

Opportunities and Challenges in Rehabilitation,
Ageing, and Independent Living:
**A White Paper by Friends of the
RAIL Research Centre**



*Friends, key informants, and contributors to the
Formal Launch of the Friends of the RAIL Research Centre*



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Authors: Friends of the RAIL Research Centre, including RAIL Research Centre staff who attended the Formal Launch of the Friends of RAIL Research Centre event at Monash University, Peninsula Campus, Frankston (Australia) on 2nd November 2023, Frankston.

This included contributions (in alphabetical order) from 13 Friends of RAIL: Bernadette Clancy, Britta Morrison, Chris Le Cerf, Coral Keren, Doug Webster, Grainne Cruickshank, Joy Green, Kristine Camilleri, Margaret Thomas, Pam Webster, Peter Clancy, Stephen Peterson, Teresa Cannon and Vincent Rovtar and 9 RAIL staff members: Aislinn Lalor, Christina Ekegren, Karine Fortin, Keith Hill, Libby Callaway, Michelle Shannon, Natasha Layton, Raphaelle-Ashley Guerbaai, and Sze-Ee Soh. RAIL Centre Director, Natasha Brusco, also contributed to planning the event and drafting this white paper with our Friends.

About the RAIL Research Centre

The Rehabilitation, Ageing and Independent Living (RAIL) Research Centre is located in the School of Primary and Allied Health Care at Monash University's Peninsula Campus in Frankston, Victoria.

The RAIL Research Centre's vision is to contribute to a world where communities thrive, with access to evidence-based programs that have positive health, economic, and social impacts and inform knowledge, policy and practice across the areas of disability, rehabilitation, ageing, and independent living.

For details, go to <https://www.monash.edu/medicine/spahc/rail/home>

Acknowledgements

We acknowledge the Bunurong People upon whose lands the workshop that informed this white paper was run, and we pay our respects to Elders past and present.

We would like to acknowledge the support of Professor Terry Haines (Head of the School of Primary and Allied Health Care) who formally launched the Friends of RAIL network - during which the round table focus group activity that informed this white paper was run - on the 2nd November 2023, Dr Em Bould for the thematic mapping image design, and all other Friends of RAIL who contributed to bringing this paper to the community.

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Key Informants and Contributors to this White Paper30



Back row from left to right: Teresa Cannon, Bernadette Clancy, Aislinn Lalor, Libby Callaway, Peter Clancy, Chris Le Cerf, Grainne Cruickshank, Margaret Thomas, Vincent Rovtar, Raphaelle-Ashley Guerbaai, Stephen Peterson, Doug Webster

Front row from left to right: Michelle Shannon, Keith Hill, Natasha Layton, Christina Ekegren, Kristine Camilleri, Karine Fortin, Joy Green, Pam Webster, Sze-Ee Soh

Absent from the image but contributors on the day: Coral Keren, Britta Morrison

Summary

A white paper is a report that ‘offers a focused description of a complex topic and presents the point of view of the author/s or body represented by the author/s - the purpose of a white paper is to give readers understanding of an issue’¹. Working with Friends of the Rehabilitation, Ageing and Independent Living (RAIL) Research Centre², RAIL staff hosted a round table focus group in November 2023. This round table aimed to listen to the views of Friends of RAIL regarding opportunities and challenges they saw across the areas of rehabilitation, ageing and independent living. The RAIL team wanted to learn from our Friends and then think about research and projects that the RAIL Research Centre may undertake that could either harness the opportunities or address the identified challenges.

What we heard from our Friends was:

- written down word for word during the round table
- analysed by RAIL team members to look for key themes or messages, using the Socio-Ecological Model³
- drafted into a report of findings
- presented back to our Friends for checking, editing and feedback
- finalised in this white paper
- wrote concluding reflections on what our Centre heard from Friends of RAIL in the white paper
- shared with our Friends of RAIL and the broader community.

We found different themes from what our Friends told us across the topics of rehabilitation, ageing and independent living. We have reported these themes using images, diagrams, and words.

We are very grateful to our Friends for their contributions and hope you enjoy reading this white paper. If you have any questions about it, please call (03) 9904 4557 or email spahc.rail@monash.edu.

This image was produced by Simon Kneebone as part of codesign research delivered by the RAIL Research Centre with collaborators including people with lived experience of dementia⁴



¹ https://libguides.uml.edu/whitepaper_style

² <https://www.monash.edu/medicine/spahc/rail/friends-of-rail>

³ <https://pubmed.ncbi.nlm.nih.gov/3068205/>

⁴ <https://onlinelibrary.wiley.com/doi/10.1111/hex.70036>

The Journey so far for RAIL and its Friends

The Friends of RAIL network was established in 2021, as one of three key stakeholder networks engaged by our Research Centre. Friends of RAIL are end-users of any of the Research Centre's outputs across the streams of rehabilitation, ageing and/or independent living, and include those people with their own personal experience of rehabilitation, ageing and independent living or disability care; family members and friends, including care partners; and other informal supporters who may provide support for decision making or be an appointed representative of a person with lived experience, and who may contribute to any stage of the research continuum. For details, go to: <https://www.monash.edu/medicine/spahc/rail/friends-of-rail>

Friends are vital to the RAIL Research Centre as they have first-hand experience of rehabilitation, ageing and/or independent living which are the key areas of research for our Centre. Friends of RAIL provide a non-clinical and non-research lived or learned experience perspective which is highly valuable in identifying and ranking our Centre's research priorities. It also helps the RAIL team to design both research and project work with consumer and community lived experience expertise central to this design. At the RAIL Research Centre, we are committed to conducting research that occurs with the community rather than only conducting research for the community. After running a variety of community engagement events for RAIL Members, Partners and Friends in 2021 and 2022, in 2022 RAIL appointed Consumer and Community Engagement Leads, Dr Aislinn Lalor (Senior Research Fellow at RAIL) and Ms Grainne Cruickshank (Consumer Representative). On 1st June 2023, the RAIL Research Centre ran the first dedicated Friends of RAIL networking event on Monash University Peninsula Campus. We formally launched the Friends of RAIL network and ran a round-table focus group activity that informed this white paper, on 2nd November 2023.

RAIL also has a Members network - consisting of Monash academic staff and students educating, learning, or researching across the areas of rehabilitation, ageing and/or independent living - and a Partners network made up of external industry stakeholders, including health, aged care and disability provider networks, research and education partners and collaborators external to Monash, and funders of rehabilitation, ageing and/or independent living research and project work. For details of these other RAIL networks, go to:

- Members: <https://www.monash.edu/medicine/spahc/rail/members>
- Partners: <https://www.monash.edu/medicine/spahc/rail/partnerships>

Message from our Friends of RAIL Co-Leads

Friends of RAIL is a consumer and community network established by the RAIL Research Centre in 2021 - for details, go to <https://www.monash.edu/medicine/spahc/rail/friends-of-rail>.

As the Friends of RAIL Co-leads for Consumer Engagement, we are delighted to present this white paper, "*Opportunities and Challenges in Rehabilitation, Ageing, and Independent Living: A White Paper by Friends of the RAIL Research Centre*".

A white paper is a detailed report that explains a complex issue and offers solutions or recommendations⁵. White papers are often used by organisations to share information, propose policies, or guide decision-making. This white paper was developed over five phases with more detail about each phase and the overarching model provided throughout this white paper:

1. Phase One: Late 2023

Key messages from three Friends of RAIL, Vince, Coral, and Chris, were collected to inform in-depth discussion at the Formal Launch of the Friends of RAIL event on 2nd November 2023.

2. Phase Two: 2nd November 2023

Building on good co-design foundations (Dawda & Knight, 2018, p. 14) and the key messages from Vince, Coral and Chris, in November 2023, the RAIL Research Centre invited our Friends to meet together in person on the Monash University Peninsula Campus to explore their individual perspectives on the challenges and opportunities that exist across the areas of Rehabilitation, Ageing and Independent Living. This process aimed to create a time and place for informed reflection upon opportunities and challenges across our Centre's three core areas of research, education and project work: that is, the areas of rehabilitation, ageing and independent living, including experiences of disability.

3. Phase Three: Early 2024

All data collected at the Launch of the Friends of RAIL event on 2nd November 2023 was collated and summarised and then developed into themes according to the Socio-Ecological Model. A summary of this data (see Appendix A) was provided to Friends of RAIL prior to the mid-year Online Friends of RAIL event on 1st July 2024.

