

*International Project Report submitted to
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Identification of Exemplary European Practices Reducing Incidence of Secondary Disabilities in People with Disabilities

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Identification of Exemplary European Practices Reducing Incidence of Secondary Disabilities in People with Disabilities

Introduction

Prevention of disabilities was considered one of the ten key topic areas in the National Council on the Handicapped Report, *Towards Independence*, that was delivered to Congress in 1986. Earlier, Marge (1980) advocated for policies and practices to prevent human disabilities as an agenda for the 1980's. The NCH report recommended that efforts mainly focus on primary prevention of disability, but suggested that tertiary disability prevention in such areas as pressure sores and urinary tract infections should also be addressed.

Following these recommendations, Congress instructed the Centers for Disease Control (CDC) to address the prevention of primary and secondary disabilities in the U.S. The CDC, in collaboration with the National Council on the Disabled (NCD) targeted three areas for research and state capacity building. These areas included: injuries to the head and spinal cord, developmental disabilities, and secondary complications (Houk & Thacker, 1989). The Centers for Disease Control quickly moved to convene a Colloquium on the Prevention of Secondary Disabilities in People with Spinal Injury on February 27-28, 1990. Colloquium participants worked together to address five general areas related to secondary disabilities: a) genitourinary and bowel complications; b) skin complications; c) neuro/musculoskeletal complications; d) cardiovascular/cardiopulmonary complications; and e) psychosocial issues. The result of this conference yielded the publication, *First Colloquium on Preventing Secondary Disabilities Among People with Spinal Cord Injuries* (Graitcer & Maynard, 1991). This conference marked one of the first times the U.S. started to develop a consensus of how best to address secondary disabilities (now called a more politically correct, secondary conditions) in persons with spinal cord injury.

As the U.S. was starting to develop its own agenda and plans about where it wanted to proceed in the area of prevention of secondary conditions, I contemplated what European nations were doing in this same area. After consulting with CDC staff and emerging experts in the area of prevention of secondary conditions, I gave the notion of examining best practices of preventing secondary conditions in European countries more serious thought. This, and with some urging by Judy Heumann and Mark Conly, I applied to the WID/Rehabilitation International IDEAS fellowship.

Report Structure

This report will be divided into two sections. The first section will be a chronological narrative of the significant events and findings from the various individuals I met while visiting the countries of Great Britain, Holland, and Sweden on the one-month journey I spent during my IDEAS fellowship. The narrative will include what I have observed to be best and innovative practices to preventing secondary conditions as well as barriers to preventing or reducing risk of secondary conditions. These best practices will be placed in tabular form with a specified organizational theme under Table 1. The report will conclude with a summary and some recommendations for U.S. adoption and adaptation.

Project Narrative.

The first portion of my trip took me to Great Britain. My first meeting was with Ms. Alison Barker, Information Officer with the Disabled Living Foundation (DLF). The DLF is a national organization that provides information and counseling on various aspects of independent living for people with disabilities and those who care for them. The organization is run by a majority of non-disabled people. Out of a board of 12 trustees only three are people with disabilities. Only 2 staff members at DLF are people with disabilities. The rest of the staff consists of physical therapists, occupational therapists, and other similar rehabilitation professionals. DLF staff stated it offers information and referral for people with disabilities regarding durable medical equipment, showing them what is available and allowing them to make their choices. The staff mentioned, however, that most of their services are rendered to other rehabilitation professionals more so than consumers with disabilities.

One service that DLF provided that I thought was noteworthy was their involvement in evaluating footwear for people with disabilities (e.g., orthopedic, diabetes, or arthritis). DLF has a “footwear advisor” who will assist people with special needs in selecting the proper shoes to accommodate their disabilities. However, many disabled individuals complain that the footwear may be functional but certainly not fashionable. Some said it was “ugly and institutional.” The cost of the footwear is paid for by Britain's National Health Service. The DLF organization co-sponsored a national conference on footwear involved with orthotic service two months after I left Great Britain.

The DLF offers a wide array of services such as a computerized database called DLF-DATA, similar to the AbleData service provided by NARIC in the United States. The organization claims DLF-DATA is the most comprehensive database in Europe with over 17,000 equipment items listed. In addition to the footwear advisory service, the Center also has a clothing and an incontinence advisory service, and an equipment centre that includes assistive technology for the kitchen, bathroom, incontinence, footwear, low-vision, and mobility. The DLF also has resource bulletins — similar to consumer reports — that describe important features when choosing a wheelchair or other piece of equipment. However, the organization does no product testing and has no system of follow-up or feedback from consumers with disabilities regarding their level of satisfaction or product effectiveness. Ms. Barker stated that the National Health Service pays for equipment, but usually only pays for the minimal amount necessary (e.g., cheap foam cushions for sitting instead of gel or air cushions). This could certainly be a barrier to reducing risk to pressure sores.

My next meeting was with the Spinal Injuries Association (SIA), an active disability advocacy and information and referral organization that provided information and support to those with spinal injuries and those who provide care to SCI people in the UK. SIA is a self-help group for people with spinal cord injuries and their families. This organization is different than DLF in that it is consumer run with the majority of the staff having some type of disability (mostly spinal cord injuries).

SIA members are referred to specialized rehab units throughout the UK to serve as peer resources. According to SIA reports there are 9 rehab units in England and Wales, 2 in Scotland, and 1 in Northern and 1 in Southern Ireland. The Stoke-Mandeville is perhaps the most famous rehab center in the UK. Unfortunately, there is no national surveillance data regarding the incidence of SCI, as this is not a reportable condition. This is a potential barrier as SCI individuals will be harder to trace and follow post SCI trauma. In contrast, The Public Health Department of Colorado

has an excellent system of identifying SCI injuries when they occur, and using the registry database as a means to follow-up on each SCI person's medical progress.

