

Family Leadership Forum Final Report

7th February 2022

Activating the Vision for Sustainable Family Leadership in WA

Report from the Family Leadership Forum 19th and 20th November 2021





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PART 1 Background



The Family Leadership Forum was initiated and hosted by **Valued Lives Foundation** as a collective community effort in collaboration with a Co-design Planning Group and with the NDIA's Local Area Coordination Partners in the Community.

The Forum was supported by an Information, Linkages and Capacity (ILC) grant through the Department of Social Services (DSS) and had strong connections to the Peer-to-Peer Networks WA project hosted by Valued Lives as well as other WA family leadership initiatives.

The forum was also strengthened by Valued Lives' strong connections to the National Alliance of Capacity Building Organisations (NACBO) and also the International Initiative for Disability Leadership (IIDL).

Information on the Forum was provided to key organisations in WA with a commitment to later provide a copy of the report and meet to discuss the future directions/next steps.

Valued Lives Foundation is a Disabled Peoples Organisation and Family Organisation (DPO/FOs). 75% of the Board identify as having a disability or provide care and support for a family member. 66% of the Valued Lives paid staff who are in a full time or part time role also meet the same criteria.

Valued Lives vision is that "People living valued lives in welcoming

communities, having real choice and real control of their own lives and a genuine voice" and mission is "Enabling vulnerable people to live valued lives in their local communities by providing, tailored planning, peer support and innovative, responsive, flexible supports and services.:

The Family Leadership Forum purpose was to rebuild Family Leadership as a viable, sustainable resource for people and families in Western Australia.

The Forum objective was to reinvigorate Family Leadership activities across WA and develop a sustainable model of ongoing support and resources for family leaders. It set out to reconnect existing family leaders (in both disability and progressively mental health) and develop the skill set of emerging family leaders. The connection with mental health is a unique feature of this collective effort, both in regard to people with psychosocial disability and the broader mental health sector.

The desired Forum outcomes were to:

- Co-design and deliver a weekend Family Leadership Forum
- Establish a network of experienced and emerging family leaders that remains connected past the life of the Valued Lives Peer- to-Peer Networks project and other "parent to parent" activity
- Provide an end of project Report which contains a consolidated narrative on why family leadership is important, mapping of some key past and current efforts in WA/nationally, process of /outcomes from the forum and future strategic directions /actions.

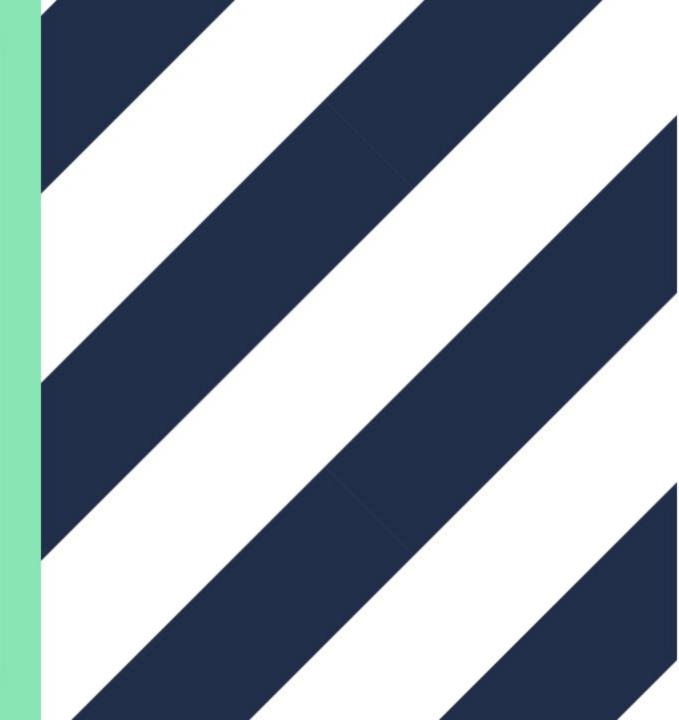
The primary audience for this forum was a combination of established and emerging family leaders (including current Peerto-Peer Networks Facilitators) and key organisational or individual supporters. The leaders came from metropolitan, regional and remote locations and from both the disability and mental health sectors. Members of the Co-design Planning Group nominated and supported 1-2 people each.

