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FROM THE EDITORS

The last few months have seen a flurry of activity with respect to the Innovia Newsletter. This activity, we should add hastily, has been borne primarily by this issue's contributors. The theme of disability again permeates our pages, as most of the contributors take up some issue with direct relevance to the topic.

We begin once again with some reflections from Innovia Director Stuart Blume, whose recent visit to Norway's University of Bergen compelled thinking on how certain categories of illness and disease rise to the attention of clinicians and researchers at the expense of others, as well as the need to focus further on identifying the characteristics of successful research. From there, we transition to a contribution written as a truly collaborative piece of work by three authors, Ton Millenaar, Mama Josephine Bakhita, and the Newsletter's co-editor Zoe Goldstein. In it, the authors focus

on the work of the Amani Centre in Tanzania, a grassroots organization operating according to tenets of *community based rehabilitation*, and dedicated to serving the needs of youth with disabilities, and their parents. Through the tireless efforts of its founder, Mama Bakhita, Amani has grown from strength to strength and had a considerable impact in the region, providing opportunities for many people with various disabilities to live more full and independent lives in the community.

Norma Morris provides a change of pace as she interweaves her own biography with reflections on the field and with observations on the nature of research. In doing so, Dr Morris provides a window onto the world of a self-described (mythical) 'policy-maker' turned soft money university researcher, working in essence at the intersection of medical sociology and science and technology studies. As she herself states, her enthusiasm with her new line of work – well, perhaps 'new' is not exactly the right word – remains to this day. And it shows.

From there we return to the theme of disability with a contribution from Wim van Brakel of the Royal Tropical Institute, the Netherlands. Dr Van Brakel shares with us a fascinating story of his motivations and interests – professional, personal, and spiritual – working in fields such as leprosy and disability prevention, in such countries as Nepal and India where he spent a great deal of time and gained considerable experience. Now

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(re)settled in the Netherlands, disability remains a priority concern with plans to create new opportunities for academic development, particularly focusing on opening the way for people with disabilities to enter higher education, and thus bring research into a more engaged environment.

Following on from this, as the final contribution for this issue, Dr Katrin Grüber from the 'Institut Mensch, Ethik und Wissenschaft' in Berlin, Germany, provides a thought provoking outline of the concept of *disability mainstreaming*. Tying all the disability-related pieces in this issue together, the notion of mainstreaming aims not only to highlight and rectify inequality – on personal, institutional, and societal levels – but to bring the issue into the mainstream in order that constructive dialogue, but most importantly action, can take place and sustainable and felt improvements be made.

We hope you enjoy, as we have, the variety offered in the pieces this month revolving around the theme of disability. Though it emerged as a somewhat unintended theme, the range of perspectives provided by our contributors – encompassing policy and research, spiritual and humanitarian motivations, professional institutional processes of change, and grassroots community activism – offer multiple angles from which to view this complex and topical issue. Innovia was established to create such a forum where connections can be made across geographical and disciplinary lines and experiential boundaries, so of course we hope that the ideas raised in this issue might be further taken up, and new contacts forged.

Dale and Zoe

REFLECTIONS

Stuart Blume

The idea behind Innovia is that research can be an instrument of empowerment in the health field. That is to say, research can be of value to organizations advocating on behalf of the rights of sick or disabled people, wherever they may be. 'Rights' here has to include the right to healthcare appropriate to people's needs and wishes but also, beyond that, the right to inclusion, dignity, and respect: to citizenship. It has to include, also, a right to participate in determining the research agenda itself; in deciding what should be studied, and how; and a right of access to research results and to whatever benefits accrue. We believe we can make a contribution in three ways. First, by building up a network of experienced researchers and scholars who share this ideal, and one in which the regions of the world are

equitably represented. Second, by making the results of research available to health advocates and patient organizations, many of which lack access to the literature in which such work mostly appears. And third, through helping build bridges between grassroots patient and advocacy organizations and their local research communities. Lack of resources holds us back of course, for Innovia has none – beyond the talents and commitment of its members.