The SIA staff mentioned that they were presently developing a national spinal cord injury manual and wish to include materials on prevention of secondary conditions. Presently this organization has fact sheets they distribute on preventative tips on secondary conditions. Fact sheet topics include bladder management for SCI men and women, bowel and bladder care, and how to advertise and interview for personal assistants. In addition SIA has developed two SCI treatment and care manuals for practitioners entitled, Nursing management in the general hospital: The first 48 hours following injury, and spinal cord injuries: Guidance for general Practitioners and district nurses. The latter two publications address such issues as prevention of pressure sores, bowel and bladder management and prevention of related secondary complications. Such resources are invaluable to general practitioners and district nurses who do not have the specific training or knowledge necessary to adequately provide quality care to persons with spinal cord injuries.

SIA took two other innovative approaches in dealing with disabilities and related secondary complications. The first approach is called the "LINK SCHEME." SIA members fill out a LINK SCHEME registration form with some basic demographic data and relevant areas in which they feel competent to offer information and assistance. The registration form has 5 topical areas such as housing, mobility, and personal. Each of the topical areas includes specific issues such as incontinence, depression, spasms, equipment, adaptations, and independent living. People with SCI from all over the United Kingdom register in the LINK SCHEME and can be linked with other SCI persons wanting needed information from their peers with similar disabilities. Thus, a person with SCI who is having problems with pressure sores might telephone, write, or visit with several other peers about what they do to keep their skin healthy. At the time of my visit, the LINK SCHEME was not yet developed into a bulletin board service format. SIA keeps all of the LINK SCHEME information in a central database that can be given to SCI persons requesting specific information and contacts.

The other innovative approach to reducing secondary conditions that SIA was experimenting with was the use of alternative therapies for people with SCI. The use of reflexology and homeopathy are such alternative treatments that are being used with SIA members. The local authorities are now paying 50% of the fees of these alternative therapies which is a positive step in increasing access to such nontraditional therapeutic approaches for SCI individuals wishing to pursue them.

My next appointment took me to meet with Pat Corns, Teresa Cole, and Rachel Stanworth of the Association for Spina Bifida and Hydrocephalus (ASBAH) located in Petersborough. As the name implies ASBAH is an association for rather than of persons with spina bifida and hydrocephalus. ASBAH was formed about 25 years ago and is designed to offer services for people with spina bifida and their families as well as teachers, practitioners, and other professionals.

One of the excellent services ASBAH offers in helping reduce the risk of secondary conditions is training. The Association offers training in a number of content areas that are relevant to spina bifida such as learning disabilities, incontinence, and mobility. Appendix 1 contains some of the workshops (study days) conducted. The study days are hosted by Disability Living Advisors (DLAs). Training is primarily targeted towards professionals, and families of people with disabilities. It was my understanding that individuals with spina bifida were not primary targets of the training

workshops. However, it was noted that some individuals with spina bifida did help participate in some of the workshops.

As previously indicated, the DLAs primarily do educating about spina bifida issues and have expertise in various areas such as continence training, mobility training, developmental issues, etc. Fieldworkers who work with spina bifida and hydrocephalus clients may refer the person and her or his family to a DLA with a specific area of needed expertise.

ASBAH also uses videotapes targeted towards specific groups (e.g., videos that discuss research about perceptual problems that children with spina bifida or hydrocephalus have as a secondary condition or comorbid condition) to educate schoolteachers and professionals that spina bifida children may have other non-obvious problems. The tapes are designed to be interactive for discussion.

Several other issues came up when talking to the ASBAH staff members. First, staff mentioned that like early polio days, parents and practitioners push children with spina bifida to walk. While this may appear immediately advantageous, irreversible physical secondary conditions may appear in later years if not carefully monitored. Second, the staff shared that ASBAH sponsors a support group called "LIFT" (Look Into the Future Today) for individuals with spina bifida age 25 and over. The function of these groups is to offer socialization and support.

The staff also shared some concerns about the socialized medicine system in the United Kingdom. For example, while the national system of health care is designed to provide uniform coverage for families who have children with spina bifida there are inconsistencies from district to district. Some families can get their urinary supplies without problems and others cannot.

There are approximately 8 Regional Health Authorities. Each region is broken down into several districts. Within districts there are general practitioners (G.P.) who each have their own budget. Given the limited budget, they may be reluctant to treat patients with chronic conditions or disabilities. Ideally, the money should follow the patient.

Youth under 16 receive exclusive care under the direction of a pediatrician. If there is a real problem, a specialist is called in for consultation. However, when the patient turns 16 or older, he or she must suddenly have to go to 4-5 different physicians instead of one. Thus, young people with chronic conditions have more consistency in their medical care and follow-up than their older peers.

Another problem that concerns ASBAH staff is that most people with spina bifida live with their folks all of their (or their parents') lives. There needs to be a better way of transitioning such individuals into the community to live more independently.

My next meeting was with the Royal Hospital and Home, Putney, of which, The Queen, and the Queen Mother are patrons. The Royal Hospital and Home (RHH) occupies a spacious campus that is dotted by a number of large older buildings. There was a wide diversity of patients that I observed at RHH including those with traumatic brain injury, cerebral palsy, multiple sclerosis, spinal cord injuries, and Huntington's and Parkinson's diseases. The majority of individuals referred to the RHH have very severe disabilities and are those often turned down by other rehabilitation centers. Many are non-verbal and have very limited ambulation abilities and have chronic disabilities of a physical and/or a cognitive nature. I noted some younger patients at the RHH, but the majority

were elder and lived in the residential part of the center. The staffs were very dedicated and professional and were committed to providing the best possible care to their clientele.

Many RHH patients with severe disabilities are on gastro-feeding regimens. The feeding has helped increase these patient's nutritional status and decreased occurrence of pressure sores. Of 62 gastro-feedings, the majority uses a milk-based supplement. The dietitian that I interviewed claimed that gastro-tube feedings are a major success in combating urinary tract infections for patients who have trouble swallowing and not taking in enough liquids by mouth.

