WORLD PSYCHIATRIC ASSOCIATION

QUALITYRIGHTS GUJARAT

A CASE STUDY OF ALTERNATIVES TO COERCION IN MENTAL HEALTH CARE

October 2020

This case study is part of a three-part series commissioned by the World Psychiatric Association (WPA) and the Royal Australian and New Zealand College of Psychiatry (RANZCP) to examine how alternatives to coercion have been implemented in a variety of mental health care settings.

In 2019, the WPA initiated the Program on Supporting Alternatives to Coercion in Mental Health Care together with the RANZCP, and appointed a Taskforce to lead the work. The project has commissioned a literature review and discussion paper as well as the series of case studies. A WPA position statement that recommends action to promote changes in practice builds on this work.

This case study series is designed to share experiences and promote understanding of existing efforts to generate change in settings operating under varying social, cultural, and economic conditions. It aims to encourage and support mental health professionals around the world to work with people with lived experience, service providers and other partners to put alternatives to coercion into practice. It should be noted that the WPA has neither implemented nor evaluated the work described in the pages that follow.

The case study series has been produced by Community Works, an organization that specialises in participatory approaches to implementing community mental health initiatives.

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This study describes work led by The Centre for Mental Health Law and Policy in Pune, India, which was enabled by dedicated support provided by Dr. Soumitra Pathare and team. The authors wish to acknowledge contributions by Dr. Pathare and Ms. Jasmine Kalha to this case study and express gratitude for their valuable insights.

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QualityRights Gujarat

1. Introduction

Overview of QualityRights Gujarat

- QualityRight Gujarat was implemented in the Indian state of Gujarat to tackle the lack of quality provision and human rights violations within mental health care
- The project ran for two years between June 2014 and November 2016 and was implemented in nine public mental health facilities (a third of the total) in Gujarat
- The QualityRights team was a collaboration between the Centre for Mental Health Law and Policy, Indian Law Society Pune, World Health Organization, Centre for Addiction and Mental Health Toronto and Schizophrenia Research Foundation India; and funded by Grand Challenges Canada

In just two years, QualityRights Gujarat led to a culture shift towards recovery-oriented care and a change in the way mental health services are delivered. The intervention led to structural changes at the state level and implementing facilities, changing the mindsets and behaviours across mental health services.

QualityRights Gujarat offer a set of lessons for how to get rights-oriented interventions legislated at state level, affect a culture change at implementing facilities and make change sustainable. Empowerment and ownership of the intervention across all stakeholders, from state officials and facility staff to caregivers and service users, was fundamental to achieving change.

This case study was completed through desk-based reviews and an expert interview. It presents a narrative exploration of how change was led.

Health care professional reading notes by service users on the "recovery tree"

2. Context

Gujarat is a state on the western coast of India with a population of 60.4 million.[1] In 2014, the year QualityRights was implemented, it had four government mental health hospitals and ten mental health wards in public general hospitals, serving approximately 280,000 individuals annually. The burden of mental health care falls largely on public health facilities with limited resources.

Gujarat was the first state in India to introduce a State Mental Health Policy in 2005/6, with 3% of its public healthcare budget allocated to mental health. The policy included a statement on protecting human rights and making services rights-oriented. To drive these changes, the state employed a Nodal Mental Health Officer, with a defined mental health mandate. Therefore, prior to QualityRights, efforts had already been made to improve the quality of mental health services in Gujarat.

However, existing mental health programmes were designed within a medical framework with little to no social interventions or community-based interactions. Health care providers typically make all treatment decisions, and those who use mental health services are seen as passive recipients of care, sometimes not even asked for consent in their treatment. Poor quality care and human rights violations are common in mental health services globally, including India. Prior to QualityRights, peer support workers had never been used in any mental health service in India.

The QualityRights intervention

QualityRights uses the World Health Organization's Quality Rights Tool Kit and capacity building tools to promote human rights and establish new standards of mental healthcare in low-resource settings. It is a framework to improve services considering local priorities, resources and needs.