Useful though a few thousand Euros, or Dollars (or their equivalent in any other currency!) would be in helping us do some of the things we want to do, there are some problems that are not so easily solved. I was reminded of this a few weeks ago.

In August I had the pleasure of teaching on a summer research school at the University of Bergen in Norway. The overall theme was Global Poverty, and some 140 PhD students from all over the world participated. Together with Jan-Kåre Breivik I taught a class that

focused on issues related to disability. There were 15 students, from Africa, Asia, North and South America, and Europe in this class. Working with them for 10 days was a wonderful and rewarding experience. One of the participants said something that has remained firmly in my head. She told us that in her country, Ghana, there is a growing burden of chronic disease (whilst traditional family-based structures of care are being eroded). However the problems posed by chronic disease receive little attention from researchers, in part because international donors are only willing to support research related to infectious diseases: seen as 'the' health problem of Africa.

This brings me to the inspiring article on the Amani Centre in this issue of the Newsletter. It is wonderful to read about what Mama Josephine Bakhita achieved in Tanzania, despite the hostility in her home community toward people with disabilities. Then the thought arises: what, if anything, could research add? Quite a lot has been written about Community Based Rehabilitation programmes over the past twenty years. There have undoubtedly been numerous expensive official evaluations. Some authors have explained how

failures have resulted from the translation of culturally inappropriate models from Northern countries [1]. It has been suggested that, in some areas, medical professionals thwarted community participation [2]. Some authors have stressed the vital importance of CBR programmes learning to collaborate with local organisations of people with disabilities [3]. One contribution that research can make, it seems to me, is through clarifying what it was that made an initiative successful. But only in collaboration with the people with disabilities concerned can we say what we mean by success.

[1] Ingstad, B. (1995) Public discourses on rehabilitation: From Norway to Botswana. In: Ingstad, B. & S.R. Whyte (eds) *Disability & Culture*. Berkeley: University of California Press.

[2] Turmusani, M. et al (2002) Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disability and Rehabilitation* 24: 558-564.

[3] Miles, S. (1996) Engaging with the disability rights movement: The experience of community-based rehabilitation in Southern Africa. *Disability and Society* 11: 501-17.

THE AMANI CENTRE, TANZANIA

**Ton Millenaar, Mama Josephine Bakhita,
Zoe Goldstein**

Introduction

Ton Millenaar

For more than 30 years I have been involved in the field of mental health and disability, first as a clinical psychologist, and after a number of years as a managing director in organizations for children and adults with disabilities. In the last years before my retirement I worked as chairman of the Board of directors in the Hartekamp Groep in the Netherlands, and since

2005 have been working as a Senior Consultant for various organisations (see www.wendingconsultants.nl).

I believe strongly that children with any disability should have the right to participate in the community. Unfortunately, they often experience stigmatization, segregation, and exclusion from society, thus they need support to achieve acceptance through de-stigmatization, integration, and inclusion, all of which are based on the Rights of Persons with Disabilities (as articulated in the UN Convention (2006) and the process of ratification following it in 2007/8) [1]. The issue of disability and rights is also linked with the

upcoming Innovia publication *Disability and Society – A Reader*, outlined in Issue 6 of the Innovia Newsletter (June 2008), and with other pieces in this current issue.

Although children with cognitive disabilities cannot (yet) take full responsibility for their own lives because of their limited intellectual 'overview' and their young age, they are able to learn how to do this step-by-step. They need people who are involved in their interests; most often this is their parents. Supporting children with special needs gives them a stronger social network and assists them to learn how to use their potential to live as independently as possible within the community. Parents for their part also benefit from guidance to learn how to educate and deal with their children. This they can receive from different sources. It can come from teachers and other professionals, who themselves have to take a broad focus beyond the individual child with a disability to encompass the child's entire network, including the community and regular (mainstream) schools. Another important source of support may come from peer groups consisting of other fathers and mothers with disabled children, which may help to strengthen their power and confirm their potential, and resist stigmatisation and oppression by citizens in the community.