The RHH staff has much expertise in wheelchair positioning for their patients and conduct weekly clinics where patients are regularly evaluated by an interdisciplinary team to determine what type of positioning prosthetics are needed. One innovative device that the RHH has developed and patented is the Matrix Wheelchair. This wheelchair consists of a seating system made up of hundreds of nylon-plastic composite moveable joints much like tinkertoys but more flexible. The seat design conforms to almost any position the therapist/molder desires and is especially valuable in helping to avoid pressure points in sacral and tuberosity areas. The wheelchair was developed through assistance from the Ministry of Health, and is also known as the "Putney Alternative Position Chair."

I also talked with Ms. A. Leo-Cruz, who is a pressure sore specialist on RHH staff. Assessment for risk to pressure sores is made as soon as the patient comes to the ward. An interdisciplinary approach (dietitian, physical therapist, occupational therapist, Ward Specialist, Ward Sisters) is used for assessment utilizing the Norton Scale Index, a well-known assessment scale. As part of the assessment procedure, photographs of pressure sore wounds are taken for measurement and documentation purposes. Ms Leo-Cruz stated that Great Britain is now trying to establish licensing standards for care facilities that would help to prevent or reduce secondary conditions such as pressure sores.

There is one last noteworthy secondary prevention strategy that I observed while at RHH. The rehabilitation care center employs "lifters" whose sole job is to go around and gently lift RHH patients with disabilities up out of their wheelchairs every two hours, for several seconds, to relieve prolonged sitting pressure on the buttocks and sacral regions as well as reposition them to a more natural and upright sitting position.

My final visits took me to the southern part of Great Britain near Portsmouth to visit with two leaders of Britain's independent living movement, Phillip Mason and Mark Walsh. The meeting was informal and enjoyed over a cup of hot English tea. Discussions with Phillip and Mark yielded several important pieces of information. First, they confirmed ASBAH's staff concern that provision of services and the procurement of needed equipment for people with disabilities was inconsistent across districts. This lack of consistency could possibly increase the incidence of secondary conditions such as pressure sores and urinary tract infections. Another issue of great concern to Phillip and Mark was the National Health Service's forthcoming revision of how they were to disburse monies for durable medical equipment (DME). According to my understanding, under the traditional system a separate fund account was kept for just DME, such as wheelchairs. This procedure was under review with the potential recommendation that the DME fund would be unencumbered and available to purchase other needed medical supplies or services.

The latter change to the system is viewed with great concern by British individuals with disabilities given the lackluster economy and already inefficient system of providing needed medical

equipment and supplies. Thus, if enacted, this law could potentially cause unintended increased risk of secondary conditions if needed durable medical equipment were not available to those who needed it (e.g., a quadriplegic left to lay in bed because her or his power wheelchair is beyond repair). Finally, both of these individuals were concerned that, in general, persons with disabilities in the United Kingdom needed to be better self-advocates and develop the empowerment skills they need to get the appropriate services. While there are some good advances being made to increase the independence of people with disabilities living in the United Kingdom, there is still more work to do.

The next part of my IDEAS Fellowship took me to the country of The Netherlands. One of the first visits I made was with a Ms. Diana Bos, a policy analyst for the Health and Social Services Department of the City of Amsterdam. She said that one of the local disability organizations works with the city to rectify any disability related problems that exist. Under present policy, Ms. Bos said that home health care aides come in to care for people with disabilities who need it. However, she mentioned that there may often be a lack of consistency as the care may not always be delivered by the same person, or at the same time. As in the U.S., people with disabilities want their own money to hire/fire their own attendants.

During the time of my visit, the Dutch social system would pay up to 70% of your regular income if you became disabled, but then it tended to be reduced to “near poverty levels,” according to Ms. Bos. Another innovative policy was that if a person with a disability could get a vehicle or money to take taxis if they had medical approval to do so. This access to transportation is provided so that the disabled individual can visit their family, or needed health care. Other reasons for receiving the transportation allowance include getting to work, social activities and to help reduce isolation.

The lack of accessible housing also presents many problems for people with disabilities. Ms. Bos pointed out that if a person becomes disabled he or she can request reasonable housing accessibility modifications (again with medical approval) from the Amsterdam housing department. If approved, the department could make the needed modifications up to \$45,000 guilders. This money is well spent when one considers the old style architecture found in Amsterdam.

When barriers to accessible transportation and housing are reduced or eliminated, people with physical disabilities are more mobile, independent, and able to get to the services they may require to maintaining good health. In a surveillance report on secondary disability prevention conducted by Seekins, Smith, McCleary, Clay, & Walsh (1990) consumers with disabilities, who were survey respondents, ranked problems with mobility and difficulties with access as the conditions with the highest problem index scores. While these two issues are not biological factors that relate to secondary conditions, the survey respondees identified the environmental barriers as significant enough to be called secondary disabilities.

In her concluding remarks, Ms. Bos stated that while there are many good health and social benefits for Dutch citizens with disabilities (e.g., work, travel allowance, housing modifications, and rehabilitation) unfortunately there is not an effective system in place to coordinate these services.

My next stop took me to visit the Revalidatie Centrum Amsterdam, a brand new 112 bed state-of-art rehabilitation center in the heart of downtown Amsterdam. Staffs were busy preparing for the grand opening to occur about 3 weeks after my visit. I received a tour and was impressed with the center's emphasis on sports activity within rehabilitation. The center had a large pool that could raise or lower the stainless steel pool floor bottom. Adjacent to the poolroom was a large

gymnasium that could accommodate wheelchair basketball games or other sport activities. I spent most of my time in discussions with one of the head physiatrists (revalidatie-arts), Dr. H.H.J van As. Dr. Van As was a gracious host, taking time out of his busy schedule to meet with me.

With reference to best practices in preventing secondary conditions he pointed out, and rightly so, that if a patient receives good rehabilitation in the first place and proper education about potential secondary conditions that may occur and how to prevent them, the patient will be less likely to have health problems. As part of the interdisciplinary rehab team, the patient has what Dr. Van As termed a “home team.” According to my understanding this “home team” was part of patient conferences but became especially active about 1-2 months before discharge from the rehab unit. The home team helps to transition the patient from hospital setting to home setting. After discharge, patients are followed up on a 3-month, one-year, and annual basis.

