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ISBN: 978-0-6482774-4-6

Preferred citation:

Christina David, Sharlene Nipperess, Ilan Wiesel & Rae West 2022, *Enhancing support services* for people with disability and complex needs living in permanent supportive housing, Social and Global Studies Centre, RMIT University, Melbourne.



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Enhancing support services for people with disability and complex needs living in permanent supportive housing

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January 2022





Acknowledgements

We would like to thank the Elizabeth Street Common Ground tenants who generously participated in this research to share their experiences of support services and life at ESCG, as well as experiences of disability and housing before this, and their hopes for the future. A small group of tenants also worked with us to develop the basis of the final recommendations given in this report and we extend additional thanks for their time and effort. We would also like to thank Launch Housing and Unison Community Housing staff at ESCG who shared their time and experience with the research team and who have supported this research from its inception.

Thank you to the members of the Research Advisory Group for their commitment to this project, their insights and suggestions, and their support in its implementation. Thank you too to Guy Johnson, Professor of Urban Housing and Homelessness at RMIT for sharing his expertise and knowledge with the research team through each phase of the project.

This evaluation was conducted on Aboriginal lands, including the land of the Boon Wurrung and Woi Wurrung (Wurundjeri) peoples of the Kulin Nation. This land was never ceded. The Social and Global Studies Centre at RMIT University acknowledges the Australian Aboriginal and Torres Strait Islander peoples of the nations of Australia, the custodians of this land. We pay our respects to ancestors and Elders, past and present. We are committed to honouring Australian Aboriginal and Torres Strait Islander peoples' unique cultural and spiritual relationships with the land, waters and seas, and their rich contributions to society.

The <u>Lord Mayor's Charitable Foundation</u> funded the research and we acknowledge their support and, in particular, that of Erin Dolan, Program Manager – Homelessness & Affordable Housing, LMCF, who oversaw administration of the project.

Table of Contents

	Acknowledgements	ı
	List of Abbreviations	4
	Executive Summary and Recommendations	5
	Recommendations	10
Ch	apter 1: Introduction and Background	16
	1.1 Project Background	16
	1.2 Elizabeth Street Common Ground	17
	1.3 Policy context – disability and homelessness	19
	1.3.1 Policy responses - Victoria	20
	1.4 Research design	21
	1.4.1 Ethics review	21
	1.4.2 Methods	21
	1.4.3 Data collection	22
	1.4.4 Stage 1: Literature review and staff interviews	22
	1.4.5 Stage 2: Tenant interviews	22
	1.4.6 Stage 3: Tenant workshop	23
	1.4.7 Data analysis	23
	1.4.8 Limitations	23
	1.5 Outline of report	24
Ch	apter 2: Disability, Housing and Homelessness: A Review of the Literature	25
	2.1 Introduction	25
	2.2 Disability and homelessness: Demographics	25
	2.3 Drivers of homelessness among people with disability	26
	2.3.1 Lack of affordable housing	26
	2.3.2 Lack of accessible housing	26
	2.3.3 Inadequate planning for deinstitutionalisation	27
	2.3.4 Limited access to disability support funding	27
	2.3.5 Social isolation and breakdown of informal care relationships	28
	2.3.6 Substance abuse and imprisonment	28

2.4 People with disability in permanent supportive housing	28
2.5 Conclusion	29
Chapter 3: Experiences of Life and Support Services at ESCG	30
3.1 Introduction	30
3.2 Vision, leadership and management	30
3.3 Tenant rights, representation and participation	31
3.3.1 Right to a safe living environment	33
3.4 Model of support and care	37
3.4.1 The value of the support provided at ESCG	37
3.4.2 The support contract	40
3.4.3 Proactive versus crisis-driven responses	41
3.5 Communication, roles and relationships	42
3.6 Workforce	43
3.7 Sense of home, belonging and community inclusion	45
3.8 Housing pathways beyond ESCG	47
3.9 Conclusion	49
Chapter 4: The NDIS and Interface with PSH/ESCG	50
4.1 Introduction	50
4.1.1 NDIS participation - ESCG tenant participant profile	51
4.2 Experiences of accessing and navigating the NDIS	51
4.2.1 NDIS services – benefits and challenges	53
4.2.2 Support coordination performance and quality issues	54
4.2.3 The relationship between knowledge, choice and control	56
4.3 Support staff roles in relation to the NDIS	57
4.3.1 ESCG and NDIS services interface	59
4.3.2 Information, privacy and consent	61
4.4 Conclusion	63
Chapter 5: Conclusion and Recommendations	64
5.1 Conclusion	64
5.2 Recommendations	66
References	76

