Perspectives on Mental Health and Wellbeing from Interviews and Focus Groups

The Community Advisory Group had posed the question to the focus group: “What advice do you have for all those who have recently been affected (disadvantaged) by the coronavirus pandemic?” Family members’ advice to the newcomers to the world of disadvantage begins with a hearty welcome.

Life in ‘Entrenched Disadvantage’ is a very different reality from that of other parts of society. Many of the family members told us that they sometimes feel as if they are not even part of mainstream society. That they are ‘other’. Saying it this way has a deep resonance, particularly for anyone interested in ideas about justice and social inclusion. We have witnessed the horrifying power of this ‘othering’ process in political discourse around the world.

Most of the focus group participants had contributed over twenty hours of interviews over the year. Through these interviews, it was clear that ‘the narrow focus on individual responsibility that has dominated political discourse and the media obscures the structural factors shaping peoples lives’. This Bulletin explores how family members encounter some of these ‘structural factors’ and how these factors, along with the many other things in their lives, affect their wellbeing.

The stories we have heard through the project provide a window into the collective wisdom of 100 families’ in depth experience of life in entrenched disadvantage in Perth, WA.

Dedication

This 100 Families WA Bulletin focuses on what we are learning from the qualitative research component of the project. We dedicate this Bulletin to the 100 family members who so generously opened up their lives to us by agreeing to participate in the research over the last year or so. After all, if what we say here does not make sense to you, a) we have failed in our primary task of listening to you, and b) how can we hope to make anyone else understand your lived experience?

If you see yourselves in the words here, we have done our job well. If not, please let us know.

Thank you all for trusting us, engaging so powerfully and sharing your life stories of hardship as well as hopes and resilience.

Since ‘we are all in this together’… welcome to our world!

The above greeting comes from a discussion about the COVID-19 public health message of “we’re all in this together” in one of the focus groups for the project. The focus groups were comprised of family members who had taken part in fortnightly interviews and were interested in further participation in the project. Family members at the focus groups had not felt like ‘we were all in this together’ prior to COVID-19, and instead often felt punished and excluded by policy approaches to people in similar circumstances to them.

The Community Advisory Group had posed the question to the focus group: “What advice do you have for all those who have recently been affected (disadvantaged) by the coronavirus pandemic?” Family members’ advice to the newcomers to the world of disadvantage begins with a hearty welcome.

Life in ‘Entrenched Disadvantage’ is a very different reality from that of other parts of society. Many of the family members told us that they sometimes feel as if they are not even part of mainstream society. That they are ‘other’. Saying it this way has a deep resonance, particularly for anyone interested in ideas about justice and social inclusion. We have witnessed the horrifying power of this ‘othering’ process in political discourse around the world.

Most of the focus group participants had contributed over twenty hours of interviews over the year. Through these interviews, it was clear that ‘the narrow focus on individual responsibility that has dominated political discourse and the media obscures the structural factors shaping peoples lives’. This Bulletin explores how family members encounter some of these ‘structural factors’ and how these factors, along with the many other things in their lives, affect their wellbeing.

The stories we have heard through the project provide a window into the collective wisdom of 100 families’ in depth experience of life in entrenched disadvantage in Perth, WA.
How we did it

The 100 Families WA project provided a unique opportunity to listen to the voice of lived experience of those in entrenched disadvantage. We recruited four hundred family members through seven not-for-profit (NFP) community service organisations. These 400 family representatives agreed to participate in an annual survey and were asked if they were interested in participating in fortnightly interviews for up to a year. We selected 100 family members to participate in interviews, and later invited those who were involved in the interviews to join in focus groups with other family member participants.

The coronavirus pandemic hit two-thirds of the way through the yearlong engagement with families, providing a profound opportunity for family members to reflect on what it meant to be disadvantaged in our society, from the perspective of those who are more experienced in how to survive in entrenched disadvantage. One family member wryly commented “we make it look easy”, but the research team learnt a lot about how complicated it can be navigating in, through and out of disadvantage.