The Co-design Planning Group had a majority of families and included the host (Valued Lives Foundation) and key supporting organisations (WA Individualised Services, Developmental Disability WA, Wanslea Family Services, Microboards Australia) and family led groups (Stepping Stones).

Mental Health Matters2 joined the planning later in the process, however, participated in the full Forum including a featured presentation.

The secondary audience were key supporting organisations, including, but not limited to DSS, NDIA, Western Australian State Government, Western Australian State Minister for Disability, Local Area Coordination (Mission Australia and APM) and Early Childhood Early Intervention (Wanslea Family Services) Partners in the Community.

PART 2
Program Overview
and Evaluation



"I want to be more available to family members in the community who need help."

- Parent who attended the Family Leadership Forum



The Forum program spanned 1.5 days (plus evening dinner) with workshops titled "Inspire, Learn Together, and Consolidate."

It was designed to be highly engaging, inclusive and interactive with a focus on developing strong content for the Forum Report, especially around the theme of sustainability. It also sought to place current family leadership efforts in the context of what has gone before and how WA family leadership efforts connect nationally and internationally.

The full program is attached as Appendix 1. Some key features of the Forum included:

Hosting by Valued Lives Foundation but very much a collaborative community partnership effort

Effectiveness of the Co-design Planning Group which not only enabled design of the Forum but also a network partnership approach where each member identified and supported 1-2 families to attend, with broad diversity in mind – thereby enabling a strong and connected core of participants. The important financial support of Valued Lives to enable family participation where travel or accommodation was requited

independent facilitator (Eddie Bartnik) worked with two experienced family facilitators (Jane Browne Eacott and Jaquie Mills)

The importance of the Welcome to Country by local Aboriginal Elder Cheryl Taylor in setting the scene for inclusion and diversity

Inclusion of mental health through the contributions of Margaret Doherty from Mental Health Matters 2. When asked about the two sectors coming together, it was noted that while there were some differences in context/culture (e.g., age of onset), there were strong similarities around a "common cause - human rights, love and dignity, the importance of connection."

A total of 26 participants plus two additional family speakers who participated in one session only.

The majority were families, followed by organisational supporters and some who were both family/organisational supporters. Families included individuals who self-identified as having a disability and also various age groups.

The quality and impact of each presentation was outstanding, and nearly all participants completed an evaluation questionnaire (rating each session on a 1-7 scale plus comments) at the end of the Forum before leaving.

At a high level, the feedback indicated:

Everyone filled in a feedback form, some were only partial as people missed a few sessions etc. So, there was nearly a full sample which is rare and makes the data more compelling.

Results for the families' group were just a touch higher than for the supporting organisations group, but overall feedback was fairly consistent across all attendees

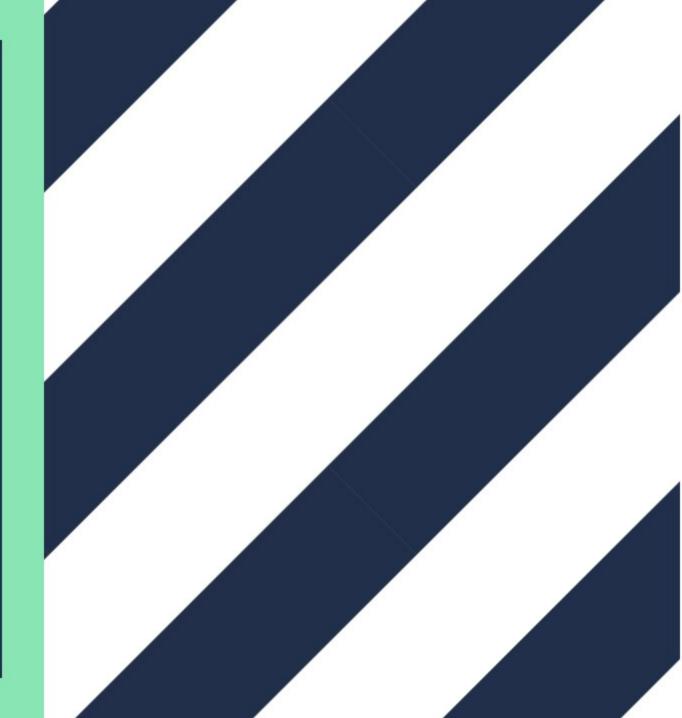
Overall forum rating for relevance was an average of 6.54/7 or 93.4% and for quality was an average of 6.41/7 or 91.4% (venue was an issue here)