During their hospital stays the patients are regularly visited by disability advocacy organizations such as Stichting De Schakel (Dutch Spinal Association) to help enlighten them about what life is like after discharge, and provide tips on how to live with a disability more independently. The Revalidatie Centrum is regularly visited by other peer physicians who provide feedback on areas where the center is progressing and areas where the center needs improvement. I was also delighted to know that disability organizations, like De Schakel also visit the Revalidatie Centrum to offer constructive criticism about what areas need improvement. Dr. van As was proud of the fact that the Revalidatie Centrum and De Schakel have a very good working relationship. This working relationship is an excellent innovation that needs to be further developed and expanded in the U.S. Such cooperation suggests that medical practitioners in the traditional medical model are open to suggestions and willing to make their services more patient-centered.

During our closing discussion Dr. van As mentioned that not all urinary tract infections are treated — at least on a continuous basis — because the patient’s urinary tract infection bacteria may become resistant to various treatment regimens. This is a practice that is often carried out in the U.S. as well. Finally, van As said that if one of his patients was discharged into the community and at some future time needed some equipment such as a wheelchair cushion the person could call the gemeenschappelijk medische dienst (GMD) or community medical services and they would see that the patient received a cushion. Dr. Van As also said the patient could call him directly for a new cushion.

While I was in Amsterdam I also had the privilege of visiting at some length with one of my country “Hosts” for my IDEAS Fellowship. Ms. Simone Tielrooy held the position of Koordinator of the Stichting Gehandicaptten Overleg Amsterdam, a local disability advocacy organization that served people of all disabilities. Ms. Tielrooy was a person who had “worked in the trenches” concerning rights and independence for Amsterdammers with disabilities and was able to give me a true and realistic vision of what life for Dutch with disabilities was really like. The following are a few points from our conversation together.

Ms. Tielrooy stated that social services have been real good but that they were getting worse because of the federal budget and fiscal revisions. Accessibility and independent living services are only delivered on the individual level. However, there are no substantive changes made at system levels to help people with disabilities become more integrated into society. With the limited resources available, people with disabilities may not always get the equipment they need and this may well be exacerbated if proposed new fiscal reduction policies go into effect.

Ms. Tielrooy shared that most disability organizations do not stress prevention of secondary disabilities. Local disability organizations usually tend to provide more of a social function for their members. There is more likelihood that national organizations like De Schakel and Gehandicaptten Raad would be more active in helping to promote reduction of secondary conditions for people with disabilities.

As part of my itinerary in The Netherlands I spent time talking to consumers with disabilities. One of the consumers I spoke with was Margaret Wildeman, Secretary of the Board of Stichting De Schakel (Dutch Spinal Cord Association). From Ms. Wildeman's viewpoint, Dutch people with disabilities have access to pretty much state-of-art when it comes to reducing risk to secondary conditions. To prevent or reduce risk to pressure sores she personally eats nutritious foods, practices good hygiene and uses a ROHO wheelchair cushion. She did have several bouts with pressure sores and major surgery to help repair damaged tissue, but is doing better now. Ms. Wildeman claimed that if she needed some medical supplies (such as those for a bladder and bowel program) she could get them at government expense. However, if a person makes too much money he or she may need to use private insurance to pay for needed supplies.

Like the Spinal Injury Association in Great Britain, Ms. Wildeman said that people with SCI call De Schakel (Dutch Spinal Association) to ask how to deal with secondary conditions such as depression, sexuality, and other medical problems. If the staff cannot offer assistance over the phone, the person is referred to another SCI person near the caller. Hopefully in the future each region in Holland will have a SCI organization to offer information and support.

Stichting De Schakel offers an annual conference that has covered such topic as coping, sexuality, tax issues, and advocacy. This year's topic is Functional Electrical Stimulation (FES). As new medical developments occur such as FES, De Schakel informs its 500 members via a bi-monthly newsletter. The newsletter provides members with information about how to keep healthy and occasionally asks rehab doctors to write an article. De Schakel tends to be unbiased in its approach, presenting both sides of an issue, such as the pro's and con's of FES.

Ms. Wildeman confirmed Dr. van As point about De Schakel's involvement with rehab centers such as Revalidatie Centrum Amsterdam. Members of the Dutch Spinal Association regularly visit rehab centers and discuss with physiatrists what are and what are not effective treatment regimens. Apparently the rehab centers value this feedback from the Dutch Spinal Association. If patients with spinal injuries report a bad experience in rehabilitation De Schakel will go and advocate for them, or perhaps write about the experience in their newsletter. The organization believes in teaching people with disabilities to be assertive and tell medical professionals what they need.

Finally, De Schakel members regularly visit universities and schools that have physical therapy, occupational therapy, and nursing programs. During their visits the students are lectured about what it is like to be a people with disabilities and are provided general information about how to work with people with disabilities. The De Schakel members may also provide tips on how to help reduce problems with secondary conditions (such as developing pressure sores on the heels while on a patient waits for prolonged periods on a transportation cart, or developing a bowel impaction because of improper bowel care by nursing staff).

Yolan Koster was another person I had spoken to about secondary conditions. Ms. Koster is Secretary of the Board of the Gehandicaptten Raad (Federation of all Dutch Organizations for the Disabled, or Dutch Council on the Disabled) which is located in Utrecht. The Gehandicaptten Raad is an umbrella organization composed of 66 different disability organizations in Holland. Some of these organizations are of people with disabilities (consumer controlled) and some of these are organizations for people with disabilities (professionally controlled). One of the goals of Gehandicaptten Raad is to establish a society where every individual regardless of ability can determine their own destiny.