The analysis team is now working out how to best re-present the stories heard from 100 voices of lived experience. It is important to appreciate that each family member is not representative of more than their own stories of their experiences and the sense they make of them. However, although each person’s story is unique, some common threads emerge. These threads may be clues that can lead us to better ways of thinking about entrenched disadvantage, and how we as a society can better support those who find themselves in similar situations in the future.

The seven NFP partner agencies agencies that referred interested family members to the 100 Families WA project varied in terms of their focus areas (grandparent carers, homelessness, mental health, family support services, community centres etc.). Each agency developed its own approach to recruitment, with varied results. The cohort of 100 family members selected for the qualitative interviews was similar in key demographics within the broader group of 400 (e.g. age and gender).

A team of up to 20 interviewers undertook the qualitative data collection. The process was structured to allow family members to tell the stories they wanted, in the ways they wanted. We planned two exercises in the early stages of engagement based on established social work methods. These were to develop a genogram (similar to a family tree) of the person’s family (as defined by them) and an eco-map of the supports in their lives (including formal agencies and informal networks of family and friends). An eco-map is a visual representation of the different people and organisations in a person’s life, and how important each is to the person.

Towards the end of the interview process family members were invited to participate in focus groups. The analysis team held four focus groups in various locations around Perth. The focus groups provided an opportunity for family members to interact with each other as well as for the analysis team to share their early work of making sense of the stories.

As the research for the project was planned as a ‘mixed methods’ approach and included surveys, interviews and focus groups, we are also working to integrate the different data gathered by the project. Discussions with the Project Team led to the suggestion to focus this bulletin on the important issue of mental health and wellbeing.

The term ‘mental health’ is not universally understood to mean the same thing to all people. For the purposes of this project, we draw on the World Health Organisation understanding of mental health as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community”.

“I’ve been down more rabbit holes than Alice [in Wonderland] trying to sort out my mental health issues... drink me, you will grow small, eat me you will grow large”
What we found out

One of the key issues emerging from the research was the profound impact issues related to mental health and wellbeing have on the journey through entrenched disadvantage. The Baseline survey had used several well-established instruments to explore family members’ mental health and wellbeing. From this data we knew that, compared to the general population, the family members interviewed had:

- Higher levels of mental distress, depression, anxiety, and mental health diagnoses
- Low scores on Quality of Life measures
- High rates of reported adverse life experiences

What the survey data did not tell us were the stories of how all these significant issues played out in people’s lives and interacted with other factors known to worsen or reduce the impact of each of these issues.

It’s not like a broken leg...something you can see on the outside, but it affects everything and is affected by everything...it is all connected.”

“It is enough to drive you mad!” Stories about mental health and mental illness

Some people made sense of their experience from within the medical model of mental illness. Their experience was dominated by stories of becoming aware of something not being right (sometimes gradually, other times suddenly) and seeking to access expert help, often via general practitioners (GPs) with referrals to psychiatrists, psychologists or other helping professionals. For some this led to a diagnosis, sometimes several, and perhaps medication. For others the path led to a diverse range of talking therapies. Family members who went down these paths tended to see themselves as sick or as patients of a system.

Sally’s story illustrates the many accounts we heard that associated events from a person’s past with the development of mental health problems. In her case it was family of origin issues and adverse experiences in her early life that she associated with developing mental illness, but the range of life experiences referenced in stories is broad and contexts varied.

We recognise and acknowledge the stories shared in this bulletin do not capture all parts of the individuals lives. They are more than these experiences. However, we share these highlighted areas to bring attention to some of the issues being raised.

Sally’s* story

Sally participated in 20 interviews. The main issues identified by Sally were associated to her family, its members and her own mental illness.

Sally’s mother had an eating disorder and depression. She was the victim of sexual assault and did not want a daughter. Sally had a strained relationship with her mother and was physically abused by her father and brother. She has tense relationships with her grandparents, particularly her grandfather, who also treats her harshly as he believes that this treatment is encouraging her to achieve more in life.

At the age of 10, Sally was sexually assaulted. She has attempted suicide, has self-harmed and experiences post-traumatic stress disorder (PTSD), borderline personality disorder (BPD), insomnia, anxiety and eating disorders. Her medication has negative effects (results in the shakes) and she has irregular contact with her psychologist.