Individual session ratings varied between 6.21/7 to 6.82/7 with an average score of 6.5/7 or 93%.

The highest rated sessions were the dinner session on mental health and the first afternoon "Inspire" session on individual stories and impact

Overall, the data shows the event was an outstanding success and highly valued by all participants.

PART 3
Outcomes from the
Family Leadership
Forum



"I plan to reinvigorate my organisation to link into Peer Networks and support families."

- CEO of Disability Support Organisation who attended the Family Leadership Forum



The following sections include the agreed wording from the meeting to cover:

- A clear narrative on what is Family Leadership and why is it important?
- Placing current Family leadership initiatives in the context of both the substantial family leadership movement before us and also the network of national and international allies and initiatives
- A strategic framework including our vision for Family Leadership in WA (2022-2027), underlying principles and key strategies, including priority next steps and key actions to activate the collaborative effort.

The consolidated narrative on what is family leadership and why is it important? follows:

What is Family Leadership?

- A unique process for each family
- A continuum of emerging to established leaders

There are different levels of family leadership: individual, leading your own family, peer to peer, collective and systemic. Outcomes include a good life for the person and a good life for the family.

Key elements include support of and investment in families plus recognition leading to co-design

When we use the term "family leadership" this is not just parents but includes the person with a disability and the extended family as well

(Margaret Rodgers, NACBO).

A helpful framework (courtesy of DDWA) is to think of the 5Rs – Respect, Research, Resilience, Reinforcements and Respite.

Subsequent to the Forum, Mary Butterworth from DDWA has also provided some helpful clarification of the term Family advocacy as follows:

"Family Advocacy is when a family member of a person with disability advocates for that person. You will support your family member to help them get what they need to live a full and equal life. Advocacy agencies can support you to learn how to advocate for your family member and how to speak out on their behalf. As a family member, you know the person better than anyone else and are often best placed to be able to promote their views and wishes."

https://www.dana.org.au/how-to-advocate/

"The value of lived experience shared was amazing."

- Attendee at the Family Leadership Forum



In addition, the Forum agreed Family Leadership is important:

to get the best possible outcomes for people with disability to support families to have a voice

to enable effective co-design of systems and services, and

because services cannot be successful without a sound understanding of family leadership.

An important part of setting the scene for the Forum was a session which included descriptions of where WA family leadership initiatives fit into the broader context and some preliminary mapping of what has gone before.

This included:

a local story of a family journey in WA through the strong times when family leadership was a core part of Local Area Coordination practice and consistent relationships and was even recognised and embedded in the Disability Services Commission (DSC) Strategic Plan. This was compared to the recent NDIS period where the emphasis has been on transition to the NDIS and funding plans and family leadership has "slipped off the radar"

a description of the role of Valued Lives as a member of a national alliance of similar organisations - the National Alliance of Capacity Building Organisations (NACBO see link: National Alliance of Capacity Building Organisations (nacbo.org.au)). There is a strong national movement collectively, however the status of each organisation and their previous local state government funding has been impacted by the transition to the NDIS

an outline of Australia's membership of the International Initiative for Disability Leadership (IIDL see link: IIMHL - Home) since 2015 and the network of family leadership organisations across the various member countries.

