



The

Reason

Why

We're

Here

 **UnitingCare**

Re Gen

**"If it wasn't for
people like us,
you wouldn't be
here."**

– Consumer Consultant –

The

Reason

Why

We're

Here

ReGen's Model
for Consumer Participation

UnitingCare ReGen is located on the traditional lands of the Wurundjeri people of the Kulin nations and wishes to acknowledge them as the Traditional Owners. ReGen pays its respects to their Elders, past and present.

The Reason Why We're Here
ReGen's Model for Consumer Participation

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This section gives a broad overview of what Consumer Participation is and why it's important in an alcohol and other drugs (AOD) service. It also outlines what, and whom, this report is for. This section will be of interest to you if you want to clarify exactly what Consumer Participation is and how it works.

WHO IS A CONSUMER?

A consumer is someone who uses AOD services. It can also include their family or significant others. (For a more detailed explanation, see page 11.)

WHAT IS CONSUMER PARTICIPATION?

Consumer Participation is the involvement of consumers in decision making about their own treatment, as well as decision making about the way the services they use operate. The aim is to enable consumers to have a greater voice in directing the agencies that provide treatment services. This could mean anything from adding a comment to a suggestion box, to helping design a new treatment program, to sitting on the board of an AOD service. (For more examples, see page 20.) Ensuring that consumers are aware of their rights is the starting point for participation.

'Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community.' (Victorian Department of Health, 2011, p 2)

WHY IS IT IMPORTANT?

Consumer Participation in AOD treatment services is essential because it seeks to ensure that the services are relevant, safe, welcoming and satisfactory to the people who use them. By involving consumers in the planning, care and treatment delivered, services can enter into a partnership with consumers, avoiding a 'top-down' approach.

ReGen believes that:

- Consumers have a basic human right to be involved in the decisions regarding their AOD treatment.
- Meaningful participation of consumers is necessary for AOD agencies to deliver the best service possible.
- Both consumers and service providers benefit from the participation process.

There is a growing research base documenting the benefits of Consumer Participation – both to the consumer and the agencies involved. Anglicare (2010) found that consumer involvement in organisations led to: improved retention in treatment; higher levels of client satisfaction; reduced client contact with the criminal justice system; and, increased progression to education, training and employment. Australian Injecting and Illicit Drug Users League (AIVL) (2011) reported that Consumer Participation led to gains in self-confidence and empowerment for the consumer.

'What is the value of engaging patients and families in improving safe care? Both research and practice show that engagement leads to safer patient care by improving the outcomes of care, improving the experience of care for individual patients, improving the work experience for caregivers, and – by helping the organisation change its processes – improving the outcomes for all patients.' (National Patient Safety Centre, 2014, p 4)

WHY IS IT IMPORTANT THAT IT'S MEANINGFUL?

To implement Consumer Participation practices, ReGen believes that AOD treatment agencies need a commitment to meaningful participation. This means actively seeking, listening to and responding to consumer input. It also means ensuring that foundations are in place for the process to be sustainable, and that its importance is communicated to everyone involved: consumers, staff, board members, funding bodies and other stakeholders. If the approach is ad-hoc or tokenistic, it's likely to be frustrating and disempowering for consumers and of little genuine use to the agency.

In the publication *Doing it With Us Not for Us* (2011), the Department of Health outlined nine principles for participation in mental health services. These are also effective guiding principles for participation in the AOD sector: Trust (which must be mutual between the agency/worker and consumer), Respect, Openness, Equal opportunity, Advocacy, Responsiveness, Shared ownership, Dissemination, Evaluation.

'Involving clients in services is not something to be undertaken lightly or hastily or simply because a policy directive demands it. It requires the building of relationships and trust.' (Association of Participating Service Users (Clarke and Brindle, 2010, p 17)

WHAT ARE SOME COMMON BARRIERS?

Whilst many AOD treatment services already use some level of Consumer Participation (e.g. complaint processes or feedback forms), increasing the level of involvement is not a simple or quick process. There are many common barriers that can arise:

- Attitudes of service providers (e.g. 'us and them' approach, power imbalances, perception that consumers aren't interested or capable)
- Attitudes of consumers (e.g. 'us and them' approach, belief that input won't be taken seriously, belief that raising concerns may negatively affect treatment, belief that they have nothing valuable to offer)
- Lack of training (for both consumers and staff)
- Lack of resources and planning (e.g. lack of clarity about tasks and purpose, funding, time allocated, leadership groups, policies and procedures, ongoing support, ineffective integration of Consumer Participation mechanisms within formal service planning)
- Concerns about confidentiality and privacy (both the consumer and the agency)

(Clarke and Brindle, 2010; AIVL, 2008, Victorian Department of Health, 2011)

It's useful for agencies and consumers to be aware of these barriers, but ReGen has found that these aren't insurmountable if proper consideration and planning is applied. This report details how we've gone about the process.

ABOUT THIS REPORT

This report outlines ReGen's journey towards implementing meaningful Consumer Participation across our services. It attempts to explain our approach, challenges and successes, and what we've learnt along the way.

This report is for consumers at ReGen, staff at ReGen and staff from other agencies. We hope that it will be useful in clarifying processes for consumers and staff at ReGen, as well as providing some guidance in the form of learned experience to staff from other agencies who are interested in implementing or improving Consumer Participation processes.

Agencies should also consult other guides and literature, as listed in the 'Future Directions' section on page 46.

ABOUT REGEN

UnitingCare ReGen is the leading AOD treatment and education agency of UnitingCare Victoria and Tasmania. We are a not-for-profit agency and have over 40 years' experience delivering a comprehensive range of AOD services to the community.

**"Consumer
Participation
gives you a sense
of purpose."**

– Consumer Consultant –

TWO

WHAT DO ALL THE TERMS MEAN?

The language used to describe different roles in the field of Consumer Participation can be confusing. Different sectors can use different words to mean different things. This section explains what each term means here at ReGen, and how we'll use the terms in this report.

TERMS AT REGEN

CONSUMER – Someone who uses AOD services (either at ReGen or elsewhere) or has used them in the past. This includes family and significant others, regardless of whether they use the services themselves. It can also include people who are refused services or refuse services. (Homeground, 2008)

The word 'consumer' can also refer to people who use mental health or primary health services but in this report, we are referring to the AOD sector.

CLIENT – Someone who is currently using ReGen's AOD services. The term is sometimes used instead of 'consumer' or 'service user'.

SERVICE-USER – Someone who is currently using ReGen's AOD services. The term is sometimes used instead of 'client'.

CONSUMER PARTICIPANT – Someone who participates in activities at ReGen, beyond their own treatment. Examples include giving presentations or contributing to project working groups. Most Consumer Participants complete two-day training. All are reimbursed sitting fees and contribute on a ad-hoc basis.

CONSUMER CONSULTANT – Someone who participates in activities at ReGen, beyond their own treatment. They undertake the same activities as Consumer Participants, but also have six-weekly meetings, have a rotating position on staff leadership groups and greater connections to other parts of the agency. All Consumer Consultants have completed two-day training, are reimbursed for their time (at the same rate as Consumer Participants) and contribute on a more committed, regular basis than Consumer Participants.

PEER LEAD – Some Consumer Consultants also work as volunteer Peer Leads. This role entails facilitating the weekly ReGen Peer Support Group, developed by the Peer Leads with the support of the Self Help Addiction Resource Centre (SHARC) and ReGen's Consumer Participation Facilitator. The Peer Leads attend regular supervision and once-off training provided by SHARC. Peer work is separate from Consumer Participation and is not covered in detail in this report.



USEFUL ABBREVIATIONS FOR CONSUMERS TO KNOW

AIVL

Australian Injecting & Illicit Drug Users League

LGBTQI

Lesbian, Gay, Bisexual, Transgender, Queer, Intersex

AOD

Alcohol & Other Drugs

NRW

Non Residential Withdrawal

APSU

Association of Participating Service Users

NSP

Needle & Syringe Program

CALD

Culturally & Linguistically Diverse

PD

Position Description

CFWG

Client Feedback Working Group

QIP

Quality Innovation Performance

CPS

Child Protection Service

SHARC

Self Help Addiction Resource Centre

CRC

Care & Recovery Coordination

SMT

Senior Management Team

DHHS

Department of Health & Human Services

SUPWG

Service User Participation Working Group

E&T

Education & Training (Department at ReGen)

VAADA

Victorian Alcohol & Drug Association

HRV

Harm Reduction Victoria

VAHS

Victorian Aboriginal Health Service

**"Everything you
try is a learning
curve."**

– Consumer Consultant –

THREE

REGEN'S JOURNEY OF CONSUMER PARTICIPATION

TIMELINE

This timeline gives a broad overview of ReGen's journey of Consumer Participation from 2007 – 2016. This section may be of interest to you if you're curious about how an AOD agency can increase their level of Consumer Participation.

PRIOR TO 2007

- ReGen used a complaints system, client satisfaction surveys and a suggestion box to gather feedback from consumers. We undertook several small-scale projects to increase our level of Consumer Participation. Whilst many of these were positive experiences for consumers and staff, they had little lasting impact on operations at the agency. There were still no budgeted funds, staffing or leadership groups allocated to Consumer Participation.

