



## In this issue:

- > FROM THE EDITORS 1
- > NEWS FROM INNOVIA **Stuart Blume** 2
- > NEEDS AND CHALLENGES IN DEVELOPING A COMMUNITY MENTAL HEALTH PROGRAMME IN INDONESIA  
**Tri Hayuning Tyas** 4
- > GETTING TO KNOW... **Geert van Etten** 6
- > DISABILITY, NEEDS, AND DEVICES **Zoe Goldstein** 8

## FROM THE EDITORS

We welcome readers of the Innovia Newsletter to our tenth issue. We are delighted to share with you a variety of insights from scholars and practitioners of all stripes, beginning, naturally, with the latest news from Stuart Blume, Director of the Innovia Foundation. Stuart shares with us two very positive recent events, regarding the future stability of the Innovia Foundation, and a new collaboration aimed at furthering Innovia's international work towards better, more representative healthcare. We continue with an insightful contribution from Tri Hayuning Tyas, whose work in Indonesia sheds light on some of the promising, but also quite challenging, features of a particularly innovative community mental health programme in Aceh.

Most readers of this Newsletter are probably unaware of the fact that Innovia is a Foundation, registered in the Netherlands. In order to understand better how Innovia works, and who is involved in making it what it is, we are pleased to introduce Geert van Etten, an active member of Innovia's Board of Management. Geert outlines for us his impressive – still ongoing – career trajectory in the international/global health arena. Finally, to conclude, co-editor of the Innovia Newsletter Zoe Goldstein outlines her recent work in Berlin – involving the collaboration of Innovia, the Institut Mensch, Ethik und Wissenschaft (IMEW), and Disabled Peoples' International (DPI) Europe – designing and implementing a study at the intersection of disability studies and science and technology research.

We invite readers to join us now as we get to know some of our colleagues and their work a little better.

Dale and Zoe

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## NEWS FROM INNOVIA

**Stuart Blume**

In the course of the last few years, we have devoted a lot of attention to trying to clarify how Innovia can best fulfil its mission. In addition to collaborative research (in partnership with patient associations, health advocacy and other community groups), two strategies were identified. One is dissemination: trying to make the results of recent research and scholarship more accessible. The other is through helping build bridges between health-related organisations and groups on the one hand, and local research communities on the other. A recent development provides us with an exciting new opportunity for pursuing both of these approaches. In June, on behalf of Innovia, I signed a collaboration agreement with the University of Otavalo, in Ecuador. This is our first such collaboration with a university.

Located 2 hours drive north of Quito, the country's capital, Otavalo is an important centre of local handicraft production and tourism. The University of Otavalo, with faculties of law, administration, tourism, and social sciences, is a key educational resource for its region. Reflecting the population of the region as a whole, some 50% of students have a language other than Spanish, mostly Kichwa, as their mother tongue. Teaching, however, is in Spanish. The Agreement that the Rector of the University, Dr Mariana Guzmán Villena, and I signed on 26 June has two parts. A "Framework Agreement" commits both parties to seeking appropriate forms of collaboration in the interests of both. The first such collaboration that we identified became the subject of a second "Specific Agreement". Innovia will collaborate with the University in developing a new Master's programme in Health Management. This new programme will offer two specialisations, in intercultural health and in disability. Many



University of Otavalo campus

Ecuadorian people make use of both biomedicine and of so-called 'traditional' or 'indigenous' medicine. Recognising their right to culturally appropriate health care, and respecting local traditions and cultures, the question arises of how the different practices can best be integrated in an effective and accessible system of health care. The social and economic integration of people with disabilities, too, is an important political issue in Ecuador.



We are now looking into how best to implement the Agreement. For my part I hope very much that I can count on the support of members of the Innovia community. Making the Agreement work is going to depend on the willingness of colleagues with the necessary expertise to devote some of their time and energy to it. I expect to be approaching some readers of this Newsletter individually in this regard, asking for their help. Collaborations of this sort are a potentially important means by which Innovia can do its work and I hope others will follow. I'm especially grateful to Maria de los Angeles Erazo, Director of postgraduate studies at the University of Otavalo, for suggesting the collaboration.