A preliminary timeline of key Family Leadership events in WA is attached as Appendix 2.

The key points to emerge from this discussion were:

Family leadership has created some of the important developments in the history of WA disability services Family leadership is a substantial national and international collective effort

Family leadership was a key foundation of the disability strategy in WA for the period 1990 -2015 however lost focus after that time in all the transition to the NDIS national Scheme

Short term project funding has created opportunities, however there is a need for a sustainable collective strategy in WA that can be a hub for all resources and leadership development and a catalyst for more systemic recognition by both governments and service providers alike. The focus must shift away from primarily funding in plans to the vision for a good life and the contributions of individuals, family, friends and the community in partnership with and supported by services.

The Forum then worked on the vision, principles and strategies for Family Leadership and generated some high-level statements which will become a working document for refinement as the collaborative process with families and partnering organisations unfolds. Most attention was spent on the strategies section so that there would be some clear next steps to carry the work forward, including engagement of broader stakeholders and further refinement of the document, including the notion of a shared Charter.

The discussion on a shared Vision for Family Leadership 2022-2027 generated a few high-level descriptions and a list of key elements which capture the key ideas arising from the discussion.

At a high level:

"We have a state-wide peer to peer family leadership network that is resourced, equipped, recognised and valued"

Or

"To grow an inclusive, sustainable, influential, knowledgeable and united group with lived experience to provide support and advocacy and to drive systemic intergenerational change for families"

Or

"In 5 years, every family feels empowered to use their voice. There is authenticity and connection."

Subsequent to the Forum, the Co-design planning group considered it to be important to include all three draft statements for the moment, recognising that the full group could usefully resolve this preferred vision at a future meeting, including separating out the longer-term vision from the 2022-2027 short term goals and plan.

"The forum reinforced the importance of value of integrating family leadership into the LAC framework and operations."

- Attendee at the Family Leadership Forum



The following draft principles were generated by the Forum:

- Recognition of the natural authority of families
- Key competencies acknowledge lived experience expertise as a valid and primary source of knowledge. Families have a unique perspective and support, (requiring unique supports & systems), as does the person with a disability. Recognise the value of family voices around the table.
- Human rights are fundamental and the UNCRPD using it as part
 of the work, a vision for ensuring PWD to live a self-determined life.
 (FUTURE GROUP WORK Establish terminology for example good
 life vs self-determined life terminology. Finding a framework so that
 all of those key elements can co-exist)
- Influence so that everyone can choose their own destiny via an individualised approach.
- If services better met the supported decision making of the individual, the families are better supported and the "competition" for resources may be reduced? Timely recognition and availability of adequate resources to address needs can make a huge impact on lives. Sensory and communication supports to underpin inclusion and supported decision making.
- Inclusive of diverse communities (e.g., CALD, Aboriginal and Torres Strait Islander peoples and LGBTQIA+)
- Encouraging connectedness between families is critical/essential to healthy family life (fosters leadership opportunities). Kids do need support but parents do too: full cup = better outcomes.

- We need to acknowledge family responsibilities and that their needs are often more intense/complex.
- Family leaders are recognised and mobilised so that families experience less of a gap between diagnosis and connection.
 Equality underpinned by equity: people are resourced according to their needs to achieve the outcome
- People with disabilities and families before professionals
- Family Leaders are critical to influence the future of key systems including the NDIS.
- Legacy Recognise record and share the learning and stories of what has gone before (intergenerational approach) Mentorship – opportunities for mentoring of emerging family leaders, developing a succession plan.
- We need people with disability to be present in university and training courses, and innovative approaches to therapy. Build the "practice of parents" and upskill families to provide side by side therapies. Recognise the shortage of professionals.
- Deliberate development of a lived experience workforce academics, practitioners, key decision makers (it is more than just support workers)
- A goal of sustainable systemic change requires the support of key organisations and professionals The FIVE R's (Respect, Research, Resilience, Reinforcements, Respite) plus 1 – Reciprocity)

PART 4
Strategies and priority actions



"Hearing people's stories and knowing family leadership is coming back on the table was great."