4. Phase Four: 1st July 2024

At this point, peer debriefing, including a review of the data, emerging themes and research process was undertaken with a group of Friends, using an online discussion (Creswell & Miller, 2000). Friends of RAIL participated in a guided discussion (based on Appendix A) to provide feedback about the identified themes across the 5 levels of the Socio-Ecological Model. Attendees were able to provide anonymous responses to questions via online polls as well as provide comments directly within the online forum either verbally or in written format. Subsequent feedback was used to inform Phase 5.

⁵ https://libguides.uml.edu/whitepaper_style

5. Phase Five: Late 2024

The following white paper was finalised with the consent of Friends who contributed to the Phase One and Two sessions. It draws on the verbatim perspectives provided by the Friends from the Phase One session, and their perspectives have been summarised (Phase Two) and mapped to the Socio-Ecological Model, with additional clarification (Phase Three) to culminate in this final version of the white paper. This white paper will initially be disseminated to Friends of RAIL attending the End of Year Friends of RAIL event for 2024 (rescheduled for February 2025), following which, it will be available to all members of the public via the RAIL Research Centre website.

Thank you for your interest in this white paper and the work of our Friends of RAIL and the RAIL Research Centre staff members in bringing this paper together as a valuable resource.

We hope you enjoy reading it.

Grainne Cruickshank
Consumer Representative
Head Friend



Grainne (with her late husband Peter)

Dr Aislinn Lalor
Senior Research Fellow
Consumer & Community Engagement Lead



Aislinn (with her reclassified Guide Dog Jazara (left) and guide in training Helga (right))

A Message from the RAIL Research Centre Stream Leads

Evidence-based practice involves the combination of three elements - best available evidence, clinical expertise, and the preferences and values of 'patients' – that is, those people participating in healthcare (Sackett et al., 2000). Identifying, understanding, and seeking the perspectives of consumers and community members in healthcare is both critical and under-researched (Hill, 2011). The Monash University RAIL Research Centre holds central to its structure the perspectives of consumers and community members. For example, consumer representatives:

- sit on the RAIL Research Centre External Advisory Committees
- are employed by RAIL as researchers to co-design and co-produce new evidence
- are contracted to offer lived experience expertise in the development of education resources, and
- through - our Friends of RAIL network - are engaged as part of critical reflection of our Research Centre priorities, activities, and capabilities (Masterson et al., 2022).

This white paper provides co-designed and co-produced evidence from Friends of RAIL regarding the opportunities and challenges across our Centre's three core areas of research, education and project work being rehabilitation, ageing and independent living, and including experiences of disability.

Our Friends of RAIL perspectives will continue to guide the work of the RAIL Research Centre, and we look forward to the range of future opportunities planned to listen to and learn from Friends of RAIL.

Associate Professor Natasha Brusco
Centre Director and Rehabilitation
Stream Lead

Professor Keith Hill
Inaugural Centre Director and Ageing
Stream Lead

Associate Professor Libby Callaway
Independent Living Stream Lead



Left to right: Associate Professor Natasha Brusco, Professor Keith Hill and Associate Professor Libby Callaway

Phase One: Messages from Some of Our Friends of RAIL

In preparation for the Formal Launch of the Friends of RAIL – and associated round table focus group – that informed this white paper, Independent Living Stream Lead Associate Professor Libby Callaway interviewed three Friends of RAIL. These three Friends have contributed their expertise within the RAIL Research Centre across research, education and/or project work and within the streams of Rehabilitation, Ageing and Independent Living since early on from the inception of RAIL. Their names are Vince Rovtar, Coral Keren and Chris Le Cerf.

The following few pages detail some of the key messages that Vince, Coral and Chris shared in these interviews, listed in point form with their guidance, and used to open the in-depth discussion undertaken with our Friends during the Formal Launch of the Friends of RAIL event and round table focus group hosted by RAIL on 2nd November 2023. We are grateful to Vince, Coral and Chris for their early contributions that helped to shape the design of the round table focus group.

Vince Rovtar



Two questions for Vince

From your lived experience perspective, what are the key opportunities that exist in Rehabilitation and Health Care?

New funding schemes like the NDIS have made available the therapy I need, which is built around my goals to help me develop my strengths and skills.

Assistive technology – like my leg brace, my off-road walker and the car rack for me to transport it, and home modifications like grab rails, a raised toilet, and a lift to get me upstairs –allow me to further my rehabilitation and stay living where I want to live.

When I went to rehabilitation, I went there kicking and screaming and didn't want to go, but with a good therapist – who tailored their input to my specific needs – I saw the benefits it gave me and I became a real advocate for it.

Peer support can help other people to engage in rehabilitation and can be an important enabler of good outcomes.

What are the current challenges that exist in Rehabilitation and Health Care from your perspective?

When you are living with disability or health condition, you risk becoming invisible to the public or may be viewed as having 'nothing to give' – I have found people may ignore you or talk to your family rather than you, and that is wrong.

Whilst going through rehabilitation, I was feeling isolated and depressed and I have needed to plan for equipment and other supports to help to change that.

Carers need as much support as their family member going through the rehabilitation – they face their own challenges, stressors and adjustment issues that need to be considered and addressed so that they can continue to support their family member in 'real life' over time.

Development of strong support teams is needed to assist a person to look forward, and not backwards, to re-enter life ... not always an easy task!

Coral Keren



Two questions for Coral

From your lived experience perspective, what are the key opportunities that exist in the area of Ageing?

There are some interesting opportunities available to maintain or enhance mental health or social connection – for example, U3A or other University short course programs and social clubs and community centres offer a range of programs linked to shared interests.

There is a very useful primary healthcare program funded by the Government which offers a nurse practitioner-led care plan discussion and development, including links to allied health professionals if required.

There are good resources available to aid fall risk management, including the availability of fall clinics for older adults that people can take advantage of.

What are the current challenges that exist specific to Ageing from your perspective?

Age discrimination can occur in healthcare programs - for example, breast cancer can occur at or after the age of 75, yet annual screening reminders cease for women at that age.

Whilst public transport can enable community travel, if transport is not accessible (like via low-rider bus or tram systems) and drivers are not considerate of the balance and mobility needs of older passengers, safety or access issues can arise.

Building design is another area where universal access is required, and architects and designers are not always trained or fully aware of various community members' access requirements.

Chris Le Cerf



Two questions for Chris

From your lived experience perspective, what are the key opportunities that exist in the area of Disability and Independent Living?

Assistive technology helps me to do the things I want to do in my day, like my mobility aids, my home automation system, and my talking book library from Vision Australia.

I now have freedom to live where I want to live - and who I want to live with - with access to the support I need as a result of my disability.

I also have the option to do the activities I want to do in my day, using the direct support I need - like going to the gym, or going to see my children compete in sporting events, or go and watch spectator sports myself (like the mighty Tigers in the AFL and AFLW!).

What are the current challenges that exist specific to disability and independent living from your perspective?

There are times when I have received incorrect advice on assistive technology, which has led to the supply of the wrong product and it has been challenging to get these errors corrected.

Sometimes it has been challenging to get nominated team members to follow through with the actions they have been given, for me to get the outcomes that I need.

Accessibility issues in the community continue to be an issue (e.g. stepless access to an allied health professional; footpaths that are damaged or a trip hazard; lack of accessible parking).

The National Disability Insurance Agency at times puts forward NDIS plan budgets that have not been set up adequately to meet my goals or needs, and so I have to appeal these decisions.

Framing our White Paper: The Socio-Ecological Model

When developing a white paper on the opportunities and challenges in rehabilitation, ageing, and independent living, it's important to consider the many factors that influence health and well-being. To do so, the adoption of a model or framework can assist with enabling this. One model, the Socio-Ecological Model is a useful framework for this because it looks at how individual, relationship, community, and societal factors all play a role in health outcomes.

Specifically, this model considers the complex interplay between individual, interpersonal, organisational, community, and public policy factors in supporting and maintaining health behaviours (McLeroy et al., 1988). In this model, the factors include:

- *Individual factors* include biological and personal factors such as age, gender, education and attitudes/beliefs;
- *Interpersonal factors* include relationships with a person's closest social circle, such as peers, partners and family members;
- *Organisational factors* include social institutions with rules and regulations for operation;
- *Community factors* include relationships among organisations, institutions, and informal networks; and,
- *Public policy factors* include local, state, and national laws and policies
(Dahlberg & Krug, 2002).