This type of intervention is best started as early as possible. It represents a variant of *secondary prevention* in the field of medicine, whereby activities are aimed at early disease detection (in the context of this article read *disability*), thereby increasing opportunities for intervention to prevent progression of the disease (in this context: the negative aspects of stigmatisation and exclusion of children with disabilities), and the emergence of symptoms.

Though the implementation of this process of integration for people with special needs has been going on in Western societies for some time now, the World Health Organization has also been trying to promote the

community based rehabilitation (CBR) approach in developing countries [2]. Interventions are to be shifted away from segregating and isolating institutions, to inclusive and participatory practices in the homes and communities of people with disabilities, and carried out by minimally trained people such as family and other community members. Aside from the social and developmental benefits that this would entail for disabled children, this approach would also reduce financial costs [3]. A representative example of such a grassroots, user-led CBR project is the Amani Centre in the Morogoro region, Tanzania, an East African country surrounded by Kenya, Uganda, Rwanda, Burundi, Zambia, Malawi, and the shores of the Indian Ocean, with a total population of around 34 million people, including about 650,000 people with various kinds of disabilities. The Morogoro region is situated roughly 200km inland of Dar es Salaam, with 5 districts and a total population of about 1.3 million people. In this area lives an estimated population of 29,000 children with disabilities. The Amani Centre began in 1992 on the initiative of Mama Josephine Bakhita – the mother of a child with intellectual disabilities – together with several other mothers with disabled children. Their collective experience was similar: giving birth to a disabled child in Tanzania has many serious consequences for the whole family. Not only does the disability bring stigma and isolation from the community, it also results in further burdens and costs for already impoverished families, making it difficult for mothers to start working. Mama Bakhita decided, together with several mothers and other involved people, to start a centre to support mothers and families with disabled children. I have asked Mama Bakhita to write down her experiences with starting the Centre, presented below, and to outline the numerous projects and advocacy activities for these children and their guardians.

The Amani Centre: Origins and future
Mama Josephine Bakhita

The Amani Centre for children and youth with intellectual disabilities formally came into being in 1992. It came about more as an anthropological consequence of events than as an institution resulting from a bureaucratic constitution of red tape Rules or Orders. As such the Centre grew up, by and by, as an apparatus for discovering, accommodating, and using existing social inventions and innovations which provided tentative solutions to the practical problems arising from disability, and which have their roots deeply sunk in traditional African settings. In this way it started with me, Mama Josephine Bakhita, who at that time had an intellectually disabled son (now the late Eric).

Eric was not born disabled, but symptoms of severe intellectual disability arose to such an extent that his host community developed socially negative tendencies and attitudes towards both mother and child. We were regarded as a bad omen. Being a seasoned social welfare worker myself, I opted out of this hostile community and moved from my traditional home to an outlying residential slum community known as Chamwino. At this new residence, I was always on the look out for mothers with similar situations to my own, and was quick in identifying quite a number with whom I joined hands under the shade of mango trees and shared slum accommodation. As a group of parents we identified ourselves with the Catholic Diocese of Morogoro and other persons of good will, and by way of this the Chamwino project matured to become the Amani Centre.

The Amani Centre then started to attract benevolent attention and support, both from home and abroad. Donor assistance began to trickle in which helped establish some sort of an administrative centre along with service facilities providing for such things as day care, education, healthcare, foodstuffs, as well as toys. As donor assistance increased, construc-

tion work went ahead providing improved rehabilitation facilities for the disabled. Amani has now established three outreach stations, and the existing figures for disability cases stand at something upward of 3,700 registered over the last few years. There is a physiotherapy unit, a mobile clinic, and provision for the referral of serious cases to a hospital-based Consultant for Comprehensive Community Based Rehabilitation Tanzania (CCBRT) in Dar es Salaam (<http://www.ccbirt.or.tz>).

Our method of approach in doing work at the Amani Centre is community based rehabilitation (CBR). Under this approach we reach the disabled in their villages through home visits. We find CBR a very useful method because it means that intellectually disabled children and youth do not become (semi-) detached from the loving care of their parents, but in fact their parents remain their de facto caregivers in day-to-day life. This also becomes a commitment, which enhances parental accountability for their disabled children. At the Mvomero outreach facility, much short term training is going on for parents and the few community workers we have, mostly in the field of nutrition, childcare, and cookery. The significance of this cannot be overemphasized in poor countries where undernourishment of disabled children and youth is endemic.