List of Abbreviations

ABI Acquired brain injury

AHURI Australian Housing and Urban Research Institute

AIHW Australian Institute of Health and Welfare

AOD Alcohol and other drugs

CHP Council to Homeless Persons

CRPD Convention on the Rights of Persons with Disabilities

DARU Disability Advocacy Resource Unit

DSP Disability Support Pension

ESCG Elizabeth Street Common Ground

HACC Home and community care

LAC Local Area Coordination

LEAP Lived Experience Advisory Program

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

PSH Permanent supportive housing

SDA Specialist disability accommodation

SHS Specialist homelessness services

UN United Nations

VALID Victorian Advocacy League for Individuals with Disability

VMIAC Victorian Mental Illness Awareness Council

Executive Summary and Recommendations

This qualitative research arose from a need to better understand the nature and impact of supports provided to people with disability and complex needs living in permanent supportive housing (PSH), including National Disability Insurance Scheme (NDIS) funding and services. This is a critical but under-researched area regarding service access and responsiveness at the intersection of homelessness, PSH models and disability. Congregate PSH models aim to offer in-house wraparound support; however, there is limited research on tenants' experience of these services and how they do or do not support wellbeing, goals related to social and community inclusion, and stable tenancy. This report provides key findings and recommendations from interviews with 12 tenants with disabilities and complex needs living at Elizabeth Street Common Ground (ESCG) and with 6 Launch Housing and Unison Community Housing staff. ESCG is a mixed-tenancy site offering PSH to 65 tenants with histories of homelessness and complex needs and has 66 single-tenancy studio apartments for affordable housing occupancy. The Common Ground model is an international approach and one type of mixed-tenancy PSH model which offers onsite support workers who provide services and coordinate other health or mental health support services for the tenants (Mercy Foundation 2020).

While the homelessness and housing sectors have documented some of the challenges associated with the transition to the NDIS (Beer et al. 2020; Council to Homeless Persons [CHP] 2017, 2018), there has been little empirical research to date that explores how people with lived experience of precarious housing and homelessness access and navigate the scheme. Similarly, there is limited understanding of how disability and housing funding and service systems interact or how people with disability living in PSH experience the intersection of these various complex systems. This project explores the dynamics at the interface between the NDIS, community supports and in-house supports at ESCG, including how tenants access and navigate these systems, and identifies the enablers and barriers to access.

The ESCG site was selected as a case study which, as an example of PSH, could contribute to our understanding of how people with diverse disabilities and complex needs are supported by in-house and external supports, what is working well and areas for development. Onsite support services are provided by Launch Housing while Unison manages the building. The type and intensity of support provided depend on individual tenants' needs. The complex opened in the City of Melbourne in 2010.

The findings are based on interviews with 12 ESCG tenants who identified as living with disability, mental health conditions and/or chronic health issues, as well as having histories of homelessness and other complex needs. Some tenants had previously been in prison and some were managing substance addiction. Length of tenancy at ESCG varied from two to 10 years. We also interviewed 4 Launch Housing support workers, one Unison place manager with former experience of ESCG and one home and community care (HACC) worker who provided support to tenants in Unison housing in the City of Melbourne. Following analysis of the interview data, the research team facilitated a workshop with tenants to discuss the key findings and co-design recommendations. The research took place in the context of the COVID-19 pandemic, during which Melbourne has spent more than 260 days in lockdown with varying levels of restrictions. This has caused significant interruption to the research but, of course, much more disruption to the lives of ESCG tenants. Some interviews were able to be conducted face to face onsite at ESCG while others were conducted online. We were still able to hold the co-design workshop with tenants face to face, however, only two tenants were able to attend.

Analysis of the findings has identified shared experiences and perspectives, as well as some points of divergence. Eight thematic areas have been highlighted for attention. Together with tenants and in consultation with the project's advisory group, a series of recommendations for practice, process and policy reforms have been developed in line with the findings. These recommendations regard the interface between the NDIS and ESCG support model and strengthening relationships with NDIS Local Area Coordination (LAC) services, internal and external service access, responsiveness and lines of accountability, factors influencing quality of life, sense of home, wellbeing, social inclusion and tenancy stability, and workforce issues. The 8 key themes are listed below, followed by detailed recommendations addressing each of these.

- The NDIS and interface with PSH/ESCG
- Vision, leadership and management
- Tenant rights, representation and participation
- Model of support and care
- Communication, roles and relationships
- Sense of home, belonging and community inclusion
- Workforce
- Housing pathways beyond ESCG

The findings highlight the critical importance to the tenants interviewed for the research of secure housing and access to embedded support, of having a place to call home, a place to house their belongings and of a place where they can live with a level of autonomy, safety and security. All tenants expressed gratitude for having these needs met. Disability-related needs were met by a combination of Launch supports and external services including NDIS funded services.