2007

- A Quality Innovation Performance (QIP) review of ReGen highlighted the importance of a comprehensive, consistent and integrated process for client participation, to ensure ReGen's high quality services continued to address client and other stakeholder needs.
- ReGen staff set up the Client Feedback Working Group (CFWG) to review and increase client involvement.
- CFWG reviewed existing feedback documents, benchmarking against the Victorian Charter of Human Rights and Responsibilities and consulting with clients and staff. They updated the feedback forms and complaints process.
- CFWG decided that a Client Charter would best describe our partnership ideals with clients. The ideals articulated in the original Client Charter included: ease of access to services; information for personal decision making; receiving adequate feedback on progress; respect and dignity; and attention to need.
- APSU encouraged ReGen to present at conferences and requested our Charter and feedback mechanisms be shared with the Department of Human Services. They also requested that we allow APSU to use these as an example with other agencies.

2008

- A two-month trial of the new processes was conducted in all service areas at ReGen, except the Port Phillip Prison program. Data was gathered and changes were made to the forms before implementing the final version across the agency.

2007 – 2013

- APSU consulted with ReGen on an informal basis, advising on Consumer Participation, the setting up of new projects and attending staff meetings.

2011

- An audit was conducted of ReGen's practices in relation to client participation, cultural diversity and family inclusiveness. The audit was in response to a QIP report from ReGen's 2010 reaccreditation, which identified a number of recommendations.

2012

- In response to the above audit, ReGen re-developed the Client Feedback Working Group, re-naming it the Service User Participation Working Group (SUPWG).

2012 – 2013

- SUPWG undertook the following activities:
 - ⦿ Developed a Consumer Participation Resources folder on the staff intranet.
 - ⦿ Reviewed the Client Charter. (See Appendix A.)
 - ⦿ Developed stronger informal relationships with key organisations that work with or represent consumers such as APSU, Harm Reduction Victoria, NEAMI, Victorian Alcohol and Drug Association (VAADA).
 - ⦿ Researched potential models of Consumer Participation and the organisational characteristics that support them.

2013

- SUPWG developed a detailed proposal for development and implementation of a Consumer Participation Facilitator role within the agency, detailing the proposed model, goals, task and actions, reporting lines and required investment.
- The ReGen Board of Governance agreed to the required investment, allocating funds for the new position in the budget.
- In May, the new Consumer Participation Facilitator commenced employment at ReGen.

2014

- Consumer Participation and the Consumer Participation Facilitator role was embedded into the North & West Metro AOD Service, which is a partnership between ReGen and Odyssey House Victoria, to deliver AOD treatment in the north and west catchments.

2013 – 2016

- Under the leadership of the Consumer Participation Facilitator, the following initiatives were formed and developed:
 - ⊙ Baseline audit of Consumer Participation activities
 - ⊙ Consumer Participation Policy & Consumer Code of Conduct
 - ⊙ Consumer Consultants Participation two-day training for consumers (three times per year)
 - ⊙ Consumer Consultant Meeting Group (Consumers Consultants)
 - ⊙ Consumer Participation Leadership Group (staff and Consumer Consultant)
 - ⊙ Peer support group
 - ⊙ ReGen Consumer Database
 - ⊙ Consumer presentations at ReGen group programs, staff meetings, innovation seminars and other events
 - ⊙ Consumer Participation in project working groups (e.g. smoking care) and new project development (e.g. Youth Catalyst Program)
 - ⊙ Consumer Consultant office space
 - ⊙ Training for consumers to participate in recruitment of staff
 - ⊙ Consumer feedback to Board meetings
 - ⊙ NW Metro AOD Services Client Satisfaction Snapshot Survey undertaken in reception areas
 - ⊙ For more examples, see 'Successes so Far' on page 40.

2016

- A secondary audit compared current Consumer Participation activities with baseline audit.
- In March, a QIP review of ReGen found that our Consumer Participation processes not only met but exceeded Standard 2.4 within Section 2 of the review: 'Confirming Consumer Rights'. An 'exceeded' rating is difficult to attain and requires leading practice to be demonstrated as well as rigorous documentation. The accreditation report noted that:

'ReGen has a strong commitment to Consumer Participation, with a comprehensive range of initiatives and approaches recognising the role of consumers in service improvement, as well as their rights to quality services and to have a say.' (QIP Accreditation Report, 2016 p 34)



FOUR

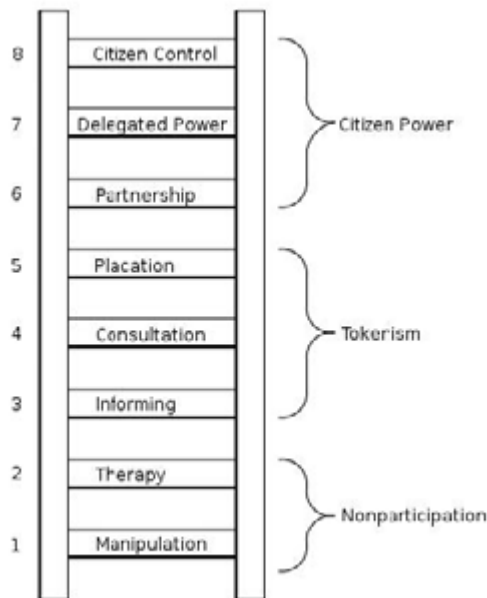
'THE LADDER' AS A STARTING POINT

This section briefly explores some theory behind Consumer Participation, by looking at a model known as 'The Ladder'. We explain what it is, how it relates to the AOD sector, and some of the problems with it. Read this section if you'd like to know more about the theory behind ReGen's own model.

THE 'LADDER OF CITIZEN PARTICIPATION'

A popular model for measuring Consumer Participation in any process is the Ladder of Citizen Participation. The Ladder was originally created by Sherry Arnstein in 1969 to describe how power was blocked from marginalised communities in America and to clearly articulate the different levels of citizen participation that were possible. In the decades that followed, the Ladder was much debated and several theorists attempted to redesign it; however, it still formed a basis for discussion about citizen participation in many areas of public life, including healthcare.

Arnstein's original Ladder looked like this:



(Sourced from Arnstein, 1969)

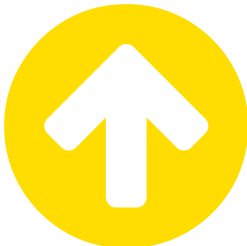
Figure 1: The Ladder of Citizen Participation

ADAPTING THE LADDER FOR THE AOD SECTOR

Since the development of Arnstein’s ladder, numerous community organisations and other services have adapted the ladder to describe processes of Consumer Participation.

In 2010, Clarke and Brindle from APSU adapted the Ladder specifically for the AOD Sector. They noted that:

“all levels of participation are necessary and valid” (p 24).

LEVEL OF POWER	LEVEL	DESCRIPTION	ACTIVITIES
HIGH	Control	All decisions are made by consumers and consumers have control of resources.	<ul style="list-style-type: none">● Consumer run organisations● Self-help groups
MEDIUM	Partnership	Consumers and providers are joint decision makers.	<ul style="list-style-type: none">● Peer workers, educators, trainers● Staff selection panels● Steering committees
LOW 	Consultation	Consumers are presented with a plan or directive designed by the service provider and invited to give feedback. Control lies firmly with service providers.	<ul style="list-style-type: none">● Suggestion boxes● Surveys● Focus groups● Service user groups
	Information	This is not Consumer Participation but it increases power, enables service users to make decisions about their own treatment and supports Consumer Participation.	<ul style="list-style-type: none">● Information to service users about services and treatment options● Charter of Rights● Complaints systems● Consumer Participation policies

(Sourced from Brindle and Clarke, 2010)

ReGen estimates that we are currently operating at a ‘medium’ level, although some activities we undertake would be classed as ‘high’ or ‘low’.

LIMITATIONS OF 'THE LADDER'

Whilst the Ladder is very useful for articulating and gauging levels of Consumer Participation in an agency or activity, ReGen has found that Arnstein's model and its adaptations can oversimplify the real process. A more nuanced model is needed, with greater focus on processes, systems, relationships and the differing degrees to which consumers may want to contribute or be able to sustain.

In creating our own, practice-based model, we wanted to address the following factors in an accurate, updated model of Consumer Participation for the AOD Sector. Many of these ideas are explored in more detail in Tritter and McCallum's 2006 essay, *The Snakes and Ladders of User Involvement: Moving Beyond Arnstein*.

- 01. Higher levels of consumer power don't always equal better services.** It's not appropriate for all treatment agencies to aim to be consumer-controlled. The real key is that whatever level an agency is operating at, that they are doing it well.
- 02. It's not all about power but also about systems.** Systems and processes need to be in place to support consumers gaining a greater voice within an agency. Changes have to integrate effectively into the current system so that they can be successful and sustainable. Some examples of systems and processes are: clear decision-making processes, training, mentoring, policies and procedures, staff education, working groups.
- 03. Interconnectedness is key.** In order to ensure sustainability, maximise effectiveness and minimise tokenism, consumer working groups need to be connected to other decision-making groups within the agency and to have clear lines of communication between them.
- 04. Different types of knowledge work together.** ReGen believes that a combination of lived experience and professional experience is essential in providing AOD treatment services.
- 05. We can achieve more as partners than we can as competitors.** ReGen clinicians aim to create a treatment partnership with clients, in order to reach the best possible outcomes for that person. At other levels of the agency, staff members and consumers work together, contributing different types of knowledge. If the focus is purely on power, as the Ladder suggests, some of the benefits of collaborating can be lost.
- 06. Not all consumers want to/are able to be involved in organisational decision making.** The model needs to incorporate different levels of individual desire and capacity to be involved. Some consumers will not be interested in contributing beyond their own treatment; some will not have the capacity to be involved at times of personal change, whilst others may find their availability for participation is reduced as they pursue work, education, family commitments and other interests.
- 07. The ladder fails to consider the direct experience of culturally diverse groups.** This includes lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) people, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) people, people with a disability, young people and women-specific groups.

