THEMHS Lived Experience Leadership Award Submission – Part B

Additional Information: Our story

In 2014 the Victorian government told parliament that it wanted to improve the autonomy, protections, the health and the social outcomes for people who use mental health services. To realize this vision, the Mental Health Act 2014 was passed, promising a focus on recovery, Supported Decision Making and the minimisation of compulsory treatment.

In order to make this vision a reality, funding for our organization, the Independent Mental Health Advocacy (IMHA) service, was announced by the Department of Health and Human Services. Our role was to make sure the promise to consumers of a human rights-based mental health system was kept. This is reiterated in Victoria’s 10 Year Mental Health Plan, where IMHA is positioned to support the mental health system to become rights focused. The Minister for Health understood the significance of this work and the negative experiences consumers have experienced in services. In launching our service, he said it would help clinical services understand:

‘They [consumers] are not just case notes, but people and citizens, and their best chance to recover is if they are centrally involved.’

For many consumers this is not their experience of the mental health system. Speaking about her past experiences with involuntary treatment, consumer academic Cath Roper said that she “felt like garbage” after being forcibly taken to hospital by police. Highlighting the need for a broader advocacy service, Roper stated that she had been helped by an advocate during this time. To her, this experience was different because:

‘…[the advocate] believed in me, was in my corner and could look at me from a perspective that wasn’t just medical.’

Since August 2015, our advocates have been standing with consumers, taking their instructions, talking with them about their rights and choices, helping them to speak up and speaking on their behalf to treating teams. Our primary purpose is to ensure that consumers are supported to make and participate in all decisions about their assessment, treatment and recovery.
To do this we regularly visit every public mental health service in Victoria to advocate, promote human rights and support self-advocacy. We connect and coordinate with Victoria’s peak consumer body, the Victorian Mental Illness Awareness Council (VMIAC), to address systems issues. And we elevate the consumer voice in all conversations we have with external stakeholders and safeguarding bodies such as the Mental Health Complaints Commissioner.

Consumers are part of our work, and they are also part of our workforce. We employ a Senior Consumer Consultant to oversee and promote Consumer Leadership and two-thirds of our advocacy workforce identify as having a lived experience of mental health issues. Our Speaking from Experience consumer advisory group has become an integral part of IMHA and Victoria Legal Aid’s work. This can be seen in our What Consumers Want, Self-Advocacy & Information Project, the ILC NDIS Peer Self-Advocacy Project, which we will detail below.

We are confident that our work leads the way for lived experience leadership in mental health advocacy services.

1. Evidence of significant contribution to the field of mental health on a local, state or national level

Lived experience leadership is important to all levels of community, government and service coordination. It helps to co-create new value to services and communities by changing cultures, informing practice and redressing traditional power imbalances. It is also reflected at government levels, with consumer leadership part of Victoria’s 10-Year Mental Health Plan.

IMHA has been active in utilizing lived experience leadership and promoting it to the legal and mental health sector.

Our report co-produced with the Consumer Peak Body

In 2016 IMHA worked closely with the Victorian Mental Illness Awareness Council to co-produce the What consumers want report, detailing what consumers groups across Victoria want from our service. To do so, we took advice from 49 consumers across 6 consultations, focusing on young people and those who have experienced homelessness, who identify as being from an LGBTI or Culturally and Linguistically Diverse background.

We see our clients as leaders in their recovery & advocacy

At a State level IMHA worked with over 2000 consumers in 2017-2018, taking their instructions and promoting them as leaders in their own treatment decisions. We work closely with consumer consultants in clinical mental health services to support their leadership role and improve outcomes for consumers more generally. In addition to this, we continue to work with VMIAC to ensure consumers are central to the mental health system, not just as receiving treatment but co-producing services, delivering and evaluating them. Our Speaking From Experience advisory group informs our individual service development and systemic work, for example inputting into submissions.

We employ lived experience leaders

Within our service, we employ a Senior Consumer Consultant who represents and promotes consumer leadership in IMHA and Victoria Legal Aid more generally. We have taken on additional consumer consultants at various times and two-thirds of our workforce identifies as having a lived experience of mental health issues. More recently IMHA has led the development of a Consumer Leadership strategy for the Mental Health and Disability Advocacy (MHDA) program at Victoria Legal Aid which incorporates IMHA and the Mental Health and Disability Law service, promoting and embedding institutional frameworks to allow bottom-up (consumer feedback) and top-down mechanisms for lived experience leadership. Victoria Legal Aid more broadly has begun to discuss and implement consumer leadership strategies in a range of
services, including its pilot child protection non legal advocacy service. This demonstrates the impact of consumer leadership across our organisation. Please read more of this in appendix 3.