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There's another piece of good news that it gives me great pleasure to report. As I'm sure everyone knows, Innovia lives a hand-to-mouth existence financially speaking. It receives no subsidies and its resources consist almost entirely of human (rather than financial) capital. Not long ago I received an email from Neil White, author of the recently published *In the Sanctuary of Outcasts* (New York, William Morrow, 2009). The book is a fascinating memoir of the time that Mr White spent in Carville, Louisiana: an institution that for a number of years served both as the last leprosarium (or 'leper colony') in the USA and as a Federal prison. Neil White has committed himself to donating some of the royalties of his book to what he sees as worthy causes. His offer of a donation to Innovia – our very first donation – came as a wonderful surprise. We are very grateful to Neil White. Perhaps if others follow his example we can give Innovia a little more stability.

Finally I would like to draw readers' attention to some recent initiatives that should be of interest.

Firstly, COHRED, the Geneva based Council on Health Research for Development, has taken an initiative that connects very closely to Innovia's work. Sylvia de Haan writes:

"The civil society group on research for health is pleased to announce the launch of its new web page  
<http://www.cohred.org/CSOEngagement/>

The group came together in 2008 as the authors of the 'Call for Civil Society Engagement in Research for Health: Toward a Post-Bamako Action Plan', an input to the Bamako Ministerial Forum on Research for Health and its Declaration. We welcome all interested organisations and people to:

1. Contribute their voice to the debate on civil society organisations' engagement in research for health.
2. Access to data on civil society organisations to help identify partners.
3. Engage with peers on how civil society organisations' can help focus research for health on people's real needs."

Second, Kapil Dahal from Tribhuvan University in Nepal has established a web-based discussion group open to "Any anthropologist from this planet, working in/on Nepal". To register please log in to <https://www.researchgate.net/group/NepaleseAnthropology>

And third, Solángel García from Bogotá, Colombia, writes to announce a conference that should be of interest to all Spanish speaking scholars and activists concerned with disability in Latin America.

La Organización Panamericana de la Salud y la Organización Mundial de la Salud, la RED de RBC (Rehabilitación de Base Comunitaria) de las Américas y el Caribe, están organizado el II Congreso Continental de RBC, el cual se realizará del 3 al 10 de Marzo del 2010 en México.

**Misión:** Promover la inclusión de las personas con discapacidad y contribuir con el posicionamiento de la estrategia RBC en las Américas y el Caribe como parte de las políticas públicas desde un escenario de articulación de sinergias, movilización de recursos, cooperación y asistencia técnica. Objetivos:

1. Romper barreras para crear un "**Mundo para Todos/as**", apoyando la aplicación de la Convención de Naciones Unidas sobre los Derechos de las Personas con

4. discapacidad, la Convención Interamericana para la Eliminación de Todas las Formas de Discriminación contra las Personas con Discapacidad y el Plan de acción década de las Américas para las personas con discapacidad
  5. Asegurar y garantizar los derechos y la dignidad de las personas con discapacidad y de su plena inclusión en la sociedad, en especial su derecho al disfrute del más alto nivel posible de salud física y mental y otros derechos relacionados.
3. Demostrar como la RBC contribuye al desarrollo inclusivo y se convierte en una estrategia aliada para la disminución de la pobreza en los países de la región.

Anyone interested in participating can write to Solangel at [amycredrbc@gmail.com](mailto:amycredrbc@gmail.com)

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### NEEDS AND CHALLENGES IN DEVELOPING A COMMUNITY MENTAL HEALTH PROGRAMME IN INDONESIA

Tri Hayuning Tyas

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The Indonesian province of Nanggroe Aceh Darussalam faces the major challenge of rebuilding society after prolonged military conflict and the devastating tsunami of December 2004. Events of the past years have meant that there is a high incidence of mental illness throughout the province, whilst there is only one mental health hospital, located in the provincial capital. People in Aceh with severe mental illness are sometimes confined for indefinite periods of time, and may also be physically restrained in various ways. This practice is known in Bahasa Indonesia as *pasung*. It is seen as a way of dealing with problematic attitudes and behaviours. About one and a half years ago I went to Bireuen District in Aceh to study the practice of *pasung*.