**"I am an
expert in my
experience."**

– Consumer Consultant –

FIVE

REGEN'S CURRENT PRACTICE

This section describes ReGen's current practice of Consumer Participation and how it works within the agency. Elements of this model may change over time, as we continue to respond to feedback and improve our practices. This section is for consumers and staff at ReGen who want a clear understanding of how Consumer Participation works here, but also for staff and consumers from other agencies who want to implement Consumer Participation practices.

CONSUMER PARTICIPATION FACILITATOR

Central to ReGen's Consumer Participation model is our Consumer Participation Facilitator. This is a full-time staff position, which started in 2013 as a .8 EFT and became full-time in September 2014. The role is essentially to promote, encourage, facilitate, coordinate and advocate for meaningful Consumer Participation within ReGen. This is achieved via the recruitment of consumers for participation activities providing training, mentoring and support.

The commencement of the role meant Consumer Participation practices could move forward in a coordinated manner, more quickly and on a larger scale. As one of our team leaders commented:

'The creation of the role has been the most important enabler of Consumer Participation at ReGen. Until that happened, we'd had lots of good will (and examples of good practice), but not the capacity to pull it all together, or maintain momentum. Until it was someone's key responsibility, the rest of us lacked the capacity to keep pushing things along, on top of our existing responsibilities. We needed someone to champion it.'

Before ReGen employed a Consumer Participation Facilitator, the SUPWG investigated several different models of Consumer Participation to decide which type would best fit our agency. They decided on the 'Facilitation and Coordination Model'.

'ReGen employs a very experienced person in the Consumer Participation Facilitator role and they have established a comprehensive program of consumer participation training... It is clear that participants of these sessions are engaged, reflective of their own treatment experiences and keen to share with others... Having consumers who are well trained and supported can have benefits for themselves, other service users and service providers alike.' (Program Manager, VAADA)

FACILITATION AND COORDINATION MODEL (...AND WHY WE CHOSE IT)

The Facilitation and Coordination model focuses on building an agency's capacity through and for Consumer Participation. This means that the Consumer Participation Facilitator needs to work with both consumers and staff.

This model encourages the support and mentoring of a number of Consumers from different services within the agency. Whilst other models engage one person to represent all consumers, ReGen felt that engaging a network of people enabled a broader spectrum of consumer views to be included in the planning of our services. It also removed the onus of one person needing to represent everyone and attend the wide variety of forums that require consumer input.

By focussing on capacity building within the agency, the Consumer Participation Facilitator Position can also address issues of change management, workforce culture and staff attitudes to Consumer Participation.

A BIT MORE ABOUT THE CONSUMER PARTICIPATION FACILITATOR ROLE

As you can see from the above, the Consumer Participation Facilitator is not a clinical role. Although there are therapeutic elements of the role, they primarily take a community and workforce development approach. Unlike clinical staff, whose chief concern is 'how is the client's treatment progressing?', the Consumer Participation Facilitator's chief concern is 'how is the client experiencing their treatment and contributing to the development of services?'.

Although this role could be delivered effectively by a person with many different skillsets, ReGen chose to employ someone who had lived experience, a thorough knowledge of the AOD and mental health sectors, experience of advocacy and strong connections to other agencies. In terms of personal qualities, we needed someone who could effectively communicate with both consumers and staff, was flexible, ethical and passionate about Consumer Participation.

THE REGEN MODEL

Informed by the literature, including the Ladder, as well as the experience of our Consumer Participation Facilitator, clinicians and consumers, ReGen created a model to represent how Consumer Participation works within our agency.

REGEN'S MODEL FOR CONSUMER PARTICIPATION

	INVOLVEMENT	UNDERTAKEN BY	ACTIVITIES UNDERTAKEN	SUPPORTED BY
CONSUMERS	All Consumers	People engaged with ReGen services - Current Treatment	<ul style="list-style-type: none"> - Contribute to decision making about own treatment in partnership with their worker - Provide feedback on own experience of ReGen services - Rate ReGen's performance in upholding principles of Client Charter - Make formal complaints - Provide suggestions for quality improvement 	<ul style="list-style-type: none"> - Rights & Responsibilities within Client Charter - Complaints process - ReGen clinical policies - Consumer feedback process
PARTICIPANTS	Some Consumers	Consumer Participants: - Current Treatment - Post Treatment	As for 'All Consumers', plus: <ul style="list-style-type: none"> - Contribute to service planning & review processes - Contribute to development of ReGen publications, including strategic plan, website etc. - Contribute to external quality reviews - Public advocacy - Support program delivery & evaluation - Support development & delivery of education & training programs 	As for 'All Consumers', plus: <ul style="list-style-type: none"> - Consumer Participation Policy & Code of Conduct - Consumer Participation training
CONSULTANTS	Few Consumers	Consumer Consultants & Peer Leaders - Post Treatment	As for 'Some Consumers', plus: <ul style="list-style-type: none"> - Membership of Consumer Consultant Meeting Group - Rotating membership of the Consumer Participation Leadership Group - Other groups & sub-committees - Rotating membership of the Clinical Governance Committee - Interview panel members for new Consumer Consultants & staff - Consumer led research & evaluation projects - Leadership of Peer Support Group - General staff meetings 	As for 'Some Consumers' plus: <ul style="list-style-type: none"> - Training (AOD & First Aid competencies; Group Facilitation, Mental Health) - Supervision by CP Facilitator (individual) & SHARC (group) - Supported pathways to employment - Consumer Participation office space

TYPES OF CONSUMER PARTICIPATION AT REGEN

Consumers at ReGen can participate at many levels. Our Client Charter outlines the basic rights and responsibilities that all clients at ReGen can expect. You can read the full Client Charter at the back of this report on Appendix A.

AT THE FOUNDATION

As a foundation, ReGen believes that all clients should have the opportunity to work in partnership with their clinician throughout their treatment. We also have the commitment to consistently seek, listen to and respond to feedback from people who use our services.

ReGen's Client Charter states that all people using our services have the right to:

- Be involved in decisions about all aspects of their treatment
- Ask a support person to be involved in discussions about their treatment
- Make an informed decision as to whether they take part in any recommended treatment
- Receive feedback about their progress throughout treatment
- Have access to any written records about their treatment through ReGen's processes

(ReGen Client Charter, 2008)

Complaints Process

ReGen considers complaints as an optimum method of ensuring that the services delivered are helpful, not harmful. This is why ReGen has connected this process with the Client Charter. With this in mind, ReGen aims to provide information to its clients regarding complaints at the beginning of treatment and at other points during their treatment episode. If needed, the Consumer Participation Facilitator can help a service user wishing to undertake a complaint.

OTHER CONSUMER PARTICIPATION ACTIVITIES

Consumer Participants

Some consumers want to be more involved in Consumer Participation at ReGen. People have different reasons for this; they may want to affect change at an organisational level, to learn new skills, to 'give something back' or simply to try something new. There are many ways consumers can contribute beyond their own treatment.

People who are interested in trying some of these activities can go on the ReGen Consumer Database. Regular emails are sent that include news about upcoming opportunities at ReGen and in the Victorian AOD and Mental Health Sectors. All people undertaking Consumer Participation activities must complete 2 days of Consumer Participation training.

Consumers can participate as much or as little as they would like, taking into account that the availability of activities can vary. All roles are flexible and work around people's lives.

Participation activities can include:

CONTRIBUTIONS TO ORGANISATIONAL DECISION MAKING	PREPARING & GIVING PRESENTATIONS	PARTICIPATING IN EDUCATION & TRAINING (E&T)	OTHER TASKS
<ul style="list-style-type: none">● Contributing to program planning meetings● Contributing to policy development● Participating on staff recruitment panels● Participating in working groups (e.g. smoking care)● Participating in quality accreditation (e.g. QIP)	<ul style="list-style-type: none">● Presenting in all-staff meetings or other ReGen events● Presenting at external forums and events● Presenting in treatment programs (e.g. Catalyst or Torque)● Presentations at info nights and pre-planning nights for treatment programs	<ul style="list-style-type: none">● Receiving training at ReGen● Training or activities at other organisations (e.g. APSU)● Contributing to ReGen's E&T content● Evaluation of ReGen's E&T services● Validation of assessments	<ul style="list-style-type: none">● Contact with media (following briefing with staff. Consumers are supported throughout and are encouraged to opt out at any stage)● Administering waiting room surveys● Providing material for websites● Providing material for newsletters● Other activities

Consumer Consultants

A small percentage of consumers wish to become even more involved in Consumer Participation at ReGen. After completing the two-day training and participating in activities, some people choose to apply to be a Consumer Consultant. Consumer Consultants form the Consumer Consultant Meeting Group (see page 29).