We have our other outreach station at Mikese. There we focus on the future of the disabled. Heavy emphasis is placed on vocational training, which includes carpentry, small scale agriculture, and craft activities for a commercial purpose – including the production of various types of handicrafts for sale – to enable them to have a self-sustained future and to provide a decent standard of living for themselves (provided other things remain constant at home and globally).

But having said so much, it is as if I have said nothing except words! Donor fatigue is already stifling our effort in the various fields of our rehabilitation work. The future is grim regarding the availability and deployment of

human and material resources in strategic areas of our operational spheres of responsibility. Moreover, appropriate public policies are not yet trickling down due to failures in ratifying the UN Convention on the Rights of Persons with Disabilities. But through dogged persistence in raising awareness, pressure groups are building up within civil society and among parents and associations for the disabled, which will hopefully be able to exert pressure in the desired direction and ensure Amani's continued work for the realisation of full lives for disabled people in the community.

Conclusion: The present and future for Amani
Ton Millenaar and Zoe Goldstein

Since its inception, the Amani Centre has developed into a significant focal point for the region. Its key position has arisen because it is a centre specifically for families with disabled children, started by those who have themselves been affected by the difficulties this can create. The development of various awareness raising programmes has been crucial, including early detection projects, and programmes for addressing the needs of children with disabilities as soon as possible after they have been recognised (in some cases this is fairly late in the children's lives as they have literally been hidden in the family house from birth). After detection, the Centre focuses on early intervention programmes, training for mothers on how to educate their child to become more independent, together with day care and respite care.

Though the Amani Centre has not received any support from public agencies,

Mama Bakhita became very skilled in obtaining funds from donors in developed countries, especially the Netherlands and Scandinavia. In addition, for several years now the Centre has also been developing income generating activities to ensure its sustainability, such as craft production and small scale farming in several rural outposts. In 2006 a strategic five year rolling plan for the Amani Centre was presented to donors [4], and I (Millenaar) and a colleague were asked by a Dutch aid organisation to advise on the continuation of this support in the future [5]. However, this request is still in process, thus the Centre's future is somewhat uncertain. It is hoped that the important work which the Amani Centre does – and the key position it occupies in the region regarding the promotion of disability rights – can be maintained and strengthened in the future.

[1] United Nations (2006) *Convention on the rights of Persons with disabilities*. New York: UN (<http://www.un.org/disabilities/convention>).

[2] WHO (2003) *Disability and Rehabilitation Status, review of disability issues and rehabilitation services in 26 African countries*.

(<http://www.aifo.it/English/Review-CBR/African>).

[3] Helander, E. et al (1989) *Training in the community for people with disabilities*. Geneva: WHO.

[4] Amani (2006) *Strategic Rolling Plan 2006-2010 for Amani*. (Unpublished)

[5] Millenaar, A. & C. Voorn (2008) *Continuing support after 2006 for Community Based Rehabilitation (CBR) programme, provided by the Amani Centre in the region Morogoro, Tanzania*. The Hague: Presented to Cordaid (unpublished).

GETTING TO KNOW...

Norma Morris

The most noteworthy thing about my career is that most of it has been outside of academia; so after a little over ten years, I am still enthusiastic and playing at being an academic. It was unbelievably liberating to stop being a senior manager at the UK Medical Research Council (with hideous responsibilities for staff and finance) to go and sit in a garret at University College London with a phone, a library card, and no salary except what I could raise myself through grants or consultancy. One of the first pieces of paying research that I got was to go round interviewing people in biomedical sciences departments in UK universities about their work and their views on science policy (this was piquant, since while at the MRC I had been one of those mythical beasts, a 'policy-maker'). I remember that one Oxbridge interviewee said to me, "Nobody tells me what to do: I am only told that I must do something". That was a highly optimistic take on academic freedom even then (this was the late 1990s), but it was roughly the deal I got at UCL's Science & Technology Studies Department.