Its core elements are:

- Improvements to mental health service delivery based on:
  - Right to an adequate standard of living
  - Right to enjoyment of the highest attainable standard of physical and mental health
  - Right to exercise legal capacity and to personal liberty and the security of person
  - Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse
  - Right to live independently and be included in the community
- Improvements in the service environment using existing available resources from facilities and government
- Training for health workers, service users and families on human rights and changes in attitudes and practices to move towards a recovery approach
- Building peer and family support groups delivered by non-specialists
- Introducing facility level policies and mechanisms to govern practices to protect against inhuman and degrading treatment, violence and abuse

1 Systematic Evaluation of the QualityRights programme in public mental health facilities in Gujarat, India, Pathare et al (2019), The British Journal of Psychiatry

3. Securing government buy-in

Securing Gujarat state's support to QualityRights was fundamental to achieving state-wide implementation of the intervention. It took the QualityRights team five years to secure state buy-in.

Fertile ground for implementation

The willingness of the Gujarat state to make mental health more quality-oriented provided fertile ground for implementation of QualityRights. The state had an existing mental health policy, a dedicated Nodal Mental Health Office and a willingness to reform mental health care. For these reasons, the QualityRights team selected Gujarat as the implementation site.

A participatory approach with government

The QualityRights team, led by Dr Soumitra Pathare, from the Centre for Mental Health Law and Policy, worked to develop a trusting relationship with the State Nodal Mental Health Officer, Dr Chauhan, over five years. Together they formed a shared vision of the reforms required to achieving rights-based mental health services. Dr Chauhan in turn, championed the intervention in government, organising the necessary state meetings and navigating the state bureaucracy. Pitches made to decision-makers within government were done jointly. Throughout QualityRights' implementation, state officials remained important stakeholders, via Advisory Team meetings, Management Committee meetings with the site-based leads and international conferences.

Being strategic about opportunities

Dr Pathare and Dr Chauhan were strategic about how they pitched QualityRights, identifying opportunities within government. They aligned the intervention to India's first National Mental Health Bill (now the Mental Health Care Act 2017), State Health Department and Quality Assurance department. In that way, they built the relevance of QualityRights from multiple angles, and it became an important contributor to achieving multiple state aims. Promoting the intervention as a quality improvement project was intentional to combat state apprehension to rights approaches in the health system.

4. Achieving changes on the ground

Stakeholders and roles

Delivery level

Facility staff	▪ Attend training on QualityRights ▪ Create and implement own facility improvement plan ▪ Identify and support peer support volunteers ▪ A subset of staff become master trainers who train other facilities on QualityRights
Service users	▪ Attend training on QualityRights ▪ Co-create and implement own recovery plan ▪ Attend peer support group ▪ Provide input for facilities' improvement plans ▪ Subset of service users become peer support volunteers
Families, caregivers and other stakeholders	▪ Attend training on QualityRights ▪ Attend caregiver support group meetings ▪ Provide input for facilities' improvement plans
Peer support volunteers	▪ Co-create service users' recovery plan ▪ Support service users' on their recovery journey ▪ Organise, develop and sustain peers support groups ▪ Advocate for service users at facilities and out of facilities ▪ Signpost to other community services

Management level and other stakeholders

Advisory Group	▪ Oversee project implementation ▪ Is made up of representatives from State Department of Health and Family Welfare, human rights advocates and mental health professionals
Management Group	▪ Manages project at delivery level ▪ Made up of heads of implementing mental health facilities, service users and family caregivers
Gujarat State Government	▪ Open up facilities to QualityRights ▪ Participates in the Advisory Group
Assessment team	▪ Evaluate the QualityRights services ▪ Made up of mental health professionals, service users and caregivers
Grand Challenges Canada	▪ Funds the intervention
QualityRights team	▪ Supported the implementation and management of the intervention ▪ Delivered QualityRights training to delivery stakeholders ▪ Made up of representatives from the Centre for Mental Health Law and Policy, Indian Law Society Pune, World Health Organization, Centre for Addiction and Mental Health Toronto and Schizophrenia Research Foundation India

QualityRights led to improvements in the quality of services and a culture change towards the non-medicalisation of mental health. The intervention empowered service users to become active participants in their own care. Family and peer support groups protected their rights, and they had a voice in facility changes. At facilities, staff ownership and buy-in for the intervention was emphasised. The QualityRights team equipped staff with the knowledge, skills and tools to enact changes at their facility.

