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## FROM THE EDITORS

Greetings to all members of the Innovia community, all over the world. We are very pleased to bring you the ninth issue of the Innovia Newsletter. We have decided to conduct a little experiment and have made this issue more international than usual by including a piece in Spanish, to reflect the broad and diverse readership base which we have been building up. The hope is that this will make the Newsletter more inclusive, and help to extend the discussion of pertinent issues related to Innovia's objectives to a broader audience. We would be interested in your comments on this new approach, and suggestions for how we could further extend the reach of Innovia's message.

To open this issue, Stuart Blume relates recent progress which the Innovia Foundation has been making, in partnership with organisations in Asia and Latin America. In

particular, the publication of a new disability reader and the completion of a bibliographic resource on Leprosy (Hansen's disease) and stigma, are two important achievements.

Following that is our first Spanish language piece, a review by Carla Donoso of deaf communities and the introduction of cochlear implants in Latin America. Donoso outlines the position of deaf people in various Latin American countries in relation to education, work, and sense of community, and traces the issues surrounding the introduction of this controversial technology. What proves most important in the broader discussion of cochlear implant technology in the Latin American context is the existence and strength of deaf 'communities', and the role of formal associations advocating deaf issues. Where such organisation and sense of collective identity is weak, and education and work opportunities for deaf people are limited, open debate and/or criticism of this so-called technological miracle remains modest. In conclusion, Carla Donoso calls for greater collaboration between social scientists and deaf communities in the region, in order to help strengthen their position and bargaining power in issues which affect them, and enable them to achieve the rights to which they are entitled.

The third contribution in this issue comes from a member of the Innovia community from Bulgaria, Vladimir Vladimirov. In this

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wonderfully personal piece, Vladimirov tells of how he overcame many barriers in his pursuit of an education, both in Bulgaria and The Netherlands, as a wheelchair user with Muscular Dystrophy. Vladimirov includes intriguing references to Communist-era attitudes towards disability, and highlights the lengthy road Bulgaria faces in achieving patient empowerment and acknowledging the rights of people with disabilities.

To conclude this issue, I, Zoe Goldstein, co-editor of this Newsletter, provide an overview of user-led mental health research taking place at the Service User Research Enterprise (SURE), at The Institute of Psychiatry, King's College London, UK. Based on an interview with Dr Diana Rose, Co-

Director of SURE, I have outlined the nature of user-led research, discussing how it fundamentally differs from, critiques, and yet complements traditional mainstream mental health research dominated by the psychiatric establishment and academia. Though many challenges and obstacles remain in the achievement of a true service user perspective in mental health research in Britain, encouraging developments are undoubtedly being made.

Many thanks for reading and being part of the international efforts of Innovia. We hope you enjoy this exciting issue!

Zoe and Dale

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## NEWS FROM INNOVIA

**Stuart Blume**

Early in Innovia's short history, we agreed that three sorts of activity would be central to its work. Innovia would try to develop collaborative and comparative research projects, in which the patient perspective is central, but which are sensitive to cultural, social, and economic variations in patient experiences and aspirations. It would help to build bridges between patient, health advocacy, and consumer organisations in different parts of the world and their local research communities. And it would try to make the results of recent research and scholarship more accessible to professionals and health advocates. Much of this research is carried out in Europe and North America and published in academic journals to which only academic colleagues have ready access. Few in the global south, whether researchers or patient representatives, can

find these journals easily.

It's a pleasure to report that some of these initiatives are now bearing fruit. Commissioned by the Thai Program (now Institute) of Health Promotion for People with Disabilities, Renu Addlakha, Patrick Devlieger, Nagase Osamu, Myriam Winance, and I (on behalf of Innovia) worked on a Reader that would make recent social scientific research on disability more available in Asian countries. The 'social model of disability' is little known there. I am very happy to say that this book has now been published by Orient Blackswan, a leading Indian publisher of social science books. Entitled *Disability and Society: A Reader* (ISBN 978-81-250-3686-9) it can be ordered online via [www.orientlongman.com](http://www.orientlongman.com). The price is 695 Indian Rupees (approximately US\$15 or €11) plus packaging and postage costs. Second, Jo Weaver (a graduate student in anthropology and public health at Emory University in the USA) has now completed an annotated bibliography on 'Leprosy (Hansen's disease)

and Stigma' on Innovia's behalf (which I discussed in Issue 8). This valuable resource will soon be accessible via the Innovia website. But this is only a first step. We hope shortly to have discussions that will lead to its becoming accessible to professionals working in the leprosy field, and to ideas for new comparative research. I hope to be able to say more about these discussions in the next Newsletter.