ReGen currently has 16 Consumer Consultants in the meeting group, including a family member. We expect this number to fluctuate as new people join and others move on.

Becoming a Consumer Consultant

Becoming a Consumer Consultant entails a greater commitment than general Consumer Participation activities. Consumer Consultants attend six-weekly meetings and are frequently engaged with higher-level participation activities in various departments (e.g. ongoing contributions to working groups, contributing to decisions about policy, etc.). Potential Consumer Consultants are interviewed by the Consumer Participation Facilitator and a current Consumer Consultant before they are approved to be a part of Consumer Consultant Meeting Group.

Prior to the interview, the applicant will be sent a list of talking points to prepare, as well as the **criteria for the Consumer Consultant role**:

01. A past or present user of ReGen services
02. Demonstrated understanding of the issues experienced by consumers of AOD services
03. Demonstrated oral communication, including the ability to participate in a group
04. Demonstrated ability in meeting preparation including the reading of documents
05. Ability to collaborate with staff and other Consumers from backgrounds that may differ from your own
06. Some ability in Microsoft Office programs or the willingness to learn

Consumer Consultant Meeting Group

Consumer Consultants from the Consumer Consultant Meeting Group meet six-weekly to discuss Consumer Participation initiatives. This meeting group reviews new policy documents, and individual members update the group on working and leadership group activities undertaken.

The Consumer Consultant Meeting Group lists its purposes as:

- To provide a forum for Consumer Consultants at UnitingCare ReGen
- For this forum to evolve with organisational change and with the needs of the individuals taking part
- To enable an opportunity to discuss any challenges or achievements that may arise as part of the Consumer Participation work
- As an opportunity for communicating new ideas and suggestions around Consumer Participation at ReGen
- To assist with facilitating the advancement and sustainability of Consumer Participation practice at ReGen
- To comment on policy and procedure pertaining to Consumer Participation.

(Terms of Reference for Consumer Consultant Meeting Group, ReGen, 2016)

As well as promoting Consumer Participation practices within ReGen, the group is also a forum for members to expand and share their individual knowledge and experience. Consultants report their activities back to the group, giving everyone a broader perspective of the agency. Several current members are highly experienced in Consumer Participation, both at ReGen and elsewhere, and sit on community councils at other agencies. These members contribute to the group an understanding of process and policy, which is essential when working within an organisation. Many Consumer Consultants also become members of APSU.

'For me, I love being able to have a voice, so that was something that really attracted me to wanting to become a Consumer Consultant.' (Consumer Consultant, ReGen)

KEY DECISION-MAKING GROUPS

Some decisions at ReGen require sign-off by several different groups. These are the key groups involved in decision-making about Consumer Participation at ReGen:

CONSUMER CONSULTANT MEETING GROUP is made up of Consumer Consultants and the Consumer Participation Facilitator. The group meets six-weekly. Recommendations generated in this meeting are communicated to the Consumer Participation Leadership Group. Requests are then forwarded to Clinical Governance, who make a recommendation to Senior Management Team.

CONSUMER PARTICIPATION LEADERSHIP GROUP is comprised of 8 – 10 member that include managers and staff from a variety of departments at ReGen, the Consumer Participation Facilitator and one Consumer Consultant (rotating position). The group meets monthly. Their chief concern is supporting Consumer Participation at ReGen. They review reports from the Consumer Consultant Meeting Group and generate ideas for improving Consumer Participation practices at ReGen, forwarding ideas to Clinical Governance who then make a recommendation to SMT.

SENIOR MANAGEMENT TEAM (SMT) includes ReGen's Chief Executive Officer (CEO), Chief Financial Officer (CFO), the two Program Directors and three (rotating) managers. This team meets fortnightly. All high-level decisions at ReGen need to be approved by SMT. SMT will seek the opinion of Clinical Governance on all clinical matters and forward any recommendations which require significant funding (outside the budget, or new treatment types) to the Board.

CLINICAL GOVERNANCE is made up of 14 senior clinical staff, managers and directors at ReGen and the Consumer Participation Facilitator (in the future, we plan to implement a rotating position for a Consumer Consultant). The group meets monthly. The purpose of Clinical Governance is to ensure that ReGen's treatment services and care are of the highest quality possible. All high-level decisions regarding Consumer Participation need to be approved here. Clinical Governance reports to the Board every six months on a range of issues including Consumer Participation.

BOARD OF GOVERNANCE (THE BOARD) ReGen is transitioning to a new central board under a single Uniting agency. The role of Consumer Participation is yet to be determined.

INTERCONNECTEDNESS OF GROUPS

ReGen believes that the interconnectedness of decision-making groups is vital in an effective Consumer Participation process. This means that groups of consumers, staff, management and the Board have clear lines of communication and report to one another. Without this, feedback, ideas, requests, complaints, queries and discussions within consumer groups would remain largely unheard by the agency.

Figure 2 shows the interconnectedness of the Consumer Consultant Meeting Group, the Consumer Participation Leadership Group, Clinical Governance and SMT. The first three groups are joined by their communication and reporting, but also by the membership of the Consumer Participation Facilitator (a rotating Consumer Consultant also attends the Consumer Participation Leadership Group and will, in future, attend Clinical Governance). SMT is linked through membership and reporting processes to Clinical Governance.

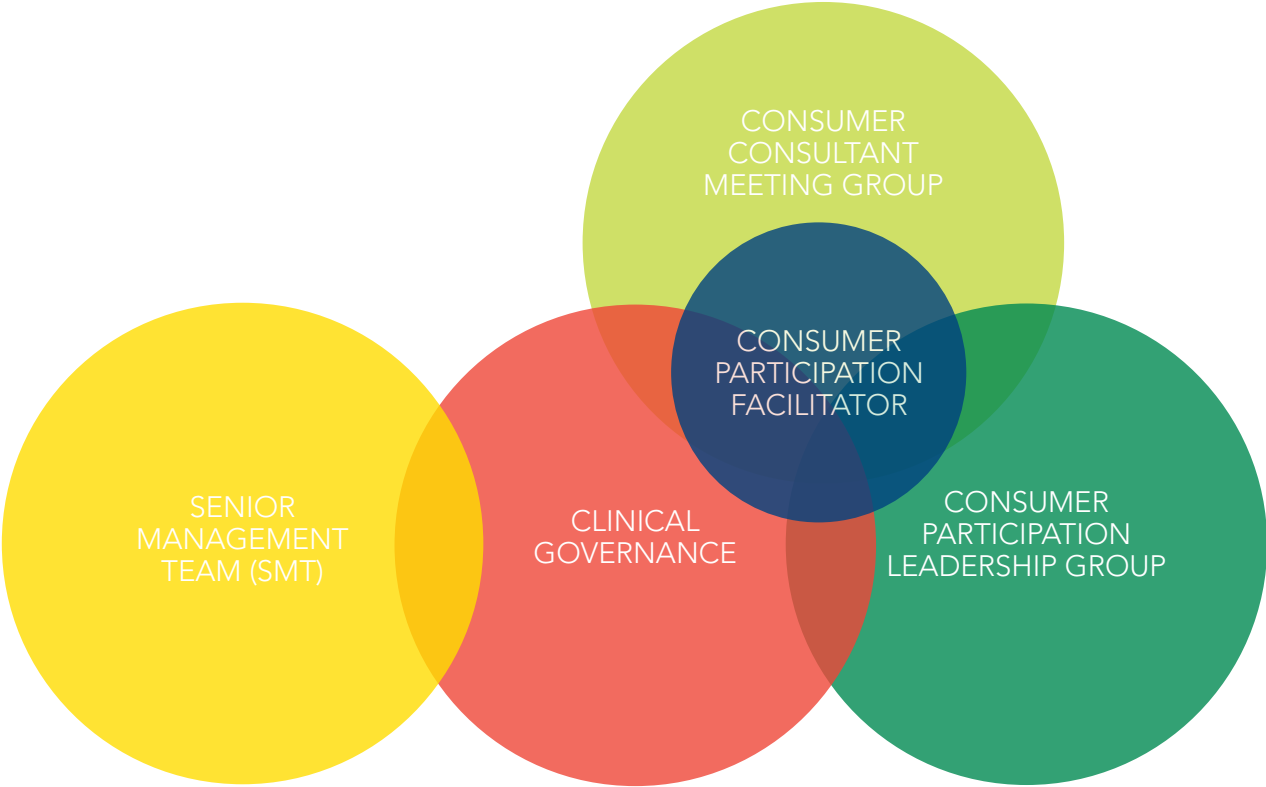


Figure 2: Interconnection of groups at ReGen

The Board does not include current staff members and does not currently include consumers. However, regular reports are made by Clinical Governance, SMT and, on occasion, Consumer Consultants themselves. Figure 3 represents the intercommunication of decision-making groups at ReGen.

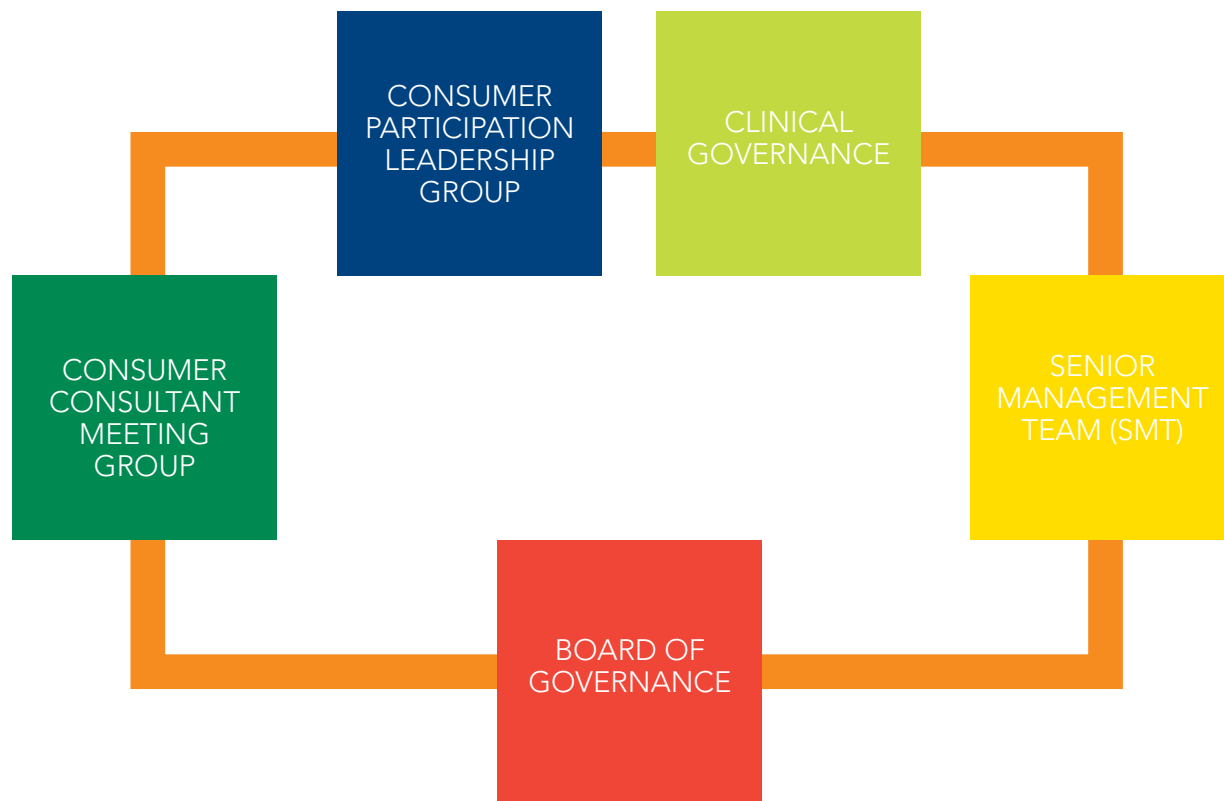


Figure 3: Communication between decision-making groups at ReGen

DECISION-MAKING PROCESSES

As some decisions at ReGen require sign-off by several different groups, the process can seem confusing. The following chart describes the decision-making processes at ReGen:

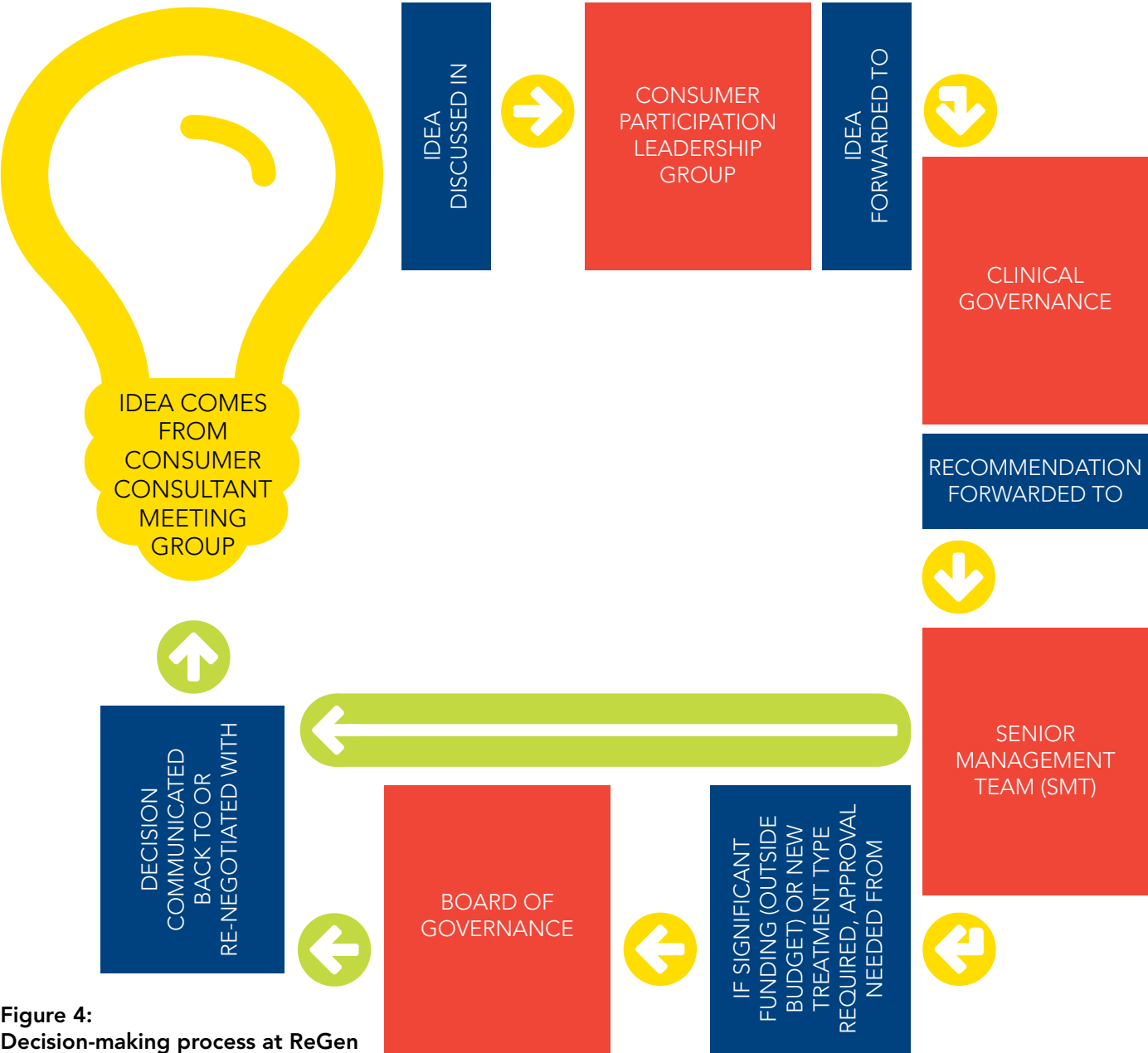


Figure 4:
Decision-making process at ReGen

This section explores what ReGen has learned through the experience of implementing and improving our Consumer Participation processes. It includes key messages, successes, challenges and ongoing questions about how to get things right. There's also a list of tips for new consumers and staff who work with consumers. This is the largest section in the report – with information for consumers, ReGen staff and staff from elsewhere – so choose which parts are most relevant to you.

KEY THEMES

In May 2016, ReGen and APSU hosted an innovation seminar for the AOD sector, titled 'Encouraging Innovation in Consumer Participation Practice'. The seminar featured presentations from consumers, service providers and researchers from: Centre for Social Research in Health at the University of NSW, APSU, ReGen, NEAMI, and Living Positive Victoria.

These are the key themes that emerged from this seminar:

- **Consumer Participation must be recognised as core business** – It is grounded in basic human rights and should be the foundation for clinical practice: you can't provide quality services without it.
- **The stakes are very high** – The consequences of poor practice by service providers can be profound. A negative initial experience with treatment services can contribute to immediate harm to vulnerable individuals and families and create long-term barriers to future engagement.
- **Information is power** – Ensuring that consumers are aware of their rights is the starting point for participation.
- **Trust is key** – If consumers don't have trust that a service will listen (and respond) to their feedback, they are unlikely to engage in participation opportunities. Consumers will respond when they see service providers demonstrating their commitment to participative practice.
- **Stigma is a major obstacle** – The impacts of stigma have an ongoing impact in consumers' willingness to engage with treatment services and participation opportunities. Stigmatising attitudes and practice by service providers need to be named and challenged whenever and wherever they occur.
- **Consumer Participation requires organisational change** – Service providers need to be ready to be challenged by their consumers in order to improve the effectiveness of their services. This is likely to require changes to staff attitudes and practice, organisational systems (including performance reporting) and culture.

AOD service systems are supposed to serve people affected by AOD use, not set up merely to serve the systems themselves.

