NDIS and Psychosocial Disability Quality and Safety Forum

TRANSCRIPT 6 of 10
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Learnings stemming from implementation of the WHO QualityRights Initiative

Forum held on 29 April 2021, 11:00AM – 12:00PM

TRANSCRIPT

HOST:

Yes, and welcome back to the NDIS and Psychosocial Disability Safety and Quality Forum. Our online audience numbers have been spiking as it's coming up to 9:30am in WA. So, a warm welcome to our WA audience. It's great to have you with us.

If you've also just joined us or joined us online, we've had a morning with the Welcome to Country Address, the Lived Experience Address, an Opening Address from Graeme Head NDIS Quality and Safeguards Commissioner and a keynote from Debra Hamilton Lived Experience Researcher.

It's time now for a video presentation we have from Dr Michelle Funk, who is the Unit Head of the World Health Organisation's Policy Law and Human Rights Team. But because of the time difference, she wasn't able to be with us via live video. And she sent us a video presentation instead.

The video is called Learning Stemming from The Implementation of the WHO QualityRights initiative, which we'll play in for you now. Here's Dr Funk.

DR MICHELLE FUNK:

Colleagues, ladies and gentlemen, I'd like to start by saying what a great honour it is to be here at this forum. And I'd like to take the opportunity to thank the organisers for inviting me to talk about the work that the World Health Organisation is doing to promote recovery and human rights in mental health, through its QualityRights initiative.

We know that mental health services in countries around the world are failing many people. Over the last several years, we've seen numerous publications and reports from countries, the UN, NGOs, and the media all highlighting that people with mental health conditions or psychosocial disabilities experience extensive and wide-ranging violations and discrimination.

We see in the healthcare context, people experienced violence, abuse, and neglect. People are also given disempowering messages by health services that take away their hope and dignity. For example, that they'll never be able to finish their education, their studies, that they're not capable of making decisions for themselves, that they should not have the hopes and goals that many people around them have because if they failed to achieve them, their condition will deteriorate.

In the community, people are actively discriminated against in education, in employment, in housing, and social services. And really importantly, we see how substitute decision making laws in many countries, severely restrict people from making decisions on all aspects of their lives. About their treatment, about how they should spend their money and where they should live, and so on. So, it's in this context, that the QualityRights initiative was created in order to push forward a recovery and human rights-based approach in mental health in countries everywhere.

QualityRights is working in several different areas. It's building capacity to combat stigma and discrimination and promote human rights and recovery. It's creating community-based services and supports that respect and promote human rights and a person centred recovery approach. It's engaging with people who have lived experience, and it's also supporting the strengthening of civil society. And finally, it's working with governments to reform policy and law in line with the CRPD, the Convention on the Rights of Persons with Disabilities, and other international human rights standards.

These are all interconnected areas which need to be addressed in order to provide a responsive mental health system and services that people want to use and find helpful. So, what I'd like to do now, is to go through each of these key areas in more detail describing the materials and tools that we've developed through this initiative, I'll then end by describing some examples of the country implementation work that has been carried out.

One of the key areas of the QualityRights initiative is to build the capacity of all stakeholder groups to promote human rights and recovery. If we're going to change the negative culture and practices that can exist in mental health, we need to build the capacity of all the different stakeholders to understand what it means to implement a human rights and recovery approach in the context of mental health. This includes capacity building for people with lived experience themselves, their families and friends, practitioners NGOs, and organisations of persons with disabilities.

As a first step to achieve this, we developed a package of face-to-face training materials in the area of mental health, human rights, and recovery. These modules are listed on this slide. There's a set of core modules on the left-hand side, and then specialised modules that go into more depth on the right hand side. The modules help firstly, to build capacity on rights and secondly, to develop the skills, to put these rights into practice.

This is the first time that we have a set of tools that show how the CRPD and other human rights standards can be practically implemented on the ground in mental health. The materials recognise that real change

requires more than an incremental increase in knowledge. It requires a fundamental shift in mentality.

The modules themselves have been developed in collaboration with more than a hundred national and international actors, including organisations for persons with disabilities, NGOs, people with lived experience, family and care partners, and mental health practitioners, policymakers, and academics.

All of the modules are interrelated and work in a systematic way to build knowledge, improve attitudes, and develop new skills to promote recovery and human rights oriented practices in mental health. And as I mentioned, all of the modules are grounded in the CRPD.

In order to reach the scale that we need to change societal norms, we have developed a really comprehensive e-training program on mental health, human rights, and recovery. And this compliments the face-to-face training materials that I described and in fact it builds - it borrows from the content of the face-to-face training materials.

And it's this e-training program and platform that is allowing us to reach, engage, and train many more people within a much shorter period of time without logistical problems and at a tiny fragment of the cost and would have been possible through face-to-face training. Through this e-training, we are able to really have the impact that we need to have. And so basically, whereas with face-to-face training, we may only be able to reach handfuls of the key stakeholders and countries, through this e-training, we really can reach thousands of people within and across countries.