Ms. Koster said that prevention of secondary conditions is not a popular issue among many physicians. They tend to think only of primary medical prevention. Disability organizations are trying to convince them to take a more proactive view of secondary conditions. According to Koster, the medical establishment still tends to follow the social model (called medical model in U.S.). If you have a certain disease or chronic condition, you can have the materials you need to prevent secondary conditions. However, many physicians are not aware of potential secondary conditions, and many people with disabilities are also not aware of secondary conditions. An example of this is the medication given to older people who have long-term needs. Physicians tend to prescribe the same amount and type of medications for older people as younger people. Physicians do not necessarily evaluate elderly people with disabilities on a case by case basis, or review their need for revisions in their medical regimens.

The Gehandicaptten Raad seeks to sensitize and influence the medical system to the needs of people with disabilities. The Gehandicaptten Raad members (people with disabilities who have successfully completed the rehabilitation process and have become integrated into the community) are regularly invited by major universities to lecture to second, third, and fourth year medical students and nursing and physical therapy schools to provide these future medical professionals with a more holistic and enlightened view towards people with disabilities. For example, one of the curriculum topics is "Norms and Values in Treating People with Disabilities in the Rehabilitation Process." The total time provided to such students is around 6-7 hours of lecture, which is a worthwhile investment of time.

The Dutch government has strict licensing standards for rehabilitation hospitals. If there are problems, patients or people with disabilities can ask health authorities to come and inspect the rehab facility and investigate alleged complaints. Ms. Koster mentioned that disability organizations often "watchdog" medical services in general to assure quality assurance. Some rehabilitation centers have a Clients Board that is made up of former and in-house rehab patients. This board functions in an advisory capacity concerning rehabilitation facility policies. It also receives patient complaints and advocates to help correct problems.

The Gehandicaptten Raad works to advocate for more advances in treating secondary conditions. Presently, the vast majority of Dutch Guilders go toward primary prevention rather than addressing secondary conditions. The Prevention Board, an official Dutch government board that is financed by part the national health insurance is composed of employees and employers organizations, health representatives, scientific researchers, members from the national council on public health. The Prevention Board mainly focuses on primary prevention in the workplace, and traffic safety.

Ms. Koster briefly discussed some gaps and barriers in the Dutch health care delivery system. Some problems exist for people with chronic and systemic illness' (e.g., diabetes, lupus). Under this situation the patient with multiple medical problems/conditions may be treated by several different specialists with no overall coordination of the treatment regime. She also mentioned that there are not adequate staff for many nursing homes which causes medical care to suffer, which in turn increases risk and incidence of secondary conditions such as pressure sores for nursing home residents. Finally, Ms. Koester concurred with Ms. Bos' and Ms. Tielrooy's assessment that federal supports for people with disabilities were clearly being reduced. For example, up until recently, if you became disabled you could receive 70% of your salary up until age 65. Now if you become disabled, you will initially receive 70% support for 1.5 years then 50% support, then later to near poverty levels.

My next visit was to the town of Arnhem where I visited hetDorp (The Village). HetDorp is a community where people with disabilities can live and work. It was founded in 1962 by A.. Klapwijk, a Dutch rehabilitation specialist, and was funded through a 24-hour radio and television telethon. The majority of people living at hetDorp are disabled. From the viewpoint of many disability advocacy organizations in the U.S. this segregation of people with disabilities is unthinkable and this view is shared by some disability organizations in The Netherlands.

I was given the standard visitor tour of hetDorp by Joop Janssen, one of the residents who was living there. During my tour I had the opportunity to visit with many of the residents and ask them about their thoughts on the issue of prevention of secondary conditions. The residents were very pleasant and shared openly about their disabilities, but from my observations, most were not well versed on the issues of secondary conditions. I briefly met with a physician at hetDorp who stated that when residents were admitted to hetDorp each was given a careful medical examination. If pressure sores were detected, they were promptly treated. Instructions were given to aides that worked with hetDorp residents to carefully monitor the residents who were at high risk for pressure sores. Regular inservices were also given to the aides on various prevention strategies to reduce incidence of secondary conditions. The physician mentioned that hetDorp residents receive physical therapy 3-5 times per week based on their need. PT activities concentrated on strengthening and range of motion to reduce contractures and maintain joint mobility.

The final stop I made at hetDorp was to the newly constructed Rehabilitation Technology Department (Rill) that was directed by Hank, a fellow wheelchair user. Hank mentioned that the Rill does lots of evaluation for people with disabilities to determine what type of assistive technology is appropriate for them. The people with disabilities provide feedback on what they do and do not like about various equipment options and then make the final decision on what they want. Hank shared that the Rill often modifies wheelchairs to assist people with disabilities to prevent pressure sores. For example, he might order a basic power wheelchair and then add a seat-tipping device that assists the person with weight shifting. From my observations in the European countries I visited, none had the sophistication of some of the U. S. power wheelchairs that offer reclining options. They may be available over there, but I did not observe people with disabilities using them or see them in durable medical equipment stores.

My last IDEAS Fellowship visit in the Netherlands took me to a top policymaker in Den Hague (The Hague), the parliamentary capitol of Holland. There I met with Dr. J. W. Brak, Directie Gehandicaptenebeleid, Ministerie van Welzijn Volksgezondheid en cultuur (Deputy Director of the Directorate for Policy of the Handicapped under the Minsitry of Welfare, Department of

Handicapped People). The principle goal of the welfare policy for the disabled is to help people with disabilities of all ages and social and cultural backgrounds to be full members of society and to have every opportunity to develop their full potential.

The disability policies that are developed for Dutch citizens with disabilities are done so with the collaboration and input of many different organizations. Appendix 2 provides a good overview of all of the key players in determining disability policy in the Netherlands. There are participants from the parliament, members of government agencies (e.g., department of Defence, Ministry of Transport and Public Works), and disability professional and consumer organizations from the national, provincial, and local levels that provide input and feedback regarding proposed legislation. This model appears more practical than the way disability policy is handled in the U.S. with part of disability issues being parceled out to the Departments of Education, Housing, and Health and Human Services, as well as other U.S. departments.

Regarding the policy of prevention, Dr. Brak said that much of the present focus is on primary prevention and not much is being done in the area of public policy related to the prevention of secondary conditions. Additionally, other pressing disability issues such as housing and societal access are on the front burners and being addressed.