Sally lives independently, wants to study and gain a driver’s licence. She has a few friends, mainly met through the mental health system, but sees them infrequently. She attends the gym often – approximately 5 times per week.

*pseudonym
Many of the stories we heard were about the challenges of finding help that was appropriate, affordable and effective, from the perspective of the person telling the story. Anything that was not free or required a user pays component meant it had to compete with other priorities such as feeding the children and keeping a roof over the family. Family members noted that very few providers bulk bill and those that do were hard for them to find. Even the costs of medications could be problematic.

Navigating the more affordable service systems is also not without its challenges. Agencies funded to deliver these services tend to work in isolation from each other. From the families’ point of view, this makes it difficult to access the help they need. In the first instance, it is difficult to know where to go. Often people find out about a service by word of mouth. Most commonly, the way families find appropriate and affordable help is by trial and error. This usually means having to go through the process of being assessed or telling their stories over and over again only to get knocked back, sometimes for what sounds to them like false or trivial reasons.

One family member recounted the story of going in to an agency after a major disaster that left them homeless, bereft of everything including identification and all personal effects except the clothes on their back. After waiting for a very long time to see someone (while observing staff engaged in idle chitchat around the water cooler); when eventually attended to, they were required to provide what they considered to be very personal information in front of other people. At the end of an extensive process, the worker told them there was nothing the agency could do, and they were dismissed to find their own way through the crisis. As the worker walked away, the family member watched as the worker regarded their reflection in a glass window and primped their hair on the way past. The family member who told this story wanted us to know how inhumane this felt to them in the midst of a major crisis.

Other family members shared many similar stories with the interviewers. One family member noted that experiences such as these ‘are enough to drive you mad’. The very dry sense of humour was not lost on the interviewer. The double meaning of attempting to access help being both ‘infuriating’ and ‘having a negative effect on a person’s mental health’ was intentional on the part of the family member.

Following the mental illness pathway has other consequences. Access to other forms of income support including sickness benefits (if employed), disability pensions and NDIS funding tend to be based on having a diagnosis or otherwise being able to substantiate claims for eligibility. The low level of payment under (then) Newstart and associated ‘mutual obligation’ requirements can make having a disability diagnosis and accessing alternate forms of support a more viable option to get needs met for those experiencing mental health challenges. For some, this perverse incentive requires them to exaggerate their symptoms to meet the threshold for assistance or spiral further in to poverty and hopelessness.

“It is not something I am proud of admitting, but when you are desperate you have to do what you have got to do to survive.”

“When you are on the streets you are invisible. People pass by and look right through you, as if you are not even there. No matter how moral a person is, you find yourself being reduced to doing things you have to, just to survive.”

The stories of family members were not intended as a blanket critique of the medical model, the psychiatric establishment, and all pharmacological interventions. Some family members told stories of how these interventions saved their lives including preventing suicide and serious self-harm.

“Several times, I was so far out there I was taken to hospital and admitted. They gave me a shot which brought me down and it saved my life, it really did.”
To add further complexity to the picture there is a third group of stories. As one participant said: "homeless people aren’t stupid you know. We can work out that if we say we are suicidal we will get help quicker.” Disclosures such as this were told as a pragmatic way to jump the queue to access support. In many service settings demand consistently outpaces supply, leading to some form of rationing. Some family members questioned why it is that they, as citizens, cannot access essential services they need and believe they should have. One said “surely in a wealthy country like Australia we can do better than this?”.

‘Living the Dream’ - Quality of life measures

The surveys canvassed measures of Quality of Life developed by the World Health Organisation. These measures addressed the domains of physical and psychological health, social relations and environment. Across all domains, family members reported lower levels of satisfaction than the general population. Many stories told about the ways that they and their families’ lives did not ‘measure up’ to others they knew about.

At the policy level, family members had a keen awareness of the public discourse about poverty and disadvantage. Political slogans like ‘the age of entitlement is over’ ‘leaners, not lifters’ and media portrayals of people dependent on support services as ‘dole bludgers’ and ‘welfare cheats’ deeply affected family members and sapped their self-esteem and sense of wellbeing. Portrayals of people in entrenched disadvantage as being responsible for their own circumstances and ‘if they do not make it, then it must be their own fault’ also deeply affected families and this is reflected in the stories they told.

