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The Quest for Better Mental Health Care

Dr Roger Gurr is a tireless human rights campaigner, trained in psychiatry in Australia and the UK, including Oxford University. Dr Gurr who set up Australia's first community-based integrated mental health service, is an associate professor in the School of Medicine at Western Sydney University. He spoke to OLGA YOLDI about a life dedicated to the service of humanity.

What drew you to work in mental health? Tell us about your work.

I almost became a chemical engineer like my father, but I applied too late for a cadetship so I studied medicine at the University of NSW. I chose the new medical school because their teaching methods were tutorial-based and included arts subjects, not just purely science, as well as a 10-week clinical term on mental health that was unheard of in 1968.

As a student I was actually allowed to treat patients and really enjoyed the interaction, so when I was a hospital resident I did a term on the psychiatry ward and again found it satisfying. Psychiatry is not a specialty most medical students are attracted to because there is a stigma attached to it. Some consider it not proper medicine, so you must be "mad" to do psychiatry.

My first year as a psychiatrist was at the Psychiatric Research Unit at Rozelle Hospital, where I was working in a neuro-psychiatric unit on cases sent from across the state. Patients experienced a mixture of biological and psychological issues. We took them off all their treatments and medications and started from scratch. The unit was staffed by psychiatrists, neurologists and neurosurgeons. I soon understood the connection between biology and psychology. I am convinced every problem is bio-psycho-social and I tend to be an evolutionary psychiatrist.

We have to look at how we have evolved as human beings. A lot of our behaviours are more programmed than we like to think. You only have to look at studies with identical twins reared apart from birth to find out they are similar as adults. What they have absorbed from their families is maybe a bit of vocabulary, but both like the same sorts of food, dress in similar colours and tend to marry the same sort of people. To believe that everyone is totally changeable is not a good idea. On the other hand, it does not make you a determinist to say we are all determined by our genes.

If one identical twin has schizophrenia only half the other twins will also have schizophrenia, so that tells you there are a lot of other factors that cause mental disorders. I now work in the prevention of early psychosis with young people at high risk of developing it, because I believe there are ways we may be able to change the trajectory set by their genes.

The literature points out that a lot of people with

schizophrenia, for instance, have trauma stories that tend to be neglected in terms of managing schizophrenia. A large proportion of the young people I see have experienced personal trauma. We should be trialling neurofeedback, now used at STARTTS, not only to deal with the basic development of psychosis, but also to get rid of verbal auditory hallucinations and to help traumatised brains to better regulate themselves.

A concern for human rights has obviously been central to your work. You were president of Amnesty International Australia during the 1980s. How did you come to be involved in Amnesty?

I spent time in Indonesia where I met an Amnesty International investigator. Indonesia went through a terrible time after Sukarno was ousted. Some 600,000 people were killed in an attempt to eradicate communism, others were put away in jail or sent into exile on islands. Afterwards their families had their identity papers coded as communist sympathisers and therefore a risk to the state. As a result, they were not allowed to get public sector jobs or education. I saw millions suffering so close to our shores in Australia, with very little outcry in our media.

I had been involved as NSW secretary of the Australia Party, which was a liberal centrist party – capitalism with a heart – largely funded by Gordon Barton. We campaigned against the Vietnam War and we almost got a senator elected in the 1972 federal election. We claim it was our preferences that enabled Whitlam to win office. The party morphed into the Australian Democrats.

I went overland to England to see the world and complete my studies in psychiatry. I wanted to remain involved in politics, but not party politics, so I joined the Ealing branch of Amnesty International (AI), where I learnt a lot and enjoyed it. That is how my direct connection with human rights started.