The model suggests that to bring about sustained change and population-level impact, it is necessary to address the multiple levels of the model simultaneously (Dahlberg & Krug, 2002).



Figure 1. The Socio-Ecological Model, adapted from McLeroy, K. R., Steckler, A. and Bibeau, D. (Eds.) (1988). The social ecology of health promotion interventions. *Health Education Quarterly*, 15(4):351-377.

Using this model, we can better understand how different levels of influence interact and affect people's ability to live independently as they age. This approach helps us create more comprehensive and effective strategies for promoting health and wellbeing in older adults, people involved in rehabilitation, and people living with disability, ensuring that our recommendations are well-rounded and address the various aspects of their lives.

Figure 1 provides a visual representation of the Socio-Ecological Model levels.

Given the importance of all five levels, we have mapped the perspectives of our Friends to the challenges and opportunities that exist across the areas of rehabilitation, ageing and independent living to each level of the model.

Phases Two to Four: Reflections from Friends of RAIL

The Rehabilitation, Ageing, and Independent Living (RAIL) Research Centre is underpinned, as the name suggests, by three key interconnected areas: Rehabilitation, Ageing and Independent Living (or Disability). The interconnection is depicted in Figure 2.

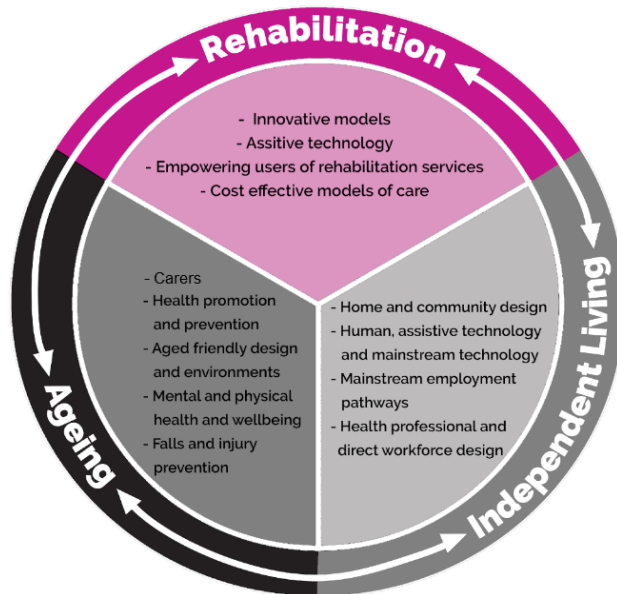


Figure 2. Streams of the Rehabilitation, Ageing, and Independent Living (RAIL) Research Centre.

A total of 30 preliminary themes were identified across the three streams (see Appendix A). An initial mapping of the Friends of RAIL views to the Socio-Ecological Model across the RAIL streams was developed (see Figure 3). These then underwent checking with Friends who had attended the Friends of RAIL Online Event on Monday 1st July 2024 (Phase Three).

Across each of the streams of Rehabilitation, Ageing and Independent Living, Friends were asked to reflect on whether:

- They understood the names of the themes;
- They liked the way the themes were presented; and,
- There was anything they didn't understand or didn't like

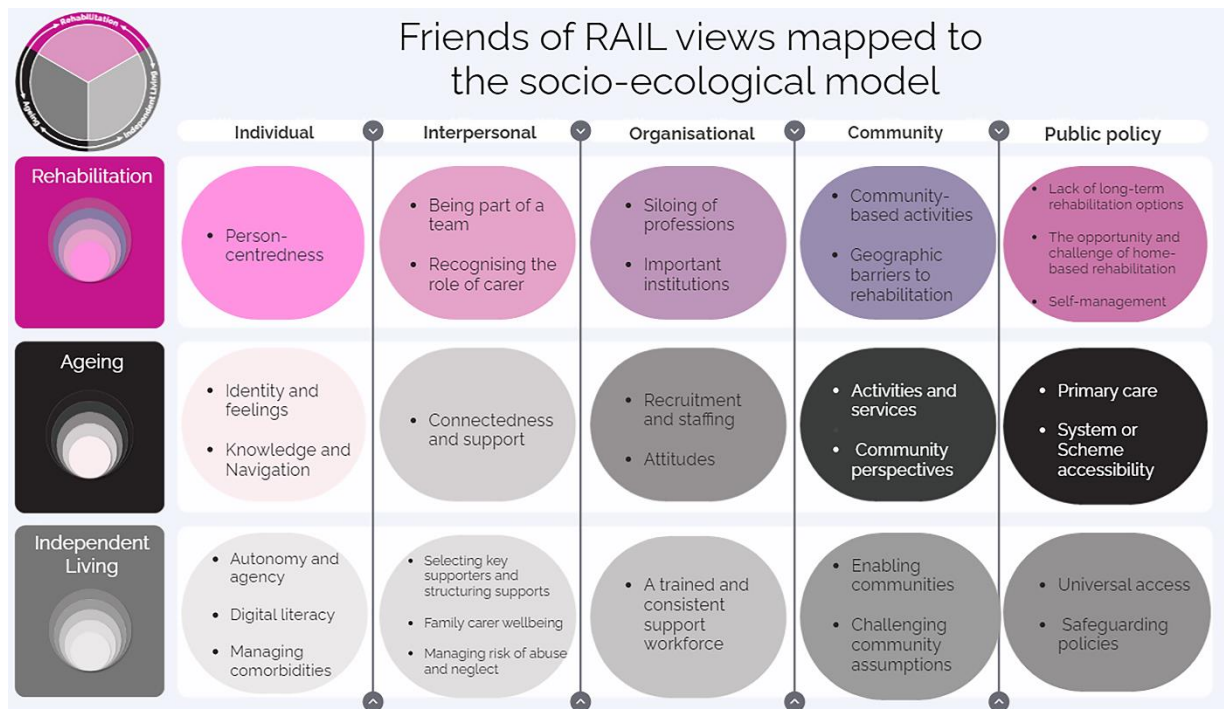


Figure 3. Initial mapping of the Friends of RAIL views mapped to the Socio-Ecological Model across the RAIL streams of Rehabilitation, Ageing, and Independent Living.

Feedback was provided and collated (see Appendix B), and subsequent revision of the mapping and themes was undertaken. To remain true to the data generated by the initial group of Friends of RAIL present at the Launch of the Friends of RAIL on 2nd November 2023, subsequent phases focussed on reflecting upon and polishing the data. Edits were made to enhance and clarify the data, whilst keeping the points as succinct and clear as possible. For example, regarding the refinement of some terminology (e.g. a theme initially named “systems and scheme accessibility” was amended to “system accessibility”), or where themes appeared to be encompassing more than one theme they were split (e.g. a theme initially named “Knowledge and Navigation” became two themes “Knowledge” and “Navigation”). In other situations, the initial theme was retained (e.g. “siloeing of professions”) and a Footnote was added to aid clarification and understanding. Therefore, not all feedback and comments were able to be incorporated. Additional points and commentary that were gathered through the multiple phases are captured in the 'Limitations' section of this white paper so that these valuable additional perspectives are captured for future use. We also note that some themes identified in one stream have relevance to other streams as well, although in some cases these may not have reached the high-level themes reported here (e.g. Family carer wellbeing was identified as a key theme in the Independent Living Stream, and as “Recognising/valuing the role of the carer” in the Rehabilitation stream; and although it did not emerge as a major theme in the Ageing stream, it is indeed a key consideration warranting strong focus in research and practice with older people).

A final visual representation of the views of Friends of RAIL mapped to the Socio-Ecological Model are presented in Figure 4. The following section of this white paper details the Friends' views for each of the themes.