It was some time before I woke up to the kinds of issues that Innovia is interested in, but I was involved with some cognate issues relating to the regulation of biological medicines (e.g. vaccines). Scientific expertise had reigned supreme here for many years. But traditional expertise had started to come under challenge from new technologies, such as the development of genetic diagnostic kits raising social, legal, and ethical questions which could not be settled by committees of scientists. Other social issues also came to the fore, such as the priorities for pushing medicines through long regulatory processes, felt to be biased towards Western, rather than developing world, needs. I was involved with a couple of international

committees (of scientists of course) doing reports on the future of biological standardisation in the late 1990s. One of the debates that for me typified the gulf between East and West was on the old issue of whether there could be one standard for the rich, and one for the poor. Representatives of rich countries virtuously agreed they would never countenance such an idea; those from poorer countries met this with weary cynicism, and pointed out publicly or privately that in practice their countries were often deprived of biological medicines of any standard. It was a matter of technological capacity to meet increasingly sophisticated standards for purity and potency as well as the costs of purchase and barriers to local production. I do not know what changes or reforms the past 10 years of economic and technological growth may have brought, and how far new configurations of power will be able to reduce such inequities.

My first contacts with Innovia came when I embarked on a project aiming to get a group of healthy and patient volunteers taking part in testing a new medical technology to take a more active interest in the technology being tried out on them. The impetus was the lack in the literature on the social shaping of technology of a patient's view, my personal unease over the disrespect implied in accepted ethical codes that regarded human research subjects as entirely passive, and a wish to question whether volunteers would want to engage anyway. It also seemed that nobody knew in any detail what the experience of taking part in research was like for those who volunteered. When I was burbling on about this to someone I met at a conference I got the response: "You should talk to Stuart Blume. He is organising a network with interests in that area". So I had the privilege of being in on the early days of Innovia, and even attending the productive (and idyllically situated) inaugural conference at Bellagio (this provided a new measure of achievement for some distinguished Innovia

members – the speed with which they sprinted up the steep slope from the accommodation blocks to the conference centre each morning!) While I have often felt on the fringes of what Innovia does, it is a fantastic forum. Where else would I get the opportunity of placing my own modest micro-social observations and conclusions on volunteer empowerment in the same context as Chee-Khoo Chan's macro-social vision of using volunteer leverage to influence pharmaceutical politics [1]?

After 8 years I am now winding up the project on volunteer experience and the terms on which they engage with technoscientific research, but it has led me to another issue that touches on issues of prevention and coercion, of interest to Innovia. Although for my project I was interviewing volunteers about their experience of research, they all (both healthy and patient volunteers) had narratives of healthcare experience which they used in various ways in managing the research encounter. Since the research was about testing novel instrumentation for detecting breast cancer – and this new technology was moreover non-invasive and pain-free – it is not surprising that painful experiences of x-ray mammography featured largely in these narratives. What was particularly striking was the stark contrast between the discourse used

by women in the relatively informal setting of the interview or between themselves, with that of published advice and guidelines (from both official sources and, interestingly, from patient groups). I plan to use empirical data to explore how the tensions revealed in the contrasting discourses are negotiated in practice. I want to understand the social dynamics underlying the persistence of a culture of suffering in this area of diagnostic medicine (including compliance in routine screening programmes), where patients (except in private), professionals, and even patient groups generally prefer to downplay pain, rather than campaign for action to reduce its incidence. I would be delighted to hear from anyone who might feel provoked to comment on this.

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[1] Innovia (2008) *The Innovia Foundation Newsletter*. Issue 5 (April).

GETTING TO KNOW...

Wim van Brakel

I love new ideas, new technologies, new ways of approaching old issues. I guess that is what attracted me to join Innovia. My first contact was through Stuart Blume – his openness and enthusiasm appealed to me. I believe in

networking and sharing ideas cross-culturally and also across disciplines. I have not contributed much to Innovia yet, but perhaps there will be opportunities in the future.