**We promote the consumer voice**

We take these lessons to the broader community, with our organization and employees taking these lessons and the consumer voice to various forums and research publications. For example, we ran a state-wide seminar on rights-based mental health care in Mental Health Week 2018. This session was attended by clinicians, who spoke encouragingly about supporting consumer rights after the session. Recently, our Senior Consumer Consultant was a keynote speaker at the Service Users Academy Symposium in New Zealand (2017). We also contributed to the development of a Supported Decision Making Policy Statement and training module for the Royal Australian and New Zealand College of Psychiatrists.

2. **Evidence of innovation and/or recognised best practice.**

The Mental Health and Disability Advocacy program understands that the future of our work is closely tied to leadership from people with lived experience. We take as axiomatic that consumers are leaders and experts in their own experience. From that starting point, our administrative procedures, methods of consultation, advocacy practice and our public promotion are shaped to reflect this expertise and breakdown barriers to good service.

**Our advocacy supports lived experience leadership**

Non-legal advocacy in mental health settings is contested. Contrary to best-interests practice, where practitioners make judgments and provide advice on a client’s instructions, representational advocacy works directly from a consumer’s instructions and expertise. We work

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from the perspective that consumers have the capacity to make their own decisions, and it is our responsibility to provide choices and amplify their voice. This is more closely aligned to Supported Decision Making as reflected in the *Mental Health Act 2014* and the *United Nations Convention on the Rights of People with a Disability*.

We have past IMHA consumers who have gone on to join IMHA’s Speaking From Experience advisory group, demonstrating that advocacy can contribute to people’s recovery journey and create opportunities for consumers to participate in system change.

**We use lived experience leadership in Speaking from Experience**

Established in 2016, our consumer advisory group, *Speaking from Experience*, provides consumer perspectives on mental health and mental health services. In doing so, Speaking From Experience provides IMHA and our Mental Health Legal Disability team, with advice on:

- Our service priorities
- How to improve consumer leadership within the organization
- How to support a consumer workforce
- Training and staff professional development
- Strategic advocacy issues, such as Victoria Legal Aid’s submission to the *Royal Commission into Mental Health, Terms of Reference*, and
- The development of a new non-legal service for parents and primary carers who are involved in the child-protection system at early stages, the *Independent Family Advocacy Service*. The service has a reference group like Speaking from Experience, and follows the same representational advocacy model endorsed by consumers

Please read more about the contributions Speaking from Experience have made by reading appendix 3.
3. Evidence of participation of mental health consumers in planning, implementation and evaluation

Consumers are at the heart of our service planning, implementation and evaluation. We do this through hiring the right people, power-sharing with consumers, and seeking continuous feedback to improve.

*We were founded on consumer views*

A non-legal advocacy service was fought for by the consumer movement prior to the introduction of the Mental Health Act. In planning the development of the IMHA service, consumer representation was ensured. IMHA’s Steering Committee prior to our development, and the Reference Group that followed for the first 18 months after establishment, both had more consumer representatives than any other stakeholder such as the Department of Health and Human services. This ensured that the program logic and evaluation frameworks placed consumer perspectives at the heart of our work. The program logic and evaluation framework were developed through co-production methodology.

SFE continues to ensure that the service’s ongoing development is informed by consumers.

*Our resources are co-produced*

In 2018, in response to feedback for more self-advocacy resources via the *What consumers want* report, IMHA initiated the [Self-Advocacy & Information Project](#). The goal of the project was to co-produce self-advocacy resources that support consumers to speak up and protect their rights. Along with the Consumer Information Working Group and Speaking From Experience providing guidance, our Senior Project Officer worked with 32 consumers across Victoria. True to coproduction principles, we ensured consumers were involved in the decision-making from the beginning (consumer views founded the project), we supported their capacity to participate (providing them information, support and time to reflect), and we addressed any power imbalances by making clear the decision-making processes and

*Figure 4* - we used co-production principles and user-experience/design-thinking methods to develop effective resources. Here we asked & mapped what steps consumers had to take if they disagreed with their diagnosis, what made it difficult, and what resources would help at that point.
opportunities for feedback. In our consultations with consumers we identified what issues mattered to consumers most, what were the difficult parts about self-advocacy and what self-advocacy resources would help.