There I became acquainted with mental health service providers based in primary health care centres, known as *puskesmas*. Starting in 2005, a programme of community mental health has been developed throughout Aceh Province. The programme was

implemented by the local government, with support from the Indonesian Ministry of Health, the WHO, and international aid agencies. Among the programme's objectives was enhanced access for people with mental health problems to psychiatric treatment by providing basic mental health services in the *puskesmas*, and improving community capacity in anticipation of increases of mental ill health problems. To support this programme, a number of general practitioners and nurses working at the *puskesmas* were trained to provide psychiatric treatment and care. A select group of people in the villages were also trained as mental health cadres to promote mental health in the community. Whilst the general practitioners tend to stay at the *puskesmas* to provide the service, mental health nurses visit the mentally ill patients at home and give support to their families. The mental health cadres work as volunteers, and help mental health nurses in the community.

In Bireuen District, I saw that people responded positively to the programme. People often had their own explanations of their mental ill health and many of them sought care from *dukun* (traditional healers) or *teungku* (religious healers). But many of them also went to the *puskesmas* to receive psychiatric

treatment. The costs, including psychiatric drugs, were covered by the government and external donors, so that people had to pay little or nothing. During the research, I learned that treatment, prevention, and promotion activities fit together well in the community mental health programme. However, apart from the financial sustainability of the programme, and maintaining the motivation of the volunteers, the quality of psychiatric treatment provided in the *puskesmas* was also seen as a challenge. Not only were the health officials in many of the *puskesmas* overworked, but they had insufficient knowledge of mental health to cope with what was often a growing number of associated adolescent health related problems, including unwanted pregnancies, drug abuse, and HIV/AIDS. Together with the Sleman District Health Office, the Faculty of Psychology at Gadjah Mada University in Yogyakarta (where I now work as a lecturer and researcher) established a programme that sends psychologists into primary health care centres. Their task is to offer services that mainly focus on mental health promotion and prevention of mental illness related problems.

The pilot project began in 2005, with psychologists going to 6 *puskesmas* (of the 24 in Sleman District). Since 2007, each *puskesmas* has one psychologist attached to it. They provide mental health services for the inhabitants of Sleman District, especially for those living in the rural areas. Only a very small charge for this psychological service is made as it is partly covered by government insurance. Psychologists provide both intra- and extramural services.

They offer individual psychological consultations in the *puskesmas*. To promote mental health, they regularly visit villages and schools. At the same time, they carry out early detection (screening) for the existence of mental health problems in the community. Although the placement of psychologists as mental health service providers in *puskesmas* is not (yet) part of the mental health system in Indonesia, the budget of the programme comes from the

Sleman local government's health budget. As yet, the health system in Indonesia has not included any kind of mental health service in primary care as part of the government system.

I see this *Psikolog di Puskesmas* programme as partly an attempt by psychologists in Indonesia to make a concrete contribution to the wellbeing of rural communities, through promoting mental health and helping people avoid mental illness related problems. It means that psychology must consider more carefully the socio-cultural context in which a person lives in relation to his/her mental health status. This includes the concepts people use to think about their mental health. These concepts may have different implications for different age groups.

When I talked to the psychologists in the *puskesmas*, they acknowledged that it was not easy to deal with local beliefs about the causes of mental ill health (usually spiritual or religious). When these local beliefs led to the stigmatisation of a person with mental health problems, the psychologists could not resist this from within the confines of their role; they could not tell people how to think. Delivering mental health promotion in the village was not an easy job either, and it was difficult to find appropriate terms or language to use. It had to be simple, familiar, and easy to understand, but most importantly, respectful. Using language that is polite and not too direct is quite important for Javanese people. Furthermore, since psychologists are not (yet) part of the health system, they do not have the authority to set up mental health programmes in the *puskesmas*. This creates problems for them to implement mental health promotion activities.

At the moment I am involved in developing a Centre of Public Mental Health in the Faculty of Psychology. This centre is expected to organise inter-disciplinary research projects on public mental health issues, to promote community mental health in many settings, and to support advocacy work for the improvement of the mental health system, first in Yogyakarta, and in the long run in Indonesia.