- **Service providers need to consider staff and management capacity** – It is a mistake for service providers to assume that they are able to engage in effective Consumer Participation practice. A key enabler of change is capacity building for staff and management.
- **Consumer Participation needs to occur across all levels of an organisation** – service providers need to demonstrate the role that consumers play in decision making within their organisations, including at a high level. Consumers' experience of participation should commence with their first contact with a service and continue throughout their use of services.
- **A systemic approach is required** – It takes time to build successful Consumer Participation systems. Preparation is required, along with ongoing review and redevelopment of organisational approaches. Training is necessary for staff, management and consumers.
- **Consumer Participation requires resources to be sustainable** – treatment providers (and funders) need to allocate resources within service models for staffing, payment for consumers' time, training etc. Without adequate resources, Consumer Participation systems will not be sustainable.
- **Consumer Participation provides great return on investment** – It improves service quality, improves practice and helps demonstrate improved treatment outcomes. It supports longer-term recovery and creates capacity for consumer-led advocacy for change.

(ReGen newsletter #AOD16)

BENEFITS TO THE AGENCY

The literature about Consumer Participation documents many benefits to agencies, such as greater cooperation between consumers and service providers and improved job satisfaction for staff (Clarke & Brindle, 2010). Here are some benefits of Consumer Participation that ReGen experiences directly:

It improves our service. First and foremost, Consumer Participation allows us to receive direct feedback and input from the people who use our service. This ensures that all of our services and practices are safe, beneficial and welcoming to the people who use them. We want to provide the best possible quality of care to our clients, and Consumer Participation is an essential element of this.

It allows for ongoing program modification. Similarly to the above point, it enables our services to improve over time, remaining relevant and useful. ReGen's non-residential rehabilitation programs, Catalyst and Torque, have changed significantly since their inceptions (in 2008 and 2013). This is due to an action-based research approach, consisting of gathering of written and verbal feedback from consumers in regular focus groups and feedback forms. Changes have included re-structuring of the timetable to allow parents of young children to attend more easily, and the addition of yoga classes to the recreational element of the program, as many respondents requested a gentler alternative to the gym.

It offers us a different type of knowledge. Consumers have an expertise developed from their experience of service use. Lived experience is valuable because it allows an agency to see things from the Consumer' perspective, making sure that services (on an individual level as well as a policy level) are designed appropriately and delivered sensitively.

ReGen believes that a combination of lived experience and professional knowledge is ideal in service and policy development.

'Without Consumer input, AOD workers are trying our hardest to assist people based on government guidelines and our own ethics/skills – sometimes this is not enough.' (Care and Recovery Support Worker, ReGen)

It lends validity to what we do. When consumers choose to be involved with ReGen after their treatment, it is reassuring to current clients and other stakeholders that our services are trustworthy and valuable. Catalyst and Torque clinicians report that program attendees relate strongly to presentations by Consumer Consultants and often place high value on their lived experience and advice.

It encourages respect between staff and consumers.

'Both staff and consumers change each other. Staff change as they see Consumer Consultants being so capable in their roles. Consumer Consultants change as they have different interactions with staff than they would as service-users. Both change their approach through this process.' (Consumer Participation Facilitator, ReGen)

It allows us to demonstrate innovation and leadership. ReGen is passionate about Consumer Participation. Finding new and genuine ways to seek, respond to and incorporate input from our consumers enables us to show leadership in this vital, developing area in the AOD sector.

BENEFITS TO THE CONSUMER

The literature about Consumer Participation documents many benefits to consumers, such as improved retention in treatment, higher levels of client satisfaction (Anglicare, 2010) and improved self-confidence (AIVL, 2011). Here are some of the additional benefits to consumers that ReGen has directly observed:

FOR THE CONSUMER IN TREATMENT:

It improves the services they receive. Current and future consumers have access to improved, more relevant and user-friendly services, thanks to feedback and input at all levels from consumers.

It makes rights and responsibilities clear, from the beginning. ReGen aims to empower its consumers with knowledge about how they can expect to be treated and is expected whilst they are in treatment.

It seeks to ensure their safety. ReGen seeks to inform every new consumer about our feedback and complaints processes. The Consumer Participation Facilitator stresses the importance of complaints to both consumers and staff.

'These processes exist to make sure we're not harming anyone and if something has gone wrong that we can rectify it. It's hard to convey this because people come into a new service and feel like they have to be obedient – based on previous service-use experience, especially if they've been in prison. People are often unwilling to speak up and it's part of my role to encourage them to do so.'
(Consumer Participation Facilitator, ReGen)

It offers a sense of hope and relief. Current consumers can find that their anxiety – about beginning (or ending) a course of treatment – is alleviated through contact with a Consumer Consultant

'When a consumer comes in for an info session, I can see the anxiety go down in the group members. Here's someone who did the program, looking really healthy, who has come out the other side. There's hope that change can happen and evidence that it's real.' (Catalyst Clinician, ReGen)

It offers a point of connection, other than the clinician. Catalyst and Torque group program clinicians report that current consumers relate strongly to presentations by Consumer Consultants and often place high value on their lived experience and advice. Participants will sometimes be more receptive to an idea coming from a Consumer Consultant than the same idea coming from a clinician.

'There was an info session where a young guy came in with his mum but he was clearly being dragged along. He was cranky and not looking up. There was an older consumer presenting that night and when he started talking about the mental health issues he'd experienced – his anxiety and depression – this young guy started looking up and listening. You could really see a transformation in him as the consumer spoke. I knew he could relate to what the consumer was saying... At the start of the session the young man was saying that he could never commit but by the end he was considering it as a real possibility and figuring out how he could re-arrange his work to do the program.' (Catalyst Clinician, ReGen)

FOR THE CONSUMER CONSULTANT:

It can provide career and educational pathways. Consumer Participation provides experience in the workplace that can be beneficial when applying for paid or volunteer work. It can provide material for a resume or a letter of support; more formalised educational opportunities (e.g. completing Consumer Participation Training at ReGen or Speakers' Bureau Training at APSU); learning more about the AOD sector and related sectors.

It enables consumers to contribute their knowledge and skills in a meaningful way. As well as giving the consumer the satisfaction of knowing they are improving services for current and future clients, many people find that contributing their expertise to something important fosters a greater sense of purpose and self-efficacy.

It provides a sense of community. Consumer Consultants get to know the staff, other consumers, the ReGen grounds and programs. This sense of belonging can be particularly helpful to people who are making positive changes in their lives. As one Consumer Consultant commented,

'The Catalyst Program gave me a sense of community and after that, Consumer Participation kept me in this community. The staff and the people here are more than just clinicians. There's a welcoming which I haven't found in the past in other areas of recovery. That's what made me want to learn more about myself because I'm driven by the fact that I can help the community. To me, community is the big word... If you're going to be in the community you need to participate in the community and you need to be invited to participate in the community – that's the warmth that ReGen throws out there.'

It provides something to do. People in early treatment can sometimes struggle to fill the time that used to be spent seeking, anticipating using or recovering from their substance use. Consumer Participation can be useful by simply offering meaningful activities in which to engage. ReGen doesn't expect long-term commitment from its Consumer Consultants because we understand that people's lives change and other opportunities arise; therefore, people are welcome to sign up for as many or as few activities as they like (depending on availability).

It offers a small amount of income. Consumer Participants and Consultants at ReGen are currently reimbursed sitting fees.

CHALLENGES SO FAR

Changing the culture of an agency always takes time and includes many challenges. Whilst ReGen has overcome some challenges as they arose, others continue to need negotiation and consideration. These are some of the challenges experienced by our consumers and staff:

Bureaucracy. Consumer Consultants can become frustrated at the slow pace of decision making in a bureaucratic organisation. Whilst ReGen prides itself on the quality of its policies and procedures, clear systems and consultative decision-making processes, these same factors mean that changes can take time to come into effect. Many consumers have no prior experience of working within a bureaucracy and can find the process confounding. As one Consumer Consultant put it:

'There's too many levels and meetings and group meetings that have to happen for even the tiniest decision to be made... it's very frustrating. The whole way it's structured can really turn consumers off.'
(Consumer Consultant, ReGen)

The danger of turning consumers off participating is a real one. They can perceive that managers who take a decision up the chain are uninvested or unwilling to make a decision. However, ReGen's approach is to try and establish well-planned initiatives of quality with policy backing, so that they can be successful and sustainable. The Consumer Participation Facilitator finds that it can be difficult to explain this to consumers.

Without compromising the importance of planning and process, the only option is to communicate clearly between consumers, staff and managers, keeping interested parties updated about a decision's progress and explaining the reasons why it might be taking some time. An added benefit of this situation is that consumers can sometimes alert us to the fact that an accepted process is overly complicated.

'As consumers, we need to understand that there has to be some sort of process, has to be checks and balances, but we can also sometimes see things from the outside and we can ask why... Just because something is the way it is doesn't mean it needs to be that way.' (Consumer Consultant, ReGen)

Distinction of the Consumer Participant/Consultant role. The Consumer Participant/Consultant is not a staff role and not a client role, although it has similarities to both. Consumer Consultants are neither employees nor volunteers. This creates a grey area in which several things are unclear.

For Consumer Participants and Consumer Consultants, this grey area can lead to confusion about practical issues like which meetings and events they are invited to/expected to attend, or in which spaces they are welcome.

When interacting with current clients this can also cause difficulties. Consumer Consultants sometimes find that clients will disclose a lot of personal information to them. Whilst this may feel therapeutic for the client, the consumer does not necessarily have the training to respond to and deal with this kind of information, or the desire to hear it.

Interacting with staff can also pose a few challenges. For example, Consumer Participants or Consumer Consultants who have finished their treatment at ReGen may be justifiably upset if a staff member treats them like a client (e.g. conducts a meeting in a counselling room rather than a meeting room or is overly directive in a co-facilitated activity). Consumer Participants/Consultants with experience of stigma can understandably be sensitive to attitudes which they perceive as discriminatory.

However, mistakes such as those mentioned above are easy for a staff member to make. The issue of the Consumer Participant/Consultant 'sitting in groups' also poses challenges for staff working with them. The boundaries are different from working with a client, and yet they may have known the person as a client a short time ago, or sometimes concurrently (see 'When a consumer undertaking participation activities is also a client' on page 39).

Consumer Participation in the AOD sector is still evolving and the nature of the Consumer Consultant role at ReGen is still being defined. Whilst there are no simple solutions, we have found a few measures can help: continued education and open discussion with all parties; a dedicated office space for Consumer Consultants and Consumer Participants; and projects such as this report which attempt to define and communicate roles. We have also compiled a list of tips for Consumer Consultants, Consumer Participants and staff working with them on page 41. The following perspectives may also be useful.

Clinical Manager, ReGen:

'When Dave was a client, I tried to celebrate his strengths and intelligence. Now that he's a Consumer Consultant, I try to use the same approach. I don't hang around Dave and see a 'drug addict'. There was a time when he was needing a particular intervention and I had some knowledge to share. Now he's got stuff to teach me, and he does.'

Consumer Consultant, ReGen:

'A professional comes armed with a body of knowledge. You can predict what they'll know. Whereas, any one of us may have a completely different knowledge base. That's why we're not professional although we are getting paid and we have some responsibilities because of that. But the responsibility isn't that we will have the solution for someone or that we will know what to do with what people tell us. That's not our responsibility.'

Consumer Participation Facilitator, ReGen:

'Consumer Participation does involve some change of attitude by staff. There's more power to consumers and you become more transparent. That can be confronting for many people... Some professionals see their qualifications as distinguishing them from consumers, but consumers have a different kind of knowledge and expertise. Knowledge doesn't have to be academic, it can also be experiential. There are certain perspectives in experiential knowledge that are extremely useful in terms of contributing to service development and government policy.'

When a consumer undertaking participation activities is concurrently a client. Although people have usually completed a course of AOD treatment when they become involved as Consumer Consultants, the nature of recovery from addiction is that some people will need to use ReGen's services again. This situation can cause some similar discomforts as those described above, as well as increased feelings of guilt or shame for the consumer. ReGen clinicians, who are working with the person as a client, need to deal with this as sensitively and professionally as possible, emphasising that recovery can be a long process, often involving lapse or relapse and that ReGen staff understand this. This is still an area that needs further resolution to ensure that consumers have access to participation opportunities but also the best possible treatment outcomes.

Intoxication. This hasn't been a big problem at ReGen but is worth exploring. We will never knowingly permit a Consumer Consultant to complete participation activities whilst intoxicated. If someone presents affected by substances, they will be respectfully asked to leave for the day. We don't have an expectation of abstinence in Consumer Consultants or Consumer Participants, but it's not appropriate to fulfil any duty at ReGen whilst intoxicated. They will always be welcome back to Consumer Participation activities.

SUCSESSES SO FAR

ReGen is pleased to report the following successes in the field of Consumer Participation:

- **Improved services.** We have altered our programs, like Catalyst and Torque, in response to consumer feedback. We believe that our services are more responsive and well-suited to our client group, thanks to consumer involvement.
- **Client Charter, Complaints Process and Feedback Forms.** We workshopped these documents with consumers and staff, benchmarking against the Victorian Charter of Human Rights and Responsibilities. Finalising and committing to their use marked a philosophical shift, towards actively seeking, listening to and responding to consumer feedback in order to improve our services.
- **Consumer Participation Leadership Group.** This group (formerly Service User Participation Working Group) paved the way for the Consumer Participation Facilitator to commence, researching models of practice and advocating for a budget allocation to fund the position. The group continues to collaborate with consumers and support Consumer Participation initiatives at ReGen.
- **Consumer Participation Facilitator.** Getting the right person in the right position at the right time. In partnership with consumers and staff, she has achieved a great deal in a short amount of time.
- **Consumer Consultant Meeting Group.** From the formation of the group in 2013 and its steady growth – from five to now 16 members in 2016.
- **Free two-day Consumer Participation training.** The Consumer Participation Facilitator designed this training to educate new participants in the role, including rights and expectations of performing the work. It includes speakers from ReGen (including Consumer Consultants), APSU, Harm Reduction Victoria and other agencies as available. The training runs three times a year.
- **Consumer position in leadership groups.** To improve advocacy and interconnection of leadership groups, a six-monthly rotating position for a Consumer Consultant was included in the Consumer Participation Leadership Group. In the future, we also plan to implement a rotating position in Clinical Governance.
- **Contribution to working groups.** Consumers have participated in several project working groups, contributing valuable advocacy, including the Smoking Care Working Group, Mother & Baby Withdrawal Unit Working Group, and South East and Youth Catalyst Working Group.
- **Presentations in non-residential rehabilitation programs Catalyst and Torque.** Consumer Consultants and Consumer Participants give presentations in group programs about their experience of using Catalyst programs. These occur at several stages: info nights, pre-planning, first week and last week. We continue to receive excellent feedback from program attendees about the impact of these presentations.

- **Dedicated office space.** After much planning and negotiation between Consumer Consultants and management, a private office space was created for Consumer Consultants and Consumer Participants. The office is upstairs with the staff offices.
- **'Encouraging Innovation in Consumer Participation Practice' innovation seminar.** In May 2016, ReGen and APSU hosted an innovation seminar on this theme at SHARC for the AOD Sector. The seminar was largely organised and facilitated by Consumer Consultants.
- **Other events.** Consumers have played a significant role in organising, facilitating and presenting at several other public events at ReGen, e.g. International Women's Day at ReGen and Overdose Awareness Day at ReGen.
- **QIP outcome.** In March, a Quality Innovation Performance (QIP) review of ReGen found that our Consumer Participation processes not only met but exceeded Standard 2.4 within Section 2 of the review: 'Confirming Consumer Rights'. An 'exceeded' rating is difficult to attain and requires leading practice to be demonstrated.
- **Embedding Consumer Participation and the Consumer Participation Facilitator role into the North & West Metro AOD Service.** This is a partnership between ReGen and Odyssey House Victoria to deliver AOD treatment in the north and west catchments.
- **Improved waiting area.** In response to consumer and staff feedback, we updated our client waiting area, providing a larger, more comfortable space with internet access, television and a good quality coffee machine.
- **Methamphetamine Family First Aid program.** In 2015, ReGen's Education & Training department created a program to assist the families of people using methamphetamine, consulting extensively with consumers and their families. The free four-hour program now runs regularly at ReGen. Agencies in Melbourne, Shepparton and Tasmania have also received training on how to deliver this program.
- **Better understanding by staff.** Consumer Consultants report that staff understanding of their role has improved over the last two years. The Consumer Participation Facilitator reports that consumer input is increasingly sought by staff. This is a certain indicator that Consumer Participation has become embedded in ReGen's organisational culture.

TIPS FOR PEOPLE UNDERTAKING CONSUMER PARTICIPATION ACTIVITIES

We've gathered tips from Consumer Consultants and the Consumer Participation Facilitator to help newcomers to Consumer Participation roles:

- 01. Your experience qualifies you to sit around the table.** You're qualified to be there and you deserve to be heard. What you have to say is important and valued.
- 02. Ask questions.** There are no dumb questions. If you don't understand something, ask. There can be a lot of jargon in this sector and you're not expected to know what it all means. Also, asking questions about the way things work is a great way to expand your knowledge.
- 03. Don't be afraid to ask to debrief.** If you've completed a presentation, workgroup or other activity and feel unsure about something that happened, overwhelmed or the need to process what you experienced, you can ask the Consumer Participation Facilitator to have a chat.

04. **Your own health and wellbeing is more important than Consumer Participation activities.** If you believe that your participation is compromising this, pull out for a while. ReGen will never put pressure on you to participate more than you are able to.
05. Likewise, remember that **you can always say 'no' to participating in an activity, for any reason.** ReGen understands that people are in recovery and will always try to be flexible. If you do need to cancel at the last minute, contact the Consumer Participant Facilitator.
06. **Be aware of your boundaries with clients.** Decide – before you begin your role – what your boundaries will be. Some Consumer Consultants decide not to mention personal details, such as: where they live, their phone number, what possessions they have, what their surname is, where they have worked. This is not out of disrespect for the client but protection for themselves (e.g. even if a client is well now, they may not be well in the future and you may not want them to know where you live). Be mindful of accepting lifts home for this reason.
07. **Remember that staff are human too.** They make mistakes like everyone else. But if a staff member treats you in a way that you think is unfair, raise it with them in a calm manner. If you're not comfortable to do that, discuss it with the Consumer Participation Facilitator. Sometimes staff (especially new staff or those inexperienced with Consumer Participation) might need reminders of appropriate language or behavior. We are learning together.
08. **If giving a presentation, breathe!** Don't rush it. Speak slowly enough for people to take in what you're saying.
09. **Ask for feedback.** If you're feeling strong enough to hear honest feedback, ask the Consumer Participation Facilitator or a staff member how you went. What did you do well and what could you improve on?

TIPS FOR STAFF WORKING WITH CONSUMER PARTICIPANTS

We've gathered tips from Consumer Consultants and the Consumer Participation Facilitator to help staff working with Consumer Participants for the first time:

01. **Consumer Consultants will require different levels of support** to perform their role, depending on experience and confidence. Ask clear questions to gauge the amount of support they need, e.g. 'Before we start, what do you need from me?'
02. **Many Consumers appreciate the opportunity to discuss an activity before it begins** (to plan, ease nerves, learn about the process, etc.). This can also be helpful to you, to ensure that they fully understand the task and that the main points will be covered. If a consumer has done the activity before they may not need to, but it's good to ask. Likewise with de-briefing afterwards. Before a presentation, it can also be helpful to make an agreement with the consumer about comments during the presentation, e.g. 'Feel free to jump in and add to what I'm saying to the group and is it okay if I do the same to you?'
03. **Don't assume that you will be the leader of a shared task.** If collaborating with a Consumer (e.g. on a presentation), approach it in the same way you would with another staff member. Decide together which elements of the task each of you will complete, recognising that you bring different types of knowledge to the project.

- 04. Acknowledge inappropriate behaviour in an honest and upfront way.** Consumers generally don't have professional treatment training, and aren't always aware of what's appropriate in a treatment setting. If a consumer speaks or behaves in a way that you think is inappropriate whilst in your program, have an honest, non-judgemental conversation with them, at a private moment. If you're unsure, speak to the Consumer Participation Facilitator.
- 05. Be mindful of using jargon and acronyms.** This can be really intimidating. Explain what things mean.
- 06. Acknowledge your commonality.** Consumers are human beings with talents, flaws and challenges, like you. They're no longer in a help-seeking position but are here to contribute their knowledge and skills, like you.
- 07. Explain the reasons behind your processes.** The consumer may not have experience of bureaucracy (so, explain why you need to check a decision with management) or may be sensitive to stigma (so, explain why they had to wait longer than expected for your meeting).
- 08. Ask the Consumer Participation Facilitator if you can sit in on a Consumer Consultant Meeting,** to further educate yourself about the process.
- 09. Read this report and other resources listed on page 46.**



OUR NEXT STEPS

Consumer Participation at ReGen is an ongoing process; however, we've come a long way in a short time. We will continue to work to ensure that consumer input is sought, listened to and responded to across all our programs.

There are three particular initiatives that we are looking forward to getting under way:

- 01.** Including consumers on recruitment panels. Consumers have already completed training to prepare them to participate in this way. We have commenced including Consumer Consultants on staff interview panels this year.
- 02.** Consumer Pathways Project. We have recently secured funds to employ a 12-month Pathways Worker, to develop and implement education/career pathways for consumers. This project will commence this year.
- 03.** We are also planning to have a rotating Consumer Consultant position on the Clinical Governance Committee.

Consumer Consultants have expressed interest in further training across a range of topics to help them perform their role more effectively; greater communication with Consumers from other agencies; and further discussion about a position for a Consumer Consultant on the Board.

YOUR NEXT STEP

IF YOU WANT TO BE A CONSUMER PARTICIPANT AT REGEN

If you currently use services at ReGen or have used them in the past, and think you would like to try Consumer Participation, your first step is to contact the Consumer Participation Facilitator at ReGen. You can call her between 9am – 5pm on weekdays on (03) 9384-8894.

Many people prefer to finish their current course of treatment before starting Consumer Participation activities, so that they can fully focus on their treatment.

Remember that family members and significant others are also welcome to participate as consumers.

IF YOU WANT TO IMPROVE CONSUMER PARTICIPIATION PRACTICES AT YOUR WORKPLACE

After reading this report, there is a variety of other documents and websites that you can consult, which will help with assessing and planning Consumer Participation at your workplace.

Use the following as a starting point:

- **Health Issues Centre:** <http://www.healthissuescentre.org.au/>
- **Treatment Service User Project, AIVL:** <http://www.aivl.org.au/stories/treatment-service-users-tsu-project/>
- **Straight From the Source.** A practical guide to consumer participation in the Victorian alcohol and other drug sector. Produced by APSU. Available at: <http://sharc.org.au/wp-content/uploads/2014/02/NP69876-APSU.pdf>
- **Doing it With Us Not For Us.** The Victorian Government's policy on consumer, carer and community participation in the healthcare system. Available at: <https://www2.health.vic.gov.au/about/participation-and-communication>

If you would like to discuss your ideas with the Consumer Participation Facilitator at ReGen, you can contact her between 9am – 5pm on weekdays on (03) 9384-8894.

The following documents are available by request. We require you to acknowledge ReGen as a source of these documents:

- 01.** ReGen's Consumer Participation Policy
- 02.** ReGen's Consumer Participation Code of Conduct
- 03.** ReGen's Client Rights and Managing Client Complaints Policy
- 04.** Client Feedback Form
- 05.** ReGen's Consumer Participation Reimbursement Policy



APPENDIX A
CLIENT CHARTER

Client Charter

You are entitled to expect and receive high quality services at UnitingCare ReGen.

This charter describes your rights and responsibilities when you participate in ReGen's services.

It is a partnership to help you achieve the best possible outcomes.

Rights

As a client of ReGen I can expect to:

- be treated with respect and dignity at all times
- have fair access to appropriate services regardless of race, gender, sexual orientation, age, religion or disability
- be involved in decisions about all aspects of my treatment
- ask a support person to be involved in discussions about my treatment
- make an informed decision as to whether I take part in any recommended treatment (except where legislated)
- receive feedback about my progress throughout treatment
- have access to any written records about my treatment through ReGen's processes to access information.

ReGen's Client Charter is consistent with the Department of Human Services AOD Client Charter and the Victorian Charter of Human Rights and Responsibilities

Responsibilities

As a client of ReGen I am expected to:

- contribute to an environment that is safe and supportive for everyone
- treat all people and their property with respect and dignity
- provide accurate information on issues that affect my treatment
- respect the privacy of others.

Privacy

I can access the information ReGen keeps about me in keeping with the agency's *Privacy and Confidentiality Policy* and the *Victorian Information Privacy Act*. I can request access to documents or the Policy directly to the Team Leader or Manager of the service I am receiving or contact the Privacy Officer at UnitingCare ReGen, 26 Jessie Street, Coburg VIC 3058 or privacy@regen.org.au.

Other relevant services and resources:

Information Privacy Act 2000 and Victorian Health Records Act 2001

Office of the Health Services Commissioner T: 03 8601 5200 or Toll free: 1800 136 066

How to contact us

UnitingCare ReGen – Main Office
26 Jessie Street, Coburg VIC 3058
T: 03 9386 2876 F: 03 9383 6705
contact@regen.org.au
www.regen.org.au

Providing feedback

Compliments, complaints and suggestions from people who use ReGen's services provide the agency with the best indication of whether its services are meeting the standards set out in the Client Charter.

ReGen values client feedback and seeks it in a number of ways, including through surveys, direct feedback from clients and workshops. We value the opportunity to respond to you about the feedback you provide, but if you choose, you may provide your feedback anonymously. If you have a complaint ReGen will endeavour to contact you within 48 hours to discuss a timeframe to deal it.

Your compliments help us know where we are performing well. Feedback on issues and problems you may have experienced help us improve the quality of our information, support and services. Your feedback will not prejudice the services provided to you at ReGen.

You can expect to:

- be given opportunities to provide feedback based on your experiences of services through ReGen
- be listened to whether you have a compliment, a complaint or a suggestion
- be able to raise concerns directly with the person involved where appropriate. In an instance where you feel it is inappropriate to raise the concern directly with the person involved you have the option to raise the matter with a Program Manager or Supervisor
- raise a concern or make a formal complaint using the ReGen's complaint's procedure
- be able to bring a support person with you whilst you provide feedback
- have your complaint managed in a timely and professional manner
- receive feedback about ways you might be able to improve the outcomes of your treatment, unless you choose to do it anonymously.

For more information see the ReGen Feedback brochure.



REFERENCES

REFERENCES

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NOTES



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'Consumer Consultants assist in the direction and services with ReGen. I think it is important that the lived experience is appreciated. It is good to be involved in helping people out with information sessions and presentations to Torque and Catalyst and seeing them come out the other side.

Participating in meetings gives you a sense of importance. Chairing the meeting is good. Everything that you try is a learning curve. I appreciate all the learning opportunities I get.

The good part of being a Consumer Consultant is that it keeps you focused. If I wasn't involved with ReGen, I am sure that the couple of lapses I had would have been more severe.

Socially it is good to catch up with fellow Consumer Consultants and welcoming new ones into the fold. Most of them come through the Torque and Catalyst programs. Because you have seen them when they first entered the program, you see how well they have come through, how much they've already achieved.

I really enjoy presenting in the groups because you know, by sharing your own experience, your story, you put a human touch to it. People see your journey and it gives them hope.

I am very proud of the [ReGen] lanyard & ID badge. I have never have had one of those things in my life. I think you feel that, for someone to give you one of those with a picture on it, that they have a belief in you.'

– Consumer Consultant –

**"It feels good when
your ideas are
taken seriously."**

– Consumer Consultant –



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YouTube: ReGen

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