A key aim of the research was to explore tenant and staff experiences of the interface between the NDIS and support systems at ESCG. Of the 12 tenant participants, 6 were receiving NDIS funding and services, and two were in the pre-planning phase. Four participants were not in the NDIS. Reasons for not accessing the NDIS included hesitancy about engaging with a new system/bureaucracy and being discouraged by hearing of others' experiences. Reflecting the broader evidence base regarding NDIS participation (e.g. Warr et al. 2017), experiences were mixed and related to tenants' knowledge of the system, capacity to navigate it and capacity to advocate for themselves or have someone advocate for them. For some tenants, NDIS funding and supports offered significant benefits in terms of equipment, services and supports. These had effectively replaced the need for Launch supports and demonstrate the collective benefits to ESCG of individualised NDIS funding. In contrast, several tenants did not feel well-supported in using their NDIS funding and services, and subsequently felt little control within the scheme. These tenants were particularly dissatisfied with support coordination services and did not know how to address this or from whom they might seek assistance.

These findings highlight the need for stronger links between LAC (the NDIS function responsible for providing information and supporting access to the scheme) and supported housing sites, where tenants with complex needs are likely to experience additional barriers to accessing and navigating the scheme. Provision of in-reach LAC support is likely to be highly beneficial. A key recommendation is that the LAC responsible for servicing the City of Melbourne should form a stronger relationship with ESCG, make regular site visits to provide more tailored information and support to tenants and staff, and work more closely with tenants and staff to develop a better understanding of specific needs. A related recommendation is that the NDIS should develop a list of specialist NDIS providers, including support coordinators, with experience and skills in working with people experiencing intersectional disadvantage due to experiences of homelessness, psychosocial disability, incarceration and/or drug and alcohol use. It is recommended that LACs provide tenants with a list of these specialist providers and support access to them. This will allow more informed choice of services. The current situation provides little guidance regarding service providers, which raises a question around the notion and value of 'choice' when, as several tenants said, they had such limited understandings of what different services could offer.

A further finding relating to the interface between the NDIS and ESCG highlights the need to develop stronger lines of communication and to review lines of accountability and responsibility. Staff spoke about the coordination and support responsibilities that fell to them when NDIS-funded services failed. This was sometimes made more difficult when they did not have access to tenants' NDIS plans and arrangements. It is recommended that the interface between inhouse supports and external service provision is reviewed with consideration given to balancing tenant privacy with Launch staff responsibilities for tenant welfare and to Unison's responsibilities regarding site maintenance and work health and safety.

Other findings concern broader issues of safety and security. Although the stability and affordability offered at ESCG were highly valued by tenant participants, there was for some a distinction between the safety enjoyed within their small apartments and the volatility, and at times threatening behaviours, they saw, heard and felt in the building's communal areas. Longer term tenant participants appeared to be most affected by this. These participants expressed a sense of real fatigue and frustration with these behaviours and environment, and a readiness to move to different, less institutional and less volatile housing. These findings point to the need for information and support to transition from PSH to alternative but equally well supported and affordable housing options.

The mix of tenants with complex histories and needs related to mental health issues, substance use, trauma and other challenges was seen by many tenant participants as problematic and there were various perspectives regarding how well Unison and Launch worked together to manage the challenges produced by this mix. Personal management strategies differed, but most tenant participants spoke of keeping to themselves. The majority of participants had only one or two social relationships with a few other tenants. These findings reflect other research exploring conceptions of 'home' in PSH settings and the importance of safe and inclusive communal spaces (Chan 2020; Parsell et al. 2015).

The data also highlights the lack of significant and sustainable opportunities for tenant voice, advocacy and representation in decision-making processes about their 'home', that is, the ESCG site. While such processes exist at broader organisational levels, efforts to develop and maintain a local ESCG tenancy advisory group have been patchy. Most tenant participants in this research expressed a desire to be more involved in participatory processes which would give voice to their lived experience, ideas and hopes. Closer collaboration between staff and tenants through codesign approaches to policy and practice decisions would be consistent with contemporary and rights-based models of participation, and likely to promote stronger engagement and belonging. Closely related to this are findings highlighting the need for improved and more transparent and responsive complaint and review mechanisms. This is an example of a process which could be developed by staff and tenants working together.

