

SELF-DETERMINATION, AUTONOMY AND ALTERNATIVES FOR GUARDIANSHIP

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Introduction

Self-determination involves the struggle for control and a voice in the key personal decisions that affect the individual. On its face, guardianship seems to be antithetical to self-determination, as it tends to shift the locus of control from the affected individual to a legally empowered agent (the guardian). A number of countries have adopted new legislation in recent years to minimize the use of guardianship, to impose only its least restrictive alternatives, and to introduce other innovations. This paper sketches those developments as well as related legal reforms in personal supports that enable people with disabilities to obtain companionship for support and other discrete forms of assistance.¹

The imposition of guardianship poses important ethical, legal and practical problems for the disability rights community. Those problems also arise for some persons who are elderly, and for other "vulnerable" people, however they are labeled, whose right to make their own decisions is challenged.

The ethical questions involve ideas of paternalism, liberty, prevention of harm and exploitation, beneficence, and the power relationships between guardian and ward. Finding better answers will implicate vital principles of self-determination, including freedom, authority, support and responsibility.² In particular, it challenges policymakers and other leaders to devise new modes for self-determined personal support through which the individual with a disability, "with the assistance of a personal agent and others the individual invites to participate, has the authority to plan for his or her own future and oversee the implementation of those plans."³

The issues of this monograph are best viewed through a comparative law perspective. Do other countries minimize the use of guardianship? Do they find alternatives to both maximize the individual's autonomy and to offer community-support services that aid the individual to participate in society's decision-making processes? Those processes can include medical, financial, rehabilitative, and other surrogate-based protective service systems. For instance, Sweden's "god man" (mentorship) law covers those various decision-making spheres for persons with protective service needs.

The community-support problems will become more acute as institutions are downsized or eliminated. Institutions were once described as the "poor man's guardianship" since the residents were under the plenary power of institutional staff who exerted a defacto guardianship. Yet nursing homes and other congregate care facilities are now under federal legal mandates to counsel residents and their families on proxy decision-making. Unfortunately, such mandates may indirectly lead to more persons being placed under guardianship as a matter of administrative or medical convenience.

Guardianship in some parts of the U.S. has become an overused legal institution in danger of collapse. It can be a blunt device for managing an alleged incompetent person's property, assuming control over his or her personal decision-making, and gaining plenary authority over virtually every aspect of financial and personal management. To some of its critics, it is a "dangerously burdened and troubled system that regularly puts the lives of persons with disabilities and persons who are elderly in the hands of others with little or no evidence of necessity, then fails to guard against abuse, theft and neglect."⁴ The legal and scientific literature is also replete with criticisms of the law and practice of involuntary guardianships involving persons with mental or physical disabilities.⁵ Scholars and reformers have documented the risk of such guardianships and similarly coercive measures intruding on fundamental liberties and privacy rights, employing vague criteria, failing to tailor appropriately and narrowly the scope of the guardian's authority, denying procedural safeguards, and lacking adequate monitoring and periodic review.⁶

Despite these perceived shortcomings, more people are being subjected to guardianship proceedings, most often due to their inability to consent to medical care. Because informed consent to treatment is a requirement of the common law of most American states as well as a mandate of the federal Nursing Home Reform Act of 1987,⁷ health-care providers are understandably concerned when a potential patient appears to lack the capacity to provide such direct consent. In part due to their lack of familiarity with the alternatives, service producers often propose guardianships when less restrictive solutions would suffice. Such problems are not only nationwide, but are encountered in Western European and other industrialized countries.⁸

There is a global search for personal support solutions that are empowering and not disenfranchising. In noting the self-determination movement's focus on empowerment, Thomas Nerney and his colleagues point out that adults "develop their own capacity and competency for self-determination."⁹ But adults do not gain that knowledge, skill, and experience from thin air, and some adults will require patience and personalized supports to enhance their self-determined options. It is the task of humane 21st century societies to recognize that the capacities of people with disabilities are not static, to help them to learn and grow, and to support wide-ranging choices commensurate with the individual's aspirations and needs.¹⁰ Such societies will spend more time listening to people with disabilities, and less time dictating to them based on the presumed superiority of the expert's answers. Such societies will reallocate resources so that instead of proffering only restrictive options, laws and policies will offer self-determination enhancing and cost-efficient support options.

a) The U.S. Position: On The Edge of Reform

Consumer and professional groups in the U.S. are concerned over both under-protective and over-protective approaches to meeting protective service and community-support needs. The issues are legally, ethically, and politically sensitive as well as technically complex since some individuals have legitimate needs for assistance.¹¹

There are other sources of complexity as well. First, the U.S. legal position is not one approach, but 51 approaches since state laws and practices vary from jurisdiction to jurisdiction. Second, depending on the context, the laws of any one state may offer many alternatives to plenary guardianship (e.g., limited guardianship, temporary guardianship, health care proxy decision-makers, representative payees for income maintenance benefits, supported training for self-advocacy, etc.). Third, and most distressingly, the resulting confusion and lack of training as to which option to use to maximize autonomy can lead to

the unnecessary disempowerment of some persons with disabilities, the fragmentation of decision-making responsibilities, the undue cost and delay of overly legalistic models, and the failure to search vigorously for available least restrictive alternatives.

Despite these difficulties, the U.S. is poised for reform in this field. Some of the reasons for this confidence include:

- the growing interest in making self-determination a reality for all people with disabilities;¹²
- a vigorous advocacy movement that criticizes and seeks to change overly protective or discriminatory laws, policies and practices;
- a system of federalism in which states, in Justice Louis Brandeis' memorable phrase, "are laboratories for innovation";¹³
- Constitutional limitations and the potential for media exposure and legislative and judicial oversight to identify and correct the most flagrant abuses of power over persons with disabilities. For example, in one notable case, an appeals court overturned some 100 guardianships that were imposed during a single morning's "assembly-line" judicial session;¹⁴
- increasingly popular communitarian ideas stressing the importance of interdependence in social relations approaches to complement individual rights approaches.¹⁵

b) The Swedish Position: Offering Support Options

Sweden has replaced guardianship with two forms of assistance. The primary and less restrictive form of support is called "the god man" (translated into English as "good man" or "mentor"). The god man is intended to be a helping and supportive aide, far different from the coercive authority figure some guardians become. In general, this statutory-based and publicly funded role provides a helping and wise advisor rather than an overseer with directive powers over the lives and properties of persons with disabilities. Based on interviews with a range of knowledgeable informants, the Swedish experience with the god man on legal, policy, programmatic and personal levels has been very positive. As this study documents, Sweden is one of the most advanced countries in developing legal techniques to reinforce rather than disregard a person's capacity for making choices.

The second form of assistance is the Forvaltare, which Swedish legal authorities translate as administrator or trustee.

