) stated that it strives, via governmental agencies at the national, regional, and local levels, to ensure that people with visual impairments – or any disability – are "guaranteed good health and economic and social stability, and also…enabl[es] the individual to lead an independent life" (p. 113). Backing up these words, the Swedish government has spent the most, percentage-wise, on expenditures for "social protection" out of all of the European Union nations: in 2005 (the latest year for which statistics are available), this amount came to 32 percent of Sweden's GDP (Eurostat Yearbook, 2009). Whether such monetary support should – or could – be replicated in non-socialist countries will be examined, especially in this era of economic uncertainty and recession.

Table 1.1

Country Overview

	U.S.	Australia	Sweden
Population	307,006,550	22,447,400	9,422,661
Geographic size (in square miles)	3,537,438	2,967,892	173,731
Residents with visual impairments	150 million	N/A*	N/A*
Annual cost of visual impairments	$51.4 billion	A$9.85 billion – A$16.6 billion	N/A*

* This information has not been released.

Statement of Purpose and Rationale for Study

Each of the three nations described above incorporates different approaches toward supports and services for citizens with visual impairments. This paper will identify each country's successful measures, so that they might be considered for implementation in countries seeking to employ equitable supports and services for people of all ages with visual impairments.

Review of the Literature

Research reveals no other studies that specifically compare and contrast the support and services at all stages of life for people with visual impairments in the U.S., Australia, and Sweden. The study that came the closest was by O'Brien and Dempsey (2004), which did complete a comparative analysis of employment services for people with disabilities in Australia and Sweden (and Finland), but that study differs from the material covered in this paper in that it did not include analyses of services in the U.S., it addressed disabilities in general instead of specifically targeting visual impairment, and it narrowed its scope to cover only employment issues instead of taking a lifespan-encompassing approach.

While many articles analyze visual impairment issues across several countries, of which one or more of the three chosen countries are included (e.g., Curcic's 2009 study, "Inclusion in PK-12: An International Perspective," which examines practices in the U.S., Australia, and Sweden, as well as 15 other countries), these studies tend to be very brief in addressing each country. Other comparative studies that included the U.S., Australia, or Sweden as the analyzed nations did provide more extensive information, but employed investigative parameters that are very narrow (e.g., these studies focus on only one particular aspect of life, such as employment or senior care options). For example, in 2003, the Organisation for Economic Co-Operation and Development (OECD), an organization that was established in 1961 to help member countries identify effective economic and social policies, published a very detailed (216 pages) report that examined employment and financial security issues for people with disabilities in 19 countries (including the U.S., Australia, and Sweden). Nissen, Sjølie, Jensen, Borch-Johnsen, and Rosenberg (2003) also used a multi-country overview approach; their study did specifically focus on visual impairments, but it only examined their prevalence in people aged 20 to 59 years old in several nations (including the U.S. and Australia, but not Sweden), and the authors did not comment on the potential implications of these prevalence rates for these individuals with impairments, or the societies in which they lived.

While such summative articles are useful for examining particular aspects of these countries' disability policies and procedures – and several of them will be referenced in the relevant chapters of this paper – they do not offer the kind of in-depth investigation that this paper provides. Additionally, the limited number of comparative studies suggests that there is room for more investigation and analysis regarding visual impairment-related policies and procedures in the U.S., Australia, and Sweden, so this paper aims to fill this gap in the literature.

Methods

Criteria for Inclusion/Exclusion

Legislation, government reports, institutional models, service agency policies, and academic studies will be included if they are intended to address disability supports and services, particularly for individuals with visual impairments, for all three countries. Legislation, policies, and methods that have been superseded will be excluded, unless their inclusion will serve to provide an historical context for current laws and procedures. In addition, the articles and other documents included in this study must have been originally published in English, unless a credible official translation is available (i.e., the Swedish federal government provides both Swedish language and English language versions of most of its legislation, reports, press releases, etc.).

Swedish research articles and other information sources that did not have a credible "official" translation available into English were excluded from consideration. This author's lack of Swedish language skills may also have inadvertently led to exclusion of some relevant data, in that this deficiency may have resulted in overlooking links to further potentially relevant information and documentation. Similarly, on occasion this author did encounter references to potentially useful data that was contained in documentation that is unavailable online or through a library; this information was excluded if requests to obtain a "hard copy" of these documents were unanswered and other means of verifying the data in question could not be located. (Please refer to the Limitations section in Chapter 6 for further details about these matters.)

Data Collection

The following descriptors were used to identify studies, legislation, policy statements, websites for agencies and other service providers, and within electronic databases (Educational

Resources Information Center, PsycINFO, and Wilson Web) and Internet search engines: United States/America(n), U.S., Australia(n), Sweden/Swedish, disability/disabilities, policy/policies, vision/visual impairments, agency/agencies, legislation, support(s), and service(s).

Some of the research for this paper was initially conducted from March through July, 2010, for a previous study that this author completed regarding Swedish special education policies and procedures for students with visual impairments. That information was double-checked for its continued relevance and accuracy before including it here. The remainder of the research for this paper was conducted between December, 2010 and September, 2011. While the search terms listed above provided the basic "starting point" for this research, this author found that the documents, legislation, and other information that they produced often led to multiple additional avenues of enquiry. For example, a search for "vision agency Australia" led to the homepage for Vision Australia, a leading national advocacy organization; investigation into this website revealed several subsites that included numerous links to a wide variety of other webpages and information sources that covered topics ranging from childhood diagnosis considerations through elder care issues, among many others. Investigating those sites often resulted in identification of even more potential topics that warranted further examination. In this way, conducting research for this thesis was like peeling an onion: each initial query led to several additional and increasingly in-depth layers of investigation. Each additional topic that was identified for any particular country then necessitated investigation of the same topic in relation to the other two countries under examination, so that comparisons among them would be possible for each subject matter.

Conclusion

People with visual impairments may face severely limited opportunities for employment, independent living, and social/community involvement. However, it is hoped that this paper's findings will further understanding of which policies, procedures, and legislation appear to be the most effective within the U.S., Australia, and Sweden, and which may be worthy of considering for implementation in other countries. Determining which measures are most effective could not only lead to an improved quality of life for people with visual impairments, but it may also help to reduce the widespread fear and misunderstanding (and the resultant discriminatory practices and attitudes) that the general public still may direct at this population.

CHAPTER 2

EARLY CHILDHOOD

If a child is diagnosed with a visual impairment very early in life, as opposed to being noticed only after the child enters the formal school system, then that disability is likely to be quite severe. Therefore, the preschool education that is provided, as well as other assistance that the child and his or her family receive when the child is at such an early age, can have a major beneficial impact. The U.S., Australia, and Sweden each offers supports and services to assist these young children and their families during these crucial early formative years.

United States

Statistics are not compiled regarding the number of U.S. children with disabilities in the newborn though preschool age range. The U.S.-based Centers for Disease Control and Prevention (CDC) does recommend that all babies get tested for various disabling conditions based on the guidelines provided in its Newborn Screening Program, but the CDC does not release statistics about the outcomes of such screenings beyond confirming that “millions” of babies in the U.S. undergo such examinations annually; further, while this program involves checking for “certain genetic, endocrine, and metabolic disorders…and hearing loss,” visual impairment examinations are not included (Centers for Disease Control and Prevention, “Newborn Screening,” para. 1, 2011). Although universal screening by local agencies or governmental offices has been suggested as an ideal means for identifying as many children with visual impairments as possible (President’s Commission on Special Education, 2002), such mass testing is prohibitively expensive and difficult to arrange for a large population of children who are not yet old enough to be legally required to attend school. Additionally, many very young children do not yet have the necessary verbal skills, or ability to remain attentive and compliant throughout a vision test, as needed for reliable results to be obtained (Calonge, 2004).

Despite such obstacles, however, early identification can have a crucial impact on ensuring a better long-term outcome for the child and his or her family (President's Commission on Special Education, 2002), in that implementing interventions as soon as possible can maximize their efficacy. As a result, the American Academy of Pediatrics recommends that children aged from birth through age 3 – 5 years regularly receive screenings that are as thorough as possible (Calonge, 2004).

Preschool Education

Once a child is formally diagnosed as having a visual impairment, there are legislative protections for that child and his or her family. One of the most important pieces of legislation for children with disabilities and their families is the Individuals with Disabilities Education Act (IDEA), which was initially passed in 1990 as the reenactment of the Education for All Handicapped Children Act of 1975, and was reauthorized in 1997 and 2004. This law mandates that early childhood intervention services must be provided, including access to governmental early-intervention educational programs such as Headstart (U.S. Department of Justice, Civil Rights Division, 2006). For preschool students, IDEA further specifies that each child with disabilities must receive a measurable Individual Family Service Plan (IFSP), with a team of parents and professionals who are responsible for creating and implementing it. There is no minimum age for eligibility for IFSP early intervention services, so a child is protected immediately upon receiving an official diagnosis. According to IDEA, Part C, an IFSP must be written that describes the child's current level of ability, and based on this assessment, the plan must identify the evidence-based services and supports needed to help the child further develop these abilities, with special attention to facilitating a successful transition to preschool. The plan must contain specific deadlines and other measurable means of assessing the outcome of services. The plan must receive parental consent before it can be implemented, and it must be reevaluated at a minimum of every six months. The Office of Special Education Programs (OSEP), a division within the U.S. Department of Education, is responsible for monitoring state and agency compliance with IDEA early childhood intervention services, and is charged with improving consistency of service delivery across the states (U.S. Office of Special Education Programs, 2004). To date, no reports have been issued to clarify if this monitoring system has been effective, and if so, to what extent.

Additional Supports and Services

Monetary benefits. If a child receives a diagnosis of a disability, and his or her parents' or guardians' income and resources fall below a specified level, then the child may be eligible to receive monthly Supplemental Security Income (SSI) payments (Social Security Administration, 2011b). The exact payment rate varies by state, and is adjusted yearly. According to the SSA, to qualify for these payments, the child's disability must be either permanent or longstanding in nature, and impose "marked and severe functional limitations" that "very seriously limit [the] child's activities" (Social Security Administration, 2011b, p. 6).

Medical coverage. If a child is found eligible for SSI payments, then most of the time, that child is also qualified to receive Medicaid, which is a health insurance program for people with low income and resources (Social Security Administration, 2011b). Another means of medical coverage is The Children's Health Insurance Program, which assists families with children (with disabilities or not) with paying for such services as prescription drug payments, vision and hearing checkups; this program is available to families who cannot qualify for Medicaid because their income is too high, yet not high enough to reasonably afford private health insurance (Social Security Administration, 2011a).

Childcare. Another important piece of legislation that affects children with visual impairments and their families is the 1990 Americans with Disabilities Act (ADA). Broadly, the ADA mandates that all people with disabilities shall have equal access to any place that is open to the public, and they cannot be excluded because of a disability. Based on this, children with disabilities cannot be barred from public childcare programs (although childcare services run by religious organizations may legally choose not to admit them). Children may only be legally excluded under certain rare circumstances; for instance, a child may be denied admission to a childcare program (or any other such "public accommodation") if his or her inclusion would pose a safety or health risk to themselves or others, or if facilitating this integration would require such major programmatic alterations or steep financial burdens that it would constitute an "undue hardship" for the provider (ADA, 1990). Considering these steep exclusion criteria, it should be difficult for a childcare provider to prove that such radical conditions exist that a child with a visual impairment should be barred from enrolling.

Associational protections. Beyond protecting a child with a disability, Title I of the ADA (1990) also provides employment safeguards for that child's parents and others with whom a relationship has been established. Under this section, anyone who has a relationship with the child – parent or other relative, friend, etc. – cannot be discriminated against because of that relationship. This may affect a very young child with a disability in that his or her parent cannot be denied a job because the potential employer fears that the parent would take off many days from work to attend to the child's needs.

Australia

In 2003, the latest year for which statistics were available, 8.3 percent of all children in Australia (317,900 individuals) had a disability (or about 1 in 12 children), though these statistics were not broken down into disability categories, or reveal how many of these children were in the infant through preschool range (Australian Institute of Health and Welfare, 2006c). However, it is estimated that of the Australians who have a visual impairment, 15 percent lost their sight before they turned four years old (Australian Institute of Health and Welfare, 2006b).

As a means of examining these youngest Australian residents with visual impairments, the Sydney Paediatric Eye Disease Study was undertaken from 2006 through 2009 (results pending as of June 2011), in which 4,000 children residing in the Sydney metropolitan area, ranging in age from six months up to six years old, were examined to determine the prevalence rates and causal factors (Centre for Vision Research, 2011). The Centre for Vision Research, the institute responsible for this study, claims that it is the first one in the world to study such a large number of participants from the population of very young children with visual impairments.

As part of its four-year Eye Health Initiative, the Australian federal government authorized A$13.8 million (U.S.$15,164,820) in research grant funding to investigate several vision-related issues; as part of this initiative, a major study was undertaken to provide recommendations on vision screening for children from 0 – 16 years old (Centre for Community Child Health, 2008). The research report for this study stated that early childhood vision screening, while potentially problematic due to the unreliability of such tests with some children, was still recommended, beginning with neonatal checks, and follow up examinations at three to six months, and again at four years (Centre for Community Child Health, 2008).

Preschool Education

The Disability Discrimination Act (DDA), enacted in 1992, provides preventive and protective mandates against discriminatory practices for all Australians, of any age. It is not just for people with disabilities; this law protects anyone who may face discriminatory practices (i.e., minorities, women, ethic or cultural populations, etc.). It also is not limited to protecting people with physical, sensory, or cognitive impairments; its coverage extends to people with debilitating diseases such as HIV/AIDS and hepatitis, or limiting conditions like back problem or arthritis. However, the DDA does make many specific references to people with disabilities, thus ensuring that they are explicitly entitled to access to all the same things in life as any other Australian citizen. These rights include being granted not just physical access to places like schools and other public areas, but also more intangible things like societal respect and dignity. In fact, the DDA states as one of its main objectives that it is meant "to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community" (DDA, 1992, Section 3).

The DDA is broken down into different categories, to address specific life areas such as education, employment, etc. Within the education section, the law stipulates "Education Standards," which delineate the obligations for equal education access for all children in every preschool and kindergarten, encompassing both public and private schools (Department of Education, Employment and Workplace Relations, 2008b). According to these Education Standards, preschools and kindergartens must consult with the parents of a child with a disability about the proper educational procedures and goals for that child, make "reasonable adjustments" in order to meet those expectations, and forbid any discriminatory or harassing practices within the school. The only exception to following these standards is when the accommodations would constitute an "unjustifiable hardship" (i.e., prohibitively expensive), or when the child's presence would pose health or safety risks to others. According to a project undertaken as part of the Disability Coordination and Regional Disability Liaison Officer Initiative, under the direction of the Department of Education, Employment and Workplace Relations, an education provider alleging that admitting a student with a disability would result in unjustifiable hardship to the institution may be required to provide extensive and detailed proof to support this claim, such as breakdowns of projected expenses, or financial statements or other documentation demonstrating how significant such accommodation/modification expenditures would be for the organization (Department of Education, Employment and Workplace Relations, 2008a). Perhaps because such high levels of proof are required of educational institutions, attempts to identify specific instances where a school successfully claimed an "unjustifiable hardship" exemption to deny access for a preschool-aged child with a visual impairment proved elusive.

Additional Supports and Services

Monetary benefits. Centrelink, the Australian federal government's agency responsible for making benefits payments to eligible citizens, provides a "carer benefit" for parents or guardians of someone (of any age) whose disabilities require "constant care" (Centrelink, 2011c). Centrelink further clarifies that this benefit will only be paid as long as the carer's income or assets do not exceed a minimum level, as designated annually. As of June, 2011, the basic carer payment rates were A$670.90 (U.S.$719.11) every two weeks for a single beneficiary, or A$505.70 (U.S.$542.04) if the carer is a member of a couple (Centrelink, 2011c).

Medical coverage. As in the U.S., Australia has a health care program named "Medicare." However, unlike the U.S. Medicare program, which is limited to people who are 65 years old or older, Australian Medicare is a universal health care system that provides coverage for every Australian citizen, not just the ones whose income and assets fall below a certain level (Department of Human Services, 2011b). This program is particularly important for young children with disabilities because of a new initiative, “Better Start for Children with Disability,” which is effective as of July, 2011, and to which the Federal government has committed, over the next four years, A$122 million (U.S.$130,356,119) to fund early intervention programs, treatments, and therapies from a wide array of medical and therapeutic practitioners (Department of Human Services, 2011a). According to the Department of Human Services (2011a), all children with disabilities under the age of 13 years old are eligible for this program, regardless of their families’ income level, but the services can be extended to age 15 years old if the child began accessing them prior to age 13 years old.

Childcare. Under the DDA’s mandate that all people with disabilities must have equal access to public premises, childcare centers are not allowed to discriminate against children with disabilities, and must make “reasonable adjustments” for these children unless it can be proved that doing so would constitute “unjustifiable hardship,” although it is unlikely that the types of accommodations that children with visual impairments would need could meet this standard (DDA, 1992, Section 5).

Associational protection. Section 7 of the DDA (1992) specifically outlines how people associated with a person with a disability are also protected against discrimination based on that disability. For instance, a parent who must take time off from work to care for a child with a disability cannot be fired or otherwise punished or penalized by an employer.

Sweden

Sweden does not keep track of the specific number of children from infancy through preschool age who have visual impairments. In fact, according to Blohmé and Tornqvist (1997), “Sweden has had no efficient and continuous registration of visually impaired children” (p. 194), and almost 15 years later, this still seems to be the case. However, diagnosing a child with a visual impairment, and subsequent determination of eligibility for interventions at the preschool level, are still considered important, and are conducted by professionals (e.g., ophthalmologists) (Sandberg, Lillvist, Ericsson, Björck-Akesson, & Granlund, 2010) using criteria-based assessments (Hård, A., Siödell, L., Borres, M., Zetterberg, I., & Siöstrand, J., 2002).

Preschool Education

Thanks to the normalization principle of the late 1960s, as described in Chapter 1, and the passage of the Special Service Act of 1968, which mandated that all children – including those with disabilities – have the right to an education (Swedish Institute, 2009), Sweden has increasingly implemented an “inclusive” educational model, wherein the goal is to educate as many students as possible in general education classrooms in their neighborhood schools, as opposed to segregating students into separate schools or classes; this includes the preschool level (European Agency for Development in Special Needs Education, 2009). However, despite these policies, it should be noted that there are actually no Swedish laws that solely address educational services and supports for students with disabilities. In fact, according to the Swedish Institute, a government agency that disseminates information about Swedish culture, education, and other interests, Sweden has no laws at all that specifically deal with people of any age with disabilities (Swedish Institute, 2007). Instead, such matters are included within broader legislation. For example, the Education Act (1985) includes clauses mandating that students with disabilities be granted equality in accessing the same compulsory education as their non-disabled peers. There is also the Discrimination Act (2008), which replaced seven earlier laws under one umbrella law; this legislation is meant to prohibit discrimination based on disability or any other grounds (i.e., sex, ethnic group, age, religion, etc.), and it is enforced by the Equality Ombudsman Agency (Ministry of Health and Social Affairs, 2009). For preschool-age children, this means that they must have equal access to appropriate “educational activities,” “health and medical care,” “social services,” and “social insurance” – to which every Swedish child is entitled, not just those with disabilities (Ministry of Integration and Gender Equality, 2009).