Friends of RAIL views mapped to the socio-ecological model

	 Rehabilitation	 Ageing	 Independent living
Public policy 	<ul style="list-style-type: none"> Lack of long-term rehabilitation options The opportunity and challenge of home-based rehabilitation Self-management 	<ul style="list-style-type: none"> Primary care System accessibility 	<ul style="list-style-type: none"> Universal access Influencing and informing policies
Community 	<ul style="list-style-type: none"> Community-based activities Geographic barriers to rehabilitation 	<ul style="list-style-type: none"> Activities and services Community perspectives 	<ul style="list-style-type: none"> Enabling communities Challenging community assumptions
Organisational 	<ul style="list-style-type: none"> Siloing of professions Important institutions 	<ul style="list-style-type: none"> Recruitment and staffing Attitudes 	<ul style="list-style-type: none"> A trained and consistent support workforce
Interpersonal 	<ul style="list-style-type: none"> The person is part of the team Recognising / valuing the role of the carer 	<ul style="list-style-type: none"> Connectedness and support 	<ul style="list-style-type: none"> Selecting key supporters and structuring supports Family carer wellbeing Mitigating / reducing the risk of abuse and neglect
Individual 	<ul style="list-style-type: none"> Person-centredness 	<ul style="list-style-type: none"> Identity and feelings Knowledge Navigation 	<ul style="list-style-type: none"> Autonomy and agency Digital literacy Managing comorbidities

Figure 4. Mapping of the Opportunities and Challenges that exist in Rehabilitation, Ageing, and Independent Living streams from Friends of RAIL across the Socio-Ecological Model.



Friends of RAIL round table focus group during the Launch of Friends event in December 2023.

The Opportunities and Challenges that exist in Rehabilitation

Our Friends identified challenges and opportunities that existed in relation to *rehabilitation*. These were analysed to identify central themes under each level of the Socio-Ecological Model (see Figure 5). Each of the 10 key themes are outlined below.



Figure 5. Themes identified within the Rehabilitation stream mapped to the Socio-Ecological Model domains.

Individual level

Person-centredness

A key individual-level theme relating to rehabilitation was the need for a person-centred approach. Our Friends identified that, ideally, rehabilitation practice should consider the interests and abilities of the individual, as well as what is both meaningful and enjoyable. Our Friends expressed that previous experiences of rehabilitation had not lived up to this standard and had been delivered in a generic, non-tailored way. This meant that rehabilitation had been insufficiently stimulating or overly challenging, leading to a lack of commitment and a perceived failure to reach their full rehabilitation potential. Opportunities to achieve person-centredness in rehabilitation could be created by discussing patients' interests and likes and undertaking a shared approach to goal setting.

Interpersonal level

The person is part of the team

A theme relating to interpersonal factors was needing to feel part of a 'team' during the rehabilitation process. Our friends who had experienced rehabilitation as an inpatient or outpatient wanted to feel that they were not alone and had people supporting their rehabilitation process, e.g. clinicians, family and other patients, and also that they were on the same level as the other members of the team, rather than feeling like their opinions were less valued. Key to achieving this was prioritising rapport-building between clinicians and patients, ensuring that there were minimal changes within a patient's allied health team, and encouraging clinicians to show respect and empathy, as well as demonstrating an awareness of the social and family context of their patients. Another opportunity for achieving this sense of a team

was participating in group-based activities with other patients, such as group exercise classes and/or group occupational therapy activities, e.g. cooking. An important acronym suggested for the ideal rehabilitation approach was 'CARE': **C**onnected/**A**wareness/**R**espect/**E**mpathy.

Recognising/valuing the role of the carer

Another interpersonal theme highlighted by our friends was recognising the important role of both informal (e.g. friends and family) and paid carers in helping patients achieve optimal rehabilitation outcomes. It was also identified that informal carers were often in need of help and advocacy themselves, as they were commonly under strain in that role. Expanding the size of the informal care team could provide an opportunity to reduce strain on individual carers. However, carers often needed assistance with asking others for help.

Organisational level

Siloing⁶ of professions

Our friends were frustrated by what they saw as a siloing of professions within rehabilitation settings. For example, a physiotherapist might be reluctant to provide an intervention if they perceived this to be the role of an occupational therapist. What this meant was that care and support might be delayed or made more complex. In addition, if there was poor interdisciplinary communication, the person undergoing rehabilitation might have had to bridge communication gaps, acting as the 'middle-man' or interpreter between clinicians. An opportunity to address this could be via case managers or taking a more 'shared approach' to delivering care.

Important institutions

Two institutions were named as key to facilitating optimal rehabilitation outcomes. For people under the age of 65, the NDIS was an important rehabilitation funder and was generally viewed positively. For older adults, the aged care system was an important funder of rehabilitation services, particularly in the community. However, issues with this system were highlighted, including long wait times for care assessments and finding the system overly complicated. Friends recognised that providing people with assistance with navigating the My Aged Care system could help to achieve timely and appropriate funding for rehabilitation.

Community level

Community-based activities

Our friends recognised that they often lacked access to stimulating and enjoyable social, physical and intellectual activities in the community. These were seen to be critical to achieving ongoing, long-term rehabilitation goals beyond formal rehabilitation admissions. In particular, age and ability-appropriate activities were valued, including the AgeStrong classes delivered by Joy Green, one of our friends. Friends suggested that older adults, in particular, could benefit from a resource listing these kinds of activities in their local community, as well as having a greater diversity of activities to choose from.

⁶ The term 'silo' refers to the situation where a system or process is isolated from other systems or processes.

Geographic barriers to rehabilitation

It was highlighted by friends that there were geographic barriers to accessing rehabilitation services. For example, people living in regional and rural areas identified not only a lack of high-quality rehabilitation professionals in the community but also a lack of specialised inpatient rehabilitation facilities. This meant that people needing specialised rehabilitation services were often admitted to facilities far from home, which placed time and financial burdens on families and other carers. Telehealth was seen as an important opportunity for reducing geographic healthcare disparities.

Public policy level

Lack of long-term rehabilitation options

For people undergoing rehabilitation, care was often perceived as being short-term, despite the long-term nature of recovery. This was highlighted by friends as problematic because there were few opportunities to receive ongoing outpatient reviews, 'booster' rehabilitation sessions, or opportunities to receive crisis interventions (e.g. following a fall). Often the only option for receiving long-term care was when people paid for private rehabilitation in the community. However, this was financially challenging for many people. One opportunity to address this issue was having more publicly-funded, community-based rehabilitation services, with this being a standard referral option post-discharge from inpatient rehabilitation. This could require changes to policy at both state government and hospital levels.

The opportunity and challenge of home-based rehabilitation

It was recognised by friends that many hospitals and health care providers had recently introduced policies aimed at delivering home-based rather than inpatient rehabilitation. While several friends highlighted that this could be a positive experience for some people, others highlighted that home-based rehabilitation often shifted the burden of care onto families. Also, some friends had indicated that home visits by clinicians could be viewed as invasive of privacy. To meet the needs and preferences of a range of people, our friends highlighted that both inpatient and home-based rehabilitation should continue to be offered, allowing people freedom of choice.

Self-management

With increasingly limited rehabilitation resources and shorter lengths of stay in rehabilitation facilities, our friends highlighted that hospital policies may need to place greater emphasis on self-management in rehabilitation. Encouraging self-management, e.g. via self-directed exercise programs, was seen as an important part of routine rehabilitation practice and policy within hospitals and the community. Such programs need to be embedded as part of a philosophy of care focussed on person-centredness and empowerment.



RAIL Team members and Friends at the Friends of RAIL Launch (December 2023) event sorting out round table discussion points onto large posters under the three streams of Rehabilitation, Ageing and Independent Living.

The Opportunities and Challenges that exist in Aged Care and Healthy Ageing

Friends of RAIL also identified challenges and opportunities that existed with *aged care and healthy ageing*. These were analysed to identify central themes under each level of the Socio-Ecological Model (see Figure 6). Each of the 10 themes are outlined below.



Figure 6. Themes identified within the Ageing stream mapped to the Socio-Ecological Model domains.

Individual Level:

Identity and feelings

The theme of individual identity and feelings was quite significant amongst our Friends, with various feelings expressed and shared amongst the group. Our Friends conveyed that a sense of being needed was important, emphasizing the need for interpersonal connections. On the other hand, there was often a reluctance to seek help, rooted in the fear of transitioning to long-term care and an apprehension towards change. Friends voiced concerns about inviting others into their home environment and expressing a strong desire to stay at home. Retirees without particular interests may face the potential challenge of losing a sense of purpose and identity, which could contribute to heightened levels of anxiety and increased reliance on medication. Engaging in activities, recognising one's skills, and finding new interests were seen as crucial for satisfaction and a sense of accomplishment. Mindfulness, training the brain, and involvement in projects, were mentioned as contributors to overall wellbeing. Additionally, the transition to long-term care was acknowledged as a form of grief, where these substantial life changes can impact health and wellbeing further. Understanding and addressing these emotional aspects are key to ensuring a holistic and meaningful experience for our Friends.