Dr. Brak said that the Dutch government is using a case manager approach in providing advice to its citizens with disabilities on various issues. This approach would encourage the case manager to discuss the pros and cons with the people with disabilities and then allow them to decide what they wish to do. The goal is to have case managers available at the district levels to allow more availability and communication. The Ministry of Welfare is also experimenting with allowing people with physical disabilities to have vouchers to pay for needed services; however, the ministry is less reluctant, at this time, to give moneys directly to people with mental disabilities and their families. (For a more complete and detailed review of the health care needs of people with disabilities in the Netherlands see the excellent 1990 IDEAS project publication written by Batavia).

The next segment of my trip took me to Sweden where again I continued to investigate best practices concerning reducing risk to secondary conditions. My first visit was made to the world famous Karolinska Institutet, a Swedish medical facility with broad medical services ranging from psychiatry to physical medicine and rehabilitation. I first visited Ms. Margreta Johnsson who works as a physiotherapist for the Institutet. It was her experience that most Karolinska patients in rehabilitation do not develop pressure sores, or many other secondary conditions. However, patients may be more at risk to secondary conditions such as alcoholic or psychiatric disabilities following discharge.

Ms. Johnsson offered several tips that are helpful to reduce risk to secondary conditions for people with physical disabilities. First, it is important to have a good mattress to sleep on to avoid pressure sore problems. Second, education on prevention of secondary conditions should be provided to the patient and his or her family. Third, the patient should receive skills training on how to regularly check their skin in areas particularly vulnerable to prolonged pressure. If the patients cannot check themselves, they need to take the responsibility to ask others to check for them. The Karolinska Institutet physical medicine and rehabilitation department schedules regular yearly check ups to follow their patient's ongoing progress. Ms. Johnsson pointed out that the patient care at the Institutet is pretty autocratic with little chance for patient feedback. This is quite different than the

approach taken by many Dutch rehab centers that invite patient and consumer feedback on patient services.

The Institutet, like its rehab counter parts in Holland does allow peers with disabilities to come in to talk with their patients undergoing rehabilitation. The peer visitors are sponsored by the Rekryterings Gruppen For aktiv Rehabilitering (The Recruiting Group for Active Rehabilitation) who comes on a monthly basis to provide information and support regarding community reentry for people with disabilities. (Information on the Recruiting Group will be presented later).

The other staff member I met at the Karolinska Institutet was Dr. Claes Hultling a physician who directs the Solberga Projektet. Dr. Hultling is a very knowledgeable individual in physical medicine and has tremendous rapport and credibility with his patients, as he is also a wheelchair user. The Solberga Projektet is taking an inventory of the approximately 350 SCI persons in Stockholm. The investigations will focus on social, psychological, and medical aspects of SCI participants. Part of the Solberga Projektet includes an attractive care unit away from the main hospital grounds where centralized SCI care and management is offered. This center serves as a hub and a source of contact for SCI people both in hospital and in the Stockholm and surrounding communities. For example, the center has a hotline that SCI people can call if they have a urinary tract infection or if their ROHO cushion goes flat to receive immediate attention. If the patient needs to receive SCI care, they can be admitted within 12 hours of first contact.

Dr. Hultling believes that psychological issues should be addressed earlier in the rehabilitation process to help provide better integration of people with disabilities. Individuals discharged from the Karolinska Institutet are excited to have Dr. Hultling as a contact source. He believes that this continued contact will have positive results in reducing incidence of secondary conditions. Dr. Hultling also believes in the role that disability organizations such as the Rekryterings Gruppen can play in visiting patients and sharing with them the importance of following prescribed medical regimens to avoid secondary conditions. These disability organizations often visit patients 2-3 weeks after their initial injury to develop peer relationships and assist the newly injured person into returning to the community.

Dr. Hultling pointed out that public transportation for people with disabilities is pretty good, at least in the cities. People with disabilities are entitled to free transportation. The city of Stockholm is purchasing a large number of minivans to transport people with disabilities within 2-3 hours response time after receiving a phone call. In addition, Stockholm has hundreds of taxis that transport Swedish citizens with disabilities at a fraction of the fare cost, when the riders show their disability ill cards.

There are a number of gaps in the Swedish health care system according to Dr. Hultling. For instance, there should be a centralized rehab center to act as a monitoring and referral agent. This might reduce the "over consumption" of elective surgeries that many people are taking. He believes that there should be more consistence from hospital to hospital in Sweden. General practitioners, however, are doing a great job in keeping up with most medical advances concerning physical disabilities.

My next visit was to meet with Helen Karn, a consumer with a disability and a board member of the Stockholm Cooperative on Independent Living (STIL). According to Ms. Karn, STIL started in 1986 as a loose association of people with disabilities who needed personal

assistance. The 2-year project worked with 26 people who employed personal assistants. It was so successful that in 1988 STIL became permanently established. Peer counseling is another one of STIL's core services.

Ms. Karn stated that in general Sweden provides the needed physical services to help people with disabilities maintain their health and that personally she receives all of the services she needs. However, some of her peers with disabilities who live in other regional health districts may not receive comparable services.

Regarding prevention of secondary conditions, health maintenance and other disability issues, Ms. Karns said that each Tuesday evening from 6-9 a group of people with disabilities would take a particular subject and discuss it. If a person is facing a particular problem, the group would talk about it and think of potential solutions. For example, if a person needed more hours of personal assistance, she or he would discuss it with other members and in many cases get a sense of solidarity to face the authorities to petition for additional personal assistance hours. Although there may be no apparent cause and effect, such additional hours may be very helpful in deterring incidence of secondary conditions for that particular individual.

My next conversation was with Adolph Ratzka, another co-founder of STIL and a internationally known advocate for disability issues such as personal assistance. Dr. Ratzka is also editor the internationally distributed Independent Living DPI Newsletter. I visited with him in his adapted apartment in Stockholm. During our conversation he demonstrated a wealth of knowledge about the Swedish health care system and resources helpful for people with disabilities.