As part of the initial evaluation of the e-training, we examined attitude and practice change for people completing the e-training and the findings have shown some highly significant positive shifts in people's attitudes, including around issues related to the need to enforce and coercion and treatment.

The rights of people to self-determination and legal capacity. In other words, to make decisions for themselves including treatment decisions. The need to provide people choice and information about treatment

options, not just proposed medication as a solution to everything. And also seclusion and restraint and the need to find alternatives to these practices.

These are all issues that are problematic in the mental health field and which QualityRights is trying to change using the CRPD Framework.

The second key area of work is to create community-based services that respect and promote human rights and a person centred recovery approach. To promote community living and inclusion, it is clear that countries need to put in place a full range of services that meet people's needs.

Services need to encourage people to make their own decisions about their treatment care and support. And the services also need to respect these choices that people make. They also need to provide a person centred holistic approach, addressing all important areas of a person's life, including relationships, work, family education, social protection, and housing, rather than having a narrow focus on symptom reduction.

Services also need to put in place strategies to end the use of coercive practices. As I've already mentioned, seclusion and restraint, and of course services that don't tolerate any form of physical, sexual, and emotional abuse. Through the QualityRights initiative, we're working to support countries to assess and transform their existing services using the QualityRights assessment, and transformation tools that we've developed. The WHO QualityRights Assessment Toolkit, for example, is being used extensively in countries. The toolkit outlines the Quality and Human Rights Standards to be achieved in mental health services, and also helps guide countries on how to measure the standards.

The standards of the toolkit are based on the CRPD and cover issues related to quality human rights and the recovery approach, including all the issues covered in the training materials that I mentioned earlier.

There is an accompanying Guidance Module on Improving and Transforming Services that we have developed to directly address the quality in human rights gaps identified as part of the QualityRights assessment process. Some of the issues we address in this Transformation Tool include changing the service culture and the power

dynamics within services, defining a shared vision for the service and working on the specific priorities as outlined during the assessment, and - as well as developing an action plan to address these using a collaborative approach involving not only staff, but also the people actually using the service.

As part of this area of work, we have also just finalised a Good Practice Guidance document, or series of documents on human rights oriented and CRPD complainant, human - community, mental health services, and supports, which will be launched on June 10.

Traditionally, by community-based mental health services, WHO has referred to outpatient clinics, mental health centres, residential homes, mental health inpatient units in general hospitals, mental health interventions delivered in primary care. But community based mental health services and supports need to be more than mental health services based or situated in the community. They need to provide care and support that people want to use and that they find helpful and that respects their dignity and rights. And traditional services don't necessarily do this.

Through this guidance, we are specifically showcasing services that do not use coercive practices, such as forced treatment, seclusion and restraint. Services that support people to make their own decisions about their treatment and care. And that respect the choices that people make. Services that promote participation, for example, engaging people with lived experience in the co-delivery of the service. And that train it's staff to be responsive to the feedback provided by people using the service in order to improve the care and support provided. And finally services that promote community inclusion by addressing all important areas of a person's life including relationships, work, family, and education. Again, rather than having a narrow focus on symptom reduction.

The WHO Guidance comprises a package of documents, including an overall document, which you can see on the left-hand side. This overall document provides concrete guidance and recommendations for setting up human rights oriented community services. This document introduces key human rights and recovery concepts that are critical to the area of mental health. It provides short, easy-to-digest descriptions of

rights based services selected from around the world. These services were selected based on an extensive search and the literature, Internet and through extensive consultation with WHO's partners and networks. It also discusses the important interface of mental health services with other sectors including housing employment and social protection sectors. And finally, it ends with a set of key recommendations for integrating rights based services into the health and social sectors. There are also seven accompanying technical packages where people can go if they want more detailed information on the services, showcased.

Each technical package encompasses a specific category of service that is required to implement a fully responsive, integrated and comprehensive mental health system. In other words, crisis services, community outreach, peer support, hospital based services, supportive living services, community mental health centres and also networks of services.

And it is in each of these technical packages that people can see the detailed level of information they may require to fully understand how each service is run and the interventions and strategies it has in place to fully respect and promote rights and recovery for its service users. Also at the end of each technical package we've mapped out practical action steps to go from idea of good practice service to a demonstration pilot of the service in order to facilitate - put in - theory into practice.

With this new Who Guidance, we want to inspire policymakers, healthcare planners, service providers and many other groups to develop and invest in new services that truly meet people's needs while at the same time, fully respecting their rights and effectively supporting them in their recovery journey.

The third area of the initiative is around capitalising on the enormous experience that comes from people's lived experience to drive change and supporting the development of a stronger civil society in order to give a voice to this experience.

People with lived experience can be key drivers of change and should be supported in this role. They need to be invited to sit at the table, to discuss policy, to discuss law, to provide their perspective, and to express how their lives are impacted. They should also be engaged to co-develop

services, to co-develop training and to be actively engaged in their delivery.