Knowledge

On an individual level, a key theme identified by our Friends revolved around personal knowledge and awareness of available resources (which Friends identified as often being limited). The importance of technology, especially websites, and digital literacy as a skill in day-to-day life was highlighted. Keeping up with the ever-changing landscape and retaining information were also valid concerns. To enhance the individual experience, there is a need for improved know-

ledge dissemination.

Navigation⁷

Navigating complex systems, including Internet banking and the use of (digital) cards, can be difficult for some. Our Friends spoke of potential challenges due to limited awareness of how to navigate or access available resources. Encouraging digital literacy and developing user-friendly systems are essential to help individuals navigate these complexities effectively.

Interpersonal level

Connectedness and support

At the interpersonal level, a central theme revolved around fostering connectedness and support and addressing various challenges. Efforts are needed to reach socially isolated individuals, utilising services and aligning with their interests while ensuring receptivity to help. Some individuals may find it challenging to initiate new opportunities due to a passive mindset, which one Friend described as a "passive penchant". Social isolation can become pronounced, especially when networks or families diminish. Maintaining social connections was mentioned as being crucial, and volunteering activities were identified as valuable avenues for engagement. Story-telling afternoon teas, like the "chatty cafe," offer spaces for meaningful interaction. Access to caregivers, particularly for transportation, was highlighted, alongside concerns about financial abuse. Attending to legal paperwork and organising affairs was emphasised for peace of mind. Establishing a reliable support network emerged as a key component in enhancing interpersonal well-being.

Organisational level

Recruitment and staffing

At the organisational level, a big focus was on hiring and training staff. Our group of Friends suggested that care staff should be chosen based on their personalities, looking for people who genuinely care. There was an emphasis on bringing in carers who are compassionate and paid according to their experience and set of skills. A challenge is the time it takes for staff to learn how to use all the available support effectively – our Friends reported that some carers wanted a better "training experience." There was also a need for improved and more thorough training for aged care staff, addressing current gaps. So, overall, making the care experience better involves smart hiring and investing in better training for carers and healthcare staff generally.

Attitudes

Our Friends spoke of both positive and negative attitudes regarding ageing and aged care. Several Friends felt the consumer voice is often undervalued and overlooked, with staff, in particular, having negative attitudes as to what the consumer can offer. An opportunity highlighted by Friends related to ongoing and increasing recognition of individuals with lived (and living) experience as experts. Similar to the CARE acronym outlined in the Rehabilitation section of this report, our Friends suggested another important acronym for the ideal approach

⁷ Navigation also links to the 'System accessibility' theme under the 'Public Policy' level. While Navigation is not specifically stated, if the systems (and underlying Schemes) are accessible then the person can navigate them.

to aged care was 'CARE': **C**ourtesy/ **A**wareness/ **R**esponsibility/ **E**mpathy. There was also recognition of the overall diversity and extent of attitudes at an organisational level and the need to have people across all cultural backgrounds involved in support and care to increase opportunities for individuals with languages in addition to English to be involved in care. This was underpinned by improving accessibility for all, both consumers and staff from culturally and linguistically diverse backgrounds.

Community level

Activities and services

Similar to their perspectives regarding Rehabilitation at a Community level, our Friends recognised that they often did not know what stimulating and enjoyable social, physical and intellectual activities existed in the community or were not able to access them. Friends asked, "*Tell me what is outside the home?*" Awareness of, and access to, activities and services were identified as vital to healthy and positive ageing. Specific services, including Neighbourhood Houses, U3A, and local libraries, were identified by several Friends as valuable and appropriate options to source more information about what was available in the community.

Other Friends reported support through their local Church. Suggested activities that were currently limited but identified included access to music programs, scrapbooking or crafts, as well as intergenerational activities and opportunities. While some Friends were aware of a list through their local council of some activities and services offered within their community, this was not apparent for all.

Community perspectives

Following on from attitudes at an organisational level, Friends felt there was generally a limited understanding of ageing and/or ageing well. This was particularly so in relation to the needs of individuals from culturally and linguistically diverse backgrounds - highlighting an opportunity for community engagement and education regarding cultural competence. Friends highlighted healthy ageing wasn't just physical health, but was broader, including cognitive, emotional, and social health. It was further discussed that there were building blocks, like good food (and access to such food), in conjunction with the opportunity to engage in physical activity and participate socially, contributed to healthy ageing. Again, recognition of how ageing is perceived within the community tended to impact the access to some of these building blocks of health.

Public Policy level

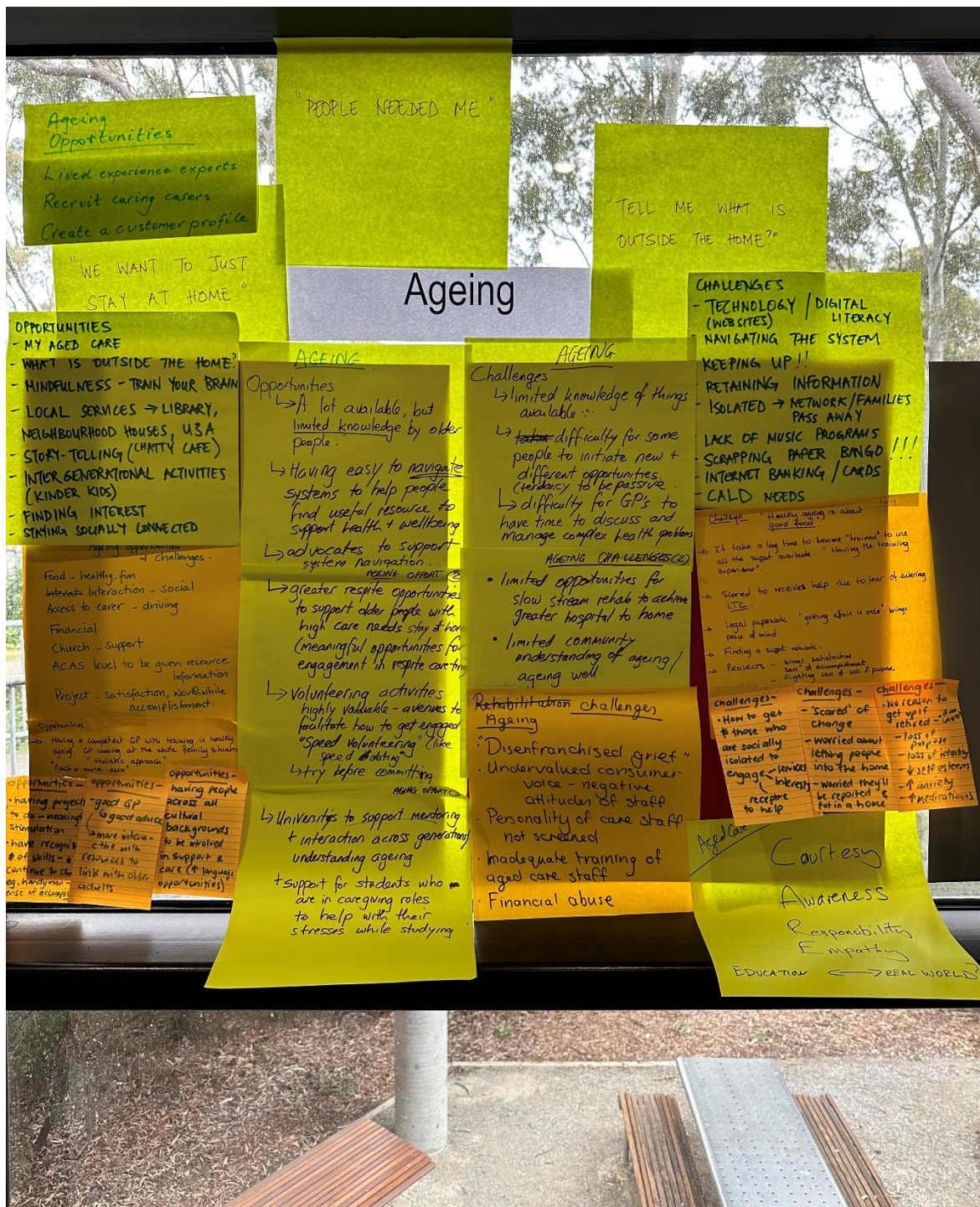
Primary care

Throughout our discussion, our Friends underlined the importance of having a trusted General Practitioner (GP) who not only imparts advice but also fosters community connections among older adults and considers the entire family dynamic. One theme that emerged was that GPs face challenges due to time constraints in addressing complex health issues. The Aged Care Assessment Service (ACAS) helps provide essential resource information, address knowledge gaps, and guide access to available services. Despite many services being available, some of our Friends added that transitioning from hospital to home is hindered by limited opportunities for slow-stream rehabilitation. Additionally, respite care needs enhancement to provide

meaningful engagement and support for older adults with high care needs, allowing them to stay comfortably at home. Overall, optimising the ageing experience involves comprehensive healthcare, accessible resources, and personalised support systems.