When I came back to Australia in 1978 I joined AI in Sydney. We managed to employ Harris Van Beek with the promise of funding his salary, and put a lot of energy into reactivating the Australian section. I was national president for five years, then national secretary through the rest of the 1980s. We set up direct mail and merchandise fundraising to turn the organisation around. We developed an AI federal parliamentary group of about 60 members and a NSW State Parliament Group. When John Howard was federal treasurer he refused to grant tax deductibility for donations to AI, but in a stroke of luck he had recently granted it to the RSPCA. I went to see him and suggested we would leaflet his electorate with the message that he would allow a tax deduction for donations to prevent cruelty to animals, but not to humans. Needless to say, we achieved our goal very quickly.

Through my work in AI and as a psychiatrist, I was aware of what was happening around the world with refugees and torture. Once I realised that an organisation had been set up in Denmark to provide treatment for traumatised refugees I became determined that we should have such a service in Australia, particularly in Sydney.

In 1988 we started the campaign and luckily managed to convince the then NSW health regional director in western Sydney to allocate funding for us to hire Professor Janice Reid, then a medical anthropologist, who had written about refugee health needs in Australia. She produced a report making the case for the establishment of a torture and trauma treatment service. We got bipartisan support in the NSW parliament, so the NSW government allocated funds and STARTTS was born in Fairfield.

We decided such an organisation should be owned by the Minister for Health for more certainty of funding. But we negotiated the creation of a management committee structure, with the members nominated by key stakeholders such as AI, Red Cross, Ethnic Communities Council, Ethnic Affairs Commission and universities, as well as some community members appointed by the minister on our advice. This structure meant there were good checks and balances and we reported directly to the minister to talk about any issues. Because we needed physical support (IT, HR, Finance) we were hosted by one of the area health services.

STARTTS began to get the majority of its funding from the federal government and local difficulties arose over the transfers of funds, so STARTTS had no choice but to become an independent non-government organisation, with the blessing of the NSW government.

You were a founding member of the Human Rights Council of Australia. Tell us about it.

AI has a narrow mandate and tight rules about local activities to protect human rights activists in perilous countries. We realised we wanted to take action on other human rights concerns, so a group of us reactivated an organisation called the Human Rights Council of Australia. Included in project work was producing The Rights Way to Development, which provided well-received advice to the UN and governments on how to include human rights conditions in foreign aid grants. Public servants who advise government were largely ignorant about this, yet governments can have real leverage in funding projects that lead to improvement in human rights and better community development

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processes. Involving local stakeholders in the receiving country helps the design of effective programs and helps avoid loss of funds to corruption.

We also did some work for the Aboriginal Reconciliation committee, to come up with ideas as to how to run activities around Australia in order to get the message across and support reconciliation. We have encouraged peak organisations to question the Australian government, to force it to have better aid programs and international approaches to assist developing nations and to solve problems more effectively.

Where does your commitment to the advancement of health and human rights originate from?

I am sensitive to human suffering because as a psychiatrist I deal with human pain all the time, and seeing people who have been tortured and traumatised is very moving. I also happened to be born gay, which was very traumatic when I was growing up. That means you become more observant about people around you, more sensitive to nuance, and because of your own pain in dealing with those issues you are actually more sensitive to other people's suffering.

People with mental health issues and their families are stigmatised and traumatised by the onset of illness, and I had a maternal grandmother with late-onset psychosis. All these groups suffer trauma as a result of attacks on their human rights: there is no health if human rights are violated.

What do you see as the relationship between human rights and mental health? How have you seen them intersect in your work?

Because the relationship is significant, there is a UN Declaration on human rights and mental health because it is stigmatised, comparatively neglected in most countries and treated very cruelly in some. Being mentally ill in most societies means being at risk of being discriminated against, in violation of human rights. In Australia there is discrimination, including in life insurance, health insurance and employment. Many people do not understand mental disorders and link them to religious ideas, witchcraft and violence. So the UN standards for services for mental health are very important.

In 1989 I helped to organise the first annual Mental Health Services Conference of Australia and New Zealand to help ensure those standards were applied. Right from the start that initiative involved consumers, carers, mental health workers from all disciplines and other stakeholders. I am still on the board and the 2017 conference is in Sydney at the end of August. I am sure there will be presentations on transcultural mental health and refugee mental health issues.