From these instructions IMHA committed to co-producing:

- 6 fact sheets on the most important issues to consumers
- 7 videos on self-advocacy, such as a video helping consumers to speak up
- A wallet-card that provides advocacy information if someone later receives compulsory treatment, and
- An online web application that helps consumers make their own self-advocacy plans.

This is in addition to advance statement, nominated person, self-advocacy guides, self-advocacy stories and more resources that were made in conjunction with our Speaking From Experience and the Consumer Information Working Groups.

But we went further than just making resources. We asked consumers about the lived reality of the obstacles they might face in using these resources – how do you see yourself accessing these resources, and what will get in the way? Consumers noted mental health staff awareness of rights and resources, the layout of units and clinics, and our website. We are now working with services to plan how to make these resources as accessible as possible to consumers using their service.

**We are accountable to consumers – consumers evaluate our service**

IMHA was established for consumers, so it must be accountable to consumers. As such, we take feedback seriously and act on it. We have made ongoing changes based on feedback we received, and it has also informed capacity building activities. These include developing and delivering a Support Decision Making package to Mental Health services in Victoria, as most consumers inform us that it is the response of the system to them that has the most detrimental impact on their recovery. It’s also why we appointed RMIT Global Social to conduct a co-produced external evaluation.

The evaluation team comprised experts in mental health law, service delivery and consumer leadership, consulting with 69 consumers who had used IMHA, 40 consumers who were eligible for but hadn’t used IMHA, 9 stakeholder body representatives, and 292 mental health
professionals, 31 mental health lawyers and 16 IMHA staff. We will provide more on the outcome of this review under category 5.

4. Evidence of partnerships and linkages

IMHA works closely with consumers, consumer peak bodies and consumer leaders and promotes lived experience leadership to internal and external stakeholders.

*We work closely with consumer organizations and peak bodies*

Since its beginning, IMHA has worked closely with the Victorian Mental Illness Awareness Council. We see our responsibility as promoting the peak body voice as well as informing them as to what consumers in public mental health services are saying. Joint projects include *What consumers want* report, a *Disability Advocacy Futures* submission, and ILC NDIS Peer Self-Advocacy Project.

*We work with services to uphold and promote consumer rights*

While we are independent from public mental health services, we work closely with services towards aligned goals around consumer rights and recovery. Examples of this are meetings to discuss advocacy themes in specific mental health services, working together to make self-advocacy and IMHA information readily accessible in units and clinics, and making changes to policies and procedures to be more consistent with human rights. In addition to this, we work closely with consumer consultants and peer workers at all public mental health services. We make efforts to support the lived experience workers to promote consumer voices within services and provide them with the tools to support self-advocacy.

*We work in partnership with mental health system stakeholders and decision makers*

We work in partnership with other stakeholders and use this work to promote lived experience leadership and perspectives. Our work with mental health services uses a systemic advocacy approach to shift culture and practice towards Supported Decision Making and greater consumer autonomy. In meeting with other safeguarding bodies such as the Second Psychiatric Opinion Service, the Mental Health Complaints Commissioner and the Office of the Chief Psychiatrist, IMHA raises systemic themes identified by consumers who use our service. These include IMHA
providing feedback on consumer and human rights perspectives on the Mental Health Complaints Commissioner’s Sexual Safety report.

5. Verification of effectiveness – quality improvement activity, data collection, and its use

IMHA consistently reaches and exceeds its KPIs and delivers for consumers. How do we do it? Through a strong Programme Logic and Evaluation framework as well as client feedback.

In the first two years of service, IMHA provided over 11,492 instances of advocacy to consumers, as well as 20,695 sessions of coaching for self-advocacy. IMHA’s latest data shows that we continue to exceed DHHS benchmarks.

**Our external review data**

**Our external evaluation** makes clear that consumers value our service and say that we are performing well.

What did it find?