System accessibility

The last key point Friends of RAIL elaborated on concerning ageing and aged care related to the Public and Policy level of accessibility - to systems and schemes (e.g. MyAgedCare and NDIS). Friends spoke of the *need for easy-to-navigate systems* to help people find useful resources, as and when they need them, to support health and wellbeing, particularly as they age. Friends felt there was an opportunity for advocates to support individuals in navigating systems.



Post-it notes with verbatim discussion points regarding challenges and opportunities in Ageing noted down during the Friends of RAIL round table focus group in December 2023.

The Opportunities and Challenges that exist in Independent Living

Finally, our Friends identified challenges and opportunities that existed concerning *disability care and independent living*. These were analysed to identify central themes under each level of the Socio-Ecological Model, with 11 key themes identified (see Figure 7). Each of these are outlined below.



Figure 7. Themes identified within the Independent Living stream mapped to the Socio-Ecological Model domains.

Individual level

Autonomy and agency

Friends of RAIL discussed the importance of self-advocacy, decision-making and autonomy in decision-making. They discussed the importance of information access to inform decision-making. Friends also discussed the benefit of social capital and support as well as the building of 'self-sufficiency'. For example, one Friend said, "Sometimes I want to do things, then and there, but I have to rely on family and friends and that can be hard. Sometimes I have to wait". Finally, the importance of enabling self-directed goals specific to significant life decisions, like where a person lives or who they live with, was highlighted – one Friend said, "Let the person live their dream" whilst another said, "Let them choose who they live with, where they live and who they work with".

Digital literacy

Through our discussion, our Friends highlighted the growing requirement for digital – especially computer – literacy to manage disability care and support. They talked of both the opportunities and challenges this need can pose. For example, Friends spoke of the importance of both assistive technology and plain language digital resources as enablers of digital literacy. They also discussed the need for these resources to be provided in Languages Other Than English to ensure the accommodation of Australia's culturally and linguistically diverse communities. Friends discussed the importance of safety in online engagement and detailed both personal and financial safety issues individuals have experienced previously and the need to mitigate such risks.

Managing comorbidities

Friends of RAIL outlined some of the potential comorbidities that may arise when living with disability, including drug and alcohol use, other addiction risks like gambling, and the potential for medication mismanagement. Friends highlighted the importance of an individual knowing how to maintain a healthy lifestyle, and being able to do so. Central to this, they discussed the importance of social support. Specifically, the importance of mitigating risks of social isolation – which can increase comorbidities – was highlighted. This included a suggested focus on building or maintaining interest-based activities that naturally offer social contact and ensure a person has the support needed to enable meaningful participation.

Interpersonal level

Selecting key supporters and structuring supports

Friends of RAIL discussed opportunities to enable positive interpersonal relationships by self-directed funding models, or service planning which enabled a person to select and roster their own support team, including both paid and informal supporters. One Friend said, “It [my support roster] is regimented but I control it”. Friends discussed the importance at an interpersonal level of matching a person and their key supporters. They suggested that this matching may occur across many domains, depending upon the personal preference of the person with disability, including by age, gender, culture, or interests and likes and dislikes.

Family carer wellbeing

Whilst highlighting the importance of social capital, and particularly informal or family support, at an individual level, Friends of RAIL also raised the importance of maintaining family caregiver wellbeing. They discussed the strain that may be experienced as part of informal caregiving roles, and how that can also raise a sense of guilt for the caregiver if this strain is highlighted to others.

Mitigating/reducing the risk of abuse and neglect

Friends of RAIL talked of negative relationships that may lead to physical, emotional or financial abuse at an interpersonal level. Some discussions then broadened to the recent Disability Royal Commission, and stories of abuse and neglect within interpersonal relationships that were shared by people with disability during Royal Commission hearings. Some potential safeguarding processes were also discussed by our Friends, including via financial administration support from family or a nominated financial administrator (e.g., State Trustees), the Office of the Public Advocate, or the NDIS Quality and Safeguards Commission.

Organisational level

A trained and consistent support workforce

A key discussion by our Friends related to the paid support workforce they may engage with. Friends highlighted that institutionalised attitudes and environment, as well as high support workforce turnover, risked poor outcomes and negative experiences for people with disability and their families. However, Friends of RAIL also highlighted growing opportunities for them to select both allied health professionals and direct support workers, and to participate in training the workforce, they engage with. They saw this as a real opportunity to enhance access to a trained and consistent workforce. They also discussed new pathways to access

the disability support workforce (e.g., by recruiting allied health students whilst they are studying for their degree).

Community level

Enabling communities

Friends of RAIL discussed the importance of supportive and enabling communities. Specifically, one Friend said, “To live independently requires better collaboration in the community, to keep socialising and reduce isolation”. Enabling communities were seen to include both supportive relationships (e.g., via reciprocal relationships between the person with disability, their neighbours or other community members) as well as enabling environments (e.g., by making available accessible community buildings and neighbourhoods). Friends discussed examples of formalised programs that build enabling communities – for example, the City of Port Phillip in Victoria has “The Linking Neighbours Program” that some Friends have found very useful.

Challenging community assumptions

Friends of RAIL discussed the importance of challenging community assumptions to enable better outcomes for people with disability and their families. This included challenging assumptions about whether key family members – like a partner – will provide disability support or if there should be structures put in place to maintain the partner relationship, by harnessing other providers of disability-specific support. Friends also discussed the importance of community members actively listening to lived experience perspectives to challenge internal biases that may exist and grow understanding of the inclusion of all.

Public Policy level

Universal access⁸

Building on the community-level focus of enabling environments, Friends of RAIL spoke of how good public policy can enable universal access and meaningful participation. Specifically, they discussed policies and systems that allowed for information access for all; took a de-institutionalisation focus; enabled the availability of a range of options for housing and support (although it was noted that more innovation is still required in this area); and enhanced accessible travel both via public transport systems as well as private vehicle and airline travel. Systemic architectural, financial and attitudinal barriers that exist for people with disability and their families were discussed, and the further inequities faced by older people with disability or people who are ageing with disability were also highlighted.