Some family members appeared to have internalised these discourses and with this effect they presented as helpless and hopeless. Others resisted, often able to articulate stories about factors outside of their control that contributed to their journey into entrenched disadvantage. A third response was to express counter-examples of family members taking responsibility and demonstrating a strong commitment to maintaining themselves and their families in the midst of extreme hardship.

Many stories also included information about family members’ life expectations. In broad terms, family members want the same things that families in the general population want. Their stories illustrate how entrenched disadvantage affects their capacity to meet their own needs. Basic physiological needs (air, water, food, shelter, sleep and clothing) are a central focus of life in entrenched disadvantage, as they are everywhere. Families in entrenched disadvantage often struggle to procure even these basics. Living at or below subsistence level, they are only one step away from the next crisis.

Families in the interview process expressed that their safety needs are often unmet. The lack of safety was a major theme for homeless people. Facing many barriers to entry into the job market or only being able to find insecure employment, many struggle to get ahead, or even keep their heads above water. Most struggle to keep a roof over their family’s heads.

Love and a sense of belonging are very important though are often strained or in short supply. We also heard that whenever someone does get ahead and have something to give to others, they can easily become overwhelmed, surrounded by requests for help from others in need.

Family members told stories of how their self-esteem often suffers, though there were many examples of outstanding courage and resilience in many of the stories. Many of the family members we interviewed sought to be the best they could be, in spite of the challenges they faced.

Families in entrenched disadvantage have the same needs as the general population but their focus is constrained to meeting their most basic survival needs.
Kurt’s story is one example of a self-confessed ‘battler’ struggling to make it in a life that has not been kind.

Kurt’s* story

Over 21 interviews Kurt told his story from birth through living in out of home care and subsequent events. Other important aspects of his story include employment and finances, which are only briefly mentioned here.

Kurt and his partner have a 3 year old child, and Kurt has a child from a previous relationship. Kurt has a history of foster care from age 4 until 18, where he experienced abuse, after being removed from alcohol and other drug (AoD) dependent parents. He now has a good relationship with his birth parents although they are now experiencing ill health and dementia. His relationship with his siblings is poor. Kurt has a history of employment in adulthood, although his qualifications are now no longer reliable in obtaining work. He has experienced AoD problems resulting in driving bans, which affect his employment opportunities, as does his residential location that is poorly serviced by public transport. Despite these challenges, Kurt is reluctant to ‘go on the dole’, because he prefers to be independent and because the nature of his casual and intermittent employment makes Centrelink applications difficult.

Kurt attributes his work ethic to learning skills at a residential college, which he valued, crediting it with his survival skills. His upbringing in foster care and resultant failures in the courts to prosecute his abusers due to lack of evidence have left him with trust issues with individuals and larger service systems. He has also had negative experiences with child support systems, despite paying child support regularly. The formula for calculating child support liabilities make it hard for those on irregular income, often leaving him financially struggling because of the time lag between payments and income. He is reluctant to use service systems, such as income support and health services, and characterises them as ‘unfeeling’, and unable to listen or respect him for what he can do.

Despite experiencing anxiety and depression, he does not consult medical practitioners nor take any medication. He was prescribed bipolar medication at the age of 9 and was prescribed steroids at 17 to help his development. He has a distrust of the medical and mental health systems and prefers to deal with these issues himself. His solution to mental health concerns is to work, but his anxiety and depression prevent him from seeking work, and the lack of work affects his mental health.

* pseudonym
Kurt’s story illustrates the complex interaction between early experiences of trauma, their potentially lifelong consequences and the resilience and perseverance expressed in coping with life in entrenched disadvantage. One of Kurt’s favourite responses to questions about how he is going is “Living the dream”.

What do you mean by wellbeing?

Many of the stories family members told referred to the notion of wellbeing rather than mental health or mental illness, or some mixture of mental health/illness and wellbeing.