Another interesting development, about which I also hope to write more next time, is a Collaboration Agreement that we plan to sign next month with the University of Otavalo in Ecuador. The student population of this university includes a large proportion of indigenous people, with a language other than Spanish as their mother tongue. The Collaboration Agreement is the brainchild of Maria de los Angeles Erazo, Director of Postgraduate Studies at the university, and will form the basis for specific activities – research, seminars, exchanges – that we will work out subsequently. It is Innovia's first such agreement with a university, and I hope many members of the Innovia community will want to support it.

I think Newsletter readers might also be interested to hear about a seminar on reproductive rights that the Thai Institute of Health Promotion for People with Disabilities organised recently in Bangkok. It dealt with the

involuntary sterilization of girls with intellectual disabilities in Thailand. Disability rights advocates, including the Asia Pacific Regional officers of Disabled Peoples' International, were among the more than 80 participants. Inclusion International was represented by Nagase Osamu, council member, who spoke about the history of eugenics in Japan, (where the Eugenics Protection Law of 1948 was finally abolished in 1996), and about Inclusion International's position paper on 'A right to life'.

Finally, there's news from Dale Rose and Zoe Goldstein, the editors of the Newsletter. Dale has recently relocated to begin a new job at the Center for Disease Control (CDC) in Atlanta, USA. I'm sure everyone joins me in wishing him well in this challenging career move. Zoe is going to spend three months working with Katrin Grüber at the Institut für Mensch, Ethik und Wissenschaft (IMEW) in Berlin. (Katrin wrote about the Institute, that she directs, in Issue 7 of this Newsletter). During her time in Berlin, Zoe is going to help develop a project with the provisional title of 'Disability, Technology and Identity', that we hope will form the basis for collaborative research in which IMEW and Innovia would both participate. Good luck Zoe! We are all awaiting the results of your work with great interest.

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## **COMUNIDADES DE SORDOS E IMPLANTE COCLEAR EN LATINOAMERICA**

**Carla Donoso**

**Co-researchers: Natalia Niño, Colombia;**

**Karina Romo, Mexico; Stuart Blume, Innovia**

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El implante coclear es un dispositivo que desde sus inicios ha sido promovido como una tecnología capaz de hacer que la gente sorda pueda escuchar. A partir de los años 80, en

la medida en que este implante se fue generalizando en los niños sordos en Estados Unidos y algunos países de Europa, las comunidades de sordos en dichos países iniciaron protestas en su contra. Inspirados por investigaciones lingüísticas que mostraban que la lengua de señas usada por los sordos constituía una lengua real, así como por otros movimientos de protesta que proliferaban en ese momento (incluyendo el movimiento de mujeres), los líderes de estas comunidades

argumentaron que la sordera no era algo a ser corregido a través de la medicina, sino que más bien era la base de una cultura y un modo de vida particular.

El implante realizado en niños a muy temprana edad era percibido por ellos como algo particularmente amenazante. El 90% de los niños sordos tiene padres y madres que no lo son, y el temor en este caso era que estos últimos serían altamente susceptibles al mensaje de que sus hijos podrían volverse “normales” (es decir, ser capaces de escuchar). Dicha opción ponía en riesgo el futuro de la comunidad basada en la lengua de señas, que dependía de que esos niños aprendieran la dicha lengua y fueran socializados en la cultura y en la comunidad de sordos.

Desde el punto de vista médico, el implante ofrecía la esperanza del (re)ingreso en el mundo oyente. Sin embargo, desde el punto de vista de los sordos, ello era un símbolo de la supresión de su lengua y cultura, algo que las personas sordas habían sufrido por muchos años. Para los representantes de clínicas y fabricantes que ofrecían este dispositivo, lo que estaba en juego era el futuro de una tecnología en la cual se habían invertido considerables recursos. Para los líderes sordos, por su parte, lo que estaba en juego era el futuro de su comunidad.

Los investigadores Natalia Niño, Karina Romo, Stuart Blume y Carla Donoso, realizamos un estudio preliminar con el propósito de describir la introducción del implante coclear en Latinoamérica, particularmente en Colombia, México y Chile, en donde recabamos información en relación al proceso y las respuestas generadas frente a esta tecnología.