Dr. Ratzka shared that Sweden has high taxes to help pay for the socialized medicine that all Swedes receive, including of course, people with disabilities. However, he went on to say that the health care system does not cater well to specific individual's needs. He cited the personal example of wishing to have a specialized power wheelchair for his mobility needs. The Swedish system only prescribes wheelchairs from a fixed range of criteria with little flexibility for specific needs. Thus, in Dr. Ratzka's view, the system has a paternalistic attitude towards consumers and denies them little personal choice about what they might need to increase their health or independence.

The Handicapp Institutet, according to Dr. Ratzka helps to find the best assistive devices for people with disabilities. The Institute has 3 occupational therapists, 1 physical therapist, and 1 technician on staff. The Institutet also has an advisory group of people with disabilities to give input and guidance. People with disabilities can receive adaptive and assistive devices free in Sweden, however, not all desired items are on the acceptable list. Disabled people can petition to receive assistive technology not on the standard equipment listing. It is noteworthy that more ROHO wheelchair cushions are prescribed more frequently than the similarly effective Jay+m cushion. Why? According to reports, the gel in the Jay cushion tends to stiffen up in the cold northern Swedish climate compared to the air-filled ROHO wheelchair cushion. Such environmental factors must also be taken into consideration when developing strategies to reduce risk to secondary conditions

As indicated by Ms. Karns and confirmed by Dr. Ratzka, people with disabilities report to a regional health center or health station that does triage to determine what each person with a disability needs (e.g., referral to a specialist or specific facility). Theoretically, this system is supposed to be responsive to the disabled person's needs. However, not all regional health centers offer

quality or responsive services. This results in frustration for those unfortunate residents with disabilities who happen to live in the region the health center serves. Hopefully, as Dr. Claus Hultling's Solberga Projektet becomes more established, Swedes with disabilities will have more continuity in the services they need, or will have an ombudsman that can advocate to the regional health centers to get what they need.

Dr. Ratzka said that many disability organizations are involved in prevention activities. One Swedish disability organization has a subcontract with health care provider organizations to provide physical conditioning for people with disabilities to go to 1-2 weeks a year to serve as a regular "tune-up". The counterpart to this is those people with disabilities who abuse the system and regularly return to rehabilitation centers needlessly. According to Dr. Ratzka, part of the reason for this is that often following successful rehabilitation, Swedes with disabilities cannot find employment and as a result become discouraged or depressed. Presently, the unemployment rate for disabled people in Sweden is 70%.

My next visit took me to the center of Stockholm to visit the Hjalpmedels Center (Technical Aids Center) that provided a comprehensive and permanent exhibition of assistive equipment for visitors, health care professionals, and people with disabilities to look at and try out. The Center is a storefront operation that carries thousands of adaptive equipment items much like the Disabled Living Foundation in Great Britain. Therapists are on duty to demonstrate and discuss the pros and cons of each item. All items in the Center are on-loan from the manufacturers (mostly Swedish) for demonstration purposes as no equipment is sold from this Center.

During 1990, 97 different manufactures were represented. Brochures are available for each piece of displayed equipment. Two of the most innovative pieces of equipment I observed were a kitchen counter and cupboard cabinets that were mounted on a wall track and could move up and down by means of a small electric motor system. This kitchen set-up could be adapted for people with varying abilities. The second piece of equipment that I thought was particularly innovative was an ostomy care station for people who were ambulatory, but needed an Ostomy appliance (see appendix 3). The box-shaped ostomy station was placed about 20 inches above the toilet stool tank. When the front door to the unit was closed, its function was undetectable, yet when the front door was opened, a small sink slid out with a small hose that went down to the toilet. Attached to the sink was a small rinsing devise much like one used in a dentist's office, yet this device also had a LED that displayed the water temperature.

These, and many other innovative devices were created because there was a demand for them, there was creativity that strove to meet that demand, and most importantly, under the Swedish health system, these innovative assistive devices could be purchased for consumers with disabilities who needed them by Swedish Tax Kroners. The other fact that really impressed me was the beauty of design that was incorporated into each of the adaptive devices. Instead of form following function, it appeared to me that function followed form. Quite a difference from the orthopedic shoes that people with disabilities in Britain complained about!

Technical Aids Centers such as this one offer a first-hand experience for people with disabilities, their families or personal assistants and rehabilitation professionals to examine the latest assistive technology available. Through such experiences new approaches to medical care and independent living can be taken to maintain a healthy lifestyle and reduce incidence of secondary conditions.

With my IDEAs Fellowship almost coming to an end, I made my last visit with the staff of the Rekryterings Gruppen (Recruiting Group). I have heard very much about this organization during my stay in Sweden. I met with Stefan Wegesborn and Magnus Andersson at the Rekryterings Gruppen headquarters, located in a small nondescript building in Stockholm.

There are about 3000 members of the Recruiting Group in Sweden. Like the Dutch disability organization De Schakel (Dutch Spinal Association) the Recruiting Group also visits rehabilitation wards on a frequent basis. The Recruiting Group also helps newly injured individuals to cope and return to society, but their emphasis is heavily focused through the medium of sports. The Recruiting Group (RG) invites people who have recently become disabled to attend training camps. In 1978 the first camp was held with about 30 people, mostly from rehab wards attending. Sports are not necessarily the ultimate goal, rather involvement in sports activities is emphasized by the RG members. Participation in sports activities helps to promote and maintain cardiopulmonary and muscular fitness as well as range-of-motion.

Following 1978 and the success of the first camp, five additional camps were held during the next two years. The early camps attracted about 50 wheelchair users and 50 non-disabled persons and were held at schools that were rented. As part of their outreach activities the RG would continue to visit rehab hospitals and act as resource persons for newly injured people. The members would introduce the notion of participation in various sports such as swimming, table tennis, archery, and weight training to the rehab patients.