We have an awards program that recognises achievements in mental health services in Australia and New Zealand, and by chairing the committee I get to see the progress being made in this field. It is sad to see the mental health services in some states going backwards, in spite of the evidence, because some governments focus on false savings rather than on delivering effective specialist services. It is unfortunate that the public system favours generalist teams in the delivery of mental health services, which have no fidelity towards any real evidence-based programs. The headspace Youth Early Psychosis Program that I am working for now, has a fidelity tool for the EPPIC evidence early intervention in psychosis model with 16 components of care, and we need to make sure that we don't stray from that.

It seems much of your career has focused on community-based integrated mental health service. What does that mean exactly and why do you think it is so important?

While studying in England I came across evidence that it is possible to manage people with mental disorders in the community as well as in hospital settings, and the treatments are the same. The only reason for keeping people in hospital is for short-term safety. When I came back to Australia I was determined to try it. The model is to provide a reliable, 24-hour service based in the community but with hospital back-up. The model is bio-psycho-social, holistically ensuring that physical health is managed with mental health, as the mind and body are not separate. The family needs to be supported and educated about the disorder.

The essential components include an extended-hours

assessment and acute care team that sees people at home or at the local hospital, and which is capable of providing continuing acute care in the community. Then multidisciplinary teams to provide longer-term service coordination, comprehensive treatment interventions and recovery programs.

People do best in their familiar home environments, where they can get on with purposeful activity and maintain relationships. Through a funding methodology roundtable I initiated with the Australian Health and Hospitals Association, PriceWaterhouse Coopers and the Mental Health Services Conference in 2008, we concluded that this would be best achieved by regional funding organisations commissioning these services on a population basis, as mental health usually loses out in the competition for health funds in current funding systems.

Early detection and intervention is essential for the best outcomes in most mental health disorders, 75 percent of which develop in the 12-25 age group. Fourteen health economic studies have shown that investing in best practice care of these young people is just about the best investment you can make in health, with a benefit to cost ratio of about 5.6 to 1. However, seems expensive initially because the rewards come through the rest of a person's life. Australia needs to invest about $2 billion more per year, which would dramatically reduce the current cost of impaired mental health of about $28 billion per year over time. The headspace Youth Early Psychosis Program aims to do this.

From a mental health perspective, what has changed over time? What has improved? What has got worse? What are the main challenges?

We still have not truly implemented the evidence from research in the 1970s and much of the evidence since then. The thinking is that mental health should be integrated with the rest of health services, but when chief executives lack funds they divert funds from mental health services to politically sensitive services. The diversion of funds intended for mental health services in NSW has been rife and hasn't improved over time. This is an argument for funding mental health services through separate independent organisations, such as the Mental Health Trusts in the UK or not-for-profit organisations such as STARTTS or Uniting Recovery in NSW.

The biggest problem in Australia is our federation and constitution. The states are supposed to be the service providers and the federal government was to provide high-level services like defence, foreign affairs etc. However the federal government has been progressively taking more tax revenue and power away from the states. It now receives 83 percent of tax revenue while the states only collect 17 percent. However states need at least 40 percent of the public dollars to provide services. So the state governments are always at the mercy of the federal government. Health sector academics and providers believe that responsibility for the health portfolio should be under one level of government. We don't care if it is under the federal or state governments. Canada and the UK have that arrangement and it works well.

When one level of government controls all the clinicians and all aspects of primary, secondary and tertiary care, it can work effectively as a unified system. Currently the federal government looks after paying private practice doctors and some allied health clinicians on a fee-for-service basis through Medicare, which is largely uncapped so they lack full control over costs. It is poorly distributed geographically and it eats up the budget, so there is less money to give to the states for health services.

While state governments look after public hospitals, they cannot cope with the growing demand. Health inflation runs at about 7-8 percent (1 percent population growth, 2-3 percent CPI, 4 percent because of new drugs and medical technology). The demand for emergency department services increases on average 2.7 percent a year, much higher than population growth, plus there are increased admission rates to other hospital wards.