My name is Wim van Brakel. I was born in South Africa, but grew up in the Netherlands. I graduated in medicine from the University of Amsterdam. Around the time of my graduation, God called my wife and me to

leprosy work in Nepal. After gaining some clinical work experience in the Netherlands, we did a cross-cultural missiology course at All Nations Christian College in the UK, followed by leprosy training at ALERT in Ethiopia. In 1986 we arrived in Nepal, where we lived and worked for the next thirteen and a half years.

While in Nepal, I developed a strong interest in research into leprosy, particularly in the prevention of disability. Even today, leprosy is still one of the leading causes of preventable neuro-disability in the world. We were granted a sabbatical, which I used to do an MSc in Epidemiology at the London School of Hygiene & Tropical Medicine, to improve my research skills. In 1994, I finished my PhD at Utrecht University based on research on epidemiological and clinical aspects of nerve damage in leprosy. Back in Nepal, I continued to be involved with leprosy and TB control, in addition to rehabilitation of people with disability, drug users, and towards the end of our time, people living with HIV/AIDS. We did work on the measurement of impairment and developed a scale for measuring activities of daily living (ADL) applicable under circumstances such as prevailed in Nepal. In between all this, we raised three lovely children, who became prototype 'third-culture kids'! Socially and spiritually, we tried to be involved members of the local church, wherever we lived.

After a brief stint in London, we moved to New Delhi, where I served as Research Coordinator for The Leprosy Mission International. During this time, I continued work on the prevention and measurement of disability, this time focussing on psycho-social aspects. We organised an international interdisciplinary 'measuring disablement workshop' attended by some 40 experts in this field from all over. This led to the formation of two multi-country research groups that developed two new cross-cultural scales. The one I coordinated developed a generic ICF-

based instrument to measure social participation: the Participation Scale (see www.ilep.org.uk for the latest English version). It contains items on work, relationships, respect in the community, etc. During the development process, we had reports back from the investigators saying that interviewees often became very emotional during the interview, saying, "This is the first time anyone has asked me questions like this and has shown interest in what concerns me most". The other group developed an ADL and safety awareness scale called 'SALSA' for use with people with neuro-disability. The Participation Scale has been very well received. It has been translated into some 20 languages already and is used in research and assessment of people with a variety of conditions.

In 2003, God opened a door to go back to the Netherlands. I was invited to join the Royal Tropical Institute (KIT) in Amsterdam as a senior adviser in their Leprosy Unit. At the Leprosy Unit we support a wide range of programmes, mostly contracted by Netherlands Leprosy Relief. While still continuing work on leprosy, my research interest broadened to the cause of many participation restrictions (often called 'social exclusion' in the disability world), namely stigma. Stigma is *the* major problem for many people affected by leprosy, HIV/AIDS, mental illness, etc. We organised an international, interdisciplinary research workshop on stigma in 2004, which led to the formation of another network: the International Consortium for Research and Action Against health-related Stigma (ICRAAS). At KIT we host a web dossier on stigma (see www.kit.nl, search for stigma and you will find both the dossier and the ICRAAS eForum). It was these stigma-related activities that led to contact with Stuart. An international association of people affected by leprosy called IDEA (Integration, Dignity and Economic Advancement – see <http://www.idealeprosydignity.org/>) that I am associated with pointed me to Stuart and the

fact that Innovia's sphere of interest includes stigma.

The latest initiative, which brings all of the above together, is to set up a unit for Disability and Development at the Athena Institute of the VU (Free University) in Amsterdam. Together with my colleagues, I have a vision for increasing higher education opportunities in the field of Disability & Development (D&D) for people from Southern countries. At the same time, we hope to promote badly needed research in this field. We hope to attract young people with a disability and enable them to take on a leadership role in D&D. To facilitate this, we plan to develop a D&D Master programme together with one or more Southern universities. The first step in this direction is a module on D&D, as part of an existing Master programme, due to start on November 24th of this year at the VU. We're

very excited with this opportunity! If you want to know more, please look up <http://studiegids.vu.nl> and type 'disability' in the 'zoeken' option at the bottom. Or email me at w.v.brakel@kit.nl. We are continuously looking for opportunities for students to do research internships related to disability & development, so if you know of or can host such students (self-funding and research-trained), I would be very pleased to hear from you!