A participatory approach to implementation: building staff buy-in

During QualityRights' implementation, the heads of the facilities were invited on a study tour to the Centre for Addiction and Mental Health in Canada. This enabled them to see first hand the benefits of peer support, removing some of their scepticism of its value. The heads of facilities formed a Management Group. The Management Group was responsible for managing QualityRights across facilities. Regular meetings enabled facility heads to drive the direction of implementation and secured senior staff buy-in.

Participation in the adaptation and delivery of QualityRights extended to staff in a range of positions and levels at each facility. While there are non-negotiable elements to its implementation, the QualityRights framework has been designed to leave a lot of space for contextualisation. Each facility developed their own improvement plans wholly customised to their context. A participatory approach meant each staff member had a voice in developing the plan. No one perspective was more important than the other. This democratic way of working was a unique experience in what was normally a hierarchical health system. The result was that all stakeholders felt the intervention belonged to them and had a shared interest in making it work.

Peer support group meeting

Peer Support Volunteer with the recovery plan

Building facility staff capacity to make changes through participatory training

> *The recovery training was enough for us to completely change our way of working*
> **Hetal Bhatti, nurse**

The QualityRights team equipped each facility with the knowledge, skills and tools to implement the changes they had identified. Training modules, with a corresponding set of tools and templates on the key concepts of recovery-oriented care and human rights were developed and adapted to be culturally appropriate per site. This included training on developing individualised recovery plans and in changing their facilities' operating policies, to promote sustainability of changes. The QualityRights team used a participatory approach to training, incorporating principles of adult learning. This opened the space for conversation across staff designations, further encouraging buy-in. Recognising the strengths everyone in the room brings was a fresh way of training for its participants. Alongside facility specific training, staff from different facilities were regularly brought together. This provided the opportunity to share learnings, information and experiences across sites. Overall, facility staff were able to develop new skills, knowledge and attitudes that enabled them to respect, protect and fulfil the rights of people using their services.

> *Earlier, I would get irritated at the sight of some of the patients here. I would make no effort to speak to them. I did what I had to do—give medicines and injections. Now things have changed, I listen and try to understand them and in doing so, make them feel heard.*
> **Ms. Nita Tank, nurse**

> *I believed mental health and human rights to be unrelated concepts… The training helped me to work through my biases. I have started believing that rights of persons with mental illness can be respected, protected and fulfilled with a little support*
> **Dr. Nazima Sheikh, medical officer**

Empowering service users through training on their rights

> *Making a plan for myself has led me to explore new areas and develop confidence in me.*
> **Ms. Sunita Bhatia, service user**

Service users were trained on their rights and the principles of recovery-oriented care. They were also guided to develop their own individualised recovery plans, which empowered service users to voice their preferences for treatment, care and support. For the first time, service users were being accepted as experts in their own lives. Control shifted from health provider to the service user, and the relationship from coercion to cooperation. The full participation of service users from the start inspired them to become active participants in their own care and treatment. They became advocates for change for themselves, their peers and at state level. Their personal stories had a strong influence on decision-makers at the State Department of Health and Family Welfare.

> *Numbers have power. Moving from a caregiver group to an advocacy group requires the help of more people to create a change in the government perspective about our rights*

Individualised Recovery Plan

Peer support workers, families and professionals help service users build their own recovery plan. The plan looks beyond medication and takes into account the service users' personal goals and meaning of wellness. Some of the questions the plan addresses include:

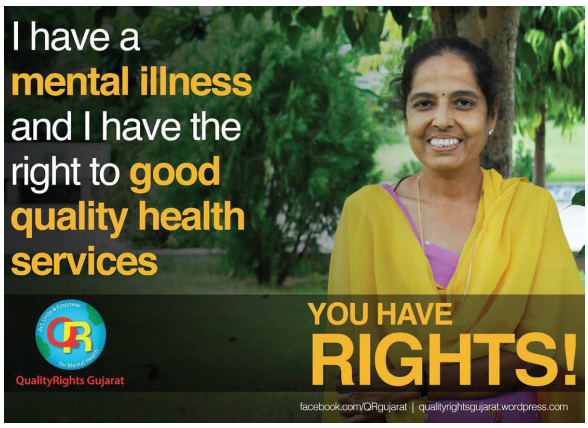
- What are my future goals?
- What triggers my distress?
- Who can support me during a difficult time?
- What can I do to keep myself well?

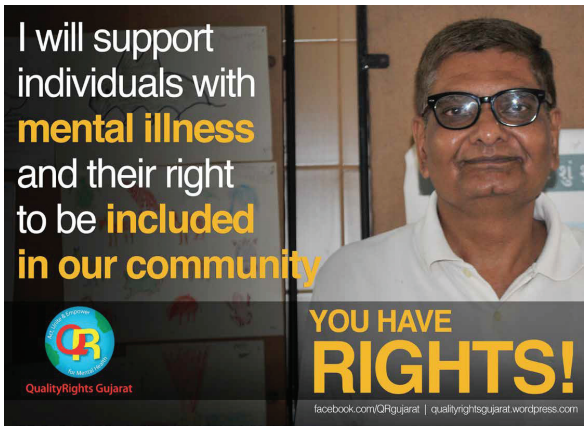
> *Thinking about my goals and dreams, and working towards achieving them has motivated me to work harder*
> **Service user**

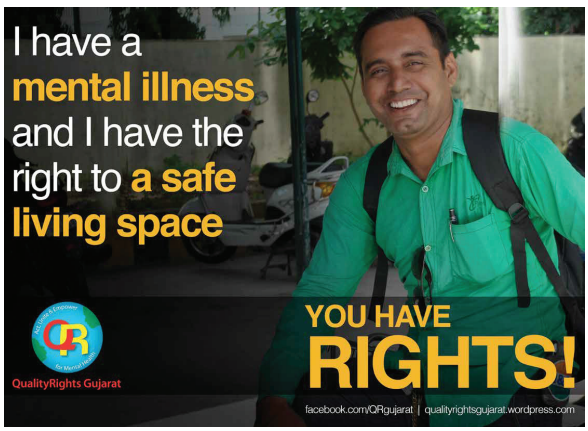
Forming family and peer support groups to safeguard service user rights

The QualityRights team built the capacity of caregivers and those with lived experience to form support groups. Peers supported service users with their individualised recovery plans and the support groups provided a safe space for service users. The support groups were instrumental to protecting the rights of service users within the facility and at home. They encouraged service users to speak up and take control of their own treatment. In addition, the support groups re-connected service users with their community and helped people feel more comfortable seeking support. Facility staff promoted the peer support groups, and were trained to identity and support individuals in the community who could take on the role. They were also consulted on facility improvements. Their suggestions and needs played an integral role in the planning and implementation of activities. Using peers to strengthen mental health care systems was a truly novel approach, and the first time it was done in India.

> *The Maitri group has motivated me to understand my right to stay in the community. Also I have become assertive to demand what I need as I consider it as a right to have it.*
> **Mr Nilesh, service user**