Substantial public preschool is available (consisting of a minimum of 525 instructional hours per school year), which is free and open to all children beginning at one year old (Ministry of Education and Research, 2009). While it is optional, 80 percent of eligible children attend (Sandberg et al., 2010). It is at this stage where most students with visual impairments are formally identified and placed within the general education system, where they are expected to follow the same curriculum as non-disabled classmates, albeit with the aid of instructional modifications as necessary to ensure that they are given ample opportunity to succeed in the general education classroom. If an evaluation indicates that a child would benefit from assistive technology or support services from a local social service agency (i.e., special education consultative services or a personal assistant), this is provided at little or no cost to the child’s family (Sandberg et al., 2010).

If more assistance is needed for a particular preschool student, special education teachers or specialists at local resource centers may advise on formulating and implementing appropriate adaptations, all according to guidelines from Sweden’s National Agency for Special Needs Education and Schools (SPSM - *Specialpedagogiska skolmyndigheten*). This agency, established in 2008 to consolidate several service provision agencies, provides advisory services to educational personnel, as well as student support services and teacher and family training services in four “Resource Centres” it operates across the country, from the preschool level through all subsequent grades (Swedish National Agency for Special Needs Education and Schools, 2008). At the preschool stage, including the child with visual impairments is considered as much a social function as an educational one: students with disabilities learn to interact in typical social situations, while their classmates learn tolerance toward others' differences (European Agency for Development in Special Needs Education, 2009).

Inculcating a sense of self-determination and self-advocacy is considered crucial for Swedish citizens with disabilities, and so attempts are made to begin educating even very young children to learn to make their own decisions and voice them. For instance, the Social Services Act (2001), which provides for equality in "economic and social security, equality of living conditions, [and] active participation in the life of the community" (Chapter 1, Section 1), expressly states that "the child's attitude shall be clarified as far as possible. Allowance shall be made for the child's wishes, having regard to its age and maturity" (Chapter 3, Section 5). In this way, the child will grow into an adult who is comfortable with asking, in an appropriate manner, for needed supports and services.

Additional Supports and Services

Monetary benefits. Social insurance payments known as a "care allowance" can help provide economic security in the event that a family incurs additional expenses specifically due to caring for the needs of a child with a permanent or long-term disability (Ministry of Health and Social Affairs, 2010). For instance, if a very young child with a visual impairment requires assistive technology to navigate typical household activities (e.g., adaptations may be made so that the child can more easily and safely enter and exit a shower or bathtub), then social insurance payments can cover the cost of that equipment. Each individual family's situation is assessed by the Swedish Social Insurance Agency (*Försäkringskassan*), with payments made according to each family's specific needs (Ministry of Health and Social Affairs, 2007c). As of January, 2010, the base annual amount payable for this benefit was SEK 42 400, which was equivalent to U.S.$6,582.52 as of June 24, 2011 (Ministry of Health and Social Affairs, 2010).

Medical coverage. Sweden's universal health care system ensures that every Swedish citizen is entitled to free access to health care at public hospitals; this system is meant to provide "financial security in illness, disability…and for families with young children" (Ministry of Health and Social Affairs, 2008, p. 8). As the Ministry of Health and Social Affairs (2008) explains, the high taxes and employee contributions necessary to run this comprehensive system is considered to be worth it because

> "A universal system has large redistributing elements that level out financial resources and living conditions…and contributes to levelling (sic) out of the incomes of individuals between the various stages of their lives. Universal welfare obviously also provides support for the most vulnerable groups in society" (p. 9).

One additional protection for potentially "vulnerable groups" such as children with disabilities is the cap on medical fees that Sweden enforces: a patient is never required to pay more than SEK 900 (U.S.$143.40) per year, regardless of the individual's health condition or the types of treatment received (Swedish Institute, 2011a).

Childcare. Under the protections of the Discrimination Act (2008), children cannot be denied access to childcare facilities on the basis of their disabilities, and must be treated equally once accepted into a program.

Associational benefits. Parents of a child with a disability may not be discriminated against by their employer because of this relationship; in fact, under the Parental Leave Act (1995), all parents – not just those whose children have disabilities – are entitled to take leave to care for the child as necessary without employer reprisals or adverse effects on wages, promotion, or distribution of work (Swedish Work Environment Authority, 2011).

Discussion

Although the U.S. and Sweden do not compile statistics about the number of young children with visual impairments, and Australia only provides estimates about the size of this population, all three countries subscribe to the theory that early screening and intervention are crucial. However, none of these nations currently mandates that such practices be undertaken, possibly because of the prohibitive costs involved, as well as the high potential for unreliability with such examinations because of the immaturity of the examinees at this young age.

Preschool Education

The U.S., Australia, and Sweden support inclusive educational practices for preschool students with disabilities, except in rare cases when this could cause harm to the child or others (which is quite unlikely in the case of children with visual impairments). Preschool is not mandatory for children in any of these countries, but it is recommended because of beliefs that such early education and intervention are beneficial for students with disabilities.

The U.S. and Australia both provide specific requirements, via legislation, for preschool students with disabilities: IDEA (2004) in the U.S., requiring an IFSP for each preschool student with a disability, and Australia’s DDA (1992), with its Education Standards, which also requires the implementation of measurable early intervention plans. Both countries specify that parental input and approval must be obtained before such educational and interventional measures can be undertaken. In contrast, Sweden’s Discrimination Act (2008) is a broad piece of legislation that requires that children be granted the right to access “educational activities,” including preschool, which is similar to the U.S. ADA legislation requiring equal access to public premises. Sweden does provide for early interventional measures, and support and services to facilitate them, but guidelines are provided through SPSM, not legislation. Further, educational interventions in Sweden are not limited to students with disabilities, but rather are given to any student who appears to need additional support.

Additional Supports and Services

Monetary Benefits. The U.S., Australia, and Sweden all offer potential monetary benefits to families with children with disabilities, but their eligibility requirements and payment methods are dissimilar. The U.S. and Australia both offer payments to families (the SSA's SSI and Centrelink's "carer benefit," respectively), but only if their income and assets fall below a minimum level, while Sweden has no such income test for eligibility. Another difference between these countries is who receives this payment: in the U.S., the payment goes to the child, while Australia and Sweden pay the parents or guardians.

Medical coverage. In the U.S., there is no guaranteed health care coverage for anyone (and in fact, certain medical conditions, such as a severe disability, may make finding an insurance provider difficult or impossible). Australia and Sweden, in contrast, both provide universal health care that guarantees coverage for all citizens regardless of age or condition. The U.S. does help low-income families with children with disabilities by offering Medicaid health coverage, or the Children's Health Insurance Program for higher-income families. Australia, with its Better Start for Children with Disabilities initiative, is the only nation studied here that particularly emphasizes the importance of medical care for its youngest citizens with disabilities.

Childcare. The U.S., Australia, and Sweden all mandate through legislation that children with disabilities must have equal access to childcare facilities – unless, as with preschools, it can be proven that their presence could harm the child or others, which is unlikely for students with visual impairments.

Associational protections. The U.S. (via the ADA, 1990) and Australia (through the DDA, 1992) both provide legislative protections for parents and guardians of children with disabilities, specifying that they cannot be discriminated against by potential or current employers because of their child's condition. This means that they must be allowed to leave work in order to care for their children without fear of reprisals, loss of promotional eligibility, reduced wages, etc. Sweden's Parental Leave Act (1995) also allows parents to leave work as necessary to care for a child without being punished by the employer, but it differs in that it offers this right to all parents, not just parents of children with disabilities.

Table 2.1

Early Childhood Summary

	U.S.	Australia	Sweden
Population with Visual Impairment	N/A*	N/A*	N/A*
Population with Disabilities in General	N/A*	N/A*	N/A*
Relevant Legislation	ADA, IDEA	DDA	Discrimination Act, Education Act, Parental Leave Act, Social Services Act, Special Service Act
Preschool Education	Available for free; no minimum age; IFSP must be provided	Available for free; no minimum age; Education Standards must be upheld	Available for free starting at one year old; accommodations must be provided
Monetary Benefits	SSI payments to the child via parents	Carer benefit payments to parents	Care allowance payments to parents
Medical Coverage	Medicaid (for low income families); The Children’s Health Insurance Program (for higher-income families)	Medicare (universal health care); Better Start for Children with Disability medical/therapeutic programs	Universal health care
Childcare	Available from all public providers unless “undue hardship” for the provider is proven	Available from all public and private providers unless “unjustifiable hardship” for the provider is proven	Available from all public and private providers
Associational Protections	Parents protected by ADA against discrimination because they have a child with a disability	Parents protected by DDA against discrimination because they have a child with a disability	Parents protected by Parental Leave Act against discrimination because they have a child with a disability

* This information has not been released.

CHAPTER 3

ELEMENTARY AND SECONDARY EDUCATION

While children with severe visual impairments have likely already been identified prior to entering the educational system, there will be cases where children with less-severe impairments will be identified after they begin attending primary school. Regardless of when this diagnosis occurs, and even if the condition is correctable to some extent, it may still necessitate supports and services to enable the child to attain the same standard of living as his or her non-disabled peers. For all children with visual impairments, regardless of their etiology or severity, entering the school system marks an important step in embarking on an inclusive lifestyle. The U.S., Australia, and Sweden all have policies and procedures in place to ensure that children with disabilities receive adequate support as they navigate their compulsory education systems and lay the foundations for the rest of their lives.

United States

The U.S. Department of Education reported that in 2007-8, 0.1 percent of all students enrolled in the public educational system were visually impaired, or about 29,000 students nationwide (U.S. Department of Education, National Center for Education Statistics, 2010). This makes visual impairment a low-incidence disability, and as a result, many general education teachers will rarely encounter these students in their classrooms. Despite these odds, educators must still be prepared to welcome these students into their schools, because if a child in their district does have a visual impairment, he or she will likely attend his or her neighborhood school. According to the American Printing House for the Blind (APH), there were 59,355 registered legally blind students in the U.S. in 2009, with only 9 percent of these students attending residential schools for the blind (American Printing House for the Blind, 2009). Of the students in neighborhood schools, it is estimated that 62 percent spent the majority of their school day in general education classes, not pull-out resource rooms or other specialized arrangements (U.S. Department of Education, National Center for Education Statistics, 2011a). While teaching a student with a visual impairment may seem daunting for teachers without special education training, the APH 2009 Annual Report states that only 5,560 (9 percent) of the students who are registered as legally blind use Braille as their primary method of reading (American Printing House for the Blind, 2009), which indicates that accommodations and assistive technology for many of the remaining students with visual impairments are not so specialized, and therefore should not be impracticable for the general education teacher.

Elementary education is mandatory for all children in the U.S.; the maximum beginning age varies by state, with the majority specifying five to seven years old; the elementary school years begin with grade 1 and, depending on the school district, continue on through grades 6, 7, or 8, when the child then transitions to the secondary education level (U.S. Department of Education, National Center for Education Statistics, 2011b). There is no national curriculum; instead, educational standards for grades are left up to each individual state to decide.

In the U.S., the division between elementary school grade levels and secondary school grade levels is rather arbitrary – some school districts may send students to intermediary “middle schools” or “junior high schools,” which can range from grade 6 through grade 9, while other districts switch students directly from elementary school straight into “high school” beginning with grade 9; a common U.S. high school model encompasses grade 9 through grade 12. The age at which students may stop attending school varies by state, but it is typically 16 years old

(U.S. Department of Education, National Center for Education Statistics, 2011b), though students are encouraged not to drop out because in the U.S., most employment prospects require a high school diploma at minimum.

One government-funded study, the National Longitudinal Transition Study-2 (NLTS2), is an ongoing 10-year investigation into the long-term educational impact of disability on 11,000+ students across the U.S., starting in 2000; these students ranged in age from 13 through 16 years old when this study began (Wagner, Newman, Cameto, Garza, & Levine, 2005). In their 2002 NLTS2 report, Wagner et al. stated that 95.1 percent of students with visual impairments graduate with a regular high school diploma, the highest success rate of any of the disability categories included in that study. However, citing the 2008 National Health Interview Survey conducted by the National Center for Health Statistics, the American Federation for the Blind (AFB) reported that 5 million of the 25.2 million Americans over the age of 18 who reported experiencing vision loss or blindness stated that they had obtained “less than a high school diploma” (American Federation for the Blind, 2009a), which means that only about 80 percent of this population graduated from high school, contradicting the NLTS2 results. Further studies will be needed to determine which of these study results more accurately reflects the real situation for people with visual impairments.

To encourage students with disabilities to finish high school and be in a position to undertake post-secondary education or employment, IDEA (2004) mandates that transition services must be provided to these students, beginning no later than 16 years old. These transition services must be included in the student’s IEP, and may include such individualized services as on the job training, assistance with gaining acceptance and ongoing participation in Advanced Placement college-level courses, etc.

Legislation

During the past three decades, the U.S. has implemented several laws that mandate that, with few exceptions, students with disabilities must be included in regular schools, in general education classrooms. Two laws in particular, IDEA (2004), as discussed in Chapter 3, and the No Child Left Behind Act of 2001, are particularly relevant when it comes to educating students with visual impairments at the elementary grade level.

IDEA. First passed in 1990, then reauthorized in 1997 and again in 2004, IDEA mandates that all students with disabilities (as specified in 13 disability categories, of which visual impairment is one) who are between the ages of 3 and 21 years old are entitled to a "free and appropriate" public school education, and be provided with adequate services and supports while they are in elementary and secondary school. One of the most powerful obligations specified in IDEA is its requirement that students with disabilities must be placed in the "least restrictive environment," which means that most students with visual impairments should be included in the general education classroom for most, if not all, instruction.

IDEA (2004) also requires that each child with a disability receive an Individualized Education Program (IEP), drawn up by a team that must include the child's parents/guardians, general education and special education teachers, school personnel such as the school counselor, and other relevant personnel, such as agents from outside service agencies that offer services particular to the child's individual needs. Ideally, the child himself or herself should also be included on this team, and be encouraged to make decisions and lead discussions whenever possible. This IEP must contain detailed descriptions of specific, measurable goals that the school will help the student receive, and designate who at the school or outside agencies will be responsible for ensuring that the student makes progress in achieving each aspect of these goals.

The IEP must be approved by the child's parents or guardians before it may be implemented, and modified at least annually, or more often if deemed appropriate by IEP team members.

No Child Left Behind. In 2001, the U.S. Congress passed into law the Elementary and Secondary Education Act, more commonly known as the No Child Left Behind Act (NCLB). In its statement of purpose, this law states that it is meant "to ensure that all children have a fair, equal, and significant opportunity to obtain a high-quality education and reach, at a minimum, proficiency on challenging State academic achievement standards..." (Elementary and Secondary Education Act, Sec. 1001). NCLB specifically states that students with disabilities must also meet these educative requirements. Schools failing to meet NCLB's criteria face severe federal monetary sanctions, giving schools additional impetus for identifying and implementing valid instructional practices.

Additional Supports and Services

Monetary benefits. SSI benefits, as described in Chapter 2, still apply to children as they progress through the elementary and secondary education levels. The only difference is that some children in secondary school may choose to work after they reach the minimum legal age to do so. This minimum is age is usually 16 years old, although certain exceptions may apply (i.e., younger children may hold such jobs as paper routes or entertainment industry positions) (U.S. Department of Labor, 2009). Working triggers a new set of earnings rules for SSI benefits eligibility. In 2011, children could earn up to $1,000 per month and still receive benefits; if the child is under age 22 years old and is in school (either secondary or postsecondary), then this earnings cap is raised to $1,640 per month or $6,600 per year, whichever threshold is reached first (Social Security Administration, 2011b).

Regardless of whether or not the child is working, SSI may only be paid until the child reaches age 18, the age of majority in the U.S.; after this point, the child's situation will be reviewed to determine whether he or she is eligible to switch to Social Security Disability Insurance (SSDI), which is a benefit paid to adults who were disabled prior to the age of 22 years old (Social Security Administration, 2011b). To be eligible for this benefit, the individual must show that the disability is longstanding or permanent, and manifested before the age of 18 years old. According to the SSA (2011b), SSDI benefits are based on the same earnings cap for the child as was the case for SSI payments to a child in school ($1,640.00 per month, or $6,600.00 annually). Because SSDI is primarily a benefit paid to adults, it will be discussed in greater detail in Chapter 4, which concerns adulthood for people with visual impairments.

Medical coverage. As outlined in Chapter 2, children with disabilities may access medical coverage through Medicaid or the Children's Health Insurance Program, as long as eligibility requirements are met (e.g., officially diagnosed disability, parental income and asset levels) (Social Security Administration, 2011a & 2011b). Both programs specify that coverage may continue until the child reaches 18 years old, at which time he or she will be evaluated for coverage under adult program criteria.

Transportation. Depending on where a student lives, there may be a reduced fare scheme for people with disabilities who use public transportation, or paratransit (door-to-door) service may be available if he or she cannot safely take public transportation independently. Such transportation-related services mainly apply to older students (i.e., high school level) who need to use public transportation or a viable alternative to travel to and from a job site. Under the public accessibility requirements mandated by the ADA (1990), as initially discussed in Chapter 2, public transportation providers may not refuse to offer service to students because of their disabilities; for instance, a student with a guide dog must be allowed to ride the bus or subway, despite any rules against bringing animals onto that transportation system.

Australia

In 2003, 89 percent of children in Australia between the ages of 5 and 14 years old who had disabilities attended their regular neighborhood schools, while 9 percent attended schools specific for their disabilities (Australian Institute of Health and Welfare, 2006c). To date, there have been no published reports indicating how many of these students have visual impairments or other disabilities, or how their enrollment statistics break down across Australia's six states and two territories (Dempsey & Foreman, 2002).

The Australian Federal government holds overarching power over broad educational policy, leaving the states and territories to pass legislation regarding the details of implementation, such as matters of curricula or designating funding for specific purposes, thereby introducing a certain amount of leeway within the regional school systems (Dempsey & Foreman, 2002; Lindsay, 2004).

All Australians must begin attending school by the age of five or six years old, and continue until age 15 or 16 years old, depending on the particular state or territory requirements (Department of Education, Employment, and Workplace Relations, 2011b). Children usually begin their formal education with kindergarten (which is voluntary, though most children attend), followed by 12 years of grade school, called "primary" (usually the first six years of schooling) and "secondary" in the remaining five or six years (Australian Bureau of Statistics, 2007). Unfortunately, to date there have been no statistics released to indicate the graduation rate of students with disabilities from secondary school. At each level, students with disabilities receive

IEPs, here named "Negotiated Curriculum Plans," the contents and terms of which are mandated by each state or territory, not the federal government.

While there are no federal laws mandating transition services for students with disabilities as they go through their secondary education years, the Australian government did spend A$18.3 million (U.S.$20,100,719) in its 2007-8 budget to set up the National Disability Coordination Officer (NDCO) Program (Department of Education, Employment, and Workplace Relations, 2009b). Through the NDCO Program, there are 31 regional representatives who will work on an individual basis with anyone with a documented disability (beginning at age 15 years old) to assist with planning, attaining, and maintaining the individual's personal postsecondary goals, such as commencing postsecondary education or employment; NDCO Officers may also provide advice and assistance to employers and educational institutions that are seeking to improve their accessibility for people with disabilities (Department of Education, Employment, and Workplace Relations, 2009b).