- Family member who attended the forum



Actions to be achieved by 2027:

- Establishing the right structure for collective effort in WA
- A Charter for organisations to sign up to, in accessible language that everyone can understand
- Develop language and content for organisations to use about Family leadership, embed in organisations DNA, website etc. WA is part of an intrinsic to a
 national and international movement
- Need a (or many) champions of change and a determined strategy to move forward
- Collaboration and making most of national and international opportunities
- WA is part of an intrinsic to a national and international movement. Connect WA initiatives to national through NACBO.
- Leverage membership of IIDL to engage with the international family leadership collaborative and events such as March and October 2022
- Consolidating and communicating the story of family leadership in WA
- · Family leadership is a nationally recognised forum, is accessible for all families, from all groups it is the one common space where we can all connect
- Use plain English for everyone and visuals to explain ideas
- · WA is part of and intrinsic to a national and international movement. Write up the Family Leadership Forum report as a key public document.
- · Connecting, sharing information and expanding reach
- Resource hub to reach out to more people (and connect existing efforts and resources) Capture stories like the ones we have had here and share them
- Regular communications/recommended readings/newsletter to share (e.g., illustrating key principles as per Eddie's example of LAC Network from the UK)
- Progressively build on mental health connections through the current engagement with Mental Health Matters 2

- Developing Key Partnerships
- Follow up meetings with key organisations following completion of the report include:
- Ministerial Advisory Council and others, (also IAC and Leighton Jay)
- Family leadership is back on the table as a recognised strategy for government and non-government organisations
- Revisit ILC framework and opportunities for partnerships between Family leadership initiatives and the work of NDIS Partners Family leadership conference in WA
- Family leadership conference to bring together the underground as well as the visible leaders, progressively including mental health Embedding family leadership concepts into policy, standards and disability plans
- Family leadership needs to be named in the State Disability
 Plan
- Introduce NDIS standards around family leadership
- Sustainable investment in family leadership
- Ongoing need for investment in family leadership it is an ongoing rather than one off issue (and there are always new families
- coming into the sector and leaders changing over); always a movement cradle to grave
- Seek corporate investment, not just government grants

Next Steps

- Contact all participants to seek consent to establish am email group (completed December 21)
- Finalise report after lap of feedback with codesign group (completed December 21) and all Forum participants in January 22 (completed)
- Co-design planning group to meet late January 22 to finalise report and plan best process for re-engagement of broader Forum participants (completed with workshop planned for March 2022)
- Commitments from Co-design Planning Group to plan for a local collaborative structure and broaden the base to ensure greater diversity and inclusiveness (ongoing)
- Need further discussion on what priority requests we might ask for when we meet with key organisations? (Priorities include some coordination resources and proposal for model coherency workshop series)
- Meetings of the Co-design Planning Group and also with key external stakeholders in February/March 2022