Legal Background

Sweden's remarkable progress in disability policies and programs is anchored in national law. For instance, the mental retardation law of 1967 created entitlements to services that led to rapid gains in community-based habilitation and individualized services for even the most severely disabled individuals.¹⁶ Another historic milestone came in 1985 with a law requiring the phasing out of all special hospitals and institutions, prohibiting new admissions, and mandating a variety of guidance and support measures, including the services of a "contact person."¹⁷ Effective January 1994, the mental retardation law was replaced by the broader law on support and services for certain disabled persons [hereinafter LSS]. The LSS provides comprehensive services as entitlements for persons with severe physical or mental disabilities, a category estimated to number 100,000 persons in a national population of over 8 million people. Not all services that benefit persons with disabilities are covered by the LSS, and the focus of this study is the "parent law" (Foraldrabalken) which regulates guardianship and some of the

less restrictive alternatives under the topic of parent-child obligations and relationships. In an amendment to this law, which became effective January 1, 1989, the Parliament (Riksdag) restricted guardianship to minors under the age of 18. Sweden thus became a pioneer in abolishing guardianship for adults with disabilities.

Disability services are highly decentralized. Although the national government legislates, regulates and offers guidance on the provision of disability services, responsibility for their implementation has devolved from the county to the municipality (kommune). For instance, each of Sweden's 270 municipalities has an office of public trusteeship administration, formerly known as offices of the "Chief Guardian," that is charged with oversight of god men and forvaltares. Part of the success of national reform initiatives stems from the willingness of the national government to subsidize the local governments, such as the decision to supply two billion kroner for creating new group homes and other community-living arrangements for persons exiting institutions to be closed. Another example of the national government's efforts to gain support from local authorities is the decision to fund the excess costs of new services under the LSS through the national budget. The LSS also sets the dividing line of 20 hours of weekly personal assistance as the point where the national government assumes the full cost of those services. (See below for further discussion of the personal assistant and the potential for local manipulation of this cost since the municipality will determine in the first instance the number of hours of personal assistance required).

Appeal to the courts is liberally provided under Swedish law. Thus, a person aggrieved by a determination of their need for personal assistance or other LSS provision can proceed through three levels of the court system: district court (Lansratt), appeal court (Kammaratt), and Supreme Court (Regeringsratt). Recent court decisions demonstrate that the courts are vigilant in protecting the civil rights of persons in god man proceedings and in enforcing entitlements even in the face of municipality arguments of insufficient funds.

In general, the political parties are supportive of disability policies and the legal reforms of the past two decades have been marked by a high degree of consensus among politicians, professionals, consumer activists, administrators, and the public.

God Man (Mentor)

Mentorship is now the preferred and predominant method of support service. According to the Swedish National Board for Judicial Administration, in 1992 some 28,000 Swedes had mentors and 4,000 had administrators. By December 1999, the numbers of persons with mentors had swelled to about 40,000 while the numbers of Swedes with administrators had declined to 3,500. The law requires that mentors be appointed instead of administrators whenever possible.

Mentorship has been in existence since 1976. At the time, some 30,000 Swedes were under guardianship. But by 1985, the availability of the mentor option had reduced the number of persons under guardianships to 17,000.¹⁸

As previously noted, guardianship has now been eliminated. This change was largely out of concern for the loss of the right to vote and the imposition of other legally imposed disabilities that stigmatized the individual and heightened his or her sense of social inferiority.

In contrast, the appointment of a god man does not alter the civil rights enjoyed by a person with a

disability. The god man is to act with the consent of the person, and has rights and duties that roughly correspond to the authority of a person acting as a power of attorney.¹⁹ However, a god man can be appointed for a person incapable of giving consent.

Such appointments are made by a district court and can be tailored to the specific needs of the individual. The duties can be limited to representation for individual rights (e.g., making an application on appeal for special services); supervision of financial matters (e.g., administering property), and/or attending to the person's other needs for support and guidance. The law emphasizes acting with the person's volition. Indeed, it gives the person remedies against the mentor who acts outside of his authority or who attempts a transaction where the person "would have been able to give his consent but did not do so."²⁰

As a flexible form of support, mentors may be appointed in a wide range of circumstance. The main use is for persons whose mental retardation, illness, or deteriorated health places that person in need of help for looking after their legal, financial, or personal interests. Other uses are to tend to the affairs of refugees, missing persons, or Swedes living abroad. For persons with disabilities, most appointments are by consent. For those persons incapable of giving consent, the court may appoint a god man upon a medical certification of the person's lack of capacity to consent.

Procedures for appointment are relatively informal, fast and without cost to the person. Application to the district court can be made by the person, a close relative, or the public trustee. Since most cases are based on direct consent, and a review of the documents by the court, the person need not appear and no hearing is scheduled. In routine cases, the appointment process takes only two to three weeks to complete, with the judge writing the protocol (court order) in ten minutes or so.

Complex cases, while infrequent, may take months. In one notable recent case, a Stockholm judge rejected the public trustee's recommendation of a god man for a mentally ill man who wished to retain his apartment, even though his recent physical disabilities made it inaccessible to him. The judge reasoned that the loss of the apartment where the man had lived for 50 years and the autonomy it implied could harm his rehabilitation, and that the better course of action would be to not take authoritarian steps but to first informally aid the man to obtain a physically accessible apartment before counseling him to surrender his old, familiar apartment.

Courts are generally vigilant in safeguarding the civil liberties at stake. In one recent case in which the lower courts failed to provide a hearing for an individual deemed senile who requested it, the Supreme Court criticized the failure to grant a hearing and remanded for a hearing on whether the person was in fact incapable of consent as the medical certificate alleged or was in need of other protection. Another exceptional case was problematic from a statutory viewpoint. A god man was imposed on a 90-year-old woman who had initially requested one and then sought to revoke her consent. The judge nonetheless declined to cancel the appointment since there was evidence that a 70-year-old man was financially exploiting this senile woman and had already drained 80,000 Kroner of her 200,000 Kroner assets. Although the statute appeared to require a medical certificate, the woman refused to consent to a medical examination and the Court, composed of a professional judge and lay judges (somewhat analogous to the jury concept), ordered the god man appointed based on the court's own observations at the hearing of the woman's obviously senile condition. The judge (who was interviewed for this study) had hoped that the woman would appeal to test this unusual exercise of the court's jurisdiction in a lacuna of the law, but no appeal was ever taken in a case which appears to have involved an involuntary appointment without a medical report. However, informants suggest that this is a rare exception to the rule of consent and that

lay judges remarked that quality of judicial scrutiny and rigorousness of review was quite high.

God men are paid for their services. This proposition also holds true for relatives, who are the most common source of appointments.²¹ The annual fee is normally around 7,000 Kr. (less than \$1,000). However, fees as high as 150,000 Kr. have been approved by the Public Trustee in a complex case. Fees are sometimes awarded in the range of 15,000-20,000 Kroner. Although professionals (lawyers, accountants, social workers, etc.) may sometimes have a caseload of 10-20 wards, the more common practice is a one-to-one relationship. Consumer activists report that in addition to parents and siblings, god men are often recruited from the ranks of the police, retired teachers, social workers, bank employees, and politicians who wish to display their civic-mindedness. If the individual with a disability lacks funds, the municipality will bear the expenses of the god man.