A key feature of PSH and the Common Ground model is provision of in-house supports. This research highlights significant variation in levels of support received by participants and also varying levels of satisfaction and experiences with access and service responsiveness. At the time of the research there were 5 Launch support staff responsible for providing accessible support for wellbeing, independent living and health related needs. Some participants felt very well supported by Launch staff and spoke of the positive regard, care and sometimes friendship they enjoyed with staff members. In contrast, others found it hard to get consistent support. Some tenants with NDIS funding no longer required support from Launch staff, while others using NDIS services

still needed different levels of support, including when NDIS services failed. Longer term tenant participants commented on the changing nature of in-house supports over time, including for some a decline in access and responsiveness, and a shift in staff culture; however, the impact of COVID-19 restrictions on staff access and capacity was acknowledged. These findings suggest that staff resources are stretched and that this has led to a crisis-response mode of operating rather than a more proactive approach to tenant support. For some participants, this meant requests for support with important but non-urgent activities such as completing forms or linking to community were not met or were delayed due to more pressing issues with other tenants. Some participants were also confused about whether they had a support plan in place and what they could or should expect of Launch support staff. These findings imply a lack of clarity regarding the 'support contract' in place between tenants and staff, suggesting a need to review this support contract to ensure greater clarity regarding what all tenants can expect and to introduce a more person-centred approach to supporting tenant needs.

Related to the above is the finding that there is currently limited focus on building and supporting skills and capacity for community participation, including links to employment opportunities. Once again, the impact of COVID-19 restrictions on movement and community access was acknowledged; however, the findings reflect the broader research (e.g. Chan 2020) in highlighting interest and desire for support to have a more 'normal' life. Tenant participants spoke of wanting the opportunity to do more normal things, to have stronger relationships and stronger connections with the broader community, and to have the opportunity to incorporate meaningful activities into their days. While several tenant participants were working and enjoyed broader social networks of family and friends, many were significantly socially isolated and this had become worse during the repeated COVID-19 lockdowns in Melbourne, when visits to the site from family and friends were restricted. Work, both voluntary and paid, was of interest to several participants; however, they reported a lack of structured support towards these goals. A key recommendation is that Launch staff should work with tenants individually and collectively to identify personal and community participation goals and develop support plans and strategies to work towards these. This might include forming relationships with community-based social enterprise organisations, training organisations and other services to develop pathways to community activities, including skill development and volunteer or paid employment.

Tenant participants also expressed a desire for the return of organised in-house activities such as classes, social gatherings and excursions. Participants, both tenants and staff, acknowledged the impact of COVID-19 restrictions on such activities and flow-on impacts on culture and engagement. Conversations with staff during the research indicated that a schedule of in-house activities will be reintroduced.

The findings detailed above highlight the complex environment in which supports are provided to tenants at ESCG and the competing needs and challenges that support staff navigate. To provide

effective and timely supports to people experiencing intersectional disadvantage, including disability, mental health issues, chronic health conditions and substance use, support staff, both internal and external, need a relatively sophisticated set of skills and relevant experience, they need to be adequately qualified and they need high-quality and consistent professional supervision, management support and ongoing professional development. There also needs to be adequate staff resourcing to meet the diversity and intensity of tenants' need. This research has identified key recommendations for the workforce relating to minimum social work or equivalent qualifications, relevant skills and experience in both the disability and homelessness sectors, professional development aligned with tenant needs such as trauma-informed care, access to mentoring and professional supervision for critical reflection, and development of career pathways to reduce turnover and maintain more consistent staffing. The research also highlights the need for resourcing that promotes a more proactive and person-centred model of support and provides adequate staffing across the 24-hour timeframe and over weekends. This model needs to clarify the support contract between tenants and Launch support staff and to ensure all tenants who wish for support have adequate time to meet with a dedicated support worker at negotiated intervals. Developing a proactive model of support is more time intensive and may require additional funding for staff positions.

Recommendations

The following recommendations respond to the findings, which highlight 8 key areas for attention. These recommendations aim to inform support, policy and advocacy reform for ESCG tenants with disabilities and complex needs, and to promote tenancy stability, quality of life and wellbeing, and opportunities for and pathways to community inclusion. A theme running through the recommendations is the need to promote, in more systematic and embedded ways, the participation of tenants in decision-making processes and to ensure that change and reform are grounded in and informed by lived experience. Workforce recommendations relate to the required knowledge and skills, supervision, resourcing and shift away from crisis-led responses to a more proactive, person-centred model of support. While these recommendations are specific to the ESCG environment, they are likely to have broader application to other PSH settings.