To reflect briefly upon my experiences, I think the community mental health programme can be implemented in various settings and using different designs. Such a programme should integrate treatment, prevention, and promotion activities. In areas where mental illness is widespread, psychiatric treatment may be needed most; though in areas where incidence is lower but there are indications of its escalation, prevention and promotion efforts should come first. Creating such community programmes poses many challenges. These include understanding the socio-cultural

contexts, identifying available human and financial resources to support the programmes, identifying features of the community that pose specific risks (or offer protection), and last but not least, political will and appropriate health policy in the area.

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## GETTING TO KNOW...

### Geert van Etten

I am a medical sociologist with a long-standing interest in health systems research. My first experience was in the developing world, in Tanzania, where I participated in a training and research project on rural health development. The project was carried out within the framework of a technical assistance scheme involving the University of Nijmegen, the Netherlands, the Tanzanian Ministry of Health, and the Medical Faculty of the University of Dar es Salaam, in the period 1969-1973. There were three components to the research. First, a study was made of various health policies, both during colonial days and after Independence, in order to determine the extent to which these policies had contributed to the relative underdevelopment of the rural health sector. Second, an analysis was made of the shortcomings in the existing health care delivery system for rural areas. The third approach concerned the training and work situation of medical auxiliaries as possible factors impeding rural health development.

In the beginning of the eighties I moved to the Dutch Ministry of Health, where I had the privilege of developing the country's first



national health research policy. The plan stressed the need for research that would be relevant from the point of view of national health policy, and for this reason the importance of health services research as well as national institutes of this kind was emphasised.

At this time I was also interested in participating in international work in this field. Thus, I became the second chairman of the Working Group on health services research, which was established in 1980 as part of the Committee on Medical and Public Health Research of the then Commission of the European Communities (EC). My main aim was to attract more funds from the EC's huge research budget and strengthen the position of

health services research within the EC's predominantly biomedical Research Programme, thus creating more opportunities for European collaboration in this area. I also started the publication of books in the Health Services Research Series published by Oxford University Press.

In addition to this, I undertook various consultancies within the WHO programme on health systems research in the WHO regions of Africa, Asia, and the Middle East. An important principle of the programme was the idea that ministries of health should be the lead agencies in formulating national health research policies and programmes. The main objective was to establish focal point units for health research, in particular health systems research, within the organisation of Ministries of Health.

When I was appointed Director of International Affairs at the Dutch Ministry of Health, the focus of my work was on international health policy, at both national and international levels. Engagement at the international level included membership on the Executive Board of WHO during the Brundtland regime, participation in the annual World Health Assembly, and an advisory role to the Minister of Health at the Health Council, the council of ministers of health in the European Union.

After retirement I returned to the field of health research. I became a Board Member of Innovia and assisted, among other things, in organising a European symposium on patients' participation in health research. I have also attended the annual conferences of the Global Forum on Health Research, an independent, international organisation committed to demonstrating the essential role of research for health in low-income countries. In 2004 the

Forum's conference took place as part of the Ministerial Summit on Health Research in Mexico. The Summit called for enhancement of global health research with a focus on health systems, as a way to achieve the health-related Millennium Development Goals. Together with colleagues on the Board of the Netherlands Society for Tropical Medicine and International Health, I explored ways to follow-up on the Summit's call to action. In collaboration with several other high-income countries, the Netherlands took the initiative, with the full support of the Dutch government, to advance the Mexican agenda on health systems research by establishing the Netherlands Platform on Global Health Policy and Health Systems Research in 2007. Its main objectives are to advise the Dutch government on health policy and health research issues in low-income countries, and to coordinate and strengthen health systems research at home and in the South.

*Geert van Etten is an Innovia Foundation Board Member. He also serves as Deputy Chairman of the Netherlands Platform on Global Health Policy and Health Systems Research, and Secretary of the Netherlands Society for Tropical Medicine and International Health.*

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## DISABILITY, NEEDS, AND DEVICES

Zoe Goldstein

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For the last three months, from June to the end of August, I have been at the Institut Mensch, Ethik und Wissenschaft (IMEW) in Berlin preparing the ground for a proposed research project on disability and technology development, entitled *Disability, Needs, and Devices: An Emancipatory Approach to Technology Development*. IMEW, whose work on disability mainstreaming was outlined by its director Dr Katrin Grüber in Issue 7 of this Newsletter, will be co-steering the research alongside Stuart Blume of Innovia, and Disabled Peoples' International (DPI) Europe. The idea for the project came about as a result of the mutual interests of all three key partners in disability studies and in encouraging more participatory approaches to biomedicine and technology.