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INSTITUT MENSCH, ETHIK UND WISSENSCHAFT AND DISABILITY MAINSTREAMING

Katrin Grüber

The principal task of the IMEW Institute situated in Berlin, Germany, is interdisciplinary and independent research. The institute was established in 2001 as a public, non-profit, limited liability company, and actively partners with nine disability and self-help organisations. The institute is funded principally by Deutsche Behindertenhilfe - Aktion Mensch, a philanthropic foundation.

The vision of the IMEW is of Mainstreaming Disability in Science, Politics, and Society. The needs of disabled people should always be considered from the very beginning in any research and legislative

project. In this brief piece, I sketch out some of the contours of disability mainstreaming undertaken at the Institute.

Mainstreaming

Disability mainstreaming is a relatively recent term. It is both implicitly and explicitly modelled on gender mainstreaming, which itself became part of the international political agenda in 1995 in connection with development aid policies. The term *mainstreaming* denotes a topic or endeavour brought from the margins to the centre of focus, with an aim to make it known and established throughout society. Disability mainstreaming, therefore, involves making the interests of people with disabilities an integral part of processes in politics, administration, society, and scientific research from the very beginning – not just as an add-on once basic decisions have already been made.

Thus while disability mainstreaming is on the one hand an instrument for achieving the equality of people with disabilities, it is on the other hand also a model or blueprint, because it requires a different approach and a fundamental change in attitudes and perspectives.

Gender and Disability

The concept of disability has created a space for pervasive inequality, the roots of which, similar to gender and gender inequalities, should be sought in society rather than in biology (Albert & Miller 2005) [1]. Since gender and disability mainstreaming serve the goal of equality, the need for change is seen to lie primarily in society and not in the individual. This standpoint corresponds to that of the social model developed by Disability Studies and contrasts with the individual/medical model of disability.

Disability Mainstreaming in Scientific Research

One element of disability mainstreaming in science and research means involving people with disabilities in decision making processes relating to research design and research topics. Until now people with disabilities have only in exceptional cases been asked what expectations they have of medical research, for example, and which issues are particularly important to them. The few investigations that have been undertaken show that there is a great difference between the perspectives of people with disabilities and those of researchers. A further step is to involve people with disabilities in processes of priority setting with regard to research funding, for example by nominating them as members of committees advising government ministries on the direction of health research programmes.

Disability Mainstreaming in Technology Politics

Disability mainstreaming in technology policy means strengthening the 'Universal Design'

approach. This takes the differing needs of people with and without disabilities into account early, at the design stage. Machines are constructed in such a way that they can be operated by as many people as possible [2]. The demand for Universal Design is also formulated in the UN Convention on the protection of the rights of people with disabilities.

The Establishment of Disability Mainstreaming in Organisations

Albert and Miller (2005) recommend the following dual-track procedure for the implementation and establishment of disability mainstreaming in ministries and administrative organs, but also in relevant organisations. They base their recommendations on experiences gained in the introduction of gender mainstreaming. On the one hand the equality of people with disabilities should now also be taken into consideration in areas where this was not previously an issue, making it an important mission for all instead of the task of just one office or department (usually the commissioner for people with disabilities). At the same time, in their opinion, such offices or departments should be retained and adequately equipped even after the introduction of disability mainstreaming. Otherwise there is a danger that the implementation process will come to a halt because the interests of people with disabilities are not highlighted in the long term.

Summary

In the preamble to the UN Convention on the Rights of People with Disabilities, disability mainstreaming is viewed as an essential component of sustainable development efforts [3]. According to Heiner Bielefeldt (2006) [4], director of the German Institute for Human Rights, the Convention has great innovative potential. He says: "The Convention is based on an understanding of disability that does not start with a negative view of disability, but expressly affirms it as a normal component of

human society and, moreover, as a source of potential cultural enrichment". It seems worthwhile to consider organising the process of implementing the UN Convention as a disability mainstreaming process.

(Translation: Hilary Coleman)

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Web: www.imew.de*

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