Attachments

Appendix 2: Timeline and Significant Milestones of FL in WA



| | Year | Key Milestones |
|---|---------------|---|
| 0 | Pre 1990's | Families founded many of the significant WA disability organisations including what are now called Activ foundation and The Ability Centre |
| 0 | | Authority for Intellectually Handicapped (AIH) had a community Board including family leaders, this continued with the Disability Services Commission (DSC). Regional Advisory Forums and then Ministerial Advisory Council embedded the voice of people with disabilities and families |
| 0 | | Local Area Coordination commenced in 1988 in Albany and LAC Framework included recognition of individuals and families and their involvement in staff selection, training, program evaluation teams and annual forums; establishment of Family Support Associations in regional areas |
| 0 | | Developmental Disability Council established 1985 to support people with developmental disabilities and their families |
| 0 | 1990's | Local Area Coordination family leadership strategy, [progressively included in DSC Strategic Plan 2005). Systematic investment in training and access to international speakers |
| 0 | | ECU Training course (National program for Leadership and Service Development) for all new LACs and families/people with disabilities and staff |
| 0 | | Family sponsorships to attend training and workshops |
| | 2010 - now | Planned Individual Networks (PIN Inc) established by Families 2006, Microboards Australia Inc established by families 2008 – both initiatives had early developmental support from LAC and DSC plus Perth Home care Services |
| 0 | | MentalHealthMatters2 established by families |
| | | NDIS trial site from 2014, My Way and WANDIS in parallel. Strong focus on transition and NDIS funding plans. WA joins national NDIS and WA LAC system disbanded and replaced with NDIS Partners in the Community |
| | | Information Linkages and Capacity Building Strategy launched 2016 through NDIA and then DSS. Disabled People's and Family Organisations funding strategy leading to Individual and Family capacity Building strategy with time limited grants |
| | | 2015 DDC Family Leadership in WA conference and support for overseas study tour to Canada |
| | | D.Dads established for fathers |
| | | Valued Lives Foundation joins NACBO – the National Alliance of Capacity Building Organisations who support Family Leadership |
| | | Family peer programs established by DDC (Side by Side) and Valued Lives (Peer to Peer) with short term funding |
| | | 2015 Australia joins the International Initiative for Disability Leadership which has a Family Leadership collaborative between member countries, Valued Lives |

KEY ELEMENTS FROM THE FORUM DISCUSSION, UNDERPINNING THE 2022-2027 VISION

- Representation of people with disability who are included in the co-design of family leadership Recognition of people and families voice back on the table
- Diversity of people and culture Inclusive
- Reaches lots of different places, cultures and regions Places where is it housed?
- A Charter of what we believe in Creating and connecting networks
- Access to information and resources to support planning and decision-making Support to be courageous
- Translator and advocacy support
- · It is not just "leaving it to the leaders or Elders" in an Aboriginal context Empowered by a collective strength and power to act
- People reclaim their power
- Support for families at the beginnings of their journey (with families who are "further down the road") Connections, a vision that people can be connected
- Sustainable family leadership that is respected and sustainably resourced
- Sharing learnings with constant opportunities for families to learn from each other. Family leaders are informed of what's available.
- Family leaders are a resource for the sector including government and community organisations



EVENT PROGRAM AT A GLANCE

FRIDAY NOVEMBER 19

CONNECT AND INSPIRE

1PM TO 5:15 PM

Informal lunch and workshop NETWORKING AND DINNER

5:15 TO 8PM

Featuring a conversation with Margaret Doherty (Mental Health Matters2) and Marita Walker about Family Leadership in Mental Health (DINNER FROM 6PM)

SATURDAY NOVEMBER 20

LEARN TOGETHER
Sharing individual journeys,
and our collective
experiences, discussion on
the principles and key
strategles of Family
Leadership

9AM TO 1:15PM

LUNCH

1:15 - 2PM

CONSOLIDATE

2PM - 3:30PM

Using our vision, goals and strategies to develop a collective plan of action for the future of Family Leadership in WA

CLOSE

3:30PM 4PM

FOR MORE INFORMATION PLEASE CONTACT

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EVENT INFORMATION

<u>Purpose</u>: To rebuild Family Leadership as a viable, sustainable resource for people and families in Western Australia

Objective

To reinvigorate Family Leadership activities across WA and develop a sustainable model of ongoing support and resources for family leaders. The purpose is to reconnect existing family leaders (in both disability and progressively mental health) and develop the skill set of emerging family leaders.

Our Desired Outcome

- To develop a weekend Family Leadership forum (1x ½ day plus evening dinner). Workshops are titled "Inspire, Learn Together, and Consolidate."
- Establishment of a network of experienced and emerging family leaders that remains connected past the life of the Valued Lives Peer-to-Peer Networks project and other "parent to parent" activity
- An an end of project Report which contains a consolidated narrative on why family leadership is important, mapping of some key past and current efforts in WA/nationally, process of /outcomes from the forum and future strategic directions/actions.

For additional information contact Valued lives www.valuedlives.org.au info@valuelives.org.au (08) 9274 7760