Legislation

DDA. As Dempsey and Foreman (2002) explained, "Australia has tended not to rely on legislation to guarantee an education, or to specify minimum educational standards for students with a disability to the extent that has occurred in the United States" (p. 31), meaning that there are no complex, detail-intensive laws such as would be equivalent to IDEA (2004) or NCLB (2001). However, all of the provisions described in Chapter 3 regarding the DDA (1992), including its Education Standards, still apply to children as they continue through their elementary and secondary grades. Under these standards, a school must not discriminate against students when it comes to deciding who will be enrolled or how admitted students will participate in the classroom (both in terms of curriculum delivery and non-academic support services such as assistive technology provisions); “reasonable adjustments” must be made to enable such inclusion (Disability Standards for Education, 2005). As noted in Chapter 3, an educational institution may be excused from meeting these requirements if it can prove that doing so would impose an “unjustifiable hardship” – but crucially, as Dempsey and Foreman (2002) explain, “this defence is available only in cases that relate to the enrolment of individuals in educational institutions, and not in relation to adjustments to meet the student’s needs that become apparent after enrolment” (p. 32).

Additional Supports and Services

Monetary benefits. The “carer benefit” described in Chapter 2 continues for parents or guardians of children with disabilities as they progress through elementary school, and for much of secondary school. However, once the child turns 16 years old, he or she is no longer eligible for the same benefits scheme as before; instead, a new set of disability monetary benefits will apply under the government’s Disability Support Pension (DSP) system. Under the DSP, a child between the ages of 16 and 18 years old will be considered eligible for monetary benefits if he or she is permanently blind, or if a visual impairment is severe enough to prevent him or her from undertaking employment or job training (Centrelink, 2011c). According to Centrelink (2011c), the government agency responsible for distributing DSPs, qualifying individuals will receive A$322.70 (U.S.$338.77) every 14 days if classified as a dependent, or A$498.70 (U.S.$523.54) every 14 days if classified as independent. Upon reaching 18 years old (but before turning 21 years old), the payment amounts change to A$365.80 (U.S.$384.02) for an individual who is claimed by a parent as a dependent or A$498.70 (U.S.$523.54) for an individual who is either independent or part of a couple.

Another form of monetary assistance that the government provides to young people with disabilities as they transition into adulthood is the “Utilities Allowance,” which is paid every quarter to DSP recipients (without children) until they reach 21 years old; under this benefit, single people are eligible for A$544.00 per year (U.S.$571.09), or A$272.00 (U.S.$285.55) for the eligible member of a couple) (Centrelink, 2011c).

Finally, upon reaching 16 years old, an individual with a disability who is on DSP who also lives in a remote area of Australia (as defined by the tax zone in which the individual lives) is additionally entitled to receive a tax-free “Remote Area Allowance” to help offset the added expenses inherent in living in this type of location. The basic payment rate, distributed every 14 days, is A$18.20 (U.S.$19.11) for a single individual, A$15.60 (U.S.$16.38) for a each member of a couple, and A$7.30 (U.S.$7.66) if the individual is claimed as a dependent (Centrelink, 2011c).

Medical coverage. Medicare’s universal coverage, including the Better Start for Children with Disability program, continues through the elementary and secondary years, as described in Chapter 2 (Department of Human Services, 2011a).

Transportation. After reaching 16 years old, an individual with a disability becomes eligible to receive a “Mobility Allowance” if his or her disability makes it difficult or impossible to safely and efficiently use public transportation (Centrelink, 2011a). To obtain this benefit, the individual must show that he or she must travel in order to get to and from a paid or volunteer job (or to interview for such work). Various conditions, such as the amount of work hours the individual undertakes and other benefits payments, determine the rate at which the Mobility Allowance is paid, ranging from A$83.00 to A$116.20 (U.S.$87.13 – U.S.$121.99) every 14 days (Centrelink, 2011a). Paratransit services or reduced fare schemes may also be available, depending on the individual's location.

Sweden

Unfortunately, there are no data collected on the number of children with visual impairments, or any other kind of disabilities, who are living in Sweden, or how many of these children attend mainstream schools, although the Children's Ombudsman (whose "main duty is to promote the rights and interests of children and young people as set forth in the United Nations Convention on the Rights of the Child") has repeatedly called for such data collection to be undertaken (Children's Ombudsman, 2004; & "About the Ombudsman for Children in Sweden," para. 2, 2011).

Beginning at age 7, all Swedish children must attend 9 years of "compulsory school," which is free if a student attends public school (Swedish Institute, 2009). Children with visual impairments are almost always included in the general education classroom, with services and supports provided on an as-needed basis, with educators and the student's family given much leeway in selecting the exact methodology for identification and assessment procedures, and in deciding what services and supports are best for each individual situation (European Agency for Development in Special Needs Education, 2009). While it is an option to place the student in segregated settings (i.e., receive instruction for a particular class in a resource room), such measures are considered generally discreditable, and should be implemented only after inclusionary practices have been ineffectual (European Agency for Development in Special Needs Education, 2009).

While there can be a wide variety of offerings from one school to the next, and even between what is provided for one student or another (Sandberg et al., 2010), such autonomy is granted with the understanding that all efforts remain focused on helping the student reach the goals enumerated in Sweden's National Curriculum (Swedish Institute, 2009). To help ensure this equality and consistency across schools, municipal and national taxes and government grants monies are distributed according to a precise "equalization system," which grants more or less funding to each district according to a formula so that equality in service is achieved throughout the nation (Ministry of Education and Research, 2009).

After compulsory school, students may attend "upper secondary school" (*gymnasieskolan*), which students normally attend from age 16 to 19 years old; as with compulsory school, this next educational level is offered free of cost to the students and their families. This phase is optional in theory but not in reality; students who drop out of high school often find it extremely difficult to obtain employment (Emanuelsson, 2003). In upper secondary school, as is the case in preschool and compulsory school, students with visual impairments are most frequently placed in general education classrooms. Assistive technology, personal assistance, and other supports and services are provided, at little or no cost to the student, if the student or the family request such continuation, and if educators or agency personnel determine that the need still exists. Upper secondary school consists of two different "tracks": academic or vocational, geared toward preparing the student for postsecondary education or employment, respectively (Emanuelsson, 2003).

Throughout compulsory school, and often continued through upper secondary school, every student with disabilities is given a formal Individualized Educational Plan (IEP), as required under the Compulsory School Ordinance (1998), to specifically outline the student's educational plans, goals, and outcome measures, as devised by the student, his or her parents, and school personnel, and how the student may best reach those goals with proper assistance from educators and relevant agencies (Isaksson, Lindqvist, & Bergström, 2007).

Because the number of students with disabilities in compulsory school or upper secondary school in Sweden is unknown, as stated above, it is impossible to know how many of these students are graduating from secondary school. However, it is officially reported that "the proportion of people who complete high school is slightly higher among those with disabilities than among those without" (Swedish Institute, "Equality in Education," para. 1, 2011b).

There is no Swedish legislation specifically mandating that transition skills training or services must be provided for students with disabilities. However, as students with visual impairments go through the upper secondary school grades, they may access such services through advocacy organizations or municipal agencies, to gain training in either employment or postsecondary educational skills. Because of Sweden's policies emphasizing social inclusion and responsibility for all citizens, even people with severe disabilities are expected to become productive members of society (Ministry of Health and Social Affairs, 2009), underscoring the importance of accessing transitional skills training for this population.

Legislation

<u>The Education Act</u>. The Education Act (1985) states that, as initially described in Chapter 2, all students must have equal access to education, and this continues throughout both the compulsory and upper secondary school years. This Act also mandates that schools must provide supports and services to any students who are struggling with school (not just students with disabilities). Any student who is deemed by educators as needing such assistance is to be provided with an IEP, as outlined above.

Discrimination Act. As detailed in Chapter 2, in Sweden, there is no specific law prohibiting discrimination based on disability. Instead, the Discrimination Act (2008) mandates that all people, of all ages, must be protected against discriminatory practices. For the school-aged child with a visual impairment, this law means that he or she cannot be denied equal access to mainstream educational services and supports.

Additional Supports and Services

Monetary benefits. The “care allowance,” as explained in Chapter 2, may continue as the child with a disability goes through the compulsory school years or until the child turns 19 years old, whichever comes first (Swedish Social Insurance Agency, 2010a).

Medical coverage. Coverage under Sweden’s universal health care system, as described in Chapter 2, continues through the school-age years, regardless of the child’s medical condition or health care needs (Ministry of Health and Social Affairs, 2008).

Transportation service. If a student’s visual impairment is so severe that he or she cannot safely and independently take public transportation, the municipality will provide door-to-door transportation service (usually in a taxi) at the same cost as public transport fares (Ministry of Health and Social Affairs, 2008). Reduced fares for public transportation may also be available in some locations.

Discussion

In general, mandatory schooling systems within the U.S., Australia, and Sweden share many similarities. The required age of matriculation and mandatory number of required years of schooling are comparable for all three countries, with their systems similarly officially divided between younger grade levels and older grade levels. All follow legislatively-mandated curricula, though Sweden implements a national curriculum, while the U.S. and Australia leave this matter up to the states or territories to determine.

However, what is known about the experiences of students with disabilities in these schools, and in particular what happens to children with visual impairments, varies greatly among these three countries. In the U.S, statistics indicate that while the number of students with visual impairments is quite small, the vast majority of these students attend mainstream schools, with the majority of them attending general education classrooms while in those schools. There are no similar data collection reports available for students with visual impairments in Australia or Sweden, although Australia does reportedly include 89 percent of all children with disabilities in mainstream schools. Information about graduation rates for this population is similarly inconclusive or incomplete. In the U.S., Wagner et al. (2005) reported that students with visual impairments have the highest graduation rate of all disabilities categories in the NLTS2 study, but the AFB (2011a) reported a much lower graduation rate for this same population. There is no information available about the graduation rates of these students in Australia or Sweden.

All three profiled countries do provide transitional services for students as they prepare to leave the mandatory educational system; however, the U.S. is the only country in this study that requires such services, starting at age 16 years old, which must be included in the student's IEP (IDEA, 2004). Australia and Sweden do not mandate that transitional services and supports must be provided, but they still do offer these services either in school (Sweden), or outside of school (Australia, through the NDCO Program).

Legislation

The legislative approach to students with disabilities is quite different among these three countries. The U.S. takes a very detailed and exacting approach (via IDEA, 2004; and NCLB, 2001), and students with visual impairments are singled out as one of 13 particular categories of people who must receive very specific support and services. In contrast, Australia and Sweden provide protection for this population through very broad legislation that covers people with disabilities across the lifespan, and there are only general guidelines regarding the educational procedures that must be implemented to ensure equality for students with disabilities; students with visual impairments are not mentioned specifically in any of this legislation.

Additional Supports and Services

Monetary benefits. All three countries continue to provide varying levels of monetary support for children as they proceed through the lower and upper mandatory school years. The U.S. and Australia continue the support programs for which eligibility began in early childhood (SSI and the carer benefit, respectively), but switch children onto different systems – SSDI (U.S.) or DSP (Australia) – in the later childhood years. Australia additionally offers these older children several more monetary allowances in addition to this basic DSP benefit. In Sweden, the monetary benefit is more consistent, with the care allowance for parents/guardians continuing unchanged until adulthood.

Medical coverage. Throughout all the childhood years, all three countries maintain the same health care coverage that was provided during the early ages (Medicaid and Children’s Health Insurance Program in the U.S.; universal health care in Australia and Sweden). The U.S. provisions are based on the child’s disability status, while the Australian and Swedish systems provide care regardless of a child’s medical situation.

Transportation. As children enter their teenaged years and independence becomes more of a priority, there are varying levels of support available to them, depending on their country of residence – and on which part of the country they call home. Reduced fares and paratransit services may be available in all three countries, but this is restricted mainly to larger urban areas. If there is public transportation available, all three nations specify, via various legislation, that people with disabilities must be granted equal access. Australia does offer additional transportation assistance to people with disabilities by giving them a Mobility Allowance, for which they may become eligible during their later childhood years, and continuing throughout adulthood.

Table 3.1

Elementary and Secondary Education Summary

	U.S.	Australia	Sweden
Population with Visual Impairment	Approximately 29,000	N/A*	N/A*
Population with Disabilities in General	N/A*	317,900	N/A*
Relevant Legislation	ADA, IDEA, NCLB	DDA	Compulsory School Ordinance; Discrimination Act, Education Act; Parental Leave Act; Social Services Act; Special Services Act
Elementary Education	Mandatory; start age ranges from 5 to 7 years old; IEP must be provided	Mandatory; start age ranges from 5 to 6 years old; Negotiated Curriculum Plan must be provided	Mandatory, starting no later than age 7; IEP must be provided

Table 3.1 (continued)

Elementary and Secondary Education Summary

	U.S.	Australia	Sweden
Secondary Education	Mandatory, normally until 16 years old; IEP must be provided, including mandatory transition plan starting no later than age 16 years	Mandatory, normally until 15 or 16 years old; Negotiated Curriculum Plan must be provided; voluntary transition services available through NDCO Program starting at 15 years	Mandatory, normally until 16 years old; IEP must be provided; voluntary transition services available through various organizations and agencies
Monetary Benefits	SSI payments to child via parents until age 18 years old	Carer benefit payments to parents until age 16; after age 16, eligible for DSP, Utilities Allowance, Remote Area Allowance	Care allowance payments to parents until age 19 years old or end of compulsory schooling, whichever happens first
Medical Coverage	Care allowance payments to parents until age 19 years old or end of compulsory schooling	whichever happens first	Care allowance payments to parents until age 19 years old or end of compulsory schooling
Transportation	Reduced fares on public transportation or paratransit service may be available depending on area of residence	Mobility Allowance; reduced fares on public transportation or paratransit service may be available depending on area of residence	Paratransit service available in all areas; reduced fares for public transportation may be available depending on area of residence

* This information has not been released.

CHAPTER 4

ADULTHOOD

Adulthood comprises the vast majority of a person’s typical lifespan, and in addition to being the lengthiest phase of life, it is also arguably the most complicated period for people with visual impairments because it is the time when compulsory attendance in an educational system ends, and the “safety net” that such systems inherently provide, is removed. For the first time, an individual with a disability may discover that he or she must act independently and proactively if the goal of becoming a productive member of society is to be realized. Continuing with postsecondary education, or finding and maintaining employment, are increasingly expected of all people, including those with disabilities, which further adds to the pressure that this stage of life may engender. The U.S., Australia, and Sweden each have different ways in which they expect their citizens with visual impairments to manage the freedom – and responsibilities – that come with attaining the age of majority.

United States

According to Ryskulova, Turczyn, Makuc, Cotch, Klein, and Janiszewski (2008), citing a 2002 CDC National Health Interview Survey, there were 19.1 million “civilian, noninstitutionalized adults” who self-reported having some form of visual impairment (including correctable conditions), which amounted to 9.3 percent of the total population (Ryskulova et al., 2008, p. 456). When only non-correctable visual impairments are examined, the national rate is 2.8 percent (Prevent Blindness America, 2008).

Legislation

ADA. After an individual with a disability reaches adulthood, IDEA (2004) and NCLB (2001) no longer apply; instead, major protections are provided under the ADA (1990). The ADA is a civil rights law that covers people with disabilities across the lifespan, though it assumes a more prominent role for adults than for children because it expands protection beyond educational settings, ensuring that this population is provided with adequate access to employment, transportation, and public buildings, among other safeguards against discrimination. But these protections are not automatic; the ADA states that it is the responsibility of the person with a disability to request needed assistance, unless the individual's disability is so severe that his or her parents or other guardians legally obtain the right to continue making decisions into adulthood. But this exception, while helpful in instances where, for example, an individual has an intellectual disability, is rarely (if ever) justified for someone who has a visual impairment with no comorbid conditions. This need for self-determination skills is a major change from the "automatic" protections and the right to a free appropriate public education mandated by IDEA (2004).

According to the Department of Justice (2006), there are seven million "places of public accommodation" to which the ADA provisions apply. All of these places must be accessible to people with disabilities, meaning that newly-constructed buildings must meet the specifications set out in the ADA, and older buildings must be altered. Such architectural particulars may include things like elevators, ramps, and other implementations that may seem to be most useful for people in wheelchairs, but which can be equally beneficial for people with visual impairments. The ADA also specifies that public transportation services must also be accessible. To encourage businesses to implement these structural changes, the government's Internal

Revenue Service (IRS) offers a $15,000 annual tax deduction under IRS Code Section 190, "Barrier Removal" (U.S. Department of Labor, Office of Disability Employment Policy, 2007).

Section 504 of the Vocational Rehabilitation Act. Another important piece of legislation for people with visual impairments is the Vocational Rehabilitation Act, Section 504 (1973), which (like the ADA) covers individuals across the lifespan, but which comes more into play for adults. Section 504 protects people with disabilities against discriminatory practices in the Federal government, meaning that they cannot be denied equal access to such things as gaining employment with Federal agencies, or receiving Federal monetary benefits such as Social Security (U.S. Department of Justice, Civil Rights Division, 2005). Section 504 also mandates that individuals with disabilities who work for the Federal government must receive "reasonable accommodation," which typically means things like screen reading software or other assistive technology for people with visual impairments.

State legislation. Many states have additional legislation that further ensures the rights and responsibilities of people with disabilities, but none of these local laws may contradict any of the Federal legislation. The scope of this state-level legislation is too detailed to be examined in this paper, but residents of each state should be aware of the variances and particulars in the levels of available support and services as mandated by that home state.

Postsecondary Education

The increased inclusion in the general education classroom, as mandated by IDEA (2004) through its "least restrictive environment" requirement, means that students with visual impairments are increasingly expected to continue on to postsecondary education along with their peers, resulting in expanded employment options. While students with disabilities in postsecondary education are enrolling at a rate 50 percent below their non-disabled peers

(President’s Commission on Special Education, 2002), studies show that there may be an upward trend in this enrollment rate. In 1995-1996, a National Postsecondary Student Aid Study reported that approximately 6 percent of undergraduates said they had a disability, and of these students, 16 percent were visually impaired (U.S. Department of Education, National Center for Education Statistics, 2000). By 2003-4, the rate of undergraduate enrollment for self-reporting students with disabilities had risen to 11.3 percent, though that report did not specify how many of these students were visually impaired (U.S. Department of Education, National Center for Education Statistics, 2006). Further signs of hope for students with visual impairments aspiring to attend college are shown in the results from the NLTS2 longitudinal study, which show that students with visual impairments are the most likely of all students with disabilities to attend a postsecondary educational institution, enrolling at double the rate of students with disabilities overall (the highest rate of any disability category); when only enrollment at four-year colleges or universities was considered, this number shot up to quadruple the rate, with 69.1 percent of students with visual impairments choosing to go on to this form of postsecondary education (Wagner et al., 2005).

Employment

Unfortunately, the relatively encouraging trend regarding enrollment rates of students with visual impairments in U.S. postsecondary education does not continue into the realm of employment; in fact, adults with visual impairments are among the least likely to gain or maintain employment out of all the disability categories (American Federation for the Blind, 2011b). Of the young adults that the NLTS2 study followed, only 22 percent were employed full-time in 2005 – a rate that was 21 percentage points less than that of participants with either learning disabilities or hearing impairments (Wagner et al, 2005). Unger, Rumrill, and

Hennessey (2005), citing U.S. Department of Labor statistics, had a slightly more positive view that same year, reporting that the employment rate for people with visual impairments between the ages of 16 and 69 years old was actually 45 percent – but noted that this was a far cry from the 75 percent employment rate for the general population. This 55 to 78 percent unemployment rate range is abysmal even when compared to the unemployment rate for people with disabilities in general, let alone contrasted with that of the general population. In 2009, the Bureau of Labor Statistics reported that the unemployment rate was 9.0 percent for the non-disabled population, while people with disabilities overall stood at a 14.5 percent rate, and the onset of the current economic recession makes it likely that employment figures for people with visual impairments have also further worsened.