El primer implante coclear se realizó en México en el año 1986, posteriormente en Colombia en 1992, y finalmente en Chile en 1994. Aunque la tasa de implantes realizados en los años noventa difiere significativamente entre los tres países, en todos ellos encontramos que los primeros implantes cocleares fueron

realizados en clínicas u hospitales privados, lo que da cuenta del carácter excluyente que tuvieron desde sus inicios. Asimismo, en Colombia y México este procedimiento no ha sido ni es cubierto por los seguros públicos de salud, mientras que Chile existe una cobertura pública altamente limitada [1].

Un estudio realizado recientemente por la Federación Mundial de Sordos [2] determinó que la situación de las personas sordas varía considerablemente entre los países latinoamericanos. Por ejemplo, en la mayoría de ellos los niños sordos tienen acceso a la educación primaria (al menos en teoría) y en algunos de ellos existe acceso a la educación secundaria. Sin embargo, sólo en muy pocos países (incluyendo Brasil, Chile, Colombia, Costa Rica, Cuba y Ecuador) existe acceso a la educación superior. En algunos países (incluyendo Argentina y Bolivia) la educación es exclusivamente oral, mientras que en otros países hay escuelas que combinan diferentes enfoques, entre los cuales muy pocos (incluyendo Chile, Colombia y México) ofrecen educación usando la lengua de señas. En casi todos los países considerados en dicho estudio la educación general y los niveles de alfabetización de los estudiantes sordos son evaluados como pobres.

El citado estudio muestra también que en Latinoamérica las posibilidades de los niños sordos de acceder a una educación basada en la lengua de señas, así como las posibilidades de los adultos sordos para trabajar y participar de vida comunitaria varían enormemente. Sus posibilidades parecen claramente mejores en países como Colombia y México (y hasta cierto punto en Brasil y Cuba) en comparación a la mayoría de los países de la región. En Chile, las posibilidades se sitúan en un nivel moderado (así como en Ecuador, Venezuela y los restantes países), siendo claramente pobres en Argentina y Bolivia.

Asimismo, encontramos variación en la envergadura y grado de organización de las

asociaciones de sordos en los países estudiados. Por ejemplo, la asociación colombiana indica tener 450.000 miembros, mientras que la de Nicaragua reporta 783 miembros y la de Ecuador 420. No obstante, muchos países – entre los que se encuentra Chile – no fueron capaces de entregar cifras en relación a sus miembros, lo que se debe sin duda a su débil nivel de asociación.

El problema organizacional fue reconocido por un líder de una de estas organizaciones en Chile [3]:

*Las organizaciones de sordos en Chile se caracterizan por su desorganización, falta de capacidad y liderazgo para trabajar mancomunadamente en pro de objetivos comunes, con visión de país, que beneficien a toda la sociedad en su conjunto. Carecen de objetivos claros, enfocándose casi en exclusiva a fines recreativos y superficiales de carácter interno (fiestas, paseos, encuentros deportivos), dejando de lado los problemas reales que les afectan como instituciones y como personas en todos los ámbitos de la sociedad. Como toda comunidad, enfrentan los mismos problemas que aquejan todos los ciudadanos de un país, sólo que en este caso los problemas adquieren un carácter bastante profundo, agravado por la discriminación y exclusión social de que son objeto, sumado a las nulas o erradas políticas gubernamentales que, en la práctica, se traducen en un fracaso tras otro.*

Los argumentos en contra del implante coclear en niños sordos, desarrollados en los países del norte, son conocidos por los líderes comunitarios en Latinoamérica y – hasta cierto punto – compartidos también. Sin embargo, los dirigentes están conscientes de sus limitaciones para difundir sus argumentos en contra del implante coclear, como lo planteó el ya citado dirigente:

*...en Chile no existen instancias realmente válidas para plantear el tema, es una pérdida de tiempo, el implante coclear como tal no existe*

*ni es prioritario para las autoridades locales. Además todos los eventos que se realizan en el país sobre el tema están organizados para “tirarse flores” [4] y no para confrontar realidades u opiniones opuestas que vayan en contra de los intereses creados.*

Ofreciendo curas milagrosas basadas en la tecnología más avanzada, los cirujanos de Latinoamérica especializados en el implante coclear han encontrado consumidores receptivos entre los padres de niños sordos más acomodados, quienes son sus principales clientes. La falta de acceso a esta tecnología, hace que se trate de un tema secundario para las organizaciones de sordos, frente a la urgencia de otros problemas más inmediatos como la falta de acceso a la educación, al trabajo, a la información y a los medios de comunicación.

Asimismo, las comunidades de sordos en la mayoría de los países de la región se encuentran mucho menos organizadas que las de los países europeos y carecen de los recursos necesarios para presionar por sus derechos. Respecto al implante coclear, más allá de su limitado uso en Latinoamérica, existe un aspecto que merece mayor reflexión: el hecho de que sea promovido como “la solución médica al problema de la sordera”, supone en términos simbólicos un atentado a la identidad de las personas sordas y a la continuidad de su comunidad. Se trata de un aspecto que merece mayor debate ya que compromete las demandas básicas de las comunidades de sordos, como son el acceso a la educación, a la información y a la socialización en la lengua de señas.

Consideramos que los científicos sociales de Latinoamérica tenemos un importante rol en el trabajo con las comunidades de sordos, especialmente apoyándoles en el desarrollo de argumentos políticos – sustentados en la teoría y en la investigación empírica – que les permitan alcanzar los derechos obtenidos en otras partes del mundo. La conceptualización de las comunidades de sordos como minorías culturales y lingüísticas es un argumento clave

para ampliar sus derechos mas allá del enfoque de la discapacidad, abriendo el espacio para debatir su lugar en las políticas multiculturales desarrolladas actualmente en Latinoamérica. Quizás una de las lecciones que han dejado los movimientos indígenas en América Latina ha sido el avance obtenido en la demanda por sus derechos culturales y lingüísticos, especialmente en áreas tan centrales como la educación. En cualquier caso, todavía queda un importante trabajo por realizar, uno que se ajusta muy bien a los objetivos de Innovia y que tiene que ver con el aporte que el mundo académico puede hacer al bienestar de las

comunidades involucradas y afectadas por el desarrollo de la tecnología médica.

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[1] En los tres países encontramos organizaciones sin fines de lucro que intentan hacer más accesible esta tecnología, especialmente para los niños.

[2] "Personas Sordas y Derechos Humanos", Federación Mundial de Sordos, enero de 2009.

[3] Entrevista realizada a Víctor Castillo, representante de la organización "Pro-sordos" en marzo de 2009.

[4] Tirarse flores: alabar o adular a otro o a sí mismo.

## **THE ROAD TO PATIENT EMPOWERMENT IN BULGARIA**

**Vladimir Vladimirov**

My name is Vladimir Vladimirov. I have Limb-Girdle Muscular Dystrophy Type 2A and have been a wheelchair user for 10 years. I studied Psychology at Sofia University 'St Kliment Ohridski', Bulgaria, and later Neuroscience at Vrije University Amsterdam. The flexible educational system in The Netherlands allowed me to attend some additional courses at another university while following my two year Master's degree in Neuroscience, so I had the wonderful opportunity to attend the department of Science and Technology Studies at the University of Amsterdam, headed by Prof. Dr Stuart Blume.

It was a wonderful adventure in the science policy world. During interesting and stimulating group discussions I learned about a lot of good and not-so-good research policies. For my part, I also contributed to the science knowledge base of my fellow students – much to their amusement – by sharing Lenin's and

other Bolsheviks' thoughts on psychology and science that I discovered in a 1980s psychology textbook. For example, during the Communist era, we – the countries of Eastern Europe – had one, tirelessly propagandised, slogan: "Everything for the Man, everything for the good of Man!" And there was the joke of a little boy adding to it, "Should I say who the Man is?" – obviously implying the head of the totalitarian state.

In truth, not everything was for the good of everyone. Whole sections of society were made invisible – people with impaired vision had special neighbourhoods made for them, people with mental problems were sent for treatment in institutions located among woodlands in the mountains, and people with mobility problems... well, they stayed at home.

So that was the starting position of our quasi-democratic society in 1989, when I was 11 years old. At that time I began experiencing serious difficulties climbing stairs, and since my school had a lot of them, I eventually had to stay at home. Fortunately, I had the obligation, hence the right, to study until my 16th birthday – that is, to finish pre-secondary school. It was

arranged for me to be visited by teachers in my home, and they happened to be very dedicated ones. Some stayed long after their specified time was over, discussing topics from the lesson which I found particularly interesting. The completion of my secondary education did not happen without hurdles, as I was over 16 years old, but I still persevered in my 'weird' desire for education.

After completing my secondary education, I decided to apply to Sofia University 'St Kliment Ohridski', but there was a problem: there was a list of 16 major types of disability, people who were 'forbidden' from applying, and I counted among them. This list included mental conditions, progressive muscle diseases, and others. It was 1997. Luckily, my parents somehow managed to convince someone responsible at the University that I would be able to study successfully. From what I recon, he was persuaded by the fact that I was physically able to write. The University was, however, mostly wheelchair inaccessible, so I met with the rector to discuss that and other issues, which were actually resolved a few years later.

After finishing my degree in Psychology, I applied for an MSc in Neuroscience in The Netherlands. Since I didn't have the financial means to study abroad, I asked for assistance from various institutions, foundations, and private companies in Bulgaria. Lucky again: this time the president responded. I mean the president of Bulgaria – Mr Georgi Parvanov. He had just played a charitable football game against ambassadors of foreign states (I think he scored and his team had won) and somehow he decided that it was a good idea to allocate some money for my education. Two private

companies also contributed some money and in 2004 I had the basic financial means to live modestly for a year in The Netherlands. The following year I was awarded a Huygens Scholarship by the Dutch Ministry of Education, so I managed to finish my study.

Since my return to Bulgaria in 2005, unfortunately so far I have not been involved much in patients' organisations. I established a small relocation company that provides services to foreigners and foreign companies wishing to settle and work in Bulgaria, and working there has been my sole occupation for the last three years. Change in patients' status in Bulgaria, as in many other parts of the world, is badly needed, and I hope that I will be able to contribute to this cause. But what needs to be changed, in my opinion?



*The President and I. Sofia 2003.*

- There should be zero-rate Value Added Tax for medical and disability equipment (it is 20% now in Bulgaria).
- Patients should have the right to choose whether or not to accept medical treatment, including emergency treatment.
- The State should stop investing tax payers' money in wheelchair inaccessible hospitals and rehabilitation centres.
- The State should be building and renovating existing hospital and rehabilitation centres in accordance with universal design / accessibility for all.

- The government should be investing 25 million Euro into new medical or assistive products to serve Bulgaria's patient population's needs, NOT in an imaginary nano-technology centre.
- A radically new 'money follows the patient' system should be implemented, and allocation of money to hospitals on an unclear or subjective basis should be ceased.
- Last, but not least, there should be a patient presence within and control over policies and conduct of the National Health Insurance Fund (Bulgarian State-controlled monopoly health organisation).

Having said that, I couldn't stop thinking of my recent visit to a psychiatrist. Guess who referred me there? It was the social services bureau! I needed to have a certified psychiatrist's

evaluation to decide whether I was 'mentally and physically fit to navigate an electrical wheelchair', in order to receive State funding to use one. Luckily, I passed. The road to patient empowerment in Bulgaria is long, but interesting!

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## **USER-LED MENTAL HEALTH RESEARCH**

**Zoe Goldstein**

**A conversation with Dr Diana Rose of the Service User Research Enterprise (SURE)**

It is challenging work going up against the whole psychiatric research establishment, questioning its established techniques and ways of thinking, but progress is being made. This is how Dr Diana Rose, Co-Director of the Service User Research Enterprise (SURE), sums up the experience of working in one of the largest units within a European university focused specifically on user-led research in mental health. The fields of mental health care and treatment, and of research into mental health issues and interventions, have long been

dominated by the psychiatric establishment and academia. Psychiatrists define the parameters of mental ill health, determine the important issues, and establish what they consider the most effective solutions. However, within the last decade or so policy makers and grant providers in the United Kingdom have shown increasing interest in incorporating service users' perspectives within the research agenda, and redressing the power imbalance that marks traditional psychiatric care and research.

Challenging work indeed, but SURE is now a well established and independently run unit within the academic research department of the Institute of Psychiatry (IoP), a component of London University's King's College. It began as a 'virtual' meeting group without funding led by Professor Til Wykes, a clinical academic,

until in 2001 it received important funding enabling it to become an 'actual' research department. Dr Rose, a service user researcher with extensive and pioneering experience in promoting user-led research, was the first employee of the new department, appointed Project Coordinator. Four years later, in 2005, she was promoted to Co-Director. Under the joint directorship of Professor Til Wykes and Dr Diana Rose, a balanced leadership approach is maintained between professional psychiatric researcher perspectives and service users' perspectives. Soon after its establishment, grants began to flow in as interest grew in user-led and user-focused research in mental health.

Currently SURE has on staff ten researchers, a significant majority of whom are *Service User Researchers*: skilled and experienced researchers first and foremost, but who have also had personal experience of mental health issues and services, experience which is used to inform their research. This is what makes the work conducted by SURE fundamentally different from – yet complementary to – most research in the mental health field. A good example of how their work differs from traditional approaches is in the use of outcome measurements for the interventions or services being studied. Unlike the outcome measures tools used in most mental health research, which are predominantly quantitative and determined by professionals, SURE develops its own tools very differently. In the initial stages of a project qualitative information is gathered from focus groups and expert patients about the issue at hand, which is used to create questionnaires with both closed and open-ended questions. These are then tested using psychometric measures to ensure and demonstrate their validity. Thus they are rigorously and 'objectively' validated according to recognised scientific standards, but are very different from traditional mental health outcome measures because they are uniquely and entirely from the service users' point of view.

The emphasis on scientific validity is important. SURE is a research unit that sits within an established academic mental health research environment, and often collaborates on joint research projects. Thus it has to try to bridge the gap between mental health service users and the psychiatric establishment. That gap is still quite large. Both within the Institute of Psychiatry itself, and among mental health professionals more generally, there is widespread scepticism regarding both service user led and qualitative research. Much of the criticism focuses on the idea that user-led research is too involved, too subjective, and has too much of an agenda. There is also a general wariness about the assumed 'softness' of qualitative research; "numbers have all the answers", some of Dr Rose's colleagues tell her. Struggles over technique and approach often break out, setting mainstream and service user researchers against one another, and raising questions of parity between the two. Funding largely dictates research priorities; now in the UK, mental health research funding often requires a service user component within a larger project proposal – a positive development in itself – thus grant applications submitted by mainstream researchers within the IoP frequently include a component led by SURE. However, this sometimes means that SURE ends up having no more than a tokenistic role in a project.

Despite being a large and well-established research unit, and despite the positive climate (at least in theory) for service user involvement in research, many of the problematic issues which SURE was set up to tackle remain. For example, the randomised controlled trial remains the 'gold standard' in practice because of its supposed neutrality. An aim of SURE has been to expose the lack of neutrality in much mainstream mental health research, for the questions asked and the agendas set reflect the partiality of those doing the asking and setting. Furthermore, Dr Rose and her colleagues at SURE know very well

what the priorities of mental health service users are, which include: troubling elements within the new Mental Health Act; medication (particularly newer, supposedly 'less toxic' medications and users' experience of them); stigma; re-evaluation of in-patient care services; and all-too-common housing difficulties for people with mental health problems. Issues for new research should be focused on these concerns. However, there is almost no overlap in practice between these priorities and the policy agendas dictating what research is carried out.

Working at the IoP alongside mainstream researchers inevitably means that compromises have to be made. Dr Rose has heard from some people that SURE, by working at the IoP alongside mainstream researchers, has 'sold out' in terms of conducting true user-led research because of such compromises. She disagrees and considers this suggestion insulting, as it implies that the SURE team have no power and cannot hold their own ground. The record shows that as the unit has grown over the past seven or eight years important advances have been made. Service users are becoming more involved in *all* aspects of mental health research at the IoP, from design and data gathering to analysis and dissemination. SURE organises training courses in research skills for local service users and also runs a clinic for colleagues at the IoP seeking advice on how to involve service users in their research. Further, it ensures that the findings from research projects are made available, accessible, and intelligible for service users by publishing results beyond academic journals. Their work has also found its way into policy: for example, Britain's National Institute for Health and

Clinical Excellence (NICE), which provides independent guidance on health promotion and the prevention and treatment of ill health, incorporated results from SURE's first research project, investigating Electro Convulsive Therapy (ECT), into its guidelines. Two of the researchers on this project had themselves received ECT.

The challenges which SURE and service users themselves face within the mainstream mental health establishment are far from over. Nevertheless, through their dedication for achieving a balanced approach in research between service user perspectives and accepted scientific rigour, SURE is slowly but surely generating broader acknowledgement of the full spectrum of realities regarding mental health issues and care, and enriching the modalities of research with alternative approaches and voices. It would be interesting to know if comparable initiatives have been taken elsewhere.

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*More about SURE:*

*[www.iop.kcl.ac.uk/departments/?locator=300&context=main](http://www.iop.kcl.ac.uk/departments/?locator=300&context=main)*