State budgets can't cope, so mental health suffers as a result. It is invisible in a way: we talk to people, administer medication and the cost is not as high as physical health, yet it is very effective. It can save money having psychiatrists working in hospitals as part of health teams that reduce lengths of stay through holistic interventions. The traumatised people we care for at STARTTS are prime examples, as they use fewer physical health services when their psychological needs are met.

So, yes, there is a need for major health reform. We need to use financial incentives to shape the behaviours of clinicians and improve corporate systems to achieve the outcomes we want. At the same time we need a population-based budget for equity of access. The Medicare system is terrible at distributing the resources. Research has found that those who got the most benefit out of Medicare for mental health services lived in Malcolm Turnbull's electorate, while the area that received the least money and resources was Mount Druitt, because poorer people get the least subsidies

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through Medicare.

What has improved in mental health has been family work. Now we understand more about the importance of dealing with people at the beginning of their disorder, because many react negatively when a young person develops psychosis. The reactions may be open hostility or over-protectiveness – a covert form of hostility – and the young person will not do well. We have learned that if you work with the whole family at the beginning, you can prevent many problems.

It was also true at STARTTS where, early in its development, we realised that providing holistic interventions for individuals was not enough, we needed to work with the family and community to create the best opportunities for renewal of trust, support and recovery.

So the main issue affecting the delivery of mental health in Australia is a lack of investment.

The Council of Australian Governments (COAG) decided to invest $2.5 million in developing the Mental Health Service Planning Framework, using 40 experts to pull together the best evidence for effective services and the resources required. This was completed in October 2013, but has been supressed because it shows we should invest more than $2 billion extra in community-based mental health services with an emphasis on the development years.

What are the solutions?

Until we get our Constitution fixed and a proper agreement between governments on an adequate amount of funding, the situation will not change. And of course, with partisan politics the way they are now, it is a very difficult thing to achieve.

More investment is needed and better leadership from our politicians, who need to make some hard decisions. Everyone knows there is waste in health, but nobody is prepared to address it effectively and politicians are scared of the power of invested interests.

That's why we campaigned for the state and national mental health commissions, because they can make proposals using the evidence base and in consultation with the stakeholders with less partisan interference. In practice, some are too attached to government policy, while others have been able to effectively make real changes.

What we also need is development of the commissioning of services through primary health networks and the funds to do so. Health sector consensus is that one level of government should manage and fund all health services, from primary to tertiary.

When I reflect on the 40 years of involvement in the politics of reform, you see the ebbs and flows and reactions. The problem is that often humans do not want to do what the evidence shows, they prefer to do the things they want to do. In psychiatry you see professionals falling into particular habits, attitudes and ways of working, and often they do not follow the criteria for fidelity to evidence.

Have you seen STARTTS changing over time?

STARTTS exists because it is clear that mainstream mental health services are not able to assist survivors of torture and trauma, because people have trouble hearing trauma stories and also feel unable to help effectively. This was shown in the early days, when we were trying to train professionals in public hospitals and mental health services. The problem is that you can get vicarious trauma from counselling survivors. You can also feel stressed because you are alone, without the teamwork and range of interventions required for successful treatment.

Initially we started to employ bicultural workers who brought the culture with them and spoke relevant languages, but then we learned several had their own trauma experiences and that can be problematic. STARTTS has had to dynamically change its clinician mix to match each wave of refugees from different parts of the world – Asia, Central and South America, the former Yugoslavia, Africa and now the Middle East.

STARTTS has been a great opportunity to innovate and apply research. In the past 28 years it has expanded and evolved. STARTTS has a community development approach as well as individual, family and group clinical care approaches, so it covers the whole spectrum and

PHOTO: DAVID MAURICE SMITH / OCULI

uses non-standard clinical mechanisms that have a positive clinical effect because they allow for physiological improvements in the brain.