IMHA has proven very successful in a challenging context. It found:

- Consumers highly valued IMHA because we protect their rights and treat them with dignity and respect
- Consumers said that IMHA provided helpful information and linked them with helpful services
- Consumers viewed advocates as communicating effectively with their treating team when advocating

**IMHA Activities**

(supporting self-advocacy, talking to clinicians, making complaints, debriefing etc)

High intensity

8565 (+357% above KPI's)

Low intensity

17486 (+233%)

Total 26051
Professionals who worked with IMHA held it in high regard.

This mirrors IMHA’s client survey data which we have reported.

The following quote is from a consumer speaking to our evaluators.

‘IMHA has achieved an enormous amount in a limited time against very significant odds. There has been clamour for change in the mental health sector for 30 years, and while change is still very slow, IMHA have adopted a model which has proved effective and efficient at changing culture and practices for the better. Other players also need to play their part, and resourcing restraints limit all serious action, but IMHA is showing the sector that things can be done differently.

IMHA advocates role model best practice, and build relationships to enable effective advocacy. Consumers hold IMHA in the highest esteem, and even the people who are the subject of IMHA’s advocacy give them either high praise or grudging respect. Our evaluation strongly supports the expansion of IMHA so it can be accessible to all who need it, and the establishment of legislative support to enable it to get on with the job.’

Conclusion

IMHA has pioneered a non-legal advocacy service, meeting and exceeding expectations in a challenging environment. In the 3 years of our operation, we have built relationships with services, exceeded quantitative expectations, and most importantly, have been valued by consumers accessing our service.

We can only do this through consumer leadership. We employ consumer leaders. We embed it in our organization and culture. We promote it to other parts of Victoria Legal Aid and beyond.

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Dr Chris Maylea, Susan Alvarez-Vasquez, Matthew Dale, Dr Nicholas Hill, Brendan Johnson, Professor Jennifer Martin, Professor Stuart Thomas, Professor Penelope Weller, (2018, Unpublished) Evaluation of Independent Mental Health Advocacy Service, RMIT Social and Global Studies Centre.
We use consumer leadership to inform our model and resources. We connect and support with other consumer leaders and peak bodies. It’s a program for consumers that is accountable to consumers.

**Referees**

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Appendix

Appendix 1: Privileging the consumer voice model

Privileging the consumer voice

Service (Service Model, Advocacy role, Structures, Policies and Procedures):

- Inherent in IMHA service model – the work we all do is to voice the consumer’s views and preferences.
- Utilising all staff skills, knowledge and experiences to provide the most responsive service we can to consumers.
- Utilising staff with a consumer perspective to assist all staff with engagement and advocacy with consumers, as well as service design and delivery.
- Utilising all staff skills to strategically advocate for individual consumer outcomes, system and cultural changes.
- Role modelling what we espouse within the service and outside the service: privileging the consumer perspective and utilising all perspectives.
- Working with Speaking From Experience (SFE) (consumer advisory group), consumer expertise used to improve the service, informing service changes including design and delivery and coproducing new resources.

Mechanisms

- Co-produced resources and evaluation, i.e. external consumer consultant/s integral to mechanisms to undertake our work.
- Co-produced IMHA professional development sessions, e.g. consumer perspective and clinical perspective.
- Establishing and maintain an environment where all staff feel comfortable sharing their perspectives and overt consumer perspectives (IMHA values), as well safe spaces to reflect on how we are interacting with each other.
- Asking for the consumer perspective – individual work, service activities.
- IMHA staff skill bank – this is an internal online resource which lists each worker’s skills or experiences. This can include training or studies that they have done, their lived experience of mental health or other identities, as well as personal qualities that can assist the team.
- Speaking from Experience
- Client evaluation mechanisms
- Assessing our work from the following frameworks: Recovery orientated practice, Human Rights, trauma informed
- Open service – seeking input from outside the service, i.e. consumer led organisations
- Formal supervision that is trauma-informed, reflective and respects the autonomy of workers. Group supervision that privileges the consumer voice. Informal support between peers who have lived experience.
- Policies and procedures to guide our work

Diagram
Appendix 2: IMHA External Evaluation, Summary of Findings

The IMHA Model

To maintain consumers’ rights using a supported decision-making approach the IMHA model delivers instruction based advocacy. Without statutory powers to ensure access, IMHA relies on a relational approach, meaning advocates engage with services and staff to ensure access to and the support of advocacy. This model is informed by the principles of self-determination and recovery and is designed to improve a consumers’ ability to self-advocate. While remaining focused on individual advocacy, IMHA also engages in community education and sector reform advocacy.