Invoking the notion of wellbeing begs further questions of definition. There have been volumes written on the topic. Many hark back to Aristotle’s writings in this area. The notion of ‘Eudaimonia’ as the essence of wellbeing (which can be translated as flourishing, happiness or welfare) is central to these writings. More recently, people like Martin Seligman, the founder of modern positive psychology, borrowed the term as the central notion of wellbeing. Others like the Nobel Laureate Amartya Sen added depth to the idea by articulating a set of ‘essential freedoms’ which he argued are both the means and the ends of achieving wellbeing. More recently still, ‘well-being’ is apparent in the World Health Organisation’s definition of mental health.

There have also been many attempts to measure wellbeing in relation to different ideas of what should be its essential domains. What constitutes wellbeing is also linked to various theories of justice, as definitions tend to beg the question of how society should be organised to maximise wellbeing for all.

Some argue that wellbeing is a ‘subjective’ idea, determined differently by each individual, and therefore cannot be objectively defined and measured. Advocates of this view often support the idea that measuring wealth, as a proxy for wellbeing, is a more appropriate way to go. Others take the view that wellbeing is a relative construct and a comparative approach is a more appropriate way of defining and measuring it. A third group argue that we should adopt an ideal of wellbeing and work towards that.

The stories family members told reflect the wide range of views about wellbeing. Some stories focused on the family member’s view of what constituted wellbeing for them. These stories sometimes included anecdotes of how families strove to maintain particular practices that were important to their subjective sense of wellbeing and adapted to their circumstances.

“Family is everything to me. I work hard to make sure that no matter how tough things are, we still manage to make time to celebrate each of the kids and their achievements regularly. Even if it is with something really, really simple, it still makes a difference.”

Many examples of maintaining wellbeing were not unique to the experience of entrenched disadvantage, such as making sure the family got together for a sit-down meal (with no screens!) once per week, or having ‘socially distanced coffee’ with the neighbours in the driveway.

Other stories focused on relative measures of wellbeing, comparing their life in entrenched disadvantage to what others have and can do. These comparisons were both positive and negative, with some family members emphasising that there are other people in worse circumstances than them and others being more aware of people who had (much) more than them.

“One of the really important things you learn by doing it tough is about what is important in life. For me this is family and friends. They are what makes my life worth living.”

“When I compare my life with others I can easily become discouraged, but when I count my blessings I think I am the richest person on earth.”
Another group of stories argued for some ideal of wellbeing, often linked to a case for a more just society. These stories appealed to some notion of rights or the entitlements of citizenship.

These profiles of groups were not mutually exclusive and some stories included elements of each. The inadequacy of current levels of income support and campaigns to increase Newstart (now Jobseeker) payments were regular topics of discussion with family members.

**Wellbeing: A lifelong quest**

Far from being ‘out there’ and unattainable, the idea of wellbeing tended for most to be something they had, more or less of, at different times under different circumstances, like ebbing and flowing currents rather than some fixed state or condition.

Stories framed around wellbeing tended to identify it as a state of mind, something over which a person has some capacity to influence or control. Family members spoke about doing things or having experiences that affected their wellbeing. Specific examples include activities like going for a walk, a run, or a ride, joining a group or club, spending time in nature, pursuing spirituality or engagement with religious or cultural practices, or spending time with people who they experienced as positive and supportive.

Family members who focused on wellbeing and holistic notions of health stand in a tradition of many who take a broader view of health including the World Health Organisation globally. These family members want our society to support people experiencing mental health challenges, including post psychosis and acute episodes of mental illness. They want to focus on attaining as full a life as possible and to not be defined by one’s illness and psychopathology.

Some family members described their journey from being diagnosed and treated for mental illness and the importance of working to improve their quality of life through various self-help disciplines.

One family member told how he had been diagnosed with schizophrenia and medicated. Over time he found he could reduce his medication and maintain himself as long as he practiced a highly regimented course of strict diet, meditation and being very careful to minimise exposure to negative influences.