In the Stockholm office, the overwhelming proportion of users of adult protective services are elderly. As of December 1999, 375 had Administrators and 4,995 had god men. [Seven years earlier the respective numbers were 163 with Administrators and 3324 with god men, thus the trend is to greater use of both types of supports]. The powers of these support persons are limited to be no more invasive than necessary. In Stockholm in 1999, Henrik Hoogland, head of the Stockholm Public Trustees Administration, estimated that 30% of the Administratorships were so limited, and 25% of the Mentorships. In 1992, his predecessor, Public Trustee Sehlin, found comparable estimates for limited powers of 25% and 40% respectively. The most common form of limitation is to economic and financial matters (forvallaegevloan), as distinguished from matters pertaining to legal rights (bevakaratt) or custody of the person (forja for personen).

Recruitment of the right type of person to be a god man is sometimes a problem. FUB (The Swedish Association for Persons with Mental Retardation) takes the view that most persons with mental retardation should have a god man as an adult. (The Swedish definition commonly limits this category to some 30,000 persons, based on cut-offs of severity set far lower than in the U.S.). Their representatives are concerned that the municipalities are largely passive, and do not take active steps (outreach) measures to identify persons needing such appointments and to supply that need such mentors. FUB's president is also concerned that many god men now lack the training, information, and motivation to fulfill the role to its true potential. Therefore, Elaine Johnsson recommends that god men receive more systematic training and orientation on the rights of persons with disabilities and their responsibilities in helping to realize those rights. She views the passage of the LSS as "a golden opportunity" for providing that orientation to god men, staff, consumers and their families.

A number of informants had additional suggestions for improving Sweden's mentorship arrangements. These suggestions included:

- greater attention to the personal support aspects of the role by god men as distinguished from the current emphasis on its financial aspects;
- closer oversight by Offices of the Public Trustee of the non-financial aspects of the mentor's responsibilities;
- more timely payment of the mentor's expenses to avoid some recruitment problems;
- more frequent replacement of god men who fail to discharge their duties or act in a way contrary to their ward's interests;
- more coordination between welfare authorities and offices of the public trustee to encourage greater use of the god man as an agent to help persons with disabilities to understand a complex

and changing network of services and legal entitlements, to more from institutions to apartments, and to cope with a greater number and variety of choices posed by living in Swedish mainstreams;

- energizing and motivating those god men who lack enthusiasm or who perpetuate the old model of guardianship authority in dealing with individuals with disabilities; and
- other steps to realize the principles of human dignity and the least restrictive alternative that are central to the premises of modern Swedish law.

Despite such shortcoming and inevitable inconsistencies, Swedes express considerable satisfaction in the theory and implementation of the law on god men and forvaltare. The critiques noted above are also healthy signs of the advocates' vigilance and the disability system's desire for continuing improvement.

Forvaltare (Administrator or Trustee)

The Forvaltare is now the device of last resort when other forms of assistance are insufficient, such as when the person with a disability objects to the decisions or appointment of a god man and property or personal interests would otherwise be seriously jeopardized. Unlike the god man who must act in consultation with the person, the administrator may take substitute decisions. This legal role resembles that of the guardian, except that person retains the right to vote in general elections.

This universality of the franchise is truly remarkable. It signals that no Swede is a second-class citizen barred from political participation on account of disability. In contrast, 42 U.S. states and 3 U.S. territories bar some individuals with mental disabilities from voting.²² Sweden no longer draws such exclusionary lines, and even permits the person with a disability to receive assistance in exercising the right to vote. Even though persons with a forvaltare have such equal civil rights, they do retain significant legal protections from any seriously improvident act. For instance, a person who has an administrator with unlimited authority and who nonetheless enters an economic transaction that he or she is not entitled to undertake will be fully protected. The administrator can not only have the transaction canceled, but can reclaim any monies spent without the person with a disability having any duty to compensate the merchant for any loss.^{23,24} Courts, however, often will limit the authority of the forvaltare, perhaps only limiting the person's ability to use credit cards, make expensive hire-purchase (installment payment) arrangements, sell valuable real estate, or manage a particular bank account. Public Trustee Sehlin anticipates an increase in the number of such appoints as more individuals with severe disabilities prepare to leave mental hospitals and special institutions to live in the community.

Given the serious consequences of such appointments, and the power of the administrator to act without the individual's assent, such cases are subject to greater judicial scrutiny, unlike god man proceedings, a lawyer is often appointed to represent the alleged disabled individual.

A less legalized model is also under consideration. An official report, titled "Parents as Administrators," has the support of the Association of Public Trustees and urges the delegation of appointment powers from the judiciary to the public trustees.²⁵ Judicial opinions on this proposal was divided with one judge favoring this administrative model since most cases are uncontested while a younger colleague felt that giving the individual the possibility of "a day in court" offered a useful libertarian check-and-balance. For now, the court role remains in the appointment, removal or replacement of mentors and administrators, and the potential review of their annual accounts.

Personal Assistant

Another means of maximizing autonomy is the liberal use of personal assistants, hired (and if necessary, fired) by the person with a disability acting as an employer. Although government funding of personal assistants has been a matter of discretion since the 1970s, the LSS made it an entitlement service as of January 1994. Consumer activists and officials expressed national pride in the new law and its showpiece feature: free personal assistant services according to the individual's needs.

Under the prior law, municipalities could be quite generous even under discretionary schemes. For instance, one Stockholm woman informed me that she received 188 hours per week, with the annual cost of this benefit amounting to 900,000 kroner a year. As the mother of a one-year-old and a two-year-old, a part-time employee in a center for independent living cooperatives, and a person with quadriplegia, she required double coverage at some parts of the day. In her opinion, the new law transformed this service from a charity to a right, and permitted people with severe disabilities to live anywhere in Sweden.

Surprisingly, this measure and the LSS in general passed the Parliament with little debate. Section 2 of the LSS makes the personal assistant a mandated support service that can either be provided directly by the government or by a cash allowance to the person with a disability.

The lack of opposition to this measure is attributed to a variety of factors. First, the Swedish political consensus on disability policies would not make it easy - or politically palpable - for any party to oppose greater independence for persons with disabilities. Second, Bengt Westerberg - the Minister for Health and Social Affairs, Vice Prime Minister, and leader of the Liberal Party - is also credited with spearheading the passage of the LSS. During the last election, he had campaigned on a pledge of passing such a law on disability rights. True to his word, he invested his significant political and personal prestige to winning support for the LSS. Some political observers noted that the Minister of Finance was a colleague of the same political party, and the endorsement of that Ministry was of critical importance to enactment of the LSS. The costs of personal assistants were projected to run 2.5 billion kroner annually, with the average user requiring 40 hours per week of assistance. Since the national government would bear the entire cost of assistants for those using over 20 hours per week, these estimates were important in convincing the political leadership that this entitlement was manageable. In fact, as of January 2000, the total cost for personal assistance is an estimated 6.5 billion kroner annually, 6 billion of which is paid by the national government and the balance by the municipalities.

The law contains certain limitations on eligibility. To keep the costs within determinate limits, the users must be under the age of 65. (The government is now reevaluating this limit, and expects to report by the fall of 2000 on the feasibility of permitting persons over the age of 65 to retain their personal assistance.) Persons living in institutions or in group homes are also outside this program's reach. The person must average a need for more than 20 hours a week to receive funding from the national government. (For those with fewer hours of service needs, the municipality remains the source of funding.)²⁸ The national program is administered by the Social Insurance Office. But unlike other insurance programs, personal assistants will be funded entirely from the national budget, and not from employers' contributions.