Such low employment rates might be surprising, in that it might be reasonably expected that people with some useful vision, as opposed to those with total blindness, might have a less bleak employment outlook, and therefore raise the rate overall for this population. However, as the authors of the 2005 NLTS2 report concluded, participants with visual impairments struggled inordinately compared to those in many other disability categories because of one major disadvantage: their inability to drive (Wagner et al, 2005). The authors reported that only 20 percent of NLTS2 participants with visual impairments held driving licenses, compared to 80 percent of participants with hearing impairments. Other categories of disabilities, such as learning disabilities, do not bar people with those conditions from driving. As a result, this severe restriction on the ability of people with visual impairments to travel easily and on one's own schedule is cited as a major reason why this population is unemployed (or underemployed) at such a higher rate.

Because of this high unemployment rate, poverty is a major problem for people with visual impairments. The AFB, summarizing the results of a 2008 National Health Interview Survey conducted by the National Center for Health Statistics, reported that 25.2 million Americans over the age of 18 years old reported experiencing vision loss or blindness; of these respondents, 3.8 million reported being “Poor,” with a further 4.7 million at the “Near Poor” level (American Federation for the Blind, 2011a).

Another main reason for this atrocious employment rate may be due to prejudice and misunderstanding on the part of potential employers. To combat this situation, the Equal Employment Opportunity Commission (EEOC) is dedicated to eradicating employment discrimination (such as refusing to consider qualified individuals for a position, implementing wrongful termination practices, distributing unequal pay for equal work, or failing to provide reasonable accommodations) by resolving complaints brought by individuals with disabilities against private employers, which is done under the umbrella of ADA (2004) Title 1 protections. According to Unger et al. (2005), people with visual impairments are the most successful at winning settlement benefits in such complaints, which means that the EEOC is able to mediate a resolution that avoids further escalation of the matter (e.g., litigation). Like the EEOC, the Department of Justice also acts in a similar dual role of watchdog and mediator regarding employment discrimination issues, except that the Department oversees government (public) employers, and the authority to do so is granted under Section 501 of the Rehabilitation Act (1973). Both the EEOC and the Department of Justice disseminate information meant to educate employers about hiring people with disabilities, emphasizing that the ADA does not give individuals with disabilities an advantage over other candidates; instead, it is meant to ensure that everyone receives equal, merit-based consideration – in other words, it “levels the playing field" (U.S. Department of Justice, Civil Rights Division, 2006). If an employer is found in noncompliance with the ADA (2004) or Section 501 (1973), he or she is forbidden to retaliate against the employee with a disability, and another complaint may be filed with the EEOC to instigate an investigation if such practices occur (Equal Employment Opportunity Commission, 2011a).

In the workplace, it has been established that "reasonable accommodations" for people with visual impairments may include assistive technology (e.g., computer screen magnifiers), large-print or Braille-formatted written materials, audio recordings of documents, a driver to provide transportation to an "essential function" of the job, and flexible start and end times that account for inflexible public transportation schedules (Equal Employment Opportunity Commission, 2011b). Not every employee with a visual impairment will need the same measures, and under the ADA (2004), it is the employee's responsibility to request needed accommodations.

But as the above-referenced statistics show, even with these legislative and agency protections in place, many people with visual impairments still struggle to obtain and maintain employment, requiring even more intensive assistance. To this end, the Federal and state governments have established the Vocational Rehabilitation (VR) Program, which is meant to help anyone with a disability who is of legal employment age in accessing training, interviewing, and on-the-job assistance, as necessary for each individual's unique situation. People with visual impairments fall under the VR's "sensory/communicative" category (the other two VR categories are physical impairments and mental impairments); it is estimated that VR participants in the sensory/communicative category spend an average of 25 months in the program (Dutta, Gervey, Chan, Chou, & Ditchman, 2008). This is roughly equivalent to the time in VR for the other two categories – 24 months for people in the mental impairments category and 28 months for people in the physical impairments category – but as Dutta et al. (2008) further outline, people in the sensory-communicative category cost the VR Program “significantly” more to assist than those in other categories (their average cost was $5,462 for their time in the program, compared to $4,816 for people with physical impairments and $3,006 for people with mental impairments), but this higher outlay could also be justified because they also had a higher rate of employment achievement (75 percent, which is 19 percent higher than that of people with physical impairments, and 20 percent higher than that of people with mental impairments). While a 75 percent employment rate may seem impressive, Dutta et al.’s 2008 study also reported that only 19 percent of people with sensory/communicative impairments obtained “professional/technical level” jobs, indicating that there may be a high rate of underemployment among those individuals who do obtain work.

Another means of assisting people with disabilities with accessing employment opportunities is the Federal government’s nationwide “Ticket to Work” (TTW) program, established in 2002, aimed at assisting people with disabilities who are currently receiving governmental monetary assistance (e.g., Social Security benefits, which will be discussed in detail later in this section) (Social Security Administration, 2011e). These beneficiaries are assigned a “ticket” that can be “redeemed” for services with the VR Program or any other employment service provider that the individual chooses, such as a local non-profit agency, or a private for-profit company, etc. In this way, the individual has more latitude in choosing where to go for employment training and placement assistance, the theory being that such competition among agencies will create a higher level of quality for the consumer (Social Security Administration, 2010). When an individual assigns his or her ticket to a service provider, that provider and the individual must create a written plan of action – in an accessible format such as large print or Braille, if necessary – in which it is stated, in measureable terms, what that service provider will do to help that individual gain whatever training he or she needs to obtain a desired position, and how the provider will assist with arranging for job interviews and other means of actually attaining the position (Social Security Administration, 2011e). Crucially, if the individual feels that the service provider is not following through on any of these obligations, he or she may withdraw the ticket ("unassign" the provider) and give it to a different agency or company (Capella-McDonnall, 2007; Social Security Administration, 2011g). While the TTW program touts its flexibility as an asset, Capella-McDonnall (2007) reported that, of all the disability categories, people with visual impairments were the least likely to terminate monetary benefits because of obtaining gainful employment, due to one major flaw in the TTW system: service providers may refuse to serve anyone, and are not required to provide a reason for doing so. In other words, a service provider may legally decline the proffered ticket simply because people with visual impairments have historically had a much worse employment rate than people in other disability categories, and they also cost more to assist. Another potential problem with the TTW program is that an individual with a disability may only assign his or her ticket to one service provider at a time (Social Security Administration, 2011g); there is no option to work with several agencies or other providers at once in order to maximize employment opportunities.

People with disabilities who are trying to come off of government assistance benefits may continue to receive these monthly payments while they work as long as their wages do not exceed an annual amount set by the SSA (Social Security Administration, 2001e). Because of the unique problems people with visual impairments face, their maximum allowable amount is set substantially higher than it is for other disability categories: in 2011, the cap was set at

$1,640 per month for people with visual impairments, compared to $1,000 per month for people with other disabilities (Social Security Administration, 2011f). For people receiving SSI, there is the Impairment-Related Work Expenses (IRWE) benefit, which assists with paying for costs such as transportation fares (i.e., if public transportation to/from the job is not available and the individual must hire a taxi service) or assistive technology that that individual personally purchases to help with job duties; these expenses are deducted from the earnings calculations when determining benefits continuation eligibility (Social Security Administration, 2011f). People with visual impairments who are enrolled in the SSDI program may instead utilize the Blind Working Expenses (BWE) benefit, which also covers work-related expenses (Social Security Administration, 2011a). Under specific direction from the U.S. Congress, the laws governing SSA payments include language mandating that individuals with visual impairments are eligible to receive exemptions on a wider range of items than people with other disabilities, so that they may also include expenses related to more disability-specific needs like guide dog maintenance and conversion of reading materials into accessible formats (Social Security Administration, 2011a).

Additional Support and Services

<u>Monetary benefits.</u> As previously described in Chapters 2 and 3, there are two benefits programs in the U.S. for which people with a visual impairments may be eligible: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) (Social Security Administration, 2010). These programs are similar in that they are both distributed by the Federal Government through the SSA, but there are also fundamental differences between the programs.

To receive SSI payments as an adult, beneficiaries must be under the age of 65 years old or have a disability, and they must additionally demonstrate that their income and other resources (i.e., real estate excluding the current residence, savings, stocks and bonds) fall below a certain level, which varies by state (Social Security Administration, 2011c). For a person with a visual impairment to qualify for this benefit, the eligibility determination rests on whether the individual is deemed "legally blind," a medical definition that the SSA delineates as follows: "We consider you to be legally blind if your vision cannot be corrected to better than 20/200 in the better eye, or if your visual field is 20 degrees or less in your better eye" (Social Security Administration, 2011c, p. 4). It is possible to work while receiving SSI, as long as the earned wages do not exceed the cutoff income amount. For people with disabilities, accommodation items and services, such as assistive technology or guide dog maintenance, are not counted toward the income calculation (Social Security Administration, 2011d). People with visual impairments receive an even higher allowance for expenses than any other group; they are allowed to exempt additional expenses such as transportation costs to and from work (Social Security Administration, 2011d). Also unlike other SSI-eligible categories, such as people who have reached age 65, beneficiaries with visual impairments do not need to have worked and contributed to Social Security taxes (Social Security Administration, 2011c). However, if someone has already been drawing SSDI benefits because his or her disability manifested before the individual turned 22 years old, then that person is not also eligible to "double dip" by also drawing SSI payments – SSI and SSDI payments are an "either/or" proposition.

SSDI is similar to SSI in that it requires beneficiaries to prove that they have a medically defined disability (the definition for legal blindness is the same as for SSI), and that their income and resource levels fall below a maximum amount; however the SSDI program is dissimilar in that it is paid to adults who were disabled prior to turning 22 years old (Social Security Administration, 2011b). SSDI has often already been paid to the beneficiaries during their childhood years, and the payments are simply carried on into adulthood as long as the disabling condition remains – but unlike SSI, SSDI requires people with visual impairments to prove that their condition has lasted at least one year, or that it is expected to be permanent (SSI has no such "duration" calculation) (Social Security Administration, 2011a). Although SSDI also allows for people to work and earn a certain amount before benefits may be discontinued, it is more common for an SSDI beneficiary to be unable to maintain employment due to the likelihood that the qualifying condition is more longstanding or severe than those more appropriate for coverage under SSI; in fact, to earn SSDI benefits, one of the factors that will be examined is whether or not the medical condition will "significantly limit your ability to do basic work activities – such as walking, sitting and remembering – for at least one year" (Social Security Administration, 2010, p. 9). Again, however, people with visual impairments are given more leeway than people in other categories: the maximum income amount under SSDI for people with visual impairments is $1,640 per month, compared to the $1,000 limit for others (Social Security Administration, 2011c).

Visual impairment, using the same medical definition of legal blindness used by the SSA for SSI and SSDI eligibility, is the only disability category singled out by the Internal Revenue Service (IRS) to receive a special tax break. In the 2010 tax season, the IRS granted people with visual impairments an additional $1,100 in earnings to be tax-exempt; the amount rose to $1,400 for individuals who are single or the head of a household (Internal Revenue Service, 2011).

Medical coverage. In most states, people who qualify for SSI benefits may also be found eligible for coverage under Medicaid, the government-administered health care program for people with low incomes and resources (Social Security Administration, 2011b). Reflecting the more stringent qualifying requirements for SSDI coverage compared to SSI, Medicare coverage is granted automatically once SSDI benefits have been paid for two years (Social Security Administration, 2010).

Housing. If a person with disabilities lives with a non-elderly family, and that family's low income level results in that family either living in public housing, or being on a waiting list for such accommodation, then that family may be eligible for "designated housing program vouchers" through the U.S. Department of Housing and Urban Development (HUD). It is the responsibility of the family to locate a suitable housing unit, but it can be either in a public housing building or through a non-government property owner; if it is the latter, HUD will contribute 30 percent of the difference in rent for the unit over the current rate for public housing, which means that the family will have a higher likelihood of obtaining "safe, decent, and affordable housing" (U.S. Department of Housing and Urban Development, "Designated Housing Vouchers," para. 1, 2011).

For people with disabilities and their families of all income levels, the Fair Housing Amendments Act (FHAA; 1988) applies, which mandates that property owners may not refuse to rent to anyone based on their race, gender, disability, etc., and that for all housing built after March, 1991, "public and common areas must be accessible to persons with disabilities." However, the FHAA's minimum standards do not dictate that every housing unit must be accessible for every person with a disability (for example, a home may be appropriate for a person with visual impairments, but not for a person in a wheelchair).

If a person with disabilities lives in public housing and modifications are needed to make areas accessible, HUD can pay for the project, but tenants with disabilities living in private residences must cover the costs themselves (though there are HUD loan schemes available to assist with funding such projects) (U.S. Department of Housing and Urban Development, 2004).

Transportation. Reduced fares or paratransit services, as described in Chapter 3, continue to be available to people with disabilities as they reach adulthood. Also, the previously-described IRWE benefit and/or the BWE benefit, which specifically help people with visual impairments, may also be used to help cover transportation costs (Social Security Administration, 2011a).

Guide dogs. One of the most visible and distinctive forms of service and support for people with visual impairments in the U.S. is the guide dog program, offered through several organizations throughout the country. These dogs can cost as much as $50,000 to train before they are ready to be matched with an individual, but this cost is not passed along to the new owner, who usually pays little or no fee to obtain the dog (U.S. Department of Labor, Office of Disability Employment Policy, 2010), though the ongoing vet and other maintenance costs are the owner’s responsibility. While guide dogs may be provided during the childhood years, they are more likely to be acquired by adults who wish to live independently. However, such assistance dogs are not always a realistic option for people with visual impairment because of the time and expense required to maintain any animal responsibly, and some people are also not amenable to having a dog around them at all times, every day, which will be required of those who take in such a dog.

Associational protection. As an indirect benefit, the ADA (1990) extends certain protections to people who are associated with the person with a disability – the “association provision,” as explained in Chapter 2 as it relates to parents of children with disabilities. This protection is not just meant to assist families, however; it has a very wide application that is meant to offer added protection for people with disabilities and their associates throughout their lives. For instance, if someone witnesses a shopkeeper discriminating against a customer with a disability by refusing to assist that person, and this witness reports the incident, then that witness is entitled to the same protections against retaliation as the person who is disabled (Equal Employment Opportunity Commission, 2011a). There is specific association protection when it comes to the workplace, as well: A non-disabled employee may file a complaint with the EEOC if he or she witnesses discriminatory practices, and the protections against employer retaliation extend to these individuals, as well (Equal Employment Opportunity Commission, 2011b). It must be noted, however, that these ADA/EEOC provisions only apply to employers who have at least 15 employees. Some states do have anti-discrimination laws that apply to smaller companies, however (Equal Employment Opportunity Commission, 2011b). In this way, it is hoped that even people who are not themselves disabled will be encouraged to intervene when necessary, furthering the message to the general public that discrimination will not be tolerated.

Community/social access. While there are no government-sponsored programs that are specifically meant to help people with disabilities to gain inclusion in meaningful social relationships, there are several agencies that can help individuals with visual impairments in this area. For instance, the AFB is a major nationwide non-profit advocacy organization, and through its website it offers a “Directory of Services Database” and a “Calendar of Events” that describe many social and cultural events around the U.S. that may be of interest to people with visual impairments. In addition, many cultural centers (such as museums or theaters) offer discounted rates for people with disabilities, which may enable increased attendance at entertainment events. Other organizations encourage people with disabilities to actively participate in cultural activities, such as the National Endowment for the Arts’ Office of

Accessibility, which is dedicated to developing and implementing inclusive artistic endeavors nationwide by offering appropriate assistive technology and other support, as well as providing education and advocacy programs about inclusive practices (Office of Accessibility, n.d.).

Australia

According to the Australian Institute of Health and Welfare (2006b), 40,800 Australians under the age of 65 are visually impaired, which would amount to less than one percent of the total population of 22,447,400 cited in Chapter 1. Of these individuals, 32.1 percent reported that they experience "severe or profound core activity limitations" as a result of their disability (Australian Institute of Health and Welfare, 2007, p. 110).

Legislation

DDA. The DDA (1992) continues to provide protections against discriminatory practices in a broad array of environments and activities, as previously enumerated in Chapters 2 and 3, as people with disabilities enter adulthood. However, these protections may become more significant as an individual enters this more independent phase of life, and indeed, this expectation of enabling all Australians to have the right of self-determination is a guiding tenant of this law, which aims not only to educate individuals with disabilities of their rights and responsibilities, but the general public, as well:

> "Central to the objectives of the DDA is the ongoing education of the public about disability discrimination... The DDA was written as a dynamic piece of legislation whose spirit and intent is to evolve to facilitate an increasingly accessible citizenship so that PwD [person with disabilities] are treated equally before the law" (Darcy & Taylor, 2009, p. 424).

This means that people with disabilities can expect to be provided with "reasonable adjustments" as they enter any building or area that is open to the general public, obtain employment, access public transportation, and pursue recreational activities. The Australian government, at both the Federal and state level, is setting an example about the importance of the DDA by voluntarily drawing up "action plans" or "equity statements" that target discriminatory or inaccessibility issues in their departments (Dempsey & Foreman, 2002).

National Disability Agreement (NDA). In another pointed demonstration of the Australian government's commitment to promoting the independence and rights of people with disabilities and protecting them against discriminatory practices, the National Disability Agreement (NDA) was passed into law in 2009 as a reauthorization of the 1986 "Disability Services Act" (which had also been previously reauthorized in 2002 as the "CSTDA," or Commonwealth State/Territory Disability Agreement) (Australian Institute of Health and Welfare, 2011). The NDA mandates that all levels of government (Federal, state/territory, and local) are legally

> "committed to their responsibilities in relation to public leadership which actively promotes the rights of individuals with disability, and encourages the community to embody these values, which are the foundation of an inclusive society" (National Disability Agreement, "Roles and Responsibilities of Each Party," 2009).

The NDA provides the means for achieving these objectives by outlining the funding and service delivery for all government-sponsored programs that assist people with disabilities to receive services such as assistance in obtaining suitable housing, employment training and placement, and rehabilitation. It also outlines how the provision of grants and other financial assistance will be provided for research and development into the most efficient and effective means of service delivery. Beyond funding and service delivery, the NDA additionally specifically cites that it aims to allow people with disabilities to “enjoy choice, wellbeing and the opportunity to live as independently as possible” (National Disability Agreement, “Outputs,” 2009), thereby underscoring that these citizens’ emotional needs are just as important as any other consideration. As of 2007, there were 164,336 Australians who accessed these services, or 22.8 percent of the population under the age of 65 years old (Department of Families, Housing, Community Services, and Indigenous Affairs, 2008). For the years 2008-9, people with visual impairments accounted for 6.1 percent of all users of NDA services (Australian Productivity Commission, 2011).

State/territory legislation. In addition to the national laws listed above, each state (and territory) also provides additional legislative support for people with disabilities, although this state/territory-level equal opportunity legislation “largely reflects corresponding legislation at [the] Federal level, which has overriding power over state legislation” (Dempsey & Foreman, 2002, p. 32).

Postsecondary Education

Statistics about the enrollment of people with disabilities in university or vocational schools were first obtained in 1996. Since that time, postsecondary education enrollment for this population has increased from 1.9 percent (in 1996) to 3.7 percent (in 2000, the latest year for which statistics are available), which is still quite low; but of these students, 17 percent were visually impaired, making it one of the more successfully-included categories studied (Employment, Workplace Relations and Education References Committee, 2002; Australian Institute of Health and Welfare, 2006a). To encourage continuing increases in these numbers, in 2008 the Australian government distributed A$6,378,000 (U.S.$6,852,133.22) to higher education providers as part of its newly-established Higher Education Disability Support Program (Higher Education DSP), which funds such things as reimbursement to the school for costs incurred while removing barriers or providing assistive technology, offering financial incentives for encouraging students with disabilities to enroll, and promoting inclusive activities and programs (Department of Education, Employment, and Workplace Relations, 2009a & 2011a).

Students with disabilities who enroll in public or private institutions of higher learning are protected under the DDA's Education Standards (Department of Education, Employment and Workplace Relations, 2008b). As initially described in Chapters 3 and 4, these Standards mandate that all students, regardless of their age or educational level, must be granted equal access to education, and that "reasonable adjustments" must be made by the educational provider to enable this access unless doing so would present an "unjustifiable hardship" for that provider.

In addition, students enrolled in a postsecondary education program continue to be eligible for support and services under the NDCO Program, as described in Chapter 3; this is the program in which regional counselors assist the individual with a disability in identifying and pursuing his or her personal life goals, including obtaining a vocational or college degree, and it continues to be available to anyone with a disability until the age of 64 years old (Department of Education, Employment and Workplace Relations, 2009b).

Employment

According to the Department of Families, Housing, Community Services, and Indigenous Affairs (2008) in its 2007 disability services census, people with visual impairments who utilized disability employment services made up 2.8 percent (2,316 individuals) of all persons accessing this service, and their employment outcome "was in line with the national average" (p. 4). This census report went on to state that it seemed to make little difference where people with disabilities lived, in terms of accessing employment assistance:

> "Consumers living in regional and remote areas were well-represented in disability employment services (36.8%) and attained a marginally lower employment outcome than their major city counterparts (59.6% compared with 61.9%)" (Department of Families, Housing, Community Services, and Indigenous Affairs, 2008, p. 4).

In fact, there are 72 disability employment agencies in rural or remote areas, comprising 8.5 percent of all such service providers; in 1999, the latest year for which rural/remote statistics are available, these 72 rural/remote service providers assisted almost 3,000 people with disabilities (Department of Families, Housing, Community Services, and Indigenous Affairs, 2001). As O'Brien and Dempsey (2004) reported, more than 70,000 people with disabilities obtained services from 301 open employment service agencies across Australia. These public and private agencies – both in the rural/remote and suburban/urban areas – provide job training and assistance with obtaining interviews, and if necessary, they will also assist with supported employment services (Department of Families, Housing, Community Services, and Indigenous Affairs, 2008). To ensure consistency in the level of service provided by each of these agencies, as of July, 2002, all of these employment service providers must be certified as being in compliance with the "Disability Service Standards and Key Performance Indicators," as established by the Federal government, before they will receive any public funding (O'Brien & Dempsey, 2004, p. 132). O'Brien and Dempsey (2004) further reported that this high level of employment support and services is such a high priority for the Australian government because it is recognized that people with disabilities can be successful in competitive jobs if they receive the proper support and access, and this, in turn, "significantly improves the quality of life of people with disabilities" (p. 134) while simultaneously reducing their dependence on continued governmental monetary support. In other words, it is viewed that investing significantly in this population in the present will prevent even more considerable funding burdens on the taxpayers in the long run.

The Department of Education, Employment, and Workplace Relations is in charge of providing public employment services for Australians who are seeking job training and placement; its Job Network branch is specifically tailored to providing such services to people with disabilities, with the emphasis on helping this population obtain competitive (not sheltered) employment (Australian Institute of Health and Welfare, 2006a). It does this by conducting an assessment of each person's skills and needs (such as equipment and assistive technology), and then using this information to generate an individualized plan outlining the training and employment goals. The Job Network has different sub-branches that provide specific support to disability categories, meaning that people with visual impairments have access to counselors who are well-versed in the special needs inherent in having this type of disability. As a further incentive, the Job Network also may pay for wage subsidies or workplace modifications in order to encourage employers to offer employment to suitable candidates who are disabled (Australian Institute of Health and Welfare, 2006a).

Disability Employment Services is another government-run specialized employment service network that helps find work for people with disabilities (as well as people who are struggling to find work because of injuries or other health issues that do not fall under traditional definitions of disability). This service is open to anyone with these debilitating conditions between the ages of 14 and 65 years old (Centrelink, 2011b).

While the Australian government has made it clear that employers are expected to give job candidates who have disabilities equal consideration for employment, and provide them with reasonable accommodations after they begin working, there is equal emphasis on the responsibilities of the individuals with disabilities themselves, as well, because

> “the trend in both federal and state government policy is to encourage individuals and families to take greater responsibility for their own well-being, for governments to provide some welfare services through a process of mutual obligation, and for access to government services to be limited” (O’Brien & Dempsey, 2004, p. 127, citing the Australian Productivity Commission).

As a result, in 2005, the Federal government initiated a “Welfare to Work” program (Dalton & Ong, 2007). Under the eligibility requirements set forth under Welfare to Work, people with disabilities who wish to receive unemployment or other monetary payments from the government must be evaluated to determine if they are eligible to work in some capacity. If they are found to be capable of working at least part-time (defined as 15 hours per week), then they must do so in order to continue receiving benefits (Dalton & Ong, 2007). The work to satisfy this requirement can be either voluntary or for wages, with for-wages recipients no longer eligible to receive the standard DSP; they are instead switched to the “Newstart Allowance,” which pays out at a lower rate. The government takes a hard line when deciding whether or not someone should continue to receive the higher DSP payment instead of the Newstart Allowance; they may be allowed to do so only “after all efforts to secure and maintain employment…have been exhausted” (Centrelink, 2011c). Even though obtaining childcare is a significant obstacle for parents with disabilities, this is not considered grounds for exemption from Welfare to Work requirements. To assist participants, the federal government provides payments for childcare expenses through its Jobs, Education and Training Child Care Fee Assistance (JETCCFA); this program is available to all low-income families, not just those with a parent with a disability (Department of Human Services, 2010). In 2006-2007, enforcement of these strict Welfare to Work standards resulted in 34,400 people with disabilities being moved onto the Newstart Allowance; in 2007-2008, 57,900 more people were changed over from the DSP to the Newstart Allowance; and in 2008-2009, 75,700 more were converted (Dalton & Ong, 2007). So, during just three years, the total number of people with disabilities who went from not working at all to doing at least doing some form of voluntary or paid employment was 168,000 individuals. In 2008, the number of people receiving DSP was 732,367, of which only 1.6 percent were visually impaired (Centrelink, 2011c).

As with adults entering postsecondary education, individuals who wish to gain employment have the same access to NDCO Program services as they had during their secondary transitional years.

Additional Supports and Services

Monetary benefits. Centrelink is the federal governmental agency responsible for making welfare payments; as described previously, the most applicable such payments for people with disabilities are usually either the DSP or the Newstart Allowance. To be eligible for a DSP or Newstart Allowance, the individual must be of working age (14 to 65 years old) and demonstrate that he or she is unable to work for a minimum of 30 hours per week, and has had (or is expected to have) this condition for at least two years (O’Brien & Dempsey, 2004). Payments received under DSP are non-taxable, but those received under the Newstart allowance are (Dalton & Ong, 2007). In 2010, the DSP rate was set at A$670.90 (U.S.$719.11) every 14 days; if the individual is a part of a couple, the payment rate drops to A$505.70 (U.S.$542.04) (Centrelink, 2011c).

Newstart Allowance rates are on a sliding scale, and depend on the wages earned and other financial resources of each individual.

Medical coverage. Medicare, the universal health care system initially described in Chapter 2, continues for every Australian throughout their adulthood years (Department of Human Services, 2011b). Under this program, all Australians are eligible to receive free health care at any public hospital and subsidized treatment with other practitioners; this system is funded through employee payroll contributions and taxes, although the universal nature of this program means that people with disabilities who do not work are still eligible for coverage under it (Department of Human Services, 2011b).

Housing. There is no federal-level housing program to assist adults with disabilities with obtaining appropriate independent housing, but there are several state- or territory-level programs that may be able to help. For example, in the state of South Australia, there are several governmental and charitable organizations that can assist with finding modified housing (or adapting an existing domicile), although the wait list for such services is long and preference is given to people "in most urgent need" (Government of South Australia, 2009).

Transportation. The Mobility Allowance, as described in Chapter 3, continues to be available to adults with disabilities, and is more likely to be utilized in this phase of life because more people are likely to meet its eligibility requirement stipulating that the travel undertaken must include trips to and from a place of employment (Australian Institute of Health and Welfare, 2006a). This allowance may also be put toward vehicle registration and license fees, although this is unlikely to be applicable to many people with visual impairments, in that most of them are unable to drive (Australian Institute of Health and Welfare, 2006a).

Guide dogs. Australians with visual impairments who wish to use a guide dog may find assistance through state and territory guide dog associations, overseen by the nationwide Guide Dogs Australia agency, which provide dogs to owners free of charge (Guide Dogs Australia, n.d.), with the owner responsible for further costs such as medical and day-to-day expenses. According to Guide Dogs Australia, the Australian government does not fund this program, so it must rely on private donations and sponsorships from individuals and businesses for its operating monies.

Associational protection. As initially described in Chapter 2, the DDA (1992) extends association protection to people who are not disabled but who are involved with, or witness, an incident relating to someone with a disability, of any age. This protection covers not only immediate family members, but also other carers, friends, and co-workers, thus ensuring that, for example, a co-worker who stands up for a fellow employee who is disabled cannot then suffer reprisals from the employer. In this way, the DDA (1992) has enforced a kind of "zero tolerance" policy when it comes to discrimination against people with disabilities and any of their associates.

Community/social access. The DDA (1992) prohibits discrimination against people with disabilities in the areas of participating in typical daily activities (e.g., obtaining goods and services, engaging in sporting activities, joining clubs, etc.). Isolation can be a common problem for people with disabilities, but especially for individuals with visual impairments, whose reliance on public transportation may inhibit access to many activities. However, Australia's unique situation of having a relatively low population spread across a wide geographical area (as described in Chapter 1) may provide some insight into helping people who are isolated find innovative ways to connect. The Vision Australia Foundation, a major non-profit agency dedicated to assisting and advocating for Australians with visual impairments, has conducted much research into teleconferencing and other low-cost Internet-based networking strategies, which may prove to be a model in other countries where people with visual impairments in rural areas otherwise risk becoming cut off from the wider world (Millner, 2002). These studies have examined the effects of “peer training,” in which people with visual impairments are taught to become online mentors for others who are still learning self-advocacy and life skills; online sessions can be either private, one-on-one counseling sessions, or group sessions meant to foster a sense of community as well as raise awareness of Vision Australia’s available supports and services. Such programs may serve as a means of giving people with vision impairment a sense of fulfillment as they are placed in a position where they are able to assist others in need. According to Millner (2002), this program resulted in “enormous benefit” to participants by “reducing depression and anxiety to isolated people experiencing sight loss” (p. 108). Williamson, Albrecht, Schauder, and Bow (2001) also conducted research into the benefits of using the Internet to help Australians with visual impairments overcome isolation, concluding that “Organizations for visual impaired people in Australia are doing an excellent job of assisting their clients to use computers and the Internet, but funding is a constant problem” (p. 700).

While many people with visual impairments in other countries are not likely to be living quite so far away from metropolitan areas as those in the Australian Outback, it should be remembered that even people with disabilities in urban areas may find themselves just as isolated from the rest of the world if access to suitable public transportation and other supports and services are not easily accessible, so these Australian services may provide an indication of what may work for a wider range of people than just those in remote rural environments.

Another unique Australian program for people with visual impairments in remote areas is the Books in the Sky program (Hillman & Poyner, 2006). This program uses the Internet to upload an audio playback mechanism and a content list that allows users to browse for literature, and then use the program to “read” the contents to the individual. Such auditory-reader software is currently readily available for most home computers (i.e., most people already have the capability to have their computer read aloud a Microsoft Word document), but the Books in the Sky program is the first one to allow people with visual impairments to access current content from newspapers, magazines, and other general literature that is not likely to be available in Braille or large print format; even things such as local government council minutes and other very localized information can be provided in through this service (Hillman & Poyner, 2006). Books in the Sky was created as a partnership between the state and local governments in the state of South Australia, the Royal Society for the Blind, and Audio-Read (the creators of the software), and this extensive governmental and agency support has made it an affordable, efficient system, allowing numerous users to quickly download the same materials at the same time (such as the daily newspaper); according to Hillman and Poyner (2006), “Books in the Sky leapfrogs existing technologies” (p. 155).

For further information and support, Australians with visual impairments may contact Blind Citizens Australia, which is an advocacy and support agency for people with visual impairments and their families throughout the country. Through branches in all of the states and territories, it disseminates information about disability legislation and policies, including coverage of social and community involvement issues (e.g., the current public debate about providing assistive technology to enable people with sensory disabilities to attend the cinema) (Blind Citizens Australia, 2011). People with visual impairments may also find support through

Vision Australia, whose website provides a comprehensive list of upcoming events (including recreational, educational, and fundraising-related events), and further community/social involvement is encouraged through its service wherein volunteers describe the visual aspects of theater or cinema performances or other cultural events to the person with a visual impairment, at no added cost to that individual (Vision Australia, 2010).

Sweden

According to Statistics Sweden (2009), the official government statistics office, in 2007 (the latest year for which statistics are available), there were 919,000 Swedish adults – defined as being between 16 and 64 years old – who were legally disabled, which comes to approximately 16 percent of the population. Within this group, people with visual impairments accounted for 6.2 percent of the total Swedish population (National Board of Health and Welfare, 2009), with 1.3 percent who are visually impaired to the point where they cannot perform typical functions even with corrections (Lilja, Mansson, Jahlenius, & Sacco-Peterson, 2003).

Legislation

Legislation and policies protecting these individuals are promulgated at a national level, as well as through regional areas (as overseen by county councils) and local municipalities (Lilja et al., 2003). The following discussion will cover only national legislation, as this is the most likely to provide the most comprehensive protections for people with visual impairments or other disabilities as they go through their adult years.

Discrimination Act. The Discrimination Act (2008), as initially described in Chapter 3, is a broad piece of legislation that forbids discrimination against any individual, but specifically those who may be particularly vulnerable based on "sex, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation, or age" (Chapter 1, Section 1). If an employer, educational institution, or a business operator violates this Act, they may face monetary sanctions (Ministry of Integration and Gender Equality, 2009).

Social Services Act. The Social Services Act, or "*Socialtjänstlag*" (commonly abbreviated as "SoL") was initially passed in 1982, but it was amended in 2001 to bolster its mandates that municipalities must take responsibility for providing needed assistance and/or care for people with disabilities and senior citizens under their jurisdictions, as assessed by a case manager who works for the municipality (Ministry of Health and Social Affairs, 2007a). This case worker must work with the individual requesting services in order to ensure that the person lives in "decent" conditions (Lewin, Westin, & Lewin, 2008), which may entail such services as help in obtaining suitable housing accommodations, or obtaining needed assistive technology (National Board of Health and Welfare, 2009). Under the SoL, municipalities and people with disabilities are meant to work together to work toward goals for that individual while staying within the available means and services found within that person's municipality – which, despite the government's redistribution scheme, may still have wide regional variances in resources (Lewin, Westin, & Lewin, 2008).

LSS. The Act Concerning Support and Service for Persons with Certain Functional Impairments ("*Lag om stöd och service till vissa funktionshindrade*," or "LSS"), passed into law in 1993, is similar to the SoL in that it also mandates that municipalities must provide needed supports and services to people with disabilities and the elderly, but the LSS is more comprehensive; for instance, it mandates that living accommodations must be "good" (as opposed to "decent" under the SoL). The LSS is significantly stricter in its mandates because it is meant to assist people whose functional impairments are much more severe and whose needs cannot be satisfactorily met under the SoL. Unlike with the SoL, the municipality's monetary and assistive resources may not be taken into consideration when determining the individual's needs under the LSS; the LSS is meant as a kind of "last resort" legislation: other support should be offered under the SoL and other legislation and policies before considering invoking LSS provisions (Lewin, Westin, & Lewin, 2008). However, it should be noted that because the eligibility requirements for individuals are quite high, many people with disabilities are not eligible for LSS provisions (Lewin, Lewin, Bäck, & Westin, 2008), so it is unlikely that most people with visual impairments would be covered under this legislation unless they have a comorbid condition.

Regional/municipal legislation. Sweden is divided into regions instead of states and territories, and into municipalities instead of counties or cities. Each of these regions or municipalities may have their own legislation and policies that provide additional support and services for people with visual impairments or other disabilities, but these laws must align with the national law or they will be invalid. For the sake of brevity, this paper will not examine these local laws, but it should be recognized that citizens may have access to varying assistance depending on where they live within Sweden.

Postsecondary Education

As is the case for younger students with disabilities, statistics are not collected about the number of people in this population who go on to postsecondary education, although those who meet entrance requirements are entitled to attend higher education institutions just like their non-disabled peers following upper secondary school. As in upper secondary school, postsecondary educational programs are designated as either academic or vocational in their focus. Because the majority of students with disabilities enter the vocational track in upper secondary school, they may be less likely to enter university or other college-level studies, even if their scores qualify them for entrance, because higher education admissions officers tend to view students on this track as “less academic and ‘theoretical’ than the [academic track]” students (Emanuelsson, 2003, p. 256). Therefore, if a student wishes to attend a higher educational program, he or she must make this intent known well in advance, so that placement on, and graduation from, the upper secondary school academic track is more likely to be achieved.

There is a Higher Education Act (initially promulgated in 1992, with several amendments through 2010) and a related Higher Education Ordinance (passed in 1993 to regulate postsecondary educational institutions), but neither of these laws contain references to students with disabilities (Swedish National Agency for Higher Education, 2010a & 2010b). In fact, the only mandates regarding parity among various populations are in the Higher Education Act, which stipulates that institutions of higher learning must offer equal treatment to men and women. Instead, students with disabilities are protected under the 2008 Discrimination Act.

Employment

In Sweden, all residents are expected to work to the fullest of their abilities, without exceptions. This is mainly because this productivity in turn provides the revenue that forms the basis of the country’s extensive welfare system, so if a significant segment of the population does not contribute, this may jeopardize the entire system’s effectiveness (Ministry of Health and Social Affairs, 2008). The Ministry of Health and Social Affairs further acknowledges that an additional reason for this insistence on a high work ethic is because employment “also provides an opportunity for personal and social development as well as social participation in the community” (Ministry of Health and Social Affairs, 2008, p. 9), which may be particularly significant for people with disabilities as they attempt to avoid the isolation that may be more likely because of their conditions. In fact, Swedish government policy unequivocally states that, based on the economic and social benefits of working, there is a strong preference for paying for job training and other employment-related assistance instead of simply handing out disability benefit checks (Ministry of Health and Social Affairs, 2008; O'Brien & Dempsey, 2004). Perhaps as a result of this deliberately ingrained national work ethic, people with disabilities have only a "slightly higher" unemployment rate compared to the general population (Swedish Institute, 2007).

The process of job training and placement services for people with disabilities is relatively straightforward in Sweden: there are no disability-specific government service agencies in this area; instead, people with disabilities are welcome to access the same employment training and obtainment services as the non-disabled population (European Blind Union, n.d.), resulting in a system that is meant to be inclusive and normalized. O'Brien and Dempsey (2004) explained this resistance to differentiating people with disabilities from the general working population as follows:

> "The aim of Swedish disability policy is full participation and equality for all its citizens. Therefore, employment policies for people with disabilities are considered as part of the general labor market policy, which is based on the principle of universal entitlement to work" (p. 130).

However, the government does specifically intervene to improve the chances of employment for people with disabilities by providing wage subsidies and grants to employers; sometimes this subsidy may go as high as covering 80 percent of the employee's salary; the government may also provide job support, such as job coaches (O'Brien & Dempsey, 2004). However, such intensive measures are meant to assist people with disabilities so severe as to significantly impact their working capacity, a situation not usually applicable to people with visual impairments.

In an effort to actively help people who are struggling to obtain and maintain employment, the Swedish government implemented a new employment service in 2007, the “New Start” jobs program. This program is open to people with disabilities, as well as anyone else who has endured a significant period of unemployment or who may be expected to run the risk of such a situation, such as people who are recovered from a serious illness, over the age of 50 years old, immigrants, and ex-convicts (Ministry of Health and Social Affairs, 2008). As of 2008, 14 percent of all New Start job placements were for people with disabilities (Ministry of Health and Social Affairs, 2008).

Another government program that may help people with disabilities with obtaining a job is the “job guarantee” for young people. This initiative, launched in late 2007, helps people between the ages of 16 and 24 years old to quickly find employment commensurate with their abilities, as a sort of “stepping stone” into the workplace and, it is hoped, eventual entrée to their career of choice. In its first year, 9 percent of its job placements were for people with disabilities (Ministry of Health and Social Affairs, 2008).

As a kind of “last resort,” the Swedish government also operates an extensive alliance of sheltered workshops across the country, mainly focusing on manufacturing and service activities (O’Brien & Dempsey, 2004). Employees in these sheltered workshops receive a normal wage, as determined by current open market standards (O’Brien & Dempsey, 2004). However, because this is aimed at assisting people with severe disabilities who are unable to find other employment, and because of the necessity for visual acuity to complete much of the work done through these workshops, it is unlikely that most people with visual impairments would use this program for their employment needs.

Additional Supports and Services

Monetary benefits. As stated earlier, the Swedish government resists paying disability-related benefits whenever possible, instead insisting that every individual make a best effort to obtain some form of employment that matches their highest capacity for work. As a result, while there is a tax-free "disability allowance" (*Handikappersättning*), administered by the Swedish Social Insurance Agency (*Försäkringskassan*), that may be paid to people age 19 or over who are unable to find a job because of the limitations imposed by their disabilities, such payments are only payable after the individual demonstrates that he or she truly is incapable of any kind of productive employment (Ministry of Health and Social Affairs, 2007c). The criteria to meet this level of impairment are substantial: the disability must be documented as being so significant that it causes "considerable difficulty" necessitating at least 20 hours of personal assistance per week with fundamental living needs (such as dressing, eating, etc.) (Swedish Social Insurance Agency, 2010a). For people whose visual impairments are severe enough to qualify them for this disability allowance, they may receive SEK 29,256 per year (U.S.$4,507.75) (Swedish Social Insurance Agency, 2010b) – an amount that is likely deliberately set so low in order to encourage individuals to instead obtain employment.

Medical coverage. As a socialist state, Sweden offers its citizens universal health care insurance, or "LASS," as mandated by the Health and Medical Services Act of 1982. This means that everyone is entitled to a "high standard of general health and care for everyone on equal terms" (Ministry of Health and Social Affairs, 2007a). Under that Act, individuals have the right to choose their health care providers, and they may elect to receive care under any provider, anywhere in the country. For people with disabilities, this coverage also includes any specialized equipment needed to assist with daily living activities (Lilja et al., 2003).

Housing. The Swedish government will provide a grant to cover any permanent home modifications that are necessary to ensure accessible and safe living accommodations, regardless of whether the property is rented or owned by the individual (Lilja et al., 2003). An individual's resources are never taken into account when delegating these housing modification grants, meaning that even someone who could easily afford to pay for such modifications may still apply for these funds, because it is believed that it is unfair to ask individuals with disabilities to personally cover the cost of a condition that they could not prevent (Lilja et al., 2003). Individuals with visual impairments may use these funds to pay for things like lowering thresholds, installing assistive technology that enables easier functioning for daily household duties, or safety measures like improved lighting (Lilja et al., 2003). Lilja et al. (2003) further reported that in 2003, the latest year for which statistics were available, there were 60,000 such modifications, at a cost of SEK 7,000,000 (U.S.$1,077,097.07), with the majority going toward people with mobility- and age-related disabilities.

In a concerted effort to reduce and eventually entirely remove the need for such home modifications, the Swedish government has long encouraged architects and builders to consider Universal Design for Living (UDL) concepts for new buildings (not just for homes, but for all public buildings) (Lilja et al., 2003).

Transportation. If a disability is so severe that it prevents an individual from effectively and safely using public transportation, the Swedish government will provide an allowance (*färdtjänst*) for door-to-door mobility assistance, such as a municipality-run alternate transportation service (or a taxi if no such service is available), which is calculated by subtracting the amount of a public transportation fare from the cost of the alternative trip (Ministry of Health and Social Affairs, 2008; National Board of Health and Welfare, 2009). There are certain restrictions on such travel, such as limits on the number of trips or the distance of the destination (Lilja et al., 2003, p).

Guide dogs. Guide Dogs Stockholm (2011) provides guide dogs for people with visual impairments in Sweden through its own facilities and through partnerships with breeders and trainers in other parts of Sweden, at no cost to the new owner (though further costs, such as veterinary bills or other maintenance expenses, are not similarly covered). Under the protection of the Discrimination Act (2008), guide dogs must be allowed into public areas (such as buildings or public transportation), even if those areas have a ban on animals.

Association protection. Although there are no legislative provisions providing protection for people who are associated with people with disabilities, the Discrimination Act (2008) does allow the Equality Ombudsman or an organization to bring an action on behalf of the person who allegedly suffered discrimination, as long as that person consents (Chapter 6, Section 2).

Community/social access. While Swedish legislation specifically mandates that people with disabilities be granted equal access to social and community activities – e.g., the Social Services Act (2001), mandating that this population has a right to “active participation in the life of the community” (Chapter 1, Section 1) – in practice there are few official services though which individuals may seek assistance with such inclusion. Additional help may be provided by the Swedish Association of the Visually Impaired (*Synskadades riksförbund*, or “SRF”), a national association that was founded in 1889 and is funded through government and private sources (Swedish Association of the Visually Impaired, n.d.). SRF is extensive: it has 170 local offices, and 24 regional branches, through which it currently services approximately 15,000 members, and it provides social and educational activities and programs across the country (Swedish Association of the Visually Impaired, n.d.).

Discussion

Available statistics indicate that the number of adults with visual impairments varies greatly across the three studied countries: in the U.S., 2.8 percent of the total population has an uncorrectable visual impairment, while 1.3 percent of Sweden's population and less than one percent of Australia's population fall into this same category.

Legislation

In adulthood, across the three profiled countries, legislative protections for people with disabilities are broad in nature, and tend to focus mainly on ensuring that this population must be given equal access to public premises and activities. While such lifespan-encompassing discrimination legislation has already been established as the status quo for Australians and Swedes throughout their childhoods, this more general legislative approach can represent quite a radical change for adults in the U.S., who may have become accustomed to the very specific requirements and protections afforded to them throughout their childhoods through IDEA (2004) and NCLB (2001). Now, as adults, they must adjust to the broader specifications and greater personal responsibilities granted to them under laws such as the ADA (1990) and Section 504 of the Rehabilitation Act (1975). While these laws also apply to children with disabilities in the U.S., they may first become vital to an individual only after the earlier-referenced children-specific laws no longer apply.

Postsecondary Education

Students with disabilities are encouraged to enter postsecondary educational institutions, because employment opportunities in all three of these profiled countries depend greatly on obtaining at least a bachelor's degree. However, it is difficult to determine how much success students with disabilities actually have with enrolling in, and graduating from, such educational institutions. Sweden, for example, does not compile any statistics about its number of postsecondary students with disabilities or their graduation rates, nor is this population mentioned in any of its higher education-related legislation (although these students may still claim protection under the Discrimination Act of 2008). The U.S. and Australia do compile such statistics, and have relatively divergent results: the latest reports indicate that enrollment for U.S. students with disabilities are almost triple the rate found at Australian postsecondary institutions, but this advantage quickly disappears after graduation, when U.S. postsecondary graduates face far worse employment prospects – especially if they are visually impaired – than they do in Australia or Sweden, as will be described next.

Employment

Of all the aspects of life examined throughout this paper, perhaps none reveals quite as sharp a division among the three profiled countries as the matter of employment for people with disabilities, and for those with visual impairments, in particular. While Australia and Sweden's reports on this matter are simple – both state that people with visual impairments have either the same or only a slightly higher unemployment rate than their nondisabled peers – the situation in the U.S. is much more bleak. Employment surveys show that in the U.S., people with disabilities have far higher unemployment rates than their nondisabled peers, and people with visual impairments appear to have the worst unemployment rate of any disability category. It is speculated that perhaps this situation is a combined result of this population's inability to drive (a skill that seems vital for maintaining a "typical" life in the public transportation-averse U.S.), and the general public's prevailing fear and prejudice regarding visual impairments, as evidenced by the study referenced at the start of Chapter 1.

The U.S. has responded to this discouraging situation by establishing employment programs such as Vocational Rehabilitation and Ticket to Work, which specifically target people with disabilities, yet the unemployment rates for this population have remained consistently high. In contrast, Australia and Sweden predominantly provide job training, placement services, and programs to people with disabilities through general employment agencies, which are open to all people (not just those with disabilities).

Additional Supports and Services

Monetary benefits. Adults with disabilities in the U.S., Australia, and Sweden may all be eligible for benefits payments from their governments, but the eligibility requirements differ significantly. While someone in the U.S. must simply demonstrate that he or she has a significant and permanent (or long-lasting) disability in order to receive full SSI or SSDI payments, citizens in Australia and Sweden must additionally show that they are incapable of working even part-time before they are allowed to collect full payments.

Medical coverage. Australia and Sweden continue to offer universal health care coverage to all adults with disabilities. In the U.S., the situation may be more difficult for this population: while Medicaid may be available to people who are disabled and who additionally have low income and assets, there may be problems finding coverage for people with somewhat higher economic status, as private health insurance companies may refuse to cover someone because of the presence of a disabling condition.

Housing. All three of the profiled countries have very different approaches to assisting citizens with disabilities in accessing appropriate accommodations. In the U.S., this is handled at the federal level, where low-income, non-elderly families living with a family member who is disabled may qualify for vouchers that enable them to live in safer, more affordable public or private housing. In Australia, there is a similar service, though here it is handled at the state or territory level instead. However, in Sweden, there are no limitations on income or assets in order to obtain housing assistance, and the emphasis is instead on assisting all people to stay in their own homes within their chosen communities, not moving them to a housing unit that is deemed appropriate. To do this, the Swedish government pays for needed modifications.

The U.S., Australia, and Sweden all have anti-discrimination legislation that protects people with disabilities from being denied tenancy because of a disability or the reasonable building modifications that such a condition may require, and they all specify that common areas in public housing must be accessible (though the guidelines may vary to the extent that not all such areas may actually be accessible for every person with a disability).

Transportation. Paratransit services or reduced fares may be offered to people with disabilities within each of the profiled countries, though their availability may vary greatly. The Australian Mobility Allowance remains the only specific transportation benefit for people with disabilities in these nations, although the IRWE or BWE benefit for U.S. citizens who are visually impaired may also be put toward mobility expenses.

Guide dogs. People with visual impairments in the U.S., Australia, and Sweden all have the right to utilize a guide dog if they choose to do so, and they must be allowed to use these dogs to help them navigate all public areas (including public transportation), even if animals are normally banned in these places. Owners will pay nothing to obtain a dog in Australia and Sweden, and they may pay nothing or a small fee in the U.S., depending on the provider. In all three nations, it is the personal responsibility of the guide dog owner to cover all subsequent expenses related to a dog’s upkeep, such as medical bills, food, grooming, etc.

Associational protection. The U.S. and Australia both have legislation to protect people who are associated with someone with a disability and file a complaint on that individual's behalf (i.e., a coworker who reports witnessing an employer discriminating against another employee). In Sweden, there is no equivalent specific legislation, although the broad nature of the Discrimination Act (2008) should cover people who find themselves in this type of situation.

Community/social access. Sweden is the only one of the three profiled countries to specify via legislation that there should be social and community inclusion for people with disabilities (through the Social Services Act of 2001). However, each of these nations have various national, regional, and local agencies and charities that may provide assistance with recreational and other social aspects of life for people with disabilities, including specific services and supports for people with visual impairments and their families.

Table 4.1

Adulthood Summary

	U.S.	Australia	Sweden
Population with Visual Impairment	19.1 million (all adults)	40,800 (adults under 65 years old)	919,000 (adults under 65 years old)
Relevant Legislation	ADA, Fair Housing Amendments Act, Section 504	DDA, NDA	Discrimination Act, Social Services Act, Act Concerning Support and Service for Persons with Certain Functional Impairments

Table 4.1 (continued)

Adulthood Summary

	U.S.	Australia	Sweden
Postsecondary Education	Students with visual impairments are enrolling at double the rate of students with disabilities overall; 69.1 percent of students with visual impairments attend 4-year colleges	Students with disabilities comprised 3.7 percent of undergrads as of 2000, of whom 17 percent were visually impaired; Higher Education Disability Support Program aims to further increase enrollment	Statistics are not collected for this population
Employment Rate	55 to 78 percent employment rate is estimated for adults with visual impairment	Employment for people with visual impairments who accessed employment services reportedly have outcomes in line with the national average	People with disabilities have a “slightly higher” unemployment rate than general population; statistics for people with visual impairment are not compiled
Employment Services	VR Program; TTW Program	NDCO Program; open (available to all people) employment agencies, which must comply with Disability Service Standards and Key Performance Indicators to receive public funding; Disability Employment Services network; Job Network; Welfare to Work	Open (available to all people) employment agencies; New Start program; “job guarantee” for young people; there are no agencies specifically catering to people with disabilities

Table 4.1 (continued)

Adulthood Summary

	U.S.	Australia	Sweden
Monetary Benefits	BWE benefit, IRS tax visual impairment tax break, IRWE benefit, SSDI payments; SSDI payments	DSP or Newstart Allowance; Jobs, Education and Training Child Care Fee Assistance	Disability Allowance
Medical Coverage	Medicaid (for adults on SSI); Medicaid (for adults on SSDI)	Medicare (universal health care)	Universal health care
Housing	HUD “designated housing program vouchers”; public housing modifications paid by HUD; private housing modifications paid by tenant	State/territory level programs provide assistance with finding and modifying appropriate housing	Municipal agencies provide assistance with finding appropriate housing; the federal government pays for necessary modifications
Transportation	BWE/IRWE benefit payments may help cover transportation costs; reduced fares on public transportation or paratransit service may be available depending on area of residence	Mobility Allowance; reduced fares on public transportation or paratransit service may be available depending on area of residence	Paratransit service available in all areas; reduced fares for public transportation may be available depending on area of residence
Guide Dogs	Provided at little or no cost; owner must pay for all subsequent medical and maintenance expenses	Provided at no cost; owner must pay for all subsequent medical and maintenance expenses	Provided at no cost; owner must pay for all subsequent medical and maintenance expenses

Table 4.1 (continued)

Adulthood Summary

	U.S.	Australia	Sweden
Associational Protection	Anyone associated with an individual with a disability is protected by the ADA from retaliation if they report discriminatory practices against that individual	Anyone associated with an individual with a disability is protected by the DDA from retaliation if they report discriminatory practices against that individual	There is no specific legislation mandating “association protection,” the Discrimination Act offers blanket protection to all people, so it would apply to associates
Community/Social Access	Various agencies and organizations provide voluntary assistance and advice for access in this area	Various agencies and organizations provide voluntary assistance and advice for access in this area	Various agencies and organizations provide voluntary assistance and advice for access in this area; equal access is mandated by the Social Services Act

* This information has not been released.

CHAPTER 5

SENIOR CITIZENSHIP

For all three of the countries profiled in this paper, much of the published research focuses on issues resulting from acquired visual impairment in the older population. This is perhaps not surprising; as a person's age increases, so does his or her chance of suffering age-related vision loss. However, it must be noted that many of the same issues that affect senior citizens with visual impairments will still have applicability to people of all ages with this type of disability – needed services and supports (e.g., efficient, safe, and reliable public transportation; assistive technology; protection against discrimination) are often the same, regardless of the age of the person affected. In other words, instead of being regarded as a low-incidence disability that is not as worthy of research funding as other, higher-incidence disabilities, perhaps this ageing demographic shift in Western countries such as the U.S., Australia, and Sweden will ultimately instigate more research that ultimately assists people with visual impairments across the age spectrum.

For people with visual impairments, the senior years carry many of the same risks that elderly people without disabilities face, such as decreased overall health, or greatly reduced social interaction and income after retiring. However, a visual impairment may trigger unique problems, such as the great anxiety and enormous life adjustments needed to successfully adapt to acquiring an age-related visual impairment. Even people who have had lifelong visual impairments may feel a greater sense of apprehension in their older years, as they fear the loss or deterioration of whatever visual acuity they do possess. For all of these reasons, it is particularly vital to investigate the impact of visual impairments on senior citizenship.

United States

Designating someone as being a “senior citizen” is an arbitrary matter in the U.S.: the minimum age requirement for this category changes depending on who is asked. As of July, 2009, the U.S. Census Bureau reported that that there were 39.6 million people in the U.S. who are considered to be “senior citizens,” defined as age 65 years old or older (U.S. Census Bureau, 2011a). However, according to the SSA, individuals who have reached 62 years old are considered to be at “full retirement age” and that agency allows individuals to begin applying for their age-related Social Security benefits payments (Social Security Administration, 2008); more on this benefit will be outlined under “Monetary benefits” below. Because the average life expectancy for U.S. citizens is 77.9 years (U.S. Dept. of Health & Human Services, 2007), this means that the majority of these senior citizens will have approximately 15 years in which they will likely have increasing health problems; in fact, these senior years are the time when people who were not previously disabled are most likely to acquire a visual impairment (Prevent Blindness America, 2008).

The four most common visual impairments in the U.S. are all age-related conditions: cataracts, diabetic retinopathy, glaucoma, and age-related macular degeneration (Prevent Blindness America, 2008). The American Federation for the Blind (2011c) reported that two-thirds of the people who are considered “legally blind” are those who have age-related diseases, with a tripled risk of acquiring this type of disease starting at age 65 years old, and a quadrupled risk beginning at 75 years old. That report further stated that senior citizens with visual impairments currently comprise 13.6 percent of the total U.S. population (which would equal approximately 41,752,890 individuals, based on a total population of 307,006,550). These numbers are likely low, however, because this report did not count people in residential facilities – and that population, it seems safe to assume, is likely to have a high incidence rate of visual impairments; indeed, vision loss may be the main reason why many people must move to such facilities. According to Lighthouse International (2011), a major visual impairment advocacy and research organization based in New York City, people who acquire a visual disability after a lifetime of good vision may find the change traumatic, triggering a significantly higher rate of major depression than among the general older population, which may require intensive counseling, rehabilitation, and other supports and services designed to help these individuals adapt their skills and avoid the sadness, stress, anger, and other common negative reactions to vision loss.