5. Outcomes

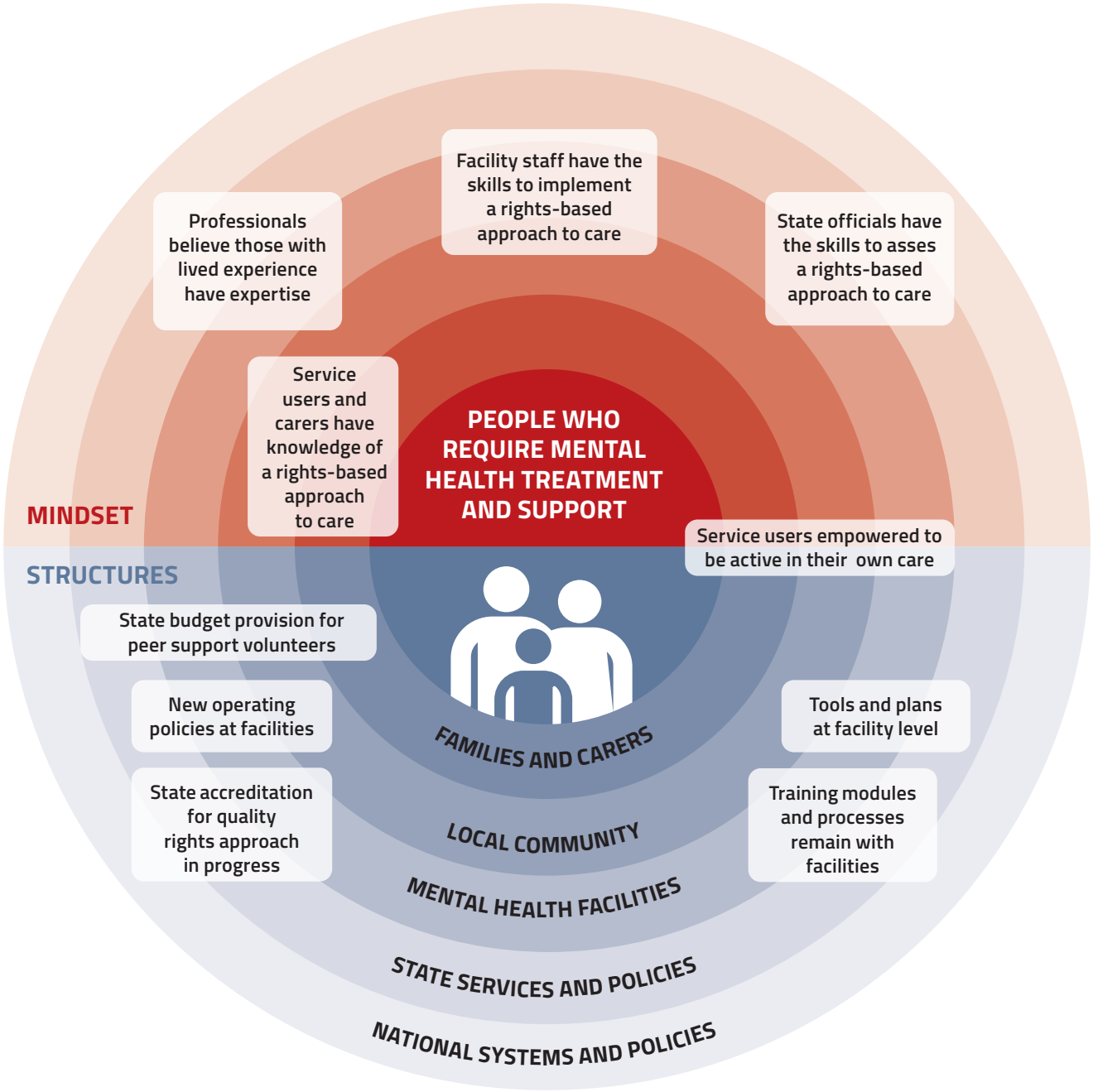
Significant improvements to quality of services in 12 months

> *Earlier, to control patients they used to either give sedatives or tie them up. Now we don't see that happening at hospitals*
> **Service user**

Evaluation results 12 months following a baseline show that QualityRights made statistically significant improvements to quality of services. These were most prominently seen in service users' standards of living, enjoyment of physical and mental health, their legal capacity and their freedom from torture or cruel, inhuman or degrading treatment. Compared to baseline scores and control sites, staff showed substantially improved attitudes towards service users. This included being more likely to see coercion as offensive behaviour and being less likely to see coercion as either protection or treatment. Service users reported feeling more empowered and satisfied with the services.
The evaluators noted that the overall changes achieved were substantial for such a low intensity intervention over a relatively short period.