The informants for this study were cautiously optimistic about the implementation prospects for this personal support service. One consumer activist noted that the Social Insurance Office was unfamiliar with running this type of direct-service program and its officials would need considerable advice and training from groups like STIL (Stockholm Cooperative for Independent Living) to ensure an effective

program. A government official who helped to design this law countered that the Social Insurance Office would have almost a year to gear-up to run it, sufficient lead time for them to learn how to carry out this new mission.

The same activist also pointed out that persons with disability would need training and counseling themselves to make appropriate use of personal assistants. She wants such persons to be "good supervisors" and not treat personal assistants "like servants," noting that people who had so long been oppressed - "who couldn't choose more than the type of sandwich to eat" in their formerly restrictive living environments - would have to work through familiar dynamics of oppression. She also noted that her cooperative of 95 members, some 20 members might need help in managing their support resources. Although most members of STIL are physically disabled, anyone can join and some members also have Down syndrome or other mental limitations. While the personal assistant concept was first concerned as an aid primarily for persons with mobility limitations, the law makes it open to persons with physical or mental disabilities. The Report of the 1989 Disability Commission, a special parliamentary commission appointed by the Government to make recommendations that led to reforms in the law for persons with severe functional impairments, underscored the inclusive nature of this provision:

We feel that the availability of [personal] assistance must be reinforced, so as to improve freedom of choice, autonomy and continuity in the personal living situation.

We therefore recommend that LSS be made to include entitlement to a personal assistant for everybody who can be deemed to need such a measure and who is included in the population to which LSS refers. The personal assistant input also implies that the individual decides or does a great deal to influence who is employed as an assistant, and also that the individual must exert a great deal of influence on the time of help. Improved availability of personal assistance will also augment the possibilities of coordinating the personal support now provided in homes, at work and in schools. We also take the view that the introduction of entitlement to a personal assistant will facilitate the resettlement of intellectually handicapped persons and long-term mental patients, for example, away from institutions.²⁹

In summary, Sweden has undertaken a revolutionary legal reform that deserves worldwide attention. Many questions await further study. Will the implementation experience under the LSS avoid undue manipulation of determined hours of need - and thus costs - by municipalities? Will user and cost projections prove reliable? Will regulations and administrative criteria fulfill the framers' liberal and inclusive intentions? Will persons with severe disabilities receive sufficient training and orientation to make appropriate use of this service? Four years after the law's implementation, the statistics are encouraging. Some 8,350 Swedes with disabilities receive over 20 hours per week of personal assistance. Another 4,000 people receive aid under other components of the LSS. An estimated 25,000 personal assistants are providing this service as of the year 2000 because some people with disabilities require more than one personal assistant in the course of a week. In summary, with personal assistance provided as a matter of right, Sweden's new law has proven a dramatic step forward in the field of disability rights and policies.

Escort Person

The LSS also creates a new entitlement to the services of an "escort person." This escort service is listed as one of the ten statutory support services.³⁰ Formerly this support was limited to blind persons who needed help to attend some special event and was provided through the social security law. This

program, however, was viewed as not functioning very well. Under the new law, a person who did not have a personal assistant but who was eligible for LSS services could arrange for an escort to accompany him or her to the cinema, a football match, or similar visit to a leisure-time activity. The person receiving this service would contact an office in the municipality, and might plan some regular trips (say once or twice a week), or could schedule for special events more flexibly. Here again the State will assume the excess costs of the municipalities beyond the existing level of escort services.

Architects of the LSS, such as Carl Leczinsky who formerly worked in the Ministry of Health and Social Affairs and is now the executive director of the National Board on Personal Assistants, believes that such support provisions will not be abused. He is confident that people with disabilities so prize their privacy that they will not unnecessarily or frivolously request the services of an assistant or an escort. Clearly the availability of an escort can help certain persons with severe disabilities to explore the world with greater confidence and safety.³¹

Implementation Prospects Under the Law on Support and Services for Certain Disabled Persons

Plans for the LSS were made during the late 1980s at a time when the economy was more auspicious and social service expectations were higher. This spirit is captured in the two excellent English language summaries of the work of the 1989 Commission on Policies for the Disabled, Disability, Welfare, Justice, presented in May 1991,³² and A Society for All: Summary, the Commission's final report issued in 1992.³³ The Commission criticized the existing "patchwork quilt" of individualized measures, and called for simultaneous, right-based efforts "to assure disabled persons of basic opportunities of social participation," and "to develop and guarantee general accessibility and distinct assumption of responsibility in every social sector, with regard to matters affecting the disabled."³⁴ These sweeping objectives were to be carried through detailed recommendations on equality and participation to make society "accessible to people with functional impairments."³⁵ Priority sectors of society included: 1) the right to basic public information, 2) local government activities, 3) housing and environment design, 4) culture, media and teaching materials, 5) travel facilities, 6) the right to basic telecommunications, 7) access to the employment sector, and 8) the right to legal protection against discrimination in "the enterprise sector." The Commission also proposed an amendment to the Swedish Constitution that would declare that law or other regulations must not imply that some citizens can be discriminated against due to disability.³⁶ It should be emphasized that not all of the Commission's recommendations were adopted by the Government, and that opposition to the constitutional amendment can be anticipated. Yet the significance of these documents - based on six successive reports - is that Sweden has a detailed blueprint, with actual funding and implementations priorities expressed, to permit persons with severe disabilities "to share, on the same terms as other members of the community, in the growth of national prosperity."³⁷ With some of these costs and adjustments spread out for periods of as long as 15 years, the Commission estimated a "total annual cost only about 0.1 per cent of GDP" (gross domestic product), resulting in expenditures in each societal sector on what it described as "a very modest scale."³⁸

The LSS has many innovative features. The definition of "certain disabled people" include persons with mental retardation, autism or autistic-like conditions, persons who became severely brain-damaged as adults, and (a new category under Swedish disability law) other persons with physical or psychiatric disabilities that are not dependent on old age and result in severe difficulties in daily living and significant needs to overcome such difficulties.³⁹ The Act lists ten support services, with only the tenth

one being unavailable to persons in the new category. These entitlements are:

1. counseling and other personal support services (such as habilitation services and therapies in the fields of psychology, social work, etc.).
2. personal assistants
3. escort services
4. contact persons
5. respite care in the home of a parent
6. respite care outside the home of a parent
7. after-school recreation program for children over age 12
8. housing in special apartments for adults
9. housing for children who cannot live in their own homes and require a "family home"
10. daily activity centers⁴⁰

The LSS offers a broad right of appeal from any denial of such services. For example, local government officials will determine the number of hours of personal assistance an individual "needs for daily living."⁴¹ An individual aggrieved with that determination might appeal to a special board of the Social Insurance Office. If still dissatisfied, the person with a disability may go to the courts and make their way through as many as three levels of judiciary. It is no wonder that representatives of STIL expressed interest in developing a legal aid program and in receiving materials on the U.S. experience with the legal services for persons with disabilities!