Interestingly, a 2008 study found that people who had acquired a visual impairment after the age of 65 years old were still found to be three times more likely to obtain and maintain employment than were people who were already visually impaired when they were between the ages of 16 and 34 years old (Dutta et al., 2008). The authors determined that this discrepancy mainly appeared to be due to the former group's more active use of the vocational rehabilitation options available to them (which, in many cases, helped them keep the jobs they already had when they applied for these services) than were the individuals in the already-impaired group.

Additional Supports and Services

Monetary benefits. The Social Security retirement benefit mentioned at the beginning of this section should not be confused with the SSI and SSDI benefits that Chapter 4 outlined; unlike those payments, this "retirement benefit" is potentially payable to every U.S. citizen after age 65, with benefits calculated on an individualized "credits" basis according to the amount that each person contributed to Social Security throughout his or her working years (Social Security Administration, 2008).

As stated above, all individuals who have contributed sufficiently to Social Security during their years of employment are eligible receive benefits checks in their older years; the current minimum age for benefits applicants is 62 years old (though the rate is being raised with successive generations; people who are young adults as of 2011 may need to work until they reach 70 years old before they will be eligible to draw full Social Security benefits) (Social Security Administration, 2008). But because of their low employment rate throughout adulthood, individuals who already have a visual impairment in their younger years are less likely to have worked enough to contribute sufficiently to Social Security to draw on these monies in old age. However, because many people with visual impairments at this level of severity were already drawing on SSDI payments (see Chapters 3 and 4), they are eligible to continue receiving these payments in their older years (Social Security Administration, 2011a). For individuals with visual impairments who did work at a level where they are not receiving SSDI, but who can nonetheless show that their wages were lower as a result of this disability (such as people who received SSI payments), the SSA will not count those wages when calculating the individual’s average lifetime wages; this has the effect of raising the overall wage average (called a “disability freeze”), which will in turn raise the Social Security benefit amount (Social Security Administration, 2011c).

Medical coverage. U.S. citizens who reach 65 years old are eligible to begin receiving health care insurance under the Medicare program (not to be confused with Australia’s universal health care system of the same name); individuals with disabilities who had already been receiving their medical coverage through Medicaid (as described in Chapter 5) may continue this benefit through their senior years (Social Security Administration, 2011b).

Housing. When they reach their senior years, people with disabilities are no longer eligible for assistance via designated housing program vouchers. Instead, all senior citizens – not just those with disabilities – are protected under the Housing for Older Persons Act of 1995, which allows housing complexes or communities to be designated for the use of older residents; these restrictions on admission to the general public are meant to increase access to appropriate and affordable housing for this older population. The Act states that a minimum of 80 percent of the housing community residents must be at least 55 years old in order to maintain this restrictive status. Older citizens with disabilities may also find help from state government-run agencies; for example, the Vermont State Housing Authority, which was the first such state housing assistance agency in the U.S. (established in 1968), states that its mission is to "promote and expand the supply of affordable rental and homeownership opportunities" for people who are older, with disabilities, or who, for other reasons, cannot obtain appropriate or affordable homes (Vermont Sate Housing Authority, n.d.).

Transportation. The reduced fare and paratransit services, and the right to accessibility to public transportation under the ADA (1990), as described in Chapters 3 and 4, continue to apply as U.S. residents with disabilities as they enter their senior years. Additionally, there may be some state or local agencies that provide transportation services to senior citizens, regardless of their disability status.

Community/social access. There are no national programs specifically meant to ensure that senior citizens with disabilities will have access to recreational and other social activities; in many areas, local agencies and charities provide such services, but because of this emphasis on local service, their availability may vary widely across the country.

Australia

While less than one percent of Australia's population under the age of 65 is considered visually impaired, as noted in Chapter 4, Taylor et al. (2006) reported that when older Australians are included, 5.4 percent of Australians are considered to have some form of visual impairment (including both correctable and uncorrectable conditions), which would equal approximately 1,212,160 individuals, based on a total population of 22,447,400. The life expectancy for Australians is 77.8 years (Australian Institute of Health and Welfare, 2006d), and once age 55 is reached, 9.4 percent are likely to become visually impaired; by age 70 the prevalence rate soars to almost 70 percent (Access Economics, 2010; Australian Institute of Health and Welfare, 2005). Forty percent of people with visual impairments reported that their condition began after they reached 65 years old, which is currently the official age at which people are considered by Centrelink as being senior citizens and eligible for an "age pension" (Australian Institute of Health and Welfare, 2006b; Centrelink, 2011a).

The majority of Australians' visual impairments are due to cataracts, age-related macular degeneration, glaucoma, and diabetic retinopathy (Access Economics, 2010), which are all age-related conditions. Recognizing that visual impairment is an increasingly crucial issue for an ageing population, and wishing to identify means of lowering prevalence rates, two large-scale studies were undertaken in Australia to specifically study the impact of visual impairment on older Australians. The first was the longitudinal Blue Mountains Eye Study, which commenced in 1992 and included re-evaluations in 1997, 1998, 1999, 2002, and 2007; this study specifically examined visual impairments in a cross-section of independently-living urban-dwelling older

Australians in the state of New South Wales that was deemed representative of this age group in the Australian population as a whole (Centre for Vision Research, 2011). The second major visual impairment study, the Melbourne Visual Impairment Project (also initiated in 1992), likewise studied older participants, but it also included people who were institutionalized as well as those who lived independently, and it further recruited participants from rural settings as well as urban residences throughout the state of Victoria (Taylor, Keeffe, Vu, Wang, Rochtchina, Pezzullo, & Mitchell, 2005). Between these two studies, 8,909 participants were studied, making these studies of particular significance. Based on these studies, it is estimated that, if no further prevention or corrective initiatives are undertaken, the percentage of Australians with visual impairments is projected to double by 2024, to 6.5 percent of the population (Taylor, et al., 2005). The Blue Mountain study further warned that visual impairment will continue to result in a rate of admission to institutionalized residential care that is twice the rate for non-visually impaired persons – a troubling outcome that does not decrease in likelihood even for people with correctable vision problems (Wang, Mitchell, Cumming, & Smith, 2003).

Despite these findings, the Australian government is careful to clarify that acquiring a disability does not mean that an individual is automatically condemned to a lower quality of life:

> "Disability does not necessarily equate to poor health or illness… Discussion of 'health expectancy' should not be interpreted as considering years with disability to be of less value than 'healthy' years (without disability) for any policy purpose" (Australian Institute of Health and Welfare, 2006d).

Demonstrating this commitment to helping older Australians cope with becoming disabled, the AIHW reported that more than half of the people who accessed their services were both visually impaired and over 65 years old (Australian Institute of Health and Welfare, 2011). As the

Australian Institute of Health and Welfare (2006a) further reports, this outreach is the result of increased awareness that “there is an acknowledged need to blend aged care and disability services more seamlessly and to improve intergovernmental linkages” (p. 542).

Additional Supports and Services

Monetary benefits. Senior citizens with disabilities continue to be eligible for the basic DSP (as described in Chapter 4), plus, at age 65 years old, there is an additional “Pension Supplement”; further, pensioners who are permanently blind have the income and asset eligibility tests waived (Centrelink, 2011c). The basic Pension Supplement amount, as of 2010, was A$20.40 (U.S.$21.90) for an individual and A$34.00 (U.S.$36.50) for couples (Centrelink, 2011c)

Medical coverage. As explained in Chapters 2 through 4, the universal health care system continues to cover all Australian citizens as they enter their senior years, regardless of their disability status or the severity of their condition (Department of Human Services, 2011c). In addition to free treatment at public hospitals, older people with disabilities may qualify for subsided services payments to carers (i.e., family members who provide in-home assistance to the individual) (Centrelink, 2011c).

Housing. Paid through the Medicare system, there are housing subsidies available to senior citizens, to enable more people to stay in their own homes as they age (Department of Human Services, 2011c). The carer payments via Medicare, as described above, may also allow more elderly Australians to continue to live in their own homes for as long as possible. For older people with disabilities who do not have a family member available to provide such care, there are several community-based programs available to provide carers, at low or no cost to the individual; these programs range from the Community Aged Care Packages (for people needing a lower level of assistance) to Extended Aged Care at Home (for people requiring extensive and long-term care) (Department of Health and Ageing, 2011).

Transportation. The Mobility Allowance, outlined in Chapters 3 and 4, no longer applies once people with disabilities retire, because eligibility for this benefit requires the individual to show that he and she uses at least part of the payment to cover travel to and from a job. There are no federal government programs to assist elderly people, with or without disabilities, with transportation issues; however, there are many state/territory and local agencies and charities that may provide such assistance. For instance, in the state of New South Wales (NSW), there is a free “Seniors Card” that enables this population to ride public transportation at a discounted rate (NSW Government, n.d.).

Community/social access. There are no federal programs to specifically promote community and social inclusion for older residents, regardless of whether or not they are disabled – this responsibility falls to state/territory or local providers, and services can vary greatly across the country. As an example, the NSW Seniors Card, described above, also entitles cardholders to discounts at many businesses and events, to encourage higher participation in the community (NSW Government, n.d.).

Sweden

Sweden has a relatively large older population: as of 2005, 17.3 percent of the total population is at least 65 years old, and this rate is expected to rise to 23.6 percent by 2050 (Ministry of Health and Social Affairs, 2007a). According to Statistics Sweden (2010), life expectancy for Swedish citizens is also relatively high; it is currently set at 79.53 years. To care for this older population, Sweden expends the most on elderly care of any European Union nation – 2.5 percent of the country’s GDP in 2005 (Eurostat Yearbook, 2009). Within this older population, people “with impaired eye sight” comprise 5 percent of the “cohabitating” people between the ages of 65 to 74 years old; this figure rises to 11 percent of this population for people who are “single” (this combined total of 16 percent of the population equals approximately 1,507,625 individuals, based on a total population of 9,422,661); when the age range included people up to 84 years old, the proportions rose to 14 percent (cohabitating) and 18 percent (single) of the total senior population (Statistics Sweden, 2008). Data regarding the most common visual impairments within Sweden’s adult population have not been released, but given the relatively (and increasingly) high rate of senior citizenry within the overall population, it seems likely that age-related conditions would be most common.

The Swedish government’s goal for all senior citizens, including those with disabilities, is to enable them “to live independently with a high quality of life,” defined as being able to

> “lead active lives and have influence on society and on their own everyday lives; be able to grow old in security and retain their independence; be treated with respect; and have access to good health and social care services” (Ministry of Health and Social Affairs, 2007a, p. 1).

To meet these mandates, municipalities and county councils are responsible for providing support and services for all older citizens within their jurisdictions, and they have a great amount of leeway in deciding how funds and resources should be allocated to meet the demand. This results in varying types of programs and priorities by region, although a baseline standard of care (both in terms of medical attention and social access and inclusion services) for senior citizens with disabilities is mandated nationally through the Social Services Act of 2001 (previously discussed in Chapters 2 and 4) (Ministry of Health and Social Affairs, 2007a). This law provides multi-year “social welfare” grants to municipalities that demonstrate efforts to institute new or improved services for this population (Ministry of Health and Social Affairs, 2007a).

Additional Supports and Services

Monetary benefits. Senior citizens with disabilities who have worked and thereby contributed to the national pension fund may begin drawing a guaranteed pension from this system starting at age 65 years old (Ministry of Health and Social Affairs, 2007c). Older people who have not been able to work, or who have a low rate of contribution to the national pension, may still receive a “top-up” pension that also becomes available once they reaching age 65 years old, though they must have been a resident of Sweden for at least 40 years to get the full rate; this pension is guaranteed by the federal government and comes out of its annual budget instead of the national pension fund (Ministry of Health and Social Affairs, 2007b). Finally, for people who are at least 65 years old but who have not met the minimum residency requirement, there is still another “means-tested benefit” payment available, mandated through the Maintenance Support for the Elderly Act (2001), which pays out at a lower rate than a “full guarantee” pension (Ministry of Health and Social Affairs, 2007b). Through these extensive social insurance schemes, virtually all residents, with or without disabilities, should have access to some form of old-age pension payment.

Additional monetary assistance may also be given to senior citizens (with or without disabilities) to compensate them for long-term care costs, such as hiring a personal assistant (Ministry of Health and Social Affairs, 2008).

Medical coverage. Sweden’s universal welfare system for all citizens, as described in Chapters 2 through 4, continues to cover people with disabilities as they enter their senior years.

The Health and Medical Services Act (1982) guarantees this comprehensive coverage, regardless of the presence of a disabling condition, or its severity.

Housing. In Sweden, it is considered particularly important for senior citizens to remain in their own homes and live independently for as long as possible, with the municipalities held responsible for overseeing that this responsibility is fulfilled, done by coordinating service agencies and medical providers as necessary (Ministry of Health and Social Affairs, 2007b). For these local governments, this may entail such things as covering home modification costs (as outlined in Chapter 4), or paying for a personal assistant to come into the home to help with things like personal care, cooking, cleaning, etc., but all measures taken must be undertaken with the end goal of allowing elderly individuals to remain in their own homes, even if their needs are extensive or their disabilities are severe (Ministry of Health and Social Affairs, 2007a). The Ministry of Health and Social Affairs (2007a) reported that, as of 2007, 93 percent of senior citizens were living in their own homes. There is not a distinction in Sweden between the needs of an elderly person, or the needs of an elderly person who additionally has a disability; regardless of the level of care needed or the reasons for it, the municipality is responsible for ensuring that each individual receives the supports and services necessary to maintain a “good” standard of living (Ministry of Health and Social Affairs, 2007a).

Transportation. The transportation allowance, as described in Chapter 3 and 4, continues to be available to people with disabilities; in fact, this service becomes available to all Swedish residents once they enter their senior years (Ministry of Health and Social Affairs, 2007a).

Community/social access. For people whose age or disability places more severe limits on their ability to travel or use assistive technology, there are additional legislative protections that enable them to continue actively participating in the community. The assistive technology provided by SRF and other agencies (also outlined in Chapter 4) also remains available for people as they become older. Under the joint authority of the Social Services Act (2001) and the Health and Medical Services Act (1982), each municipality is required to maintain a Social Welfare Board to assist people who cannot work with accessing "meaningful" daily activities, planned on an individualized basis (Ministry of Health and Social Affairs, 2007b). This benefit is open to anyone who is unable to work because of age- and/or disability-related limitations, and who therefore needs to find recreational or other activities that enable him or her to participate in the community. For people who need such assistance for less than 20 hours per week, the Social Welfare Board may recommend providing a "companion service," by paying someone (often a family member) to help the individual participate in social activities, thereby reducing the possibility of isolation for that person (National Board of Health and Welfare, 2009).

Discussion

The definition of "senior citizenship" varies, depending on which agency within each of the profiled countries is surveyed. However, for the various services and supports described in this chapter, this stage of life is typically considered to begin between 62 to 65 years old.

The U.S., Australia, and Sweden all have similarly high life expectancies, but they all also share the common problem of having their older citizens face a greater risk of developing a visual impairment than they do at any other stage in life. The most common visual impairments are the same for the U.S. and Australian residents, and they are all conditions that predominantly affect older people – cataracts, diabetic retinopathy, glaucoma, and age-related macular degeneration. (There are no available data about the most common visual impairments in Sweden, although it seems reasonable to assume that these same conditions are also well-represented there.)

Additional Supports and Services

Monetary benefits. Each of the three profiled countries provides monetary benefits to assist older citizens, regardless of whether or not they have disabilities; in each nation, there are provisions for people who have contributed to pension schemes and those who have not, so that nobody is left with nothing in their old age. In the U.S., people who had been receiving SSDI may continue to receive it, but for most people, coverage is granted through the Social Security retirement benefit. Australia is similar, in that it continues benefits payments to DSP recipients, but the majority of people instead receive a “Pension Supplement” instead. In Sweden, people who have worked and contributed to the national pension fund may begin drawing pension payments in their older years, but even people who have not worked (or worked long enough) are still eligible for a “top up” pension.

Medical coverage. Older U.S. citizens may begin receiving health care coverage under the Medicare program, but those people who had already been enrolled in the Medicaid program prior to entering their older age may continue to receive their coverage through this program instead. In Australia and Sweden, the universal health care systems continue to apply, regardless of age, or disability status or severity.

Housing. In each of the three profiled countries, there are provisions to assist older people with accessing appropriate housing, although the approaches taken are quite varied. In the U.S., the Housing for Older Persons Act (1995) allows for the creation of housing communities that are reserved for senior citizens, which provides more access to safe and affordable accommodations. In Australia and Sweden, the emphasis is instead on helping people remain in the same homes that they had lived in throughout their earlier years. In Australia, this is done through governmental “carer payments” that help to cover the expenses of providing in-home care for older people, regardless of the level of care required. In Sweden, municipalities are responsible for providing support and services as are deemed appropriate to enable their older residents to stay in their own homes for as long as possible, and with a good standard of living.

Transportation. As was the case in earlier stages of life, older citizens of each of these three nations may be able to utilize paratransit services or reduced fares for public transportation, depending on where they live. Of these three countries, only Sweden provides a governmental transportation allowance to its older residents to assist them with their mobility.

Community/social access. Assisting older citizens, including those with disabilities, to continue to participate in recreational and other community activities is not formally provided by the government in either the U.S. or Australia; this is left up to state/territory or local agencies and charities. In contrast, Sweden does mandate that there must be help with social inclusion for its older residents, requiring municipalities to maintain a Social Welfare Board to offer individualized activities for this population.

Table 5.1

Senior Citizenship Summary

	U.S.	Australia	Sweden
Population with Visual Impairment	Approximately 41,752,890	Approximately 1,212,160	Approximately 1,507,625 (between 65 to 74 years old)
Life Expectancy	77.9 years	77.8 years	79.53 years
Relevant Legislation	ADA, Section 504	DDA	Discrimination Act, Health and Medical Services Act, Maintenance Support for the Elderly Act, Social Services Act

Table 5.1 (continued)

Senior Citizenship Summary

	U.S.	Australia	Sweden
Most Common Visual Impairments	Cataracts, glaucoma, diabetic retinopathy, age-related macular degeneration	Cataracts, glaucoma, diabetic retinopathy, age-related macular degeneration	N/A*
Monetary Benefits	Social Security retirement benefit starting at age 62 years or continuation of SSDI	DSP; Pension Supplement starting at 65 years	Starting at age 65 years: guaranteed pension for people who have contributed to the national fund through work earnings taxes; "top up" pension for those who did not work or contributed at a lower rate and who have resided in Sweden for 40+ years (a "means-tested payment" is provided to those who do not meet this minimum residency requirement)
Medical Coverage	Medicare, starting at age 65 (or continuation of Medicaid for SSDI recipients)	Medicare (universal health care); subsided services payments to carers providing in-home assistance	Universal health care
Housing	May access designated housing for older residents starting at 55 years	Housing subsidies via Medicare system; Community Aged Care Package; Extended Aged Care at Home program	Municipalities responsible for providing appropriate housing and paying for necessary modifications

Table 5.1 continued

Senior Citizenship Summary

	U.S.	Australia	Sweden
Transportation	Reduced fares on public transportation or paratransit service may be available depending on area of residence	Reduced fares on public transportation or paratransit service may be available depending on area of residence	Paratransit service available in all areas; reduced fares for public transportation may be available depending on area of residence
Community/Social Access	Various agencies and organizations provide voluntary assistance and advice for access in this area	Various agencies and organizations provide voluntary assistance and advice for access in this area	Various agencies and organizations provide voluntary assistance and advice for access in this area; equal access is mandated by the Social Services Act

* This information has not been released.