The foundation for the project is the well understood yet under-utilised and/or under-facilitated benefits of involving people with disabilities in the conception, development, and distribution of technologies, especially including but not limited to those specifically aimed at improving the functioning and quality of life of disabled people. These include prostheses, orthoses, hearing aids, wheelchairs, and insulin pumps, but could also include telecommunication devices, Internet technologies, and public transport systems. The overall aims of the project will be not only to provide still further proofs of the importance of user involvement, but also to address the structural and attitudinal barriers preventing this from being realised, and to show how user involvement can be achieved in practice.

Historically, people with disabilities have had an ambiguous relationship with technology. Technologies in some cases can enable participation and increase functioning, but in others can exclude and disable. Perhaps what matters is not only the technology as such, but also how it is presented and used, and the conditions under which people who might use

it actually live. A good example of this ambivalent relationship is provided by the cochlear implant, on which Stuart Blume has written. These devices have been widely heralded as a breakthrough technology, allowing deaf people to hear and lead 'normal' lives. It is becoming clear, however, that for many users the benefits are rather less than these claims suggest. Furthermore, many people in the Deaf community are strongly opposed to cochlear implants for they are seen as a serious threat to Deaf culture and identity, and to the future of their community [1]. Making matters even more complicated, in many countries of the global south there are hardly any organised Deaf communities, and furthermore the price of the implant puts it out of reach of everyone except deaf children born into rich families (see Carla Donoso's piece on cochlear implants in Latin America in Issue 9 of this Newsletter). Attitudes to modern communication technologies within the Deaf community are similarly ambivalent. On the one hand texting and MSN provide young deaf people with new forms of sociality. On the other hand, older leaders of the community worry that long established Deaf clubs are dying out because young people no longer go to them.

Given the significant yet ambivalent roles technologies play in disabled people's lives, it is clearly important to understand them from the perspective of disabled people themselves, and it seems self evident that they should have a more involved role developing and designing technology. However, taking a more active role means looking beyond merely offering a choice as to which (existing) technologies to use in daily life, but rather earlier involvement in all stages of the research and design process, providing input on which technologies are developed in the first place, and how they are designed. This means seeing disabled people as more than simply 'end users', but rather participants from the beginning.

As far back as 1982, the Office for Technology Assessment (OTA) in the United

States highlighted the lack of consideration for the research and design of *appropriate* technology for people with disabilities, arguing that “In theory, assuring maximum effectiveness, efficiency, and relevance in the development and application of technologies requires the extensive involvement of those who will use the technologies – the consumers. In practice, however, there is fairly little involvement” [2]. Though written over 25 years ago, and reiterated and supported countless times over the years – by researchers, activists, and in political and legislative circles – many argue that fundamentally the situation has scarcely changed.

The UN Convention on the Rights of Persons with Disabilities, adopted in 2007, provides further impetus and normative grounds for greater involvement of people with disabilities in the decisions and issues which affect them, including the development of technology. Thus the time seems right to investigate existing relationships between people with disabilities and the development of new technologies; to identify the structural and ideological barriers that prevent emancipatory involvement, despite national and international calls for it; and to work towards creating best practice examples and advice for improving the situation.

At this stage, the project is still being developed, but some important steps forward

have been taken. On the 29<sup>th</sup> and 30<sup>th</sup> of August 2009 DPI held a conference in Budapest, Hungary, at which Dr Katrin Grüber from IMEW presented a draft Discussion Paper outlining the background and goals for the project. She posed questions aimed at stimulating discussion that would help us further clarify the concepts and research methods to be used. The involvement of DPI at this stage is crucial for ensuring that the project is not only examining emancipatory practices in technological research and development, but also engaging in them itself.

The discussions at the conference were fruitful, and new people from the disability community have come on board to comment upon and contribute to the project. The next step will be to complete a research proposal, something which is expected within the coming months. The project is an exciting and topical one, and IMEW, Innovia, and DPI are all looking forward to starting it.

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