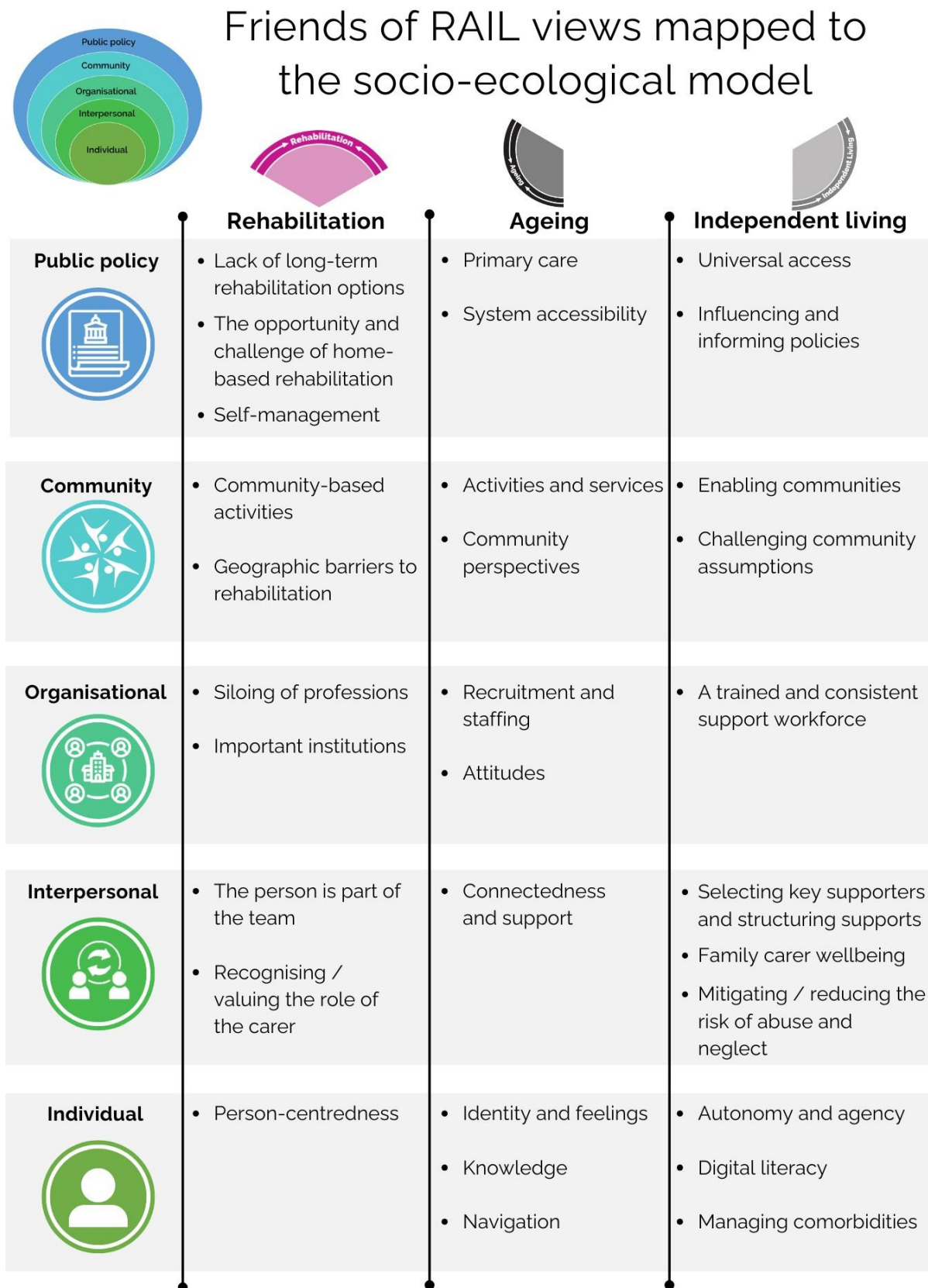
Influencing and informing policies

One key issue Friends of RAIL highlighted was that currently, specific to both disability and aged care and support, people are often required to access a largely untrained or under-qualified workforce. At a policy level, Friends felt that the limited qualifications (e.g. a certificate level or no qualifications) were a policy issue that may impact safety. For example, Friends discussed disability systems like the National Disability Insurance Scheme – that do not fund

⁸ Additional terms (such as towards universal access) or alternate terms (such as access for all) were discussed in subsequent phases, however the overarching 'universal access' was retained, noting it may cover these elements.

time for individualised worker training but rather mandate that the provider of services incorporate this into more generic training as part of their core business – may lead to reduced manual handling skills and subsequent workplace injuries for key support staff.

Figure of the mapping of the Opportunities and Challenges in Rehabilitation, Ageing and Independent Living to the Socio-Ecological Model



Limitations

As outlined in Phases Two to Four: Reflections of Friends of RAIL, to remain true to the data generated by the initial group of Friends of RAIL present at the Launch of the Friends of RAIL on 2nd November 2023, edits in the revision phases were made to enhance and clarify the data, whilst keeping the points as succinct and clear as possible. This section however outlines additional points and commentary that were gathered through the multiple phases that add valuable additional perspectives for future consideration. These points were:

- Friends also commented on the 'Community' level asking whether this included culturally and linguistically diverse (CALD) groups and Aboriginal and Torres Strait Island people. This was something that had not arisen in the November 2023 discussion however is highlighted as crucial for all streams of RAIL.
- Additional notes were made regarding the family carer's wellbeing not being just about health and the social aspect of wellbeing, but also importantly, about the financial aspect and cost implication.
- Literacy was also discussed with specific considerations regarding expansion beyond just digital literacy but also consideration of medical/health and legal literacy.
- Factors relating to cost (e.g. cost of appropriate services, the additional cost of transport, etc) and overall cost/benefit and economic evaluations were also noted not to have been initially included in preliminary discussions for the preparation of this white paper. Cost considerations are also crucial for RAIL to consider when addressing opportunities and challenges across the RAIL streams.
- Lastly, while we know alternate terms can enrich and add specificity to factors (e.g. Access for all – see previous footnote), additional terms (such as towards universal access) or alternate terms (such as access for all) were discussed in subsequent phases, however, the overarching initial terminology (e.g. 'universal access') was retained, noting it may cover all of these elements.

Concluding Reflections

From the RAIL Research Centre by Listening to Our Friends

This white paper highlights several key challenges and opportunities that align closely with the RAIL Research Centre's focus on rehabilitation, ageing, and independent living. One of the primary challenges identified is the increasing demand for personalised rehabilitation programs that can adapt to the diverse needs of an ageing population. This challenge presents an opportunity for the development of innovative technologies and methodologies that can enhance the effectiveness and accessibility of rehabilitation services.

In the context of ageing, the white paper underscores the importance of creating supportive environments that promote healthy ageing and prevent the onset of age-related conditions. This includes leveraging advancements in smart home technologies and wearable devices to monitor health metrics and provide timely interventions as well as access to services and support to navigate these services. The integration of these technologies can significantly improve the quality of life for older adults, enabling them to live independently for longer periods. It was also noted that negative attitudes regarding ageing exist but are improving, ageism remains evident and can impact outcomes for healthy ageing.

Furthermore, the paper discusses the critical role of community-based initiatives in supporting independent living. By fostering strong community networks, safeguarding risks (e.g. barriers to the built environment, training and workforce) and providing resources for self-management, individuals can maintain their independence and reduce reliance on institutional care. This approach not only enhances individual well-being but also alleviates the burden on healthcare systems.

Lastly, but by no means least, consumers and the community must be central to the RAIL Research Centre approach. As identified by Friends, there is a desire for clinicians to see an individual as a whole person - respecting their dignity and as a human being – not just seeing them as a patient, consumer or client, but rather as a partner in their care.

Overall, the challenges and opportunities outlined in the white paper, as identified by the Friends of RAIL, emphasise the need for a multidisciplinary approach that combines technological innovation, consumer and community engagement, and personalised care strategies. These efforts are essential for advancing the RAIL Research Centre's mission to improve rehabilitation outcomes, support healthy ageing, and promote independent living. Further, there must be genuine consumer and community engagement across all levels and streams.

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Appendix A: Phase Three Documentation

The following outlines the documentation provided to Friends of RAIL prior to attending the Online Friends of RAIL event on 1st July 2024:



Thank you for registering for our Online Friends of RAIL event!

The following is a document for you to read and think about before the Friends of RAIL online event on Monday 1st July.

We want to find out what you think about a document called 'Friends of RAIL views mapped to the socio-ecological model'. We wrote this document after our November Friends event. The socio-ecological model was used because what Friends told us was important to their health and wellbeing for the 3 streams of RAIL (Rehabilitation, Ageing and Independent Living) fell into 30 themes across 5 levels:

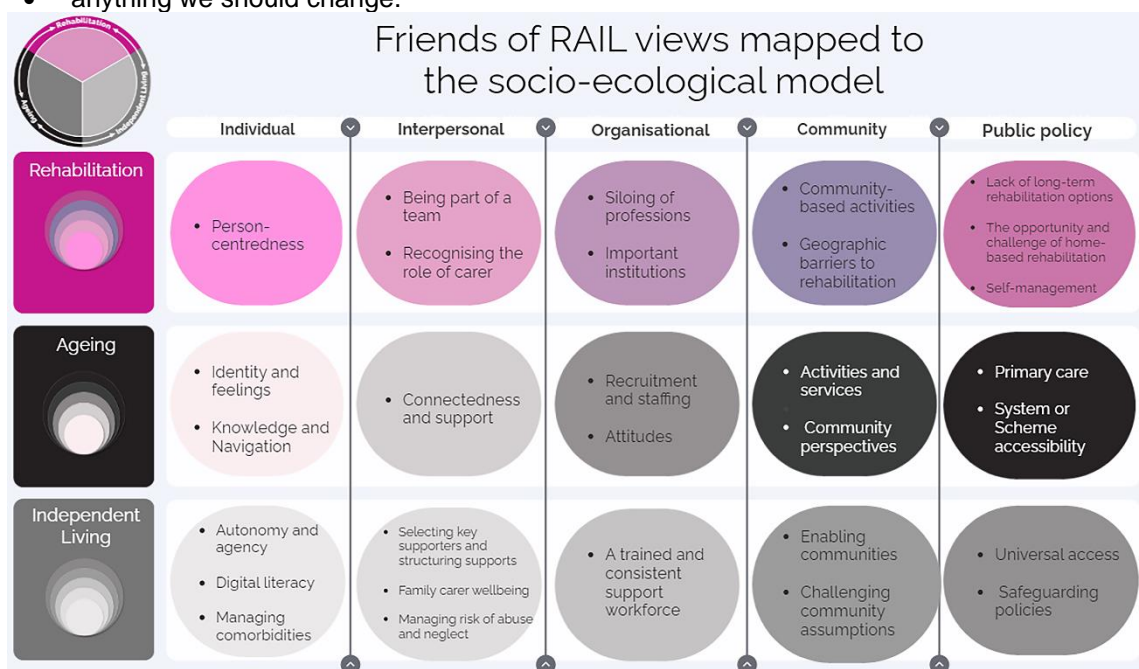
- Individual
- Interpersonal
- Organisational
- Community
- public policy.