The Swedish model seems based on offering multiple forms of support. In theory, an individual could have a god man and a person's assistant, or a god man and a contact person. Thus, measures can be labored to the unique needs of the individual. Other statutory supports include assistance in the labor market with an estimated 20,000 Swedes receiving practical help on their jobs with allowances paid to their employer (ranging from a few hundred kroner for technical working aids to over 170,00 kroner a year for sheltered employment on a yearly basis). Specialized support in higher education is anticipated to cover some 1,000 persons annually in universities, technical schools, and adult-folk school. Sweden seeks to cover most support needs, offering real, concrete help to increasing the individual's autonomy in daily living, work, education and leisure-time activities. Officials and activists can be justifiably proud of the new law's promise, hailed as "the biggest reform" in Sweden's policies on disabilities.

Evaluation of Swedish Legal Reforms to Increase Autonomy and Integration

Sweden has made steady progress in moving persons with disabilities into the mainstreams. Legal reforms and legal institutions have played significant parts in those advances. This assessment is based on the following trends:

1. Statutory coverage is broader. Sweden has replaced a law that focused on mental retardation with one (the LSS) that encompasses the range of severe disabilities.
2. Guardianship has been effectively abolished. Sweden now offers a continuum of supportive services, none of which disenfranchise adults with disabilities, regardless of the degree of impairment.
3. Services that were once offered on a discretionary basis are now legal entitlements. The provision

of personal assistants and escort persons are dramatic examples of this trend.

4. By law, residential institutions are being closed and replaced with support services and living arrangements that are based in the community. Since the first entitlement legislation in the field of mental retardation in 1968, steady legal pressure has helped to create group homes and other community-based living arrangements. Once initiated, the process of deinstitutionalization has moved quickly and without real opposition. One smaller county in the north-Jamtland has already eliminated their institution. In the major southwestern population center of Gothenburg, Juri Sonn, Director of its mental handicap services, reports that over 600 persons have moved from institutions in his region, with only a handful of persons lacking specific post-institutional placement plans. More than 100 previously institutionalized persons moved in 1992, 80% going to single-person flats in rehabilitated buildings housing 5 to 7 persons. With good personal support available to these residents, publicity is largely positive, and adverse reactions from neighbors are rare. Similar developments have occurred throughout Sweden as moratoriums on new admission and legal mandates to phase-out institutions are implemented.
5. The end of institutions and guardianship reflect national commitments to least restrictive alternatives and optimal autonomy for persons with disabilities. A strong national consensus in favor of this position is expressed in law, policy and budgetary decisions. There is strong parliamentary support and unified public opinion in favor of greater independence and self-determination for persons with disabilities.
6. Access to the courts ensures that remedies are available. Appeal processes are open at administrative and judicial levels. The courts have proved willing to ensure that disability laws are observed by local governments, despite arguments of staff or funding scarcities.
7. The god man concept is viewed as a success in offering an unintrusive form of decision-making support. The god man offers a flexible, free, and relatively simple method of securing a mentor for persons whom in other countries or eras might have faced restrictive guardianships.
8. Refinements in mentorship and administratorship arrangements are still needed. These refinements could stress greater attention to the personal, non-financial aspects of those roles, and the provision of better training and orientation for mentors.
9. Mentorship arrangements and other protective services that do not legally disable the individual are feasible in other countries. These concepts are certainly "exportable" to other countries. Although the mechanics, procedures and nomenclature will certainly vary from country-to-country, the Swedish experience offers an admirable legal model for other countries to consider.
10. The principle of least restrictive alternatives is being vigorously applied in Sweden's theory and practice of disability law. Although Sweden did not enact an antidiscrimination law such as the ADA until 1999 and lacks the tools for large-scale legal intervention such as the civil rights class action so common in the U.S., its leaders have found effective means to advance the rights of persons with disabilities that are articulated in international human rights standards. In the words of the 1989 Disability Commission, "we have also attached very great importance to strengthening individual opportunities of autonomy and influence with regard to measures of personal support and service."⁴² This commitment is in evidence in small and large matters. Even the special problems of immigrants with disabilities have not been overlooked. They have been targeted for outreach activities, information and planning to "ensure that responsibilities and duties are not shirked when individuals need linguistic or other assistance in order to obtain necessary

support."⁴³ All this is in keeping with the pledge of "A Society for All" that aims to distribute the opportunities for the good life to all persons, disabled and non-disabled alike.

c) The German Position: Reforming a Traditional Guardianship Law

Germany has also undertaken a thorough reform of its guardianship law. In 1992, the Parliament replaced the procedures of interdiction ("legal incapacitation"), guardianship and curatorship with one flexible measure. The German term for this measure is Betreuung, the law is called Betreuungsgesetz, and the agent performing this role is a Betreuer. According to Ulrich Hellmann, an expert on this law and an attorney for Bundesvereinigung Lebenshilfe (the National Association for Persons with Mental Handicaps, whose name "Lebenshilfe" means "Help for Living"), the law permits flexible measures that are sensitive to principles of the least restrictive alternative and procedural justice.⁴⁴

Guiding Principles for the Preservation of Rights

Several principles reinforce the law's shift from the denial of rights to the preservation of liberty. These features include:

- the principle of necessity which bars appointment if the person can manage independently or with the support of other social services;
- the principle of flexibility which limits the scope of the betreuer's authority in order to conform to the constitutional principle of the least restrictive alternative;⁴⁵
- the principle of self-determination which permits a durable power of attorney as a substitute for a betreuer, which requires the betreuer to *"follow the wishes of the supported individual as long as the well-being of the handicapped person is not likely to be impaired,"*⁴⁶ and which recognizes that the person's well-being includes *"the possibility to lead a self-determined life to the highest possible degree."*⁴⁷
- the principle of rights preservation, expressed in "the principle of subsidizing sufficient practical support" (avoidance of legal measures) and the "avoidance of formal legal incapacitation" with the result, that unlike the old law, the appointment of a betreuer does not automatically deprive the person with a mental handicap of such fundamental rights as the rights to vote, to marry, and to make a will.⁴⁸

This statutory protection for self-determination is a significant legal advance, particularly the express recognition of helping people to "lead a self-determined life." Realizing these noble aspirations is the challenge for the future.

Procedural Safeguards

The new law has added several procedural rights to safeguard the individual's liberties and interests. These checks include:

- a personal interview by the judge of the Guardianship Court with the person with the disability, generally at the person's permanent residence;
- the power of the person to bring appeals from guardianship hearings and to participate fully in the proceedings, regardless of legal capability;
- the certificate of an expert that describes the person's medical, social and psychological condition as well as makes recommendations regarding the tasks and duration of the betreuer's role;
- the appointment, if necessary, of "a supporting curator" to aid the person in the determination process;
- the requirement of a so-called "final conversation" between the judge and the individual to explain the investigation's results, the expert's findings, and the betreuer's identity and scope of authority; and
- the durational limit of no more than five years for the betreuer's appointment.⁴⁹

Protecting Zones of Autonomy and Limiting the Substituted Decision-Maker's Powers

The German law attempts to preserve zones of autonomy for the person with a disability by limiting the authority of the betreuer. For instance, the appointment can be restricted to personal or financial matters rather than to impose plenary authority over all of the affairs of the supported person. Only if the person's decisions would seriously jeopardize his or her personal well-being or finances will the Guardianship