The use of music, sport, Capoeira dance, craft groups and so on has been vital. For example, we had women from South-East Asia who had been raped, but who could not talk about it within their culture and were able to do so in the context of social activities such as pottery classes.

Refugees from South and Central America came to Australia needing ideologically based therapies, whereas those coming from South-East Asia needed more symbolic therapies. Because of the differences in culture, religion and political belief systems of different groups, STARTTS has had an incentive to keep changing. We now receive refugees from Africa and other long-term refugee camps because Australia has a non-discriminatory approach to taking refugees, which is to be applauded. A high proportion is from Arabic majority countries such as Iraq and Syria.

It has been very gratifying, providing opportunities for the excellent staff in STARTTS to innovate and seeing the results coming through. We have been blessed with having really creative and committed staff. The internal processes encourage staff to imagine better things, while also having the controls and the tools to ensure it is done effectively.

Sustainability of torture and trauma services around the world is of concern to our board. We need to look at how we can help improve the fund-raising efforts for the international torture and trauma services. There has been a contraction in government funding to the UN Fund for Torture Victims and with the surge in refugees into Europe, some governments are redirecting funding for refugee services to internal providers. There is a risk that the Trump Administration will dramatically cut its funding. Some services in poor countries have already closed because of a lack of funds.

STARTTS has an interest in sharing its skills with foreign services, helping them to provide improved services locally. Now you can run an interactive training course in Sydney that can be viewed around the world.

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The training team will be a growing part of STARTTS because of its increased need to cope with growth and inevitable staff turnover.

Can you highlight your most fulfilling moments and achievements?
I have had the most joy out of involvement with STARTTS, because right from the beginning we saw the opportunities for great progress for very damaged people.

My involvement with Amnesty International (AI) was satisfying because it was about working with lots of other people in fighting for justice across the world. There are local groups writing letters about prisoners of conscience and raising funds. AI also enables you to go all the way through the political process. We had a federal parliamentary group with 60 members that I was responsible for, and we had a state parliamentary group that helped get bipartisan support for STARTTS. I remember when Bob Hawke was visiting China and there were five political prisoners AI had identified as really needing help, so we convinced Hawke to raise those issues in his discussions with the Chinese leader. To back him up so it was not Hawke alone, we also asked the Dutch and Canadian foreign ministries to raise the same cases at the same time so it was much more effective and those five political prisoners were released. It is about having the understanding of how politics works and if many voices say the same thing, it is very effective.

My clinical work is also very satisfying, especially seeing young people responding, and preventing problems. Experiencing young people emerging from their personal difficulties and finding new ways to go forward is always inspiring. I now have the opportunity to apply neurofeedback to help prevent some transitions to psychosis, eliminate verbal auditory hallucinations and reduce the effects of developmental trauma.

You are on different boards and groups, how do you fit it all in?
I did not have children so I have had more time and it is a case of running my life in phases. For instance, I was very involved with AI for 10 years through the 1980s and I made a conscious decision to leave. I had committed to build the organisation, but then there comes a time for a new generation to take over. Now I am 70 it is time for a decade of research activity.

In terms of human rights, do you think there has been an improvement?
People think we have more depression and oppression these days. It is more in the media, but I don't think so. We humans will remain humans. Our evolution can only take place very slowly and so changing the culture is slower than changing other things. But the world has not really changed – we just hear every detail because of global media. The concern now is that despots have new techniques to control populations with electronic surveillance and media. Where before they would do so by obvious brute force, now they can do it more subtly – but it is still brutal.

I believe Democracy is hard to bring into traditional societies. It took Europe many centuries and many wars, and the thought of going to Iraq and removing the strong man and just expecting instant democracy, was an act of great stupidity and ignorance. People who have power and money often do not have the knowledge to make the right decisions.

The philosopher Karl Popper says "For every action you take, there will be an unforeseeable reaction", and I think that's absolutely true. I have seen throughout my professional life that with all the reforms I have been involved in: you take two steps forward, but one step back. That is the way it is.