Representational advocacy means advocates represent the person’s preferences and wishes as expressed by them. They will not make an assessment as to whether a person’s instructions might be influenced by mental illness. They advocate irrespective of whether other people, including the advocate, clinicians, carers or family members agree with a particular preference. This is in opposition to the ‘best-interests’ model commonly adopted in mental health services, in which the professional takes responsibility for determining and acting in the best interests of the consumer. To do this, IMHA uses a supported decision-making approach, where people make their own decisions but are provided with support to do so. The supported decision-making paradigm is consistent with a representational approach and the Convention on the Rights of Persons with Disabilities, and its application in the best-interests substituted decision-making framework of contemporary compulsory mental treatment is the source of many of the tensions and barriers identified during the evaluation.

The IMHA model is recovery-oriented and incorporates empowerment principles to improve individual consumer’s ability to self-advocate. IMHA is proving successful in building this capacity, however consumers were clear that individual advocacy may still be necessary for the future, particularly if they were in crisis or where self-advocacy had failed. IMHA has developed a self-advocacy toolkit and resources, which at the time of writing are being reviewed prior to implementation. The evaluation identified opportunities for providing support to family, friends and carers to act as advocates for people who use mental health services.

A third part of the IMHA model is its relational aspect. This requires advocates to develop relationships with consumers to enable supported decision-making, and with clinicians to ensure access and opportunities for advocacy. This model was necessary for effective advocacy as the power to make treatment decisions lies with the treating team. Participants identified that this
was largely successful, with advocates generally maintaining good relationships while advocating strongly for consumers. This was limited by the time advocates could spend building these relationships. IMHA was poorly perceived by mental health professionals when advocates did not have good relationships with services and staff. The adversarial approach adopted by some advocates was reported to work well for individual consumers but resulted in strained relationships that were seen as having a negative impact on individual outcomes and future advocacy opportunities.

**IMHA’s Performance**

The **overall findings from the evaluation are overwhelmingly positive**. All participant groups gave positive feedback. The areas for further development that were identified related to systemic issues that were beyond IMHA’s control, such as the identification of new opportunities for increased effectiveness, resource constraints and the newness of the service. The evaluation identified that IMHA was being implemented as intended, and is consistent with the establishing documentation, policies and procedures, program theory and logic model. IMHA is **reaching a broadly representative population**, although it has focused on inpatient settings and is **not easily accessible in the community**. IMHA is exceeding key performance indicators by 357% for high-intensity contacts and 233% for low-intensity contacts.

![Service delivery against key performance indicators](image)

*Figure 1 – IMHA Service Delivery KPIs Aug 2015 to Aug 2018*

IMHA staff demonstrated consistency with IMHA’s values of integrity, respect, person-centred, curiosity and reflectiveness. The central tenet of IMHA’s service – rights based representational advocacy – was consistently portrayed by advocates and valued by consumers. IMHA advocates supported consumers in a range of areas, primarily around discharge, and participation in
decisions around treatment and care. IMHA also provided information and referral to other services, most often legal services, SPOS and the MHCC.

Consumers highly valued IMHA. Consumers appreciated having an advocate present irrespective of whether they were able to achieve the desired outcomes. Mental health professionals who had interacted with IMHA held it in high regard, whereas those who had not had contact (particularly those in the community) held neutral views. The issues regarding IMHA that were raised by mental health professionals largely related to a misunderstanding of the model and occasional examples of IMHA advocates not adhering to the model.

Appendix 3: Consumer Leadership & Engagement Strategy Stage 2 (Introduction & 1 Year Achievements)

Consumer Leadership and Engagement Strategy (CL&ES) MHDA Achievements

March 2018 –March 2019

Year One Achievements

The first Consumer Leadership and Engagement Strategy has been reviewed and the achievements against the listed goals and objectives are:

Goal 1 - Raise awareness of what consumer leadership is and how it can lead to improvement of consumer experiences and outcomes.