Court issue a special decree that authorizes the betreuer to consent to specific personal decisions. *In general, the appointment of a betreuer does not affect the legal capacity of the person to make decisions of a personal nature.*

These legal reforms result in the following general rules:

- medical examination or treatment is permitted only with the patient's informed consent, unless the betreuer has the court's authorization for substituted consent;⁵⁰
- medical treatment that has a high risk to life or to causing severe and permanent impairment requires the Guardianship Court's additional declaration of consent;⁵¹
- Sterilization by substituted consent requires the Court's additional declaration of consent and the appointment of a special betreuer and compliance with strict criteria (i.e., no opposition by the person of any kind, permanent incapacity to consent, high risk of pregnancy, no practicable contraceptive alternative, any pregnancy would be life-threatening or "cause a severe physical or mental impairment of the pregnant woman that could not otherwise be prevented, and the method of sterilization employed must leave the highest chance of reversibility");⁵²
- additional safeguards against coercive measures, i.e. the Guardianship Court must issue its additional declaration of consent before an individual can be placed in a closed institution, or be subjected to mechanical measures or medication that will limit the individual's liberty or freedom of movement.

In selecting a betreuer, the Guardianship Court must abide by the individual's choice. If the individual has not expressed such wishes, the Court should give priority to relatives or other persons with a close relationship to the individual, consistent with the individual's well-being and the avoidance of possible conflicts of interest.⁵³ A natural person (i.e. individual) selected for this task must be able to give personal support to the person with a disability. If no such natural person is available, legal entities ("juridical persons") such as private social service associations or public authorities may be selected. The preference for the individual betreuer, however, is so strong that these legal entities are under a statutory duty to recruit, train and support such individual betreuers and to notify the Court whenever the appointment can be transferred to such an individual.⁵⁴

Strengthening the Consumer's Rights in Practice

Full implementation of these reforms will take some time. An estimated 350,000 Germans were under some form of guardianship before the new law's enactment. Applying these new legal standards to so many individual circumstances will take new resources. Significant financial and other hurdles must be overcome before the law in the statute books will be fully realized. For instance, the German states (lands) complain that costs are higher than expected, with the workload of guardianship judges nearly doubling as a result of the new procedural safeguards. Additional court staff and payments for expenses and salaries of betreuers, also contribute to those costs.⁵⁵

Provisions in the sixteen German states remain quite uneven. Under the Betreuungsgesetz, private, non-profit advocacy organizations (called Betreuungsverein) are to be created in each city and county to recruit, orient, train and advise volunteer betreuers. The professional staff of these advocacy organizations will also accept appointments that can not be handled by volunteers. However, the federal law only entitles those professionals who have assumed appointments to be paid by the state. Most of the

supported persons are poor, and for those with bank accounts of less than 4500 DM (approximately U.S. \$2700) the services of a betreuer are to be free of charge.⁵⁶

Unfortunately, mounting caseloads, especially within Public Guardianship Authorities, are undermining the law's benevolent intentions and its ideal of individualized advocacy. Even before the new law, a 1989 survey documented that the average public guardian staggered under a caseload of 107 persons. The problems now may even be worse, as German reunification⁵⁷ and a "steady increase of absolute numbers" of people under legal protection orders has increased the service demands on public and private organizations in this field.⁵⁸

Other factors can also undermine the voices and rights of consumers. Old attitudes may persist as part of the legacy of "the traditional, paternalistic guardianship-system" that predated 1992 legal change.⁵⁹ In addition, consumers do not exert a sufficient self-advocacy presence and check on these processes. Germany lacks sufficient "People First" or other peer-groups to pressure for change. One positive step, however, is the mandate under legal regulations to organize "committees for participation in decision-making in residential facilities and sheltered workshops."⁶⁰ However, according to Hellmann, the absence of a self-advocacy group's presence to support independent life-planning undermines the proper application of the 1992 law. He states that:

a very important element in the network of Betreuung that could contribute very effectively to a successful implementation of the Betreuungsgesetz with its guiding "Principle of Necessity," is still missing.

In summary, "the jury is still out" on the effectiveness of the German reform. Although the law itself contains many substantive and procedural advances, it requires stronger public support and financing to realize those statutory gains. Excessive paternalism may be difficult to avoid under even a reformed guardianship law. But the energy of many committed judges, advocates, advocacy associations, and betreuers offers a brighter promise for the future. As one example, the High Civil Court of Berlin has vigorously applied the new law to withhold the judiciary's consent for the use of potent drugs for the treatment of mental illness that would result in unwanted changes in the patient's personality and mentation. This type of disability rights precedent suggests that the self-determination philosophy underlying the 1992 law is indeed being taken seriously.

d) Notes on the Reexamination of Guardianship Laws in Other Countries

Other industrialized nations are also reforming their existing guardianship laws and stressing self-determination. A few brief examples will suffice.

In 1999, Israel put into force the Equal Rights for People with Disabilities Law. The law is intended to both reform supports and prohibit discrimination based on disability. A striking feature of this enactment is its clear focus on self-determination. To this end, Section 4 states that "[a] person with a disability has the right to make decisions that pertain to her/his life according to her/his wishes and preferences; this right shall be exercised in conformity with the law." The prominent place of this provision in the law's opening chapter on basic principles signals that expanding individual autonomy is a major purpose of Israeli disability legislation. Other purposes include the protection of the individual's dignity and freedom. The law also enshrines the right to "equal and active participation in all the major spheres of life," and the right to an appropriate response to the individual's needs, in such a way as to "enable her/him to live with maximum independence, in privacy and in dignity, realizing her/his potential to the

full."⁶¹ It is worth noting that these provisions apply to a broadly defined group of people with disabilities, including those with severe physical, emotional, or mental disabilities, including cognitive disabilities that substantially limit the person in one or more major spheres of life.⁶² Although inspired by the Americans with Disabilities Act (ADA), the law promises to advance wider aims than the ADA, committing Israeli society to strengthen disability rights based on "the principle of equality and the value of human beings created in the Divine Image."⁶³

The law has already sparked consumer activism and debate. In seeking the same rights as all other Israeli citizens, disability rights activists have taken to the streets. In a protest unique in this country's history, a rally and sit-in that began outside the doors of the Ministry of Finance concluded only after a 37-day protest in the corridors and the streets surrounding the ministry. Protest leaders had met with both the powerful Minister of Finance and the Prime Minister, blocked traffic in the streets, captured the national media's attention, and even provoked motions of "no confidence" in the government [a parliamentary step that could in theory have led to toppling the current coalition government]. Although their goals included the prompt implementation of the Equal Rights law (especially the appointment of the Commission for Equal Rights for People with Disabilities), they primarily focused on more generous supports and disability benefits. Their main aims were to improve the freedom to live where people wish to live, to use convenient transportation, and to obtain work in real jobs. They also sought the consumer representation promised by the Equal Rights law. To date, appointments have not yet been made to the Commission's Advisory Committee, a majority of whose members are to be persons with disabilities. Thus, the law sets an ambitious agenda for disability rights and self-determination. Indeed, the activists are returning to the legislative branch to seek enactment of provisions on support services, public accommodations, and other parts of the draft Equal Rights bill that were not adopted in 1998 when seven chapters of the law were first passed. In summary, the 37-day protest was a successful demonstration of self-determination by a sector of the Israeli public previously viewed as weak and unassertive.