At the online event on Monday we will ask the Friends of RAIL some questions using a zoom survey (zoom call the survey a 'poll'). We want to know if:

- you understand the names of the themes
- you like the way the themes are presented
- there is anything you don't understand or like.

All of your answers will be anonymous - this means that no one will know your answers. If you choose, you can join the group talk, and tell us more about:

- what you think about the document
- anything we should change.



We explain the themes for each stream of RAIL in detail below.

For the **Rehabilitation** stream, there are 10 themes:

1. person-centredness
2. being part of a team
3. recognising the role of carer
4. siloing of professions
5. important institutions
6. community-based activities
7. geographic barriers to rehabilitation
8. lack of long-term rehabilitation options
9. the opportunity and challenge of home-based rehabilitation
10. self-management.

The figure below shows how we have presented the themes in the document:



At the online event on Monday we will ask 3 questions using a zoom survey. For the rehabilitation stream, we want to know if:

- you understand the names of the themes
- you like the way the themes are presented
- there is anything you don't understand or like.

For the **Ageing** stream, there are 9 themes:

1. identity and feelings
2. knowledge and navigation
3. connectedness and support
4. recruitment and staffing
5. attitudes
6. activities and services
7. community perspectives
8. primary care
9. system or Scheme accessibility.

The figure below shows how we have presented the themes in the document:



At the online event on Monday we will ask 3 questions using a zoom survey. For the ageing stream, we want to know if:

- you understand the names of the themes
- you like the way the themes are presented
- there is anything you don't understand or like.

For the **Independent Living** stream, there are 11 themes:

1. autonomy and agency
2. digital literacy
3. managing comorbidities
4. selecting key supporters and structuring supports
5. family carer wellbeing
6. managing risk of abuse and neglect
7. a trained and consistent support workforce
8. enabling communities
9. challenging community assumptions
10. universal access
11. safeguarding policies.

The figure below shows how we have presented the themes in the document:



At the online event on Monday we will ask 3 questions using a zoom survey. For the independent living stream, we want to know if:

- you understand the names of the themes
- you like the way the themes are presented
- there is anything you don't understand or like.

We look forward to seeing you on Monday, and you sharing your thoughts with us.

Appendix B: Phase Four Documentation

Feedback and general comments received by the Friends of RAIL at the Online Friends of RAIL event on 1st July 2024 were collated (as per below) and were used to inform the revisions and final drafting of this white paper. To remain true to the data generated by the initial group of Friends of RAIL present at the Launch of the Friends of RAIL on 2nd November 2023, subsequent phases focussed on reflecting upon and polishing the data. Edits were made to enhance and clarify the data, whilst keeping the points as succinct and clear as possible. Therefore, not all feedback and comments were incorporated. Additional points and commentary that were gathered through the multiple phases are captured in the 'limitations' sections so that these valuable additional perspectives are captured for future use.

Friends of RAIL online event – 1st July 2024 - Summary

Question 1: Do you understand the names of the themes?

Question 2: Do you like the way the themes are presented?

Question 3: Is there anything you don't understand or like?

General comments about the model:

- Friends commented on the use of the Socio-Ecological Model asking whether it included Health and Wellbeing noting that it may feel a bit too distinct from what one could think of Health and Wellbeing.
- The meaning of the Socio-Ecological Model had to be researched by some Friends.
- The headings (individual, interpersonal, organisational, community and public policy) get lost a bit when looking at the whole picture as they are small and grey – it would be good if they could visually stand out more.
- Friends also commented on the 'Community' level asking whether this included CALD groups and Aboriginal and Torres Strait Island people – limitation to be reported in the white paper.
- Does the 'Interpersonal' level include family?
- Friend commented on the separation of the levels within the model while in reality, there are connections between each level – RAIL to think about how the model is visually represented.

Rehabilitation stream themes:

- The theme 'Siloing of professions' was unclear to some Friends. Reflecting on the term 'siloing', a Friend commended RAIL for the multidisciplinary approach RAIL is using in their research.
- No mention of the person at the 'Interpersonal' level (it is currently all about externals and not the person themselves). It would be good to connect back to the individual ('involved person' or 'consumer' could be used).
- Being part of a team – the person needs to be part of the team, not just treated by the team so the theme 'Being part of a team' could be replaced with 'The person is part of the team'.
 - *The person and their close others are part of the team?*
- Need the main focus on the individual.
- At the 'Interpersonal' level, it is not just about 'Recognising the role of carer' but also understanding.
 - *Beyond recognising and understanding, perhaps also valuing the role of the carer? (chat)*
- At the Public Policy level, there is currently no mention of cost.

Ageing stream themes:

- A Friend noted that 'Navigation' currently sits in the model under the 'Individual' level but that for them, 'Navigation' is about the interface between the individual and the systems they are trying to navigate – being under the 'Individual' level might feel like we are putting the responsibility on the individual and their families to do the navigation while we should perhaps look at the public policies/community responsibility.
 - This could be linked up to the 'System and Scheme accessibility' theme under the 'Public Policy' level. If the schemes and systems are accessible then the person can navigate.
- Knowledge and navigation should be two separate points.
 - Knowledge covers the systems but also medical and legal literacy while navigation is more about navigating the systems.
 - Medical and legal literacy should be identified in the knowledge area.
- Some Friends reflected on the 'System and Scheme accessibility' noting that the term 'Scheme' was unclear.
 - Perhaps it could just be 'System accessibility'? *'Scheme' is current Australian jargon... could be systems and programs?*

Independent Living stream themes:

- The 'Organisational' level currently includes 'A trained and consistent support workforce' but the users should also be trained as there is an interaction between the organisation and the person that goes both ways. If the users are not trained, then the support workforce is disadvantaged.
 - It also links to the navigation.
 - It is fine to keep it under the 'Organisational' level but the users should be added.
 - *One of the key considerations in my thinking is that as people age they have the overall support that enables them to maintain the kind of lifestyle they are used to and want to continue with. If this is covered here, then good.*
- Family carer wellbeing is not just about health and the social aspect of wellbeing but also about the financial aspect and cost implication. Digital literacy should be expanded to digital, medical and legal literacy.
 - This is linked to 'Managing risk of abuse and neglect'.
 - Cost/benefit/economics evaluation is currently not included in the themes but will need to make sure that RAIL highlights this in the narrative.
- On the theme of 'Managing risk of abuse and neglect':
 - *Should it be managing or mitigating/reducing the risk of abuse and neglect?*
 - The verb 'managing' is not very active, while we want to reduce the risk so perhaps choosing a different verb might improve this theme?
- Friends sought clarification on 'Universal access' meaning that currently sits under the 'Public Policy' level.
 - Adding a word or a verb might help clarify the theme? 'Towards universal access' or 'Minimal standards of universal access' or 'Access for all'
 - RAIL team to review the wording from the Launch event to try to pick up some of those verbs that have been populated by Friends.
- Friends reflected on the wording of the theme 'Safeguarding policies' noting that it is large and might not be the best term used.
 - 'Protecting' policies?
 - More about embedding the programs into the mainstream funding models.
 - Need to review the terminology used by Friends around the word 'safeguarding'.
 - Sustainability is a key aspect as we don't want to just run something once but we want to have something that is ongoing.
 - *And maybe there are policies you don't want to safeguard or keep. Maybe you want to finish them if they're not helpful.*
 - *Influencing and informing policy?*