> *When I visit the ward, I can observe a change in the attitudes of the staff nurses*
> **Ms Janaki Patel, peer support volunteer**

> *There is also a change in the way I think about patients. You know tying patients up, or putting them inside locked rooms is NOT ok... this has changed, ever since I first came to the hospital. How to listen to the patients, understand their needs and respond to their needs while maintaining boundaries is important...*
> **Bilkish Patni, nurse**



Changes to mindset and structures across QualityRights' stakeholders

Beyond improvements to the quality of services, the intervention resulted in structural changes at implementing facilities and the state level. The training modules, processes, tools and plans remain with facilities and operating policies have changed to reflect new practices. The state has budgeted for peers support volunteers across Gujarat state and an accreditation process for a quality rights approach to mental health services is in place. Mindsets of all stakeholders have shifted. Service users are empowered to be active in their own care and professionals at facility and state level believe those with lived experience have expertise. All these stakeholders have the skills and capacities to implement changes.

> *After attending the human rights training as part of the QualityRights project, I feel strongly about a need to create a feedback policy in our facility...I think this will help us to improve our services and our relationship with the patients.*
> **Mr Kartik Mistry, Mental Health Professional**

An intervention that can be delivered at scale

QualityRights Gujarat was implemented as a public health programme with potential for large-scale expansion and delivery. The World Health Organization's innovative framework for implementing Quality Rights was designed for low resource settings. Peer support groups are a cost effective means of accessible support for service users. The training delivered to service users, facility staff and its stakeholders used a master trainer model, where trainees went on to train others. In addition, the QualityRights team are working on a quality accreditation process based on the principles of the intervention, with the intention of rolling it out across facilities in Gujarat.

6. Challenges to sustainable change

Short term funding and facility staff turnover challenged QualityRights' sustainability. Implementing the intervention alongside community support would increase its impact.

Grant-based funding is short-term

QualityRights was funded by a donor agency, Grand Challenges Canada, for two years. While many gains were made, it was a challenge to effect sustainable systems change in a two year time frame. For QualityRights' activities to have continued after 2016, the Gujarat state needed to take over funding responsibility. This was a difficult ask given its resource constraints.

Despite this, the team made impressive gains in securing funding from the State Mental Health Authority for peer support volunteers and the support groups across Gujarat. At an international conference with policy makers and politicians, peer support volunteers spoke of their journey on a personal and community level. This was the first time decision makers heard from someone with lived experience. The QualityRights team felt this interaction facilitated peer support volunteer funding.

In addition, to promote sustainability, the team continue to work on a quality accreditation process based on the intervention for all mental health facilities within Gujarat.

Staff turnover

A government policy enabling staff to transfer easily across facilities means there is high staff turnover. Only 58% of staff enrolled at baseline were working at the same services and available for follow up 12 months later. However, the QualityRights team note that if the intervention was implemented across all facilities in the state, staff turnover would be less problematic. Equally, training modules and tools are left with facilities therefore new staff members could be onboarded to the intervention.

Implementing a broader range of interventions

Recovery is associated with access to other services such as education, housing and employment which are not always sufficient or available in the community. Supplementing clinical support with community based interventions better supports recovery.

7. Lessons learned

QualityRights Gujarat offer a set of lessons for how to get rights-oriented interventions legislated at state level, affect a culture change at implementing facilities and make change sustainable.

Legislating a rights-oriented intervention

Be strategic about when and how to gain government buy-in for an intervention. Align the intervention to as many government aims as possible. It takes time to convince state decision makers, and a participatory approach with government stakeholders helps.

Affecting culture change at facility level

Empower service users on their rights and build their and their caregivers' capacity to fight for them. Build ownership of the intervention across all stakeholders at the facility, and equip them with knowledge, skills and tools to enact change.

Making change sustainable

Supplement facility based support with community interventions to increase impact. Recognise the limitations of short-term grant support, and design the intervention with long-term implementation in mind. Continue to engage state decision makers throughout implementation to secure their continued support for the intervention. Amplify the voices of service users to advocate for their rights and sustained change.

8. References and further reading

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