In Austria, legal reforms in 1984 led to the development of limited guardianships. As of 1981, some 27,000 persons were under a form of plenary guardianship. According to Rudolph Foster of the University of Vienna's Institute for Sociology, the 1984 law had been expected to lead to a marked decrease, but instead after an initial decline the number of persons under guardianship has again climbed to about 23,000. Three professionally staffed organizations provide guardianship services as well. Under a new commitment law, patient advocates are also appointed for each committed mental patient.

The Austrian law on guardianship has also been credited with influencing the reforms in Germany. One of the main goals of the 1984 law had been to destigmatize the provision of protective services.

After long deliberations, the Netherlands appears on the verge of adopting a mentorship law. For almost two decades, activists have criticized the existing law on guardianship of the property (curatele) for its formality, expense and failure to address the personal needs of its subjects.⁶⁴ Jan Meiresonne, then executive director of the National Association for the Care of the Mentally Retarded, had proposed in 1974 a mentorship law (mentorschap). By 1994, a government bill on this subject (Wet op het mentor schap) is expected to come into force. The bill recently passed its first reading in Parliament. According to attorney Marcia Roozendaal, the law has several innovative features. It would 1) pay mentors, even if they are relatives; 2) give preference for the appointment of relatives; 3) pay attention to the wishes of the person with a disability as to the choice of mentor; 4) require periodic review and limits on the duration of appointments; and 5) permit flexibility to limit the appointment to financial or personal matters. Under the principle of the least restrictive alternative, a local magistrate could authorize a

mentorship for personal matters (mentorschap) or limited guardianship for only financial matters (onder bewind stelling). In contrast, a plenary guardianship (onder curatele stelling) can only be ordered by a federal judge, presumably with greater formalities and procedural safeguards. If enacted, these measures will offer the Dutch a wider continuum of supportive options.

The United Kingdom is also reviewing its guardianship laws. Two official reports - one for Scotland and the other for England and Wales - urge revision of the current traditional legal provisions.

In 1983, Spain modified its guardianship laws. The range of supports now include forms of temporary guardianship (guarda de hecho), a guardianship limited to representation in a specific legal proceeding (defensor judicial), "prolonged minority" (prolongacion patriae potestar), guardianship of property (curatela); and total or plenary guardianship (tutela).

Finally, New Zealand's law on this subject is noteworthy for its comprehensiveness and its emphasis on tailoring measures for the least intrusion into the affairs of the person with a disability.

As this discussion reveals, countries in different regions and legal cultures are embracing newer models of support, and diversifying the measures that can deal with the universal needs for support for people who have difficulty taking informed and voluntary decisions for themselves.

From Paternalism to Partnership: Concluding Observations

Around the world a movement for enhanced self-determination is gaining momentum. It is expressed in international human rights documents such as the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities⁶⁵ and the European Union's statement on principles of legal protection.⁶⁶ It is reflected in the rise of self-advocacy groups and in legal reforms on a variety of fronts. This monograph has sketched some of those reforms, especially in the development of mentorship arrangements and other support services that do not disenfranchise persons with disabilities. The lessons that can be learned from the Swedish, German, and Israeli experiences, and that of other reforming nations need to be widely disseminated and carefully assessed. For instance, the Swedish god men (mentors), the German incorporation of self-determination principles in new guardianship laws, and the dreams of equality and consumer preference embodied in the Israel Equal Rights for People with Disabilities Law all bear close inspection as activists in the United States and other countries explore paths to progress and true partnerships.

It is time for a thorough review of guardianship and alternative personal supports in the fifty states and other jurisdictions of the United States. For too many people with disabilities, disempowering plenary guardianships are in place when less intrusive and more consensual forms of support would suffice. Calls from self-advocates and from scholars demand such reforms that will replace the paternalism of the past with authentic partnerships for the future. As cases like the U.S. Supreme Court's *Olmstead v L.C.* decision fuel the drive for deinstitutionalization, and the consumer faces more personal decisions and options, the urgency for reform becomes ever more apparent.⁶⁷

Leading organizations in the field have long recognized this need. Three decades ago, the International League of Societies for the Mentally Handicapped [now Inclusion International] sharply criticized custodialism and outmoded forms of guardianship as "an ancient institution which is in urgent need of revitalization to meet the needs of this century."⁶⁸ The League charged that institutions were "conducted at best on paternalistic lines, and at worst as an oligarchy in which the disenfranchised

residents have no individual or collective voice in their affairs, no control over their environment and no way of changing, protesting, or appealing against conditions under which they might be living, whether benign or harmful."⁶⁹ Those words remain true as we approach a new century and a new millennium.

The American Association on Mental Retardation has now lent its prestige to the drive toward full recognition of the right to self-determination. In its 1999 position paper, it defined this term as "the right to act as the primary causal agent in one's life, to pursue self-defined goals and to participate fully in society." The Association thus urged service providers to protect the rights of individuals to "make fundamental life choices, to enhance their authority to act in accordance with those choices and to build capacity of communities to embrace the active participation of all community members." By helping to develop mentorship and other non-coercive support arrangements, professionals can help to realize these aims. In this way, guardianship can be minimized and reserved for situations of clear and present necessity. The problem with guardianship, after all, is that it lets the courts into the lives of people with disabilities, and can have a number of negative consequences that may reduce the rights of the affected individual to less than the civil rights that even convicted felons possess.⁷⁰

Finally, people with disabilities have created grass-roots pressure through a comprehensive disability rights movement to demand change. No one better personifies that movement than Justin Dart Jr., its senior statesman and the 1998 recipient of the Presidential Medal of Freedom. At the American Bar Association's national conference on disability law and policy he spoke forcefully for the need for an empowerment revolution. Such a revolution could accelerate the desirable changes in support services identified in this monograph. Referring to the movement as reaching a historic crossroads, Dart declared:

Our present social programs have reached their limits. We need a clarified vision. Persons with or without disabilities will never fully achieve any of their legitimate goals until there is a revolution of empowerment, a revolution to eliminate primitive practices and stereotypes and to establish a culture that focuses the full force of science and democracy on the individual's potential for self-determination, productivity, and quality of life.⁷¹

Around the globe the stirrings of this empowerment revolution and its impact on primitive or overprotective legal measures can be felt. Sweden and Israel have already decoupled guardianship and loss of civil rights. Today the citizens of those countries can exercise the right to vote regardless of any protected status. With ingenuity, political will, and legal reforms, more citizens with disabilities can be emancipated from avoidable guardianships. As people gain in decision-making skills and capabilities, the institution of guardianship can shrink or be replaced by less intrusive and formalistic measures. The movement for self-determination can be a force for such long overdue changes.

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¹¹ Robert Dinerstein, Stanley S. Herr, and Joan O'Sullivan, A Guide to Consent (American Association on Mental Retardation, 1999).

¹² See, e.g., Speaking for Ourselves and People First of Tennessee, "The Society for the Furtherance of Self-Determination" (guest editorial), in Common Sense No. 4, at 3 (July 1999)

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¹⁴Michigan Ass'n for Retarded Citizens v. Wayne County Probate Judge, 49 Mich. App. 487, 261 N.W.2d 60 (1977).