Another family member recounted his journey post-diagnosis of mental illness and the many ways he found to manage his life and responsibilities including care for his children as a sole parent. Although he was keen to look for work, his GP recommended that he shouldn’t work and wrote him an exemption from mutual obligation requirements. This, in combination with his own consideration of his caring responsibilities and his mental illness management, led to a narrower job search to better suit his needs (e.g. only part time or FIFO work).

These stories, and others, illustrated a complex relationship between mental health and illness and ideas about wellbeing. What is most striking about such stories is the strong sense of individual responsibility that is evident in the ways family members talk about their wellbeing journey.

“It has taken me a while to be able to let go of the things I know are not good for my wellbeing.”

Some family members told stories that related their experience of mental health/mental illness and wellbeing to other factors in their lives. That is, family members wanted to talk about the social, environmental and economic factors that shape their lives. There are different trajectories among the stories. For some, poverty and disadvantage, a consequence of inequitable access to social, economic and political resources and opportunities, can lead to diminished mental health and wellbeing, while for others deteriorating mental health and wellbeing are believed to lead to poverty and disadvantage.

Certain experiences were sadly prevalent in many stories.

Negative experiences like abuse and neglect, particularly in the early years, played a large part in the trajectory of family members’ lives. How family members recounted
their stories also varied. For some, these early traumatic events were life defining as they struggled throughout their lives to overcome the impact of early trauma. Others mentioned these adverse events almost casually and in passing.

One family member in her 50s disclosed that, for over 35 years, she had never spoken about her experiences of sexual abuse, but wanted to use the interview process to tell her story of how this abuse had shaped her life.

Another young female spoke about two experiences of sexual abuse, which she disclosed to her parents. Her parents did not believe her (both alleged perpetrators were close family friends). She told how this led to a breakdown in family relations, leaving home at a young age, living on the streets and in insecure accommodation, self-medicating drug use and later mental health problems, psychiatric treatment including several stints of inpatient treatment in a psychiatric ward, and life on a disability pension.

In both of the stories above, the impact of adverse life experiences was considered to be the most significant factor contributing to their deteriorating mental health. Many other stories recounted equally traumatic events, but the way the stories were told it was much less clear exactly how much the family member felt these events affected them and their life trajectory. Some stories were told with a hint of bravado. It is hard to tell if this was a defence mechanism to cover up the pain, an expression of battle-hardened resilience, or exhausted resignation to a life of seemingly never-ending adversity.

Some family members talked about their struggles to get help to deal with the effects of trauma in their lives. The corrosive impact on mental health from exposure to violence in a range of contexts was a particularly strong theme.

“When you are on the streets you live in constant fear and have to be hyper vigilant all the time. You even learn to sleep with one eye open.”

“You can’t imagine how stressful it is to live in a home with the threat of violence always there.”

“I am in public housing now, so that’s good, but I still need to watch out, my neighbours are always going off about something.”

The issue of trauma-informed practice is particularly relevant to these stories. A growing field of theory and practice, trauma informed approaches explore new, evidence based practices to help people recover from the effects of traumatic stress.

The therapeutic principles that underlie trauma informed practice resonate strongly with the aspirations we have heard from family members through the qualitative research process. They speak to the personal and interpersonal challenges and developing or relearning the skills to function in an environment that is conducive to healing.

It’s all about relationships

Another strong theme through many of the stories related to the importance of the social realm. Stories of isolation, loneliness and the absence of positive social support, from family, friends and neighbours were linked to reduced mental health. Conversely, stories about positive and supportive social relations were highly valued by family members. Many participants commented that they valued the opportunity to participate in the interview process as it gave them an opportunity to tell their stories and be heard, which was, for many, a rare experience.

Stories that focussed on wellbeing tended to take a broad view of the many domains of human experience and the ways in which they impact a person’s wellbeing. In the focus groups we discussed these domains (family of origin, family members and their families, social networks, the service system and the macro social settings) and family members could identify many specific examples of impact from each domain and interactions between domains.

A very strong impression from all the family members’ stories is that relationships are very important,
regardless of domain. Family members tend not to discriminate between politicians, people that work for government, NFPs or neighbours when it comes to relationship quality. Empathy is critical across the board. Good listening skills are never out of fashion, for professionals as well as family and friends. The family members who spoke with us all demonstrated a well-developed capacity to discern when someone was being genuine and when they were just going through the motions. This applies particularly to professionals engaging with family members.