Through QualityRights, we make sure that civil society, we make sure that civil society actors and people with lived experience are involved in and inform everything that we do. And this is what gives QualityRights its unique strength. We also advocate for people's participation. People with lived experience in all actions taken at country level because all actions in mental health will fall short, if countries don't seriously and meaningful engage people with lived experience.

To date through the QualityRights initiative, we've developed several guidance documents to promote this engagement with civil society and to promote lived experience and the integration of lived experience into their whole infrastructure around mental health and service delivery.

We've developed so far two Peer Support Modules that provide guidance on setting up individualised peer support and also setting up peer support groups within the services and the community more generally. We've also developed two modules around setting up an operating civil society organisations led by people with lived experience and conducting effective advocacy campaigns to integrate human rights based approach in mental health and social sectors. As I said earlier, these materials alongside all the resources we've developed, have all benefited from the in-depth guidance and advice from people with lived experience and civil society organisations, in particular, the organisations of persons with disabilities.

So, now to the fourth area of work, which is around supporting countries to reform national mental health and related policies and laws in line with the CRPD and other international human rights standards. We have recently kick started the development of new guidance for countries on policy and law which will replace some of the old guidance that we developed on these issues which was formulated before the coming into the force of the CRPD.

A lot of work needs to be done provisions on involuntary admission and treatment need to be replaced with provisions that promote supported decision making and advanced directives. Laws need to include provisions to end seclusion restraint and other coercive practices and

policy and law need to explicitly promote community inclusion, participation and empowerment. Probably this is going to be the most challenging aspect of our work. And this is because it requires a fundamental change to the legal processes in place in countries at the moment, and indeed processes that have been in place for decades.

Although we don't yet have examples of any perfect laws in countries, some countries have recently developed legislation that is going in the right direction. So, for example, Spain, Peru, the Philippines, Georgia and India, have developed legislation recently that promotes the right to legal capacity and which specifically includes provisions around supportive decision making and advanced directives. And this is really positive. However, even these laws have their shortcomings and have a way to go before they are fully compliant with the international human rights standards.

Now a word about implementation of QualityRights. Country level implementation is starting to expand quite rapidly. We started with small pilot projects in different countries, many years ago. We then had the opportunity to carry out a comprehensive state-wide implementation of QualityRights in the state of Gujarat in India from 2014 to 2016. This was a hugely important project, which involved QualityRights assessments of services, the development of service transformation plans at each of the services, extensive training on human rights and recovery and the recruitment of peer support workers and services and creation of peer support groups of people with lived experience and family members.

And the analysis of these activities have shown excellent results and impact. And it's been published in the British Journal of Psychiatry in 2019. Staff in these services showed substantially improved attitudes towards people using services. Service users reported feeling significantly more empowered and satisfied with the services being offered. And we noticed important improvements in all the standards of the five themes assessed with the QualityRights assessment toolkit.

Now, we've moved on to a new phase of large-scale Countrywide implementation of quality rapes in 11 countries. These include from the African region Ghana and Kenya, Southeast Asia - Indonesia, we're just

getting some work going. We are doing some work in Lebanon. In Europe. Armenia, Bosnian and Hercegovina, the Czech – Checzia (as said), Estonia, Romania, Turkey. And I'm really pleased to say that more recently we've been approached by several high income countries, concerning the implementation of QualityRights. All these countries are putting in place multiple strategies and efforts to roll out the QualityRights e-training, face-to-face training capacity building as well - the QualityRights assessment and transformation work amongst other QualityRights actions in countries.

Here on this slide, I just wanted to highlight some of the achievements so far, but using the case of Ghana, particularly because they were the first to launch the QualityRights e-training nationally back in early 2019. So, they're the furthest along in terms of reaching out to their population. And we're really pleased to say that for the QualityRights e-training platform so far close to 18,000 people have registered on the platform. And 11,000 people have actually started the training course with over 9,000 who have completed the course and been awarded their certificate.

And this is really an important to achievement because it's not just one module in this course, it's really a 15 hour quite intensive course that people have completed. So, by the time they get to the end of the course, they really would have had to have understood all the concepts which I've highlighted in this presentation.

We're also hearing directly from users of the e-training themselves that they're finding the training rewarding and even life changing. And I've included some quotes that we've received directly from the platform users on this slide. So, we hear people saying, it's life-changing. They're extremely grateful for the World Health Organisation to provide it, the training. And you know, many people expressing that they regretful how that have been practicing in the past and how now, because of the training, they've completely transformed their way to approaching mental health with the service users that they come into contact with.

I would like to end my presentation now by saying that now more than ever, we have an enormous opportunity to build a better mental health support system that truly respects people's human rights. It's clear that

there is a recognition of the need to do so in Australia and elsewhere and as I hope to shown in this presentation, we have many excellent tools to make this a reality.

Thank you very much and i hope that we will be working together one day soon.