¹⁵ E.g., Martha Minow, "When Difference Has Its Home: Group Homes for the Mentally Retarded, Equal Protection and Legal Treatment of Difference," 22 Harvard Civil Rights-Civil Liberties Law Review 111 (1987).

¹⁶ Law No. 940, The Act on Provisions for Certain Mentally Retarded Persons (Dec. 15, 1967).

¹⁷ Law No. 569, The Act for Special Care for Persons Suffering from Disturbed Psychological Development (June 13, 1985).

¹⁸ Stanley S. Herr, Law and Mental Retardation: International Trends and Reforms, 38 International Digest of Health Legislation 849, 858 (1987).

¹⁹ Allan Everett, "The New Sweden Guardianship Law" (June 7, 1989) (unpublished paper).

²⁰ Id. at 2.

²¹ Parents acting as the mutual guardians of their minor children are not eligible for guardianship fees.

²² Bruce Sales, et al., Disabled Persons and the Law: State Legislative Issues 100-104 (1982).

²⁴ Everett, supra note 19, at 4.

²⁵ Betankande fran Formyhderskap Utredingen, Foraldra Som Formyndare (SOU 1988:40).

²⁶ ²⁵ LSS, § 9(4).

²⁷ One client, Michael W., released from a mental retardation institution in the 1970s, lived an essentially reclusive life in a downtown apartment. His social contacts were largely limited to the sporadic interventions of his lawyers and social workers. They helped him to maintain his fiercely cherished independence. An ongoing "contact person" would have been an ideal service for him.

²⁸ According to Anna Åkerrén, legal adviser to the Swedish Social Ministry, "[a] person that is entitled to a personal assistant gets 178 Swedish crowns from national government funding for every assistance hour exceeding 20 hours a week. The amount is supposed to cover costs for the assistant's wages and additional social fees, administration and education. The person can choose to be the employer of the assistant. He or she can alternatively choose to let the municipality, a private enterprise or an organization employ the assistant."

²⁹ Report of the 1989 Disability Commission, Disability, Welfare, Justice: Summary 22 (SOU 1991:46)

³⁰ LSS § 9(3).

³¹ For a tragic reminder of the courage of people with guide dogs who face the risks of city travel, see Ronald Sullivan, Blind Woman Killed by a Subway Car: Victim Falls on Tracks and Is Hit By a Passing Train in Midtown, N.Y. Times, July 8, 1993, at B3, col. 4.

³² SOU 1991:46.

³³ SOU 1992:52.

³⁴Id. at 9.

³⁵Id. at 12.

³⁶Proposed § 16a to the Constitution Act, SOU 1992:52 at p. 63 (Swedish-language version).

³⁷A Society for All, supra, id. at 1.

³⁸Id. at 47.

³⁹LSS § 1(3) (the new category not previously enumerated under the mental retardation law).

⁴⁰This type of day care is limited to persons with mental retardation, autism, autistic-like condition, or brain damage. The reason for this narrowed eligibility was described as simply a compromise driven by cost factors.

⁴¹LSS, § 6. The local authorities are also responsible for determining an individual's needs for housekeeping services which is distinguished from the personal assistant who attends to more intimate help such as dressing, toileting and bathing.

⁴²Disability, Welfare, Justice, supra note 29, at 31.

⁴³A Society for All, supra note 33, at 37.

⁴⁴This section draws on interviews with Ulrich Hellmann, and his very informative paper presented at XIX International Congress of the International Academy of Law and Mental Health, at the panel on "Minimizing Guardianship, Maximizing Autonomy: Least Restrictive Alternatives in Surrogate Decision-Making" in Lisbon, Portugal, June 14, 1993. The author was the chair of this comparative law and policy session.

⁴⁵Id. 4 (§§ 1896-1897 BGB).

⁴⁶Id.(§ 1901 BGB).

⁴⁷Id.(§ 1901[1] BGB).

⁴⁸Id.at 10.

⁴⁹Idat 8-9. (§§ 66-69 FGG).

⁵⁰Id. at 5 (§ 1904 BGB).

⁵¹Id. at 5 (§ 1904 BGB).

⁵²Id. at 5-7 (§ 1905, 1899[2] BGB). As an indication of the hesitation of the Parliament to approve any such nonconsensual sterilization in light of the Nazi history, the Parliament required the federal government to report every four years on the practical results of implementing this aspect of the law.

⁵³Id. at 7 (§ 1897 BGB).

⁵⁴Id. at 8 (§§ 1900, 1908).

⁵⁵Id. at 15. In the Bavarian state, the costs for voluntary and private professional betreuers along are estimated at 22 million German marks (DM, roughly equivalent to U.S. \$13 million). Volunteers can receive their expenses, while private professionals (usually lawyers or social workers) are paid on an hourly basis.

⁵⁶Id. at 13.

⁵⁷The former East German law, dating from 1961 and providing for curatorship under the Family Law, was rarely invoked due to the citizen's fear of state involvement in their lives. Hence a pent-up need for legal measures may lead to an increase in legal proceedings in the eastern regions of Germany.

⁵⁸Id. at 12.

⁵⁹Id. at 11.

⁶⁰Id.

⁶¹Equal Rights for People with Disabilities Law, 5758-1998, Sec. 2. [Israel].

⁶²Id. Sec. 5.

⁶³Id. Sec. 1.

⁶⁴Stanley S. Herr, Rights into action: Protecting human rights of the mentally handicapped, 26 Catholic U. Law Review 203, 276-278, 286-287 (1976).

⁶⁵Open for signature by members of the Organization of American States as of June 8, 1999. Article V calls for governments to promote participation by persons with disabilities and their organizations in developing measures to implement this human rights treaty. Article I clarifies that a "necessary and appropriate" declaration of legal incompetence does not constitute discrimination under this treaty. Some human rights experts have urged that states adopt a "reservation" [amendment] striking this clause.

⁶⁶European Union Principles Concerning the Legal Protection of Incapable Adults: Recommendation No. R(99) 4 and Explanatory Memorandum (1999).

⁶⁷See Tommy Olmstead, Commissioner, Georgia Department of Human Resources v. L.C., 527 U.S. 581 (1999).

⁶⁸International League of Societies for the Mentally Handicapped, Symposium on Guardianship of the Mentally Retarded 10 (Brussels, author, May 1969).

⁶⁹Id. at 29

⁷⁰See Joan O'Sullivan, "Adult Guardianship for the Disabled -- A Serious Matter," 1 Advances in Aging, no. 3, at 7 (University of Maryland at Baltimore Geriatrics and Gerontology Education and Research Program, Fall 1999) (quoting Claude Pepper, the late U.S. representative and champion of older Americans, who wrote: "The typical ward has fewer rights than the typical convicted felon - they no longer receive money or pay their bills. They cannot marry or divorce . . . It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception . . . of the death penalty.")

⁷¹Justin Dart Jr., speech presented at ABA conference "In Pursuit . . . A Blueprint for Disability Law and Policy" in American Bar Association Commission on Mental and Physical Disability Law, Disability Law and Policy: A Collective Vision 1 (1999).