Having a relationship with someone who knew how to access systems and get things done (competence) was always highly valued. Many stories focussed on interactions between agency staff and family members. The outstanding workers always displayed empathy towards the person and competence in finding ways of accessing relevant support that met the needs of the family member. They never gave people the run around. They went out of their way to demonstrate respect for the person. Many stories also illustrated how outstanding workers always worked with people and respected their autonomy, not treating them as passive recipients of welfare services nor abandoning them to their own devices. Principles of reciprocity, mutuality and partnership appeared to be the hallmark of such outstanding workers and agency staff.

Grandparents caring for their grandchildren deserve special mention concerning the importance of relationships. At a time when most are considering cutting back or retiring, these extraordinary family members are stepping up to be primary carers for their grandchildren, for a range of reasons. Though their circumstances varied widely, the most notable feature is that their caring roles have contributed to financial hardship. Their stories powerfully illustrate the importance of care in our society, as well as the sometimes-intense personal cost to carers.

The other group of carers worthy of special mention are Aboriginal families where many, particularly females, but also some exceptional males, struggle to provide care for family and extended family, often in very disadvantaged circumstances.

Conclusions

We asked family members how they wanted their stories told. We heard that people in entrenched disadvantage do not want to be treated as bystanders but as active agents in their own lives and stories. They do not want to be blamed and written off as defective humans. They are keen to take responsibility and ‘give something back’. The main message they wanted us to share is that they are just like everyone else. They want good things for themselves and their families. They want to be active citizens in a world where they can meet their own needs as well as access the support they need to overcome the challenges they experience along the way. They also want to help others achieve their goals. The drive to become the most they can be in life is an essential part of human nature. We all share in this drive. The society we all want to live in is one that takes seriously the goals we all share, and the demands of justice.

To the family members: on behalf of the qualitative analysis team and the interviewers, it has been a great honour to have the opportunity to hear your voices and learn from your stories. We are humbled by your courage and encouraged by your strength. We have learnt so much from you about the complexity of living in entrenched disadvantage in Perth, Western Australia.

It seems impossible now to think of mental health and wellbeing in these circumstances without acknowledging the many ways that social policies, service systems and organisations interact with you, your families and friends - for good and for ill.

It is more than clear to us that a lot needs to change to make a real difference for you and your families. There are no easy answers or “quick wins”.

On behalf of the 100 Families WA Project Team we want to thank you for your gracious, open, and very real contributions. We will continue to share our insights from the interviews in a full report, due for release in May 2021.

We cannot make any promises at this stage, except that we will continue to reflect on all you have said and work with our networks to relay what you have said faithfully. It is our hope by pursuing honest dialogue we will find some ways to support you and others in similar situations better in the future.
100 Families WA is a collaborative research project between Anglicare WA, Jacaranda Community Centre, the Centre for Social Impact University of Western Australia (CSI UWA), the UWA Social Policy, Practice and Research Consortium, the UWA School of Population and Global Health, Wanslea Family Services, Centrecare, Ruah Community Services, UnitingWA, MercyCare, and WACOSS. 100 Families WA has a commitment to ongoing engagement in the project of those with lived experience of poverty, entrenched disadvantage and social exclusion.

The ultimate aim of the project is to develop an ongoing evidence base on poverty, entrenched disadvantage and social exclusion in Western Australia that will be used by the policy and practice community in Western Australia continuously over time to understand better the lives of those in low income poverty, entrenched disadvantage and social exclusion, the impact and effectiveness of the community sector and government initiatives and service delivery processes and what those in entrenched disadvantage see as important for positive change.

The project has received in-kind support from all partners, seed funding from the Centre for Social Impact supported by The Bankwest Foundation and the School of Population and Global Health (UWA). At the 2018 WACOSS Conference, the Premier of Western Australia, the Honourable Mark McGowan announced the $1.75 million grant on behalf of Lotterywest for the 100 Families WA project.

Citation: