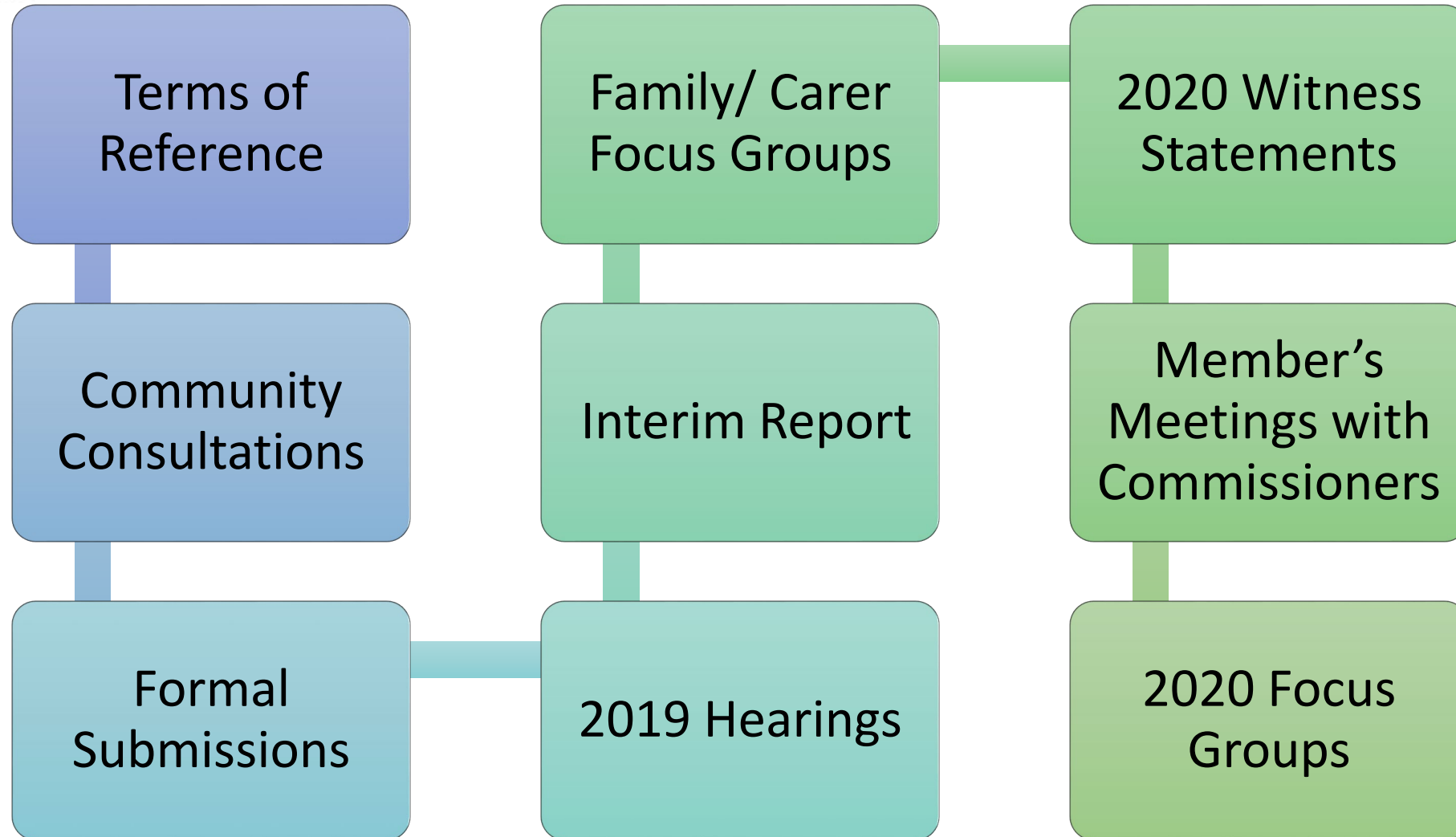


Engaging Family and Carers in the Royal Commission into Victoria's Mental Health System



2019 Overview

Community Consultations

- RCVMHS held 60 across Victoria (20 regional)
- Tandem representative at almost every one to support & engage family/carers

Submissions

- Assisted 100 family members to engage in submissions process
- Interviews to support people to capture their experiences
- Tandem's submission highlighted member's experiences & ideas for change

2019 Hearings

- Several carers gave evidence across the 3 weeks
- CEO Marie Piu & longtime Tandem member Kali Paxinos appeared for CALD carers
- Day 9 specific to Family & Carers

2019 Overview continued

Focus Groups

- Up to 30 Family/Carers attended two metro & one regional focus group (Gippsland region)
- One specifically for young carers aged 16-25 years –expressed this was their 1st experience of being ‘heard’
- Focus groups looked at ‘current state’ of issues & ‘future state’ of what people want to see change

Interim Report

- Chapter for Family/Carer’s captured issues & experiences, lacked insight regarding specific recommendations
- Included many Family/Carer case studies & quotes from submissions Tandem supported
- Family/Carers appeared to be on the periphery

Family/Carers on the Agenda

- Across Dec 2019 – April 2020 Tandem in regular communication with the Commission
- Surveyed Family/Carers to share findings with RCVMHS during several meetings
- As they began conceptualising the future system we ensured Family/Carers stayed on the agenda

2020 Overview (…Tandem expanded our RC Team!)

Witness Statements

- Hearings cancelled due to C19 – RCVMS adapted to collecting 150 witness statements and hosting online panel discussions
- Tandem board members, CEO & carer academic's participated in panel discussions on implementation & governance topics
- Dr Melissa Petrakis made a formal witness statement highlighting evidence-based Family Inclusive Practice and respite models
- Many who made submissions & joined focus groups through Tandem went on to complete formal witness statements

Family/Carer Personal Stories

- Tandem also submitted Family/Carer Personal Stories from individuals who were yet to participate in the RCVMS process
- Included experiences from: regional carers, carers supporting multiple family members, sibling carers, carers U16, a father's caring experience, dealing with crisis responses, mental health tribunal and CTO's, and caring during COVID-19

Developing the Evidence-Base

- Tandem connected the Commission with various carer academic's & service's utilising Family Inclusive Practice models
- Report on the 'gendered nature of mental health caring' via Women's Mental Health Alliance
- Report highlighting needs of 'aging carers' and those caring for aging consumers via Mental Health Victoria
- Family Peer Support Interventions report: evidence-base for models & investment in LEW workforce to deliver peer support

Tandem Members Meet with Commissioners

April & May

Family/Carers questions for Commissioners to respond to which focused on:

- Embedding family-centred practice models within services
- Community models of care that allow people to get support before becoming acutely unwell
- Ensuring a better range of supports for family/carers
- Striking a balance between consumer rights & family/carers needs in care planning

August

Family/Carers presented their experiences & ideas to Commissioners & members on:

- Better access to info for Family/Carers
- Financial support & the CSF
- Employment
- Relational recovery & a whole of family approach
- Peer support & the LEW
- Mental Health & wellbeing supports for carers
- Psychoeducation for Family/Carers

2020 Online Focus Groups

May - June

Focus: The challenges & the future

- CALD Family/Carers
- Family/Carers of children U12 with mental health issues
- Young carers
- 2x LGBTQIA+ Family/Carers - one in partnership with Drummond St, for which we delivered a report to RCVMHS
- Aboriginal & Torres Strait Islander carers – in partnership with VACCHO

July – August

Focus: Testing potential reform models

- Crisis responses
- Entry pathways (including assessment & intake)
- AOD / Dual diagnosis
- Community Integrated Mental Health Services
- Bed-based Services
- Carers of children U15 with mental health issues
- Carers of children aged 15-25 with mental health issues
- Digital Information Sharing

Tandem supported 14 of the 70 RCVMHS online focus groups in 2020, meaning 20% were specific Family/Carers focus groups

YOUNG CARERS

Focus Group 4 June 2020

We Respect and Acknowledge

28 Focus Groups so far!

8000 Submissions

Today's Focus: **Design the Future**

Your Voice is KEY

Challenges

Services Don't Communicate

My Mum has to retell her story it's traumatic

Ten sessions are Not enough...

FINANCIALLY CAN'T AFFORD PSYCHOLOGISTS

Need more Medicare

I was 16 & had to become key carer for our family

RIFTS with my older brother

it took years to UNRAVEL the TOLL it took on ME

the FAMILY wasn't CONSIDERED when MUM WAS ADMITTED

I fell through the cracks

Focus on CRISIS not Recovery

MUM HASN'T HAD the THERAPY she needs

Gets sent home from Hospital without a Recovery Plan

the CARER becomes the SUPPORT WORKER

I DON'T HAVE the SUPPORT I NEED

SUPPORT WORKER REQUIRED

it would Take the PRESSURE OFF

I IDENTIFY as a COPMI

CHILD of a PARENT with MENTAL ILLNESS

IT WAS a REVELATION to LEARN the TERM & that I WASN'T ALONE

DIAGNOSTIC APPROACH

a Refugee Background MEANS SERVICES can be TRAUMATIC for HER

MUM has a LONELY & ISOLATED life in AUSTRALIA

I CAN'T TALK to HER about the SERVICES I access

ONE SIZE FITS ALL

COMPLEX CASES DON'T FIT

EATING DISORDER, PSYCHOID, BIPOLAR

STIGMA CAN PREVENT PEOPLE ASKING for HELP

in AUSTRALIA & in FAMILIES

a BIG THING HAPPENED TODAY but my PSYCHOLOGIST ONLY AVAILABLE for 30 minutes... then in 3 weeks

STAFF are TOO BUSY to SUPPORT ME

3 Week WAIT for SUPPORT...

Doesn't then FEEL that I CAN TRUST...

SERVICES DON'T GIVE ME INFORMATION?

AT TIMES MUM'S BEEN DISCHARGED & GONE DOWN HILL

WHY DIDN'T they CALL ME so I could TELL THEM what I KNOW?

THERE NEEDS TO BE MORE COMMUNICATION

a PHYSICAL ILLNESS LENSE is APPLIED to MENTAL ILLNESS

an INDIVIDUAL is PART of a BROADER CONSTELLATION

PROFESSIONALS Need to KEEP this in MIND

PEOPLE in the CONSTELLATION HAVE ISSUES that IMPACT ON US

the Future

SCHOOL LISTENED to ME!

PSYCH'S

Be AWARE of YOUNG CARERS

with ORGANISATIONS in CONTACT with FAMILY

PREVENT RETELLING STORIES

Mixed AGE CARERS' GROUPS

age SHOULDN'T be a LIMIT

MY SIBLING GETS BETTER CARE than MY DAD

Holistic CARE

HEADSPACE PROPER SUPPORT

NOT JUST a CAREERS COUNSELLOR

PREVENTATIVE INFORMATION SHARING

CONSUMERS & FAMILY

BULK BILL HISTORY SHARED

we're ARTICULATE because of what WE'VE OVERCOME

EDUCATION

HELP US UNDERSTAND from YOUNG AGE

REDUCE DISPARITY between CARE of DIFFERENT AGES

assessed on Need, NOT 10 SESSIONS

UNTIL RECOVERY

I DON'T HAVE MEDICARE

DESIGN SUPPORT by REALISING CASES, NOT TIME LIMITATIONS

PEER SUPPORT

they NORMALISE THINGS and VALIDATE US

More NEEDED for YOUNG COPMI

GIVE US THE OPTION to CONTINUE with ONE PERSON (REGARDLESS of AGE)

PROVIDE ONLINE

ANONYMOUS SUPPORT those who are REGIONAL

for FREE

FAMILIES don't NEED to KNOW

NOT JUST CRISIS PREVENTION for CARERS

if a PARENT is ILL it's ALMOST an ASSUMPTION that the CARER will TOO

MIGRANT & REFUGEE BACKGROUNDS

CAN LEAD to AVOIDANCE of SERVICES until there's a CRISIS

GIVE FOCUS to BUILD GROUPS that CAN HELP

CULTURALLY, SOME PEOPLE may NOT TALK EASILY

we Need MORE HELP

CHOOSE CLINICIANS with LIVED EXPERIENCE

LIVED EXPERIENCE is KEY

INDIGENOUS PRIORITISATION

they SEEM to be OVERLOOKED

MEDICARE COVER ALL COSTS

UNTIL RECOVERY

INTERNATIONAL STUDENTS

SERVICE CONSISTENCY & FOLLOW UP

HOW ARE YOU CONTACTED?

PEER SUPPORT

the ONLY ONES with TIME

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INTERNATIONAL STUDENTS

SERVICE CONSISTENCY & FOLLOW UP

HOW ARE YOU CONTACTED?

FUNDING not CONSIDERED for US

CONSIDERATION for CARERS

MUM CAN'T WORK for LONG PERIODS

CHANGE ELIGIBILITY CRITERIA

FUNDING

MORE NDIS for SUPPORT WORKERS

WAIT LISTS ARE TOO LONG

WHAT do YOU MEAN WE CAN ONLY HAVE 2 FAMILY SESSIONS?!

SUPPORT WORKERS are STRETCHED THIN

1 CAN'T DRIVE...

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Key Themes

Mental health Family/Carers need access to supports in their own right, including:

- Tailored respite options
- Navigation support
- Mental health & wellbeing
- Psychoeducation
- Peer support options

Trauma informed care for carers & Family Inclusive Practice models must be core business, embedded across the system

Invest in & expand LEW, with resourcing for CLEW to deliver Family/Carer peer support interventions

Early intervention supports are vital for Family/Carers too, such as:

- Family assessments & mapping of informal support people
- COPMI need support
- Access to therapeutic family interventions

What's Next

Tandem are supporting the final stages of engagement



RCVMHS have begun writing the final report due in Feb 2021



Tandem continuing our campaign for Mental Health Family & Carers