Tasks completed include:

- A presentation to Victoria Legal Aid’s (VLA) Senior Executive Team (SET) by Indigo Daya (Consumer portfolio holder at DHHS) and Wanda Bennetts (Senior Consumer Consultant) in February 2017.
- An assessment of organisational readiness through the completion of a desk top audit regarding what Consumer Leadership looks like currently at VLA.
- An attitudinal organisational readiness survey was completed by managers across Victoria Legal Aid and the results will be used to inform the organisations’ Client Service Strategy.
- Awareness raising of the Senior Consumer Consultant role and Speaking from Experience (SFE) Group.
- Development of SFE profile, vision and key messages.
- A Communication strategy.
To date, SFE has provided input into organisational initiatives including:

- The [Child Protection Legal Aid Service Review](#), leading to 36 recommendations. One implemented recommendation was the development of an Early Intervention Unit featuring non-legal advocates. The resulting [Independent Family Advocacy Service](#) (IFAS) follows the same representational advocacy model as IMHA, and is supported by the IFAS reference group, with people who have lived experience of the child-protection system.

- The development of a campaign and communications plan regarding the Supreme Court decision on ECT, and the implications for practice in mental health services.

- IMHA’s external evaluation facilitated by RMIT.

- The Senior Consumer Consultant presenting at the Family Law team planning day to promote consumer leadership and lived experience perspectives.

- Input into mental health modules that train all Victoria Legal Aid staff.

SFE has also inputted into the Professional Legal Education Mental Health module which is accessible to all VLA lawyers. The Senior Consumer Consultant meets with all new IMHA and MHDL staff. A student placement that concluded in 2018, worked with SFE to led a project on Access to IMHA Advocacy.

**Goal 2 - Build foundations for meaningful and sustainable consumer leadership: Capacity Building, Innovation and sustainability.**

Tasks completed include:

- Payment guidelines for consumers to be remunerated for their casual work with IMHA. This has been shared with other VLA areas and external stakeholders.

- An policy for consumers to sit on interview panels for recruitment to IMHA and MHDL roles. - Consumers have sat on interview panels for every new IMHA staff member since its establishment and began sitting on panels for MHDL staff in November 2017.

- The development of a casual consumer workforce (CWF) through the establishment of SFE.

- Orientation for new Speaking from Experience members.

- Media training for Speaking from Experience members.
• A Speaking from Experience planning day and report that identifies areas to progress for SFE.
• The creation of a database of interested consumers - opportunities and information is forwarded to people on the database periodically.
• Strategic external relationships between the Senior Consumer Consultant and other consumer workers in similar level roles from the Mental Health Complaints Commissioner, Mental Health Tribunal, Department of Health and Human Services, and the Victorian Mental Illness Awareness Council.

Goal 3 - Starting to embed consumer leadership at Mental Health and Disability Legal team (MHDL) & IMHA: Consolidation

Contribution to systemic reform has occurred through:

• Input into the MHDL ECT campaign (as noted above).
• Regular meetings between Senior Consumer Consultant and IMHA and MHDL program managers.
• A presentation and workshop by Senior Consumer Consultant at the Victoria Legal Aid Civil Justice Program off-site day (a day devoted to reflective practice and professional development) which provided an opportunity for each of the programs within Civil Justice to begin their thinking and planning around what CL will look like for them.”
Appendix 4: Examples of our co-produced self-advocacy resources

We coproduced the below resources through the Self-Advocacy & Information Project:

- **Self-Advocacy Model**
  Tips and steps to self-advocacy.
  Available in video.

- **Self-Advocacy Plan**
  A workbook to make a self-advocacy plan.

- **Self-Advocacy Stories**
  Examples of self-advocacy.

- **I want more say in my treatment**
  Your rights and options to have more say. To be available in video.

- **I want to make a complaint**
  Your rights and options to make a complaint.
  To be available in video.

- **Nomination Person Guides & Templates**
  Available in Auslan video.

- **I want to feel safe while I am receiving treatment**
  Your rights and options to feel more safe. To be available in video.

- **I want leave temporary from hospital**
  Your rights if you need to negotiate leave. To be available in video.

- **Advance Statement Guides & Templates**
  Available in Auslan video.

- **I want to change my treating team**
  Available in video.

- **I don’t want compulsory treatment**
  Available in video.

- **Our online web app**
  An online app that helps you step through self-advocacy. Being finalised.

- **Wallet-card**
  A wallet-card with the basic information on IMHA and self-advocacy.