CHAPTER 6

SUMMARY AND CONCLUSION

Visual impairment is not just an area of personal concern for the individuals who have this type of disability; it is also an area of great interest for society overall because of the economic and systemic implications that it engenders. Even “First World” countries such as the U.S., Australia, and Sweden are increasingly being forced to confront these issues with the rising proportion of their senior citizen populations, and the heightened risk of visual impairment this brings. However, as this paper has shown, each of these three countries is attempting to address this situation through various policies and procedures, the outcomes of which impact not only these older citizens, but people with visual impairments of all ages.

Summary

The U.S., Australia, and Sweden have all historically used institutionalization as a means of providing care for people with disabilities, but each of these nations have since rejected this approach and instead embraced the notion that all citizens, regardless of disability status, have the right to full and equal participation in society. Each of these countries has tried to fulfill this ideal through legislative protections, supports, and services that are sometimes similar to each other, but often quite different, resulting in each nation attaining its own unique and varied results for its citizens with visual impairments. If, as these countries’ policies profess, the ultimate goal for their citizens with disabilities is to enable their full inclusion and participation in society, what do the findings of this study appear to indicate?

Legislative Impact

Perhaps the most influential and distinctive means through which these countries provide protections for people with visual impairments are their various legislative measures. Unlike Australia and Sweden, the U.S. has disability-specific laws, including mandates specifically regarding the education of children with disabilities (IDEA, 2004; NCLB, 2001) and for protecting people with disabilities overall (ADA, 1990; Section 504 of the Rehabilitation Act, 1975), but does this mean that the U.S. system is more effective for these citizens? Or does it just mean that there is that much more bureaucratic red tape for citizens with disabilities to cut through to gain appropriate protections, supports and services? Some might argue that Sweden and Australia's lack of pinpointed legislative protection means that people with disabilities (of any age) may not receive adequate attention and assistance. However, it also could be argued that including this population's needs within general education legislation reinforces the fact that they are part of the overall society, instead of a group that must be singled out and regarded as fundamentally "different." In effect, perhaps this refusal to legislatively single out people with disabilities is the ultimate inclusive measure.

Unfortunately, while all three of the profiled countries have policies in place for enabling the majority of children with visual impairments to enter childcare, preschool, and mandatory education, the lack of statistics about this group within Australia and Sweden frustrates efforts to draw any meaningful comparisons for this age group. Until such data are collected for all of these countries, it will be difficult, if not impossible, to gauge whether the U.S., with its complex laws regarding educative measures for students with disabilities, should be emulated because it is encouraging better outcomes for its youngest citizens with disabilities, or if these regulations are so labyrinthine and daunting as to discourage compliance, or even encourage educator backlash against these students. Unfortunately, even the President's Commission on Excellence in Special Education (2002) concluded that the latter outcome is the more likely reality:

> "At all levels, the Commission finds that the emphasis on IDEA paperwork requirements is unnecessarily onerous… Teachers spend far more time completing documentation and paperwork than is merited by any educational or civil rights compliance purpose" (p. 11).

While it might seem easy to declare that the U.S. system is therefore inferior to the Australian and Swedish systems, it should be noted that there is not yet enough information available to determine whether those nations' resistance to detailed legislation regarding their students with disabilities has encouraged a higher degree of educational success for this population, or whether their more broad approaches simply foster different but equally serious types of problems.

The findings in this study reveal another difficulty for children as they progress through the educative years which is common to each of these countries: transition services may be offered too late to help many students with disabilities. In the U.S., transition services must be provided no later than the student's 16th birthday, but this is the age at which many states allow students to drop out. Australia and Sweden, with their voluntary transition services, are not required to provide any transitional training at any age. The result may be that the students with disabilities, already much more likely to drop out and be in need of support and services to acquire an adequate standard of living, may be legally bypassed for the transition services they need the most. U.S. data indicate that students with disabilities have a much higher dropout rate than their peers, signaling that there may be many such students who are falling through the cracks with regards to learning needed life skills; data about dropout rates are unavailable for Australian and Swedish students with disabilities, so it is not possible to tell how many of those students are similarly being overlooked or ignored.

One key indicator of success or failure is the issue of adult employment outcomes. A person's ability to obtain and maintain a meaningful occupation may influence every other aspect of adult life – it provides the means for financial independence, social interaction, and may be crucial to fostering a sense of self-worth. Therefore, it is a reasonable expectation for people with disabilities, including those with visual impairments, to aspire to fulfilling careers. However, judging by the high unemployment rate of adults with disabilities in the U.S. – and in particular, the abysmal results in this area for people with visual impairments – the answer seems to be that the U.S. system, while clearly well-intentioned, does not ultimately provide a high level of positive long-term outcomes in this important area. Even U.S. programs like Ticket to Work, which is touted as being a comprehensive means of providing a high degree of attention and assistance to people with disabilities, may be just be another example of how convoluted, complex regulations may actually serve to undermine success more than encourage it. In contrast, Australia and Sweden appear to offer their citizens much more favorable employment outcomes, despite the fact that neither country offers any disability-specific federal legislation at all, and provide job training and assistance to the majority of people with disabilities through the same means accessible to any other citizen. However, true comparisons between these countries' success levels in this area are frustrated by the lack of specific data on employment rates for people with visual impairments or other disabilities in Australia and Sweden.

Another indicator of success for people with visual impairments – or any other disability – may be found in the rate at which they become or remain dependent on government financial assistance in their adult years. Again, this is an area in which the U.S. system may be judged as comparatively flawed, in that its more lenient eligibility requirements appear to provide no real incentives for people with disabilities to remove themselves from the payment rolls and seek gainful employment. Once deemed eligible for government assistance, a person with a permanent disability may continue receiving payments indefinitely, even if that individual is capable of working to some extent, and whether or not he or she makes any efforts to do so. Indeed, it can be argued that there is actually a disincentive for these individuals to work, as the cutoff income rate to continue receiving benefits is set so low that an individual may decide that it is better to remain dependent on the government than to work a low-wage job that offers no health insurance or other benefits. This situation can easily lead to chronic unemployment for this population. In contrast, Australia and Sweden, while recognizing that there may be rare circumstances where a person truly is too incapacitated to work, still provide restrictions and regulations that encourage citizens to work to their fullest extent possible, in order to encourage their financial independence, social involvement in the community, and personal sense of well-being. Also, these nations' universal health care systems mean that individuals do not have to remain on governmental assistance just to continue receiving health care coverage. In this way, relatively few people remain wholly dependent on the government payouts for their entire lives. In the U.S., however, such lifelong dependence is a real danger for many people with disabilities, thus ensuring that perhaps more people than necessary live at or near the poverty level, and additionally run a higher risk of being socially isolated. In particular, the alarmingly high unemployment rate for people with visual impairments, despite their relatively high success rate in postsecondary education, is a clear indicator that the U.S. system needs to be further examined and changed. It should be noted that the U.S. federal government is in the process of reforming the health insurance system, which could lead to increased medical coverage and employment options for people with disabilities. According to the Department of Health and Human Services (2010), this revised system, as outlined in the Affordable Care Act that was signed into law by

President Obama in 2010, is scheduled for full implementation for all Americans by 2014; provisions within this legislation that may particularly impact people with disabilities are: mandates that people with preexisting conditions cannot be denied health insurance coverage; abolishment of payment “caps” that limit the amount of expenses and types of procedures that insurers will cover; and increasing patients’ choices for health care providers (U.S. Department of Health and Human Services, 2010). Providing this type of expanded health care “safety net” may encourage more people – with or without disabilities – to choose to obtain employment instead of remaining on government assistance, because doing so will no longer entail risking losing health care coverage.

Finally, the fact that all three of the profiled countries are facing an increasingly higher proportion of elderly citizens, and this population’s increased risk of acquiring visual impairments, adds further urgency to the matter of discerning which of these countries’ policies for this age group are most effective. While each of these nations provide various supports and services to their older citizens with disabilities, none of them have yet undertaken any sweeping initiatives regarding this specific population and its unique problems and needs. However, it is expected that finding better solutions will become a higher priority within these nations, as their proportion of older citizens increase and the corresponding impact on society is increasingly felt. In particular, Sweden, with its socialistic system, may be in particular danger if this demographic shift is not adequately addressed:

> “As the number of elderly people in the population increases, there is a growing concern about society’s ability to cope with their needs at a time of restricted national economic resources. These circumstances are leading to an increasing gap between needs and resources” (Lilja et al., 2003, p. 133).

Although Sweden may be in a particularly vulnerable position if it does not attend to this situation, all three of the profiled nations may find themselves at increased financial and social risk if this issue is not seriously addressed. The silver lining here is that increased attention necessitated by the ageing baby boomer generation may spark research and policy changes that will have a beneficial impact on citizens with visual impairments of all ages.

Limitations

While every attempt was made to make this examination as thorough, comprehensive, and objective as possible, there are some limitations that should be acknowledged. The most potentially harmful of these limitations is the author's own potential cultural biases: as a lifelong U.S. citizen, and as a legally blind person, this author has experienced the workings of the U.S. disability support system on a personal level, which has often led to frustration or sometimes even anger; this may result in undue criticism of the potential benefits and an over-emphasis on the shortcomings of the U.S. system. It could be that this may lead to overly generous admiration of how other countries appear to treat their own citizens with visual impairments.

Another limitation engendered by this author's U.S. residency may be that there was increased access to U.S.-related information compared to that available for the other nations, which may have skewed the results. The majority of the research for this paper, by necessity, was done via the Internet, which may mean that some information about Australian and Swedish policies and procedures simply were not located because they are not available online. Additionally, while the Swedish government appeared to make all of its information available in both the Swedish and English languages, there likely was other information, such as research articles and agency publications, that was overlooked simply because this author does not speak Swedish, and therefore did not identify this content as being of importance. Additionally, it must be remembered that just because a country's polices and legislation promise certain services and supports, it does not necessarily follow that is actually the case in reality. The fact that Australia and Sweden are geographically so far away as to make personal observations of these systems impossible means that there may be a disconnect between what is publicly stated as being available to citizens with visual impairments or other disabilities, and what is actually available in day-to-day life for these people.

A further limitation may be the fact that these three countries were chosen by the author for examination, so more varied or meaningful results might have been obtained if different nations had been selected. For instance, the inclusion of a non-Western or non-First World nation might have led to more dramatic insights. For instance, it may be more valuable to examine the policies and procedures within a Muslim country, where a person with a visual impairment may face the unique problem of being unable to use a guide dog because Muslims consider dogs to be unclean; this means that it is considered culturally appropriate to forbid guide dogs from public areas (Encyclopedia of Religion and Nature, 2004). Future research might uncover alternative means and methods for assisting people with visual impairments that could be considered for implementation on a wider scale.

Conclusion

This paper has sought to describe and analyze supports and services across the lifespan for people with visual impairments in the U.S., Australia, and Sweden. Comparisons and contrasts between these geographically, politically, and socially diverse countries were made as a means of developing insight into contemporary policies and procedures, as well as evaluating the relative effectiveness of these measures. While it is concluded that much work remains to be done in this area, in terms of achieving the inclusive societies that each of these nations professes to hold as an ultimate goal, it is also found that each of these countries has put forth significant effort in recent decades, through legislative mandates and public policies, to assist this population through various means. It is hoped that the increasing awareness within these and other nations of the economic and social impact of visual impairments will result in even more improved and expanded future policies and procedures that will benefit people of all ages with this disability, so that these individuals may lead productive and fulfilling lives.

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APPENDIX A

ACRONYMS AND ABBREVIATIONS

A$	Australian dollar (currency)
ADA	Americans with Disabilities Act (U.S.)
AAP	American Association of Pediatrics
AFB	American Federation for the Blind
AIHW	Australian Institute of Health and Welfare
APH	American Printing House for the Blind
BWE	Blind Work-Related Expenses (U.S.)
CDC	Centers for Disease Control and Prevention (U.S.)
CSTDA	Commonwealth State/Territory Disability Agreement (Australia)
DDA	Disability Discrimination Act (Australia)
DSP	Disability Support Pension (Australia)
EEOC	Equal Employment Opportunity Commission (U.S.)
FHAA	Fair Housing Amendments Act (U.S.)
Higher Education DSP	Higher Education Disability Support Program (Australia)
HSO	*Handikappförbundens samarbetsorgan* – Swedish Disability Federation
HUD	Department of Housing and Urban Development (U.S.)
IDEA	Individuals with Disabilities Education Act (U.S.)
IEP	Individualized Education/al Program/Plan (U.S./Sweden)
IFSP	Individual Family Service Plan (U.S.)
IRS	Internal Revenue Service (U.S.)
JETCCFA	Jobs, Education and Training Child Care Fee Assistance (Australia)
IRWE	Impairment-Related Work Expenses (U.S.)
LSS	*Lag om stöd och service till vissa funktionshindrade* - Act Concerning Support and Service for Persons with Certain Functional Impairments (Sweden)
NCLB	No Child Left Behind Act (U.S.)
NDA	National Disability Agreement (Australia)
NDCO Program	National Disability Coordinating Officer Program (Australia)
NLTS2	National Longitudinal Transition Study-2
OECD	Organisation for Economic Co-Operation and Development (international)
OSEP	Office of Special Education Programs (U.S.)
Section 504	Section 501 of the Vocational Rehabilitation Act (U.S.)
Section 504	Section 504 of the Vocational Rehabilitation Act (U.S.)
SEK	Swedish krona (currency)
SoL	*Socialtjänstlag* – Social Services Act (Sweden)
SPSM	*Specialpedagogiska skolmyndigheten* – National Agency for Special Needs Education and Schools (Sweden)

Appendix A continued: Acronyms and Abbreviations

SRF	*Synskadades riksförbund* – Swedish Association of the Visually Impaired
SSA	Social Security Administration (U.S.)
SSDI	Social Security Disability Insurance (U.S.)
SSI	Supplemental Security Income (U.S.)
TTW	Ticket to Work program (U.S.)
U.S.	United States
VR Program	Vocational Rehabilitation Program (U.S.)

APPENDIX B

DISABILITY LEGISLATION TIMELINE

Year	Legislation
1947	Social Security Act (Australia)
1968	Special Service Act (Sweden)
1973	Vocational Rehabilitation Act (U.S.)
1974	Handicapped Persons Assistance Act (Australia)
1975	Education for all Handicapped Children Act (U.S.)
1978	Senior Citizens Act (U.S.)
1981	Human Rights Commission Act (Australia)
1982	Social Services Act (Sweden)
1985	Education Act (Sweden)
1986	Human Rights and Equal Opportunity Act (Australia)
1986	Disability Services Act (Australia)
1988	Fair Housing Amendments Act (U.S.)
1990	Individuals with Disabilities Education Act (U.S.)
1990	Americans with Disabilities Act (U.S.)
1992	Disability Discrimination Act (Australia)
1995	Parental Leave Act (Sweden)
1995	Housing for Older Persons Act (U.S.)
1997	Individuals with Disabilities Education Act reauthorized (U.S.)
1998	Compulsory School Ordinance (Sweden)
2001	No Child Left Behind Act (U.S.)
2001	Social Services Act (Sweden)
2002	Commonwealth State/Territory Disability Agreement (Australia)
2004	Individuals with Disabilities Education Act reauthorized (U.S.)
2008	Discrimination Act (Sweden)
2009	National Disability Agreement (Australia)
2010	Affordable Care Act (U.S.)

APPENDIX C

U.S. RESOURCES FOR VISUAL IMPAIRMENT

Office/Agency	Website	Purpose
American Federation for the Blind	http://www.afb.org/	National non-profit advocacy organization for people with visual impairments and their families and associates
Equal Employment Opportunity Commission	http://www.eeoc.gov/	Federal agency for eradicating employment discrimination
National Federation of the Blind	http://www.nfb.org/	National advocacy organization for people with visual impairments and their families and associates
Prevent Blindness America	www.preventblindness.org/	Nonprofit organization dedicated to raising awareness about vision loss in the U.S.
Social Security Administration	www.ssa.gov/	Federal agency responsible for various benefit payments and programs (SSI, SSDI, Ticket to Work, etc.)
U.S. Department of Justice, Civil Rights Division	http://www.justice.gov/crt/	Federal agency to promote equality for groups experiencing discrimination
Vocational Rehabilitation Program	Each state runs its own VR Program site; for example, Georgia’s is http://www.vocrehabga.org/vrfacts.html	Provides assistance with job training, placement, and maintenance for people with disabilities

APPENDIX D

AUSTRALIAN RESOURCES FOR VISUAL IMPAIRMENT

Office/Agency	Website	Purpose
Australian Institute of Health and Welfare	http://www.aihw.gov.au/	National agency for health and well-being within the Australian federal government
Blind Citizens Australia	http://www.bca.org.au/	National advocacy and support agency for people with visual impairments and their families and associates
Centrelink	http://www.centrelink.gov.au/	Federal agency responsible for various benefit payments and programs (DSP, carer benefits, Welfare to Work, etc.)
Department of Education, Employment, and Workplace Relations	http://www.deewr.gov.au/	Federal department in charge of overseeing educational policies, providing public employment services, etc.
Medicare	http://www.medicareaustralia.gov.au/	Universal health care provider
NDCO Program	http://www.deewr.gov.au/NDCO	Program for assisting with transition, employment, and other assistive services for people with disabilities
Vision Australia	http://www.visionaustralia.org.au/	National non-profit advocacy organization for people with visual impairments and their families and associates

APPENDIX E

SWEDISH RESOURCES FOR VISUAL IMPAIRMENT

Office/Agency	Website	Purpose
European Agency for Development in Special Needs Education	http://www.european-agency.org/	Overview of member countries' special educational supports and services
Government Offices of Sweden (*Regeringskansliet*)	http://www.sweden.gov.se/	Information about legislation and governmental agencies
National Association for Disabled Children and Youths (*Riksförbundet för Rörelsehindrade Barn och Ungdomar*)	http://www.rbu.se/	Support, services, and advice for children with disabilities and their families
Swedish Association of the Visually Impaired (*Synskadades Riksförbund*) *	http://www.srf.nu/	Support and services for citizens with visual impairments
Swedish Institute (*Svenska Institutet*)	http://www.sweden.se/	Information about a wide range of social, cultural, political, and business topics
Swedish National Agency for Education (*Skolverket*)	http://www.skolverket.se/	Information about the public school system
Swedish National Agency for Special Needs Education and Schools (*Specialpedagogiska Skolmyndigheten*)	http://www.spsm.se/	Special educational supports and services, advice, and educational materials
Swedish Social Insurance Agency (*Försäkringskassan*)	http://www.forsakringskassan.se/	Disability benefits payments information (social insurance)

* This website is in Swedish only; all other websites are available in both Swedish and English language versions.