As a new organization the Recruiting Group wished to expand but had no capital to do so. The Swedish Department of Social Welfare observed the wonderful efforts of the Recruiting Group on people with disabilities and provided them with 3.5 million Kroners (\$500,000 US) to run 2 one-week beginner camps, 1 one-week follow-up camp for 50 participants, and 1 one-week child-parents camp. In addition, the Recruiting Group ran a one-week camp for stroke survivors and a five-day camp for women on the topic of sexuality.

Most recently the Recruiting Group established a collaborative relationship with an organization that owns an Olympic style sports stadium complete with pool, handball, basketball, volleyball, tennis, and 110 and 200 meter tracks in addition to other sports activities. The facility is named Bosons (island), which is located on an island near Stockholm. The RG now has sports and related activities for people with disabilities during two 15-week tern1S each year. The Stockholm government and several Foundations gave 5 million Kroners to fund this three-year project at Bosons Idrottsinstitut.

Camp participants paid about 300 Kroners (about \$42 U.S.) to attend the 15 week camps. They attend half-days for 3 days a week and receive information and training about physical fitness, sports training, nutrition, sexuality, wheelchair equipment recommendations, and self-esteem. Besides the two 15-week tern1s, the RG also sponsors a 2-3 week camp in the summer. Throughout all of the training the RG emphasizes the positive (e.g., "work with what you have").

As part of its training at the Recruiting Group camps, prevention strategies to reduce occurrence of secondary conditions is emphasized. For example, participants are told about the importance of completely emptying their bladders to avoid infections, and to try to avoid taking too many medications if at all possible. According to RG staff, the majority of sports camp graduates are less likely to develop pressure sores than non camp participants. There is no empirical proof to this

anecdote, but it appears to be a plausible outcome given the emphasis on health maintenance, nutrition, and information provided to participants about preventing pressure sores.

The Recruiting Group gets its message out to consumers with disabilities and its members through publications such as KICK and Aktivt Liv (Active Life). In addition, the RG also provides lectures to physical therapy and occupational therapy schools and also provides regular inservices to hospital staff.

IDEAs Project Summary

For the most part, this research experience has been very useful and provided a number of innovative strategies that can be used alone or in combination with various approaches to reduce incidence of secondary conditions. The majority of the best practices identified are from disability advocacy organizations and their members who are working with people with newly acquired disabilities. Several of the best practices and policies are innovative in that each of the countries visited provided a National Health Insurance plan that was paid for by citizens' tax dollars. It should be noted that the majority of the best practices that I observed or were described to me were not accompanied by empirical evidence to substantiate the effectiveness of the particular intervention being presented.

Recommendations for U.S. Adoption and Adaptation

Based upon the IDEAS Fellowship study on identifying exemplary European practices to reduce incidence of secondary conditions in people with disabilities several recommendations for are presented for consideration to help reduce incidence of secondary conditions in the U.S.

First, rehabilitation centers and the consumers with disabilities they serve should work to foster greater collaborative relationships. Such partnerships are already started between rehab units and some independent living centers such as ParaQuad, Ann Arbor CIL, and Southeastern Minnesota CIL. The objective of these partnerships is to offer peer counseling and assistance with facilitating transition of new rehabilitation patients into the community. European disability advocacy organizations such as De Schakel, Gehandicaptent Raad, and The Recruiting Group pushed the relationship one step further by monitoring rehabilitation services and providing regular feedback to rehabilitation administration. Thus, if patients are being released into the community and there is a trend of unnecessary secondary conditions that develop among those discharged from rehabilitation (e.g., urinary tract infections, pressure sores, contractures) disability advocates and consumers can inquire about teaching practices, rehabilitation training regimens, and equipment prescription. Traditionally rehabilitation units are evaluated by professional peers such as those in the Council on Accreditation of Rehabilitation Facilities (CARP). While this organization recognizes and promotes high quality standards for rehabilitative care, patients who are recipients of rehabilitative services should also have a role in providing feedback on the quality of services received.

Second, people with disabilities need to have better access to pertinent information that will help them reduce incidence of secondary conditions. Storefront operations that contain medical equipment for review and demonstration should be made available. Competent staff, including consumers with disabilities and rehabilitation professions, at such centers should be objective in discussing equipment needs with customers and offer pros and cons about each piece of equipment.

Consumers with disabilities in the U.S. presently go to Medical Equipment Suppliers to get their information about various equipment or supplies that might meet their needs. Unfortunately, many equipment dealers are biased and tend to push specific products they carry rather than examine the pros and cons of various pieces of equipment (e.g., recommending a foam cushion instead of also presenting a ROHO or Jay cushion as another alternative. Additionally, the suppliers will not have the diversity of equipment that consumers may need or be interested in learning more about. Perhaps medical suppliers could provide their products "on permanent loan," and with the help of foundations, defer the associated costs of funding large exhibit stores in several major U.S. cities to allow people with disabilities, their families, and rehabilitation professionals the opportunity to have "hands-on" experience with the products.

Perhaps local public health departments might offer special training courses on bladder and bowel management to targeted populations such as parents of children with spina bifida, people with physical disabilities, and to geriatric populations who have a difficult time maintaining continence. In the U.S. we often think of the "quick fix" to handle the problem. There are millions spent on adult incontinence pads that might be avoided if those affected could receive the proper training for effective bladder management.

Third, the federal government must address the problem of housing and transportation accessibility in our society. Such barriers prevent people with disabilities from effective integration into our society which can cause psychological stress that may result in other associated secondary conditions. Lack of access is also a definite barrier in getting to needed medical care when the person with a disability needs it.

Finally, the availability of excellent health care and assistive technology to reduce incidence of secondary conditions is of little value if persons with disabilities cannot afford to utilize these resources. Common to each of the countries I visited was the policy of socialized medicine. The U.S. needs to strongly consider how to include how the 43 million Americans with Disabilities can access affordable health care. The medical industry has one of the highest yearly escalation in inflation costs. Fiscal reform must start within the medical industry in cooperation with third-party payers with the goal of providing reasonable care for all America's citizens.

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