The NDIS and interface with PSH/ESCG

1. Launch Housing support staff should develop a stronger relationship with the LAC service designated to the City of Melbourne and organise regular in-reach visits offering onsite information and NDIS advice and support to ESCG tenants. Regular LAC visits to ESCG should aim to provide tenants with accessible information about accessing the scheme and pre-planning as well as tailored advice regarding principles for selecting and using NDIS services, about rights as NDIS participants, and review and complaint processes. These visits should aim to build tenant confidence and awareness of the NDIS and its benefits. Regular onsite LAC presence and more robust relationships would also benefit

ESCG support staff and build their capacity. LAC staff could also use these regular site visits as an opportunity to gain insights into the needs of ESCG tenants and how NDIS services can be developed to cater for the needs of people living in PSH, particularly in relation to social isolation, lack of community engagement, psychosocial disability and the impacts of chronic homelessness on health and wellbeing.

- 2. LAC staff should offer onsite tenant-focused NDIS information seminars on relevant topics such as choosing an external service provider, the role of support coordination and plan managers, what to expect from an NDIS disability worker, choosing NDIS disability workers, your rights as a tenant and dealing with service providers. In addition to building knowledge, these seminars may help build confidence and self-advocacy skills.
- 3. The LAC team should develop a short list of specialist services skilled in working with people experiencing intersectional disadvantage and complex needs including psychosocial disabilities, histories of homelessness and substance use. A short list of suitably skilled and experienced service providers would be a significant resource for ESCG tenants and staff, and would help prevent issues raised in the interviews regarding NDIS services ill-equipped to work with people with complex needs. Ensuring that tenants are more informed about the experience and skills of providers, including support coordination, would not limit choice but in contrast build capacity for more informed choice. Likewise, the National Disability Insurance Agency (NDIA) should ensure that NDIA planners keep tenants' complex needs in mind when supporting service choices. It is hoped this model will build a more relational approach and reduce the transactional way in which some NDIS services are currently being provided to ESCG tenants.
- 4. Launch staff should receive training and up-to-date information about the NDIS process to build and maintain their knowledge and capacity.
- 5. Information should be provided to tenants about independent disability and mental health advocacy organisations in order to build their capacity and assist in navigating service systems including the NDIS; for example, the Disability Advocacy Resource Unit, Victorian Advocacy League for Individuals with Disability, Self Advocacy Resource Unit, and Victorian Mental Illness Awareness Council. These organisations could be invited to ESCG as guest speakers.
- 6. The interface between in-house supports and external service provision should be reviewed in consideration of how to balance tenant privacy issues with Launch staff responsibilities for tenant welfare and Unison's responsibilities. This should include reviewing tenant documentation and guidelines regarding access and privacy.

- 7. Creation of a dedicated NDIS support role onsite at ESCG should be considered. This role would support tenants to access and navigate the NDIS, support selection of services and address support coordination issues if this fails. This role would assist with tenant concerns and complaints regarding NDIS services as well as with plan review, promote active and effective use of NDIS plans, and act as the key ESCG liaison with the LAC team.
- 8. Development of a tenants' group to share information about NDIS experiences should be considered with the aim of sharing information about preferred service providers, including support coordinators, as well as tips for increased choice and control in the scheme.

Vision, leadership and management

9. There should be clarification of place management and support service roles, responsibilities and accountabilities about the most problematic issues, such as those relating to the occurrence of challenging and volatile behaviours in communal spaces. It is recommended that Unison and Launch work with an ESCG advocacy group to gain insight into the most problematic issues at ESCG and, together with tenant representatives, develop understanding about lines of accountability and responsibility regarding these issues. This information needs to be clearly communicated to tenants in accessible formats, for example, written information, tenant meetings, one-on-one conversations, an updated charter of responsibilities.

Tenant rights, representation and participation

- 10. Launch Housing and Unison should work with tenants to develop a more collaborative culture and strategies for co-design approaches to policy and practice development at ESCG.
- 11. There should be development and resourcing of an ESCG tenants' advisory group with codesigned terms of reference and resources for skilled facilitation to promote sustainability. This group would feed into Launch's Lived Experience Advisory Program (LEAP) but remain specifically focused on ESCG matters and experiences. Information about the advisory group and tenant representatives should be disseminated widely to promote visibility of the process and encourage tenants to engage with their representatives regarding issues to be raised.
- 12. Existing complaint and suggestion processes should be reviewed together with tenant representatives to ensure that these processes are accessible, transparent and responsive, the processes are well advertised and the actions arising from complaints are clearly communicated both collectively and to individual tenants who have raised complaints.

- 13. Links with disability and housing advocacy groups (e.g. Tenants Victoria) should be reviewed to ensure tenants are provided with clear and accessible information about their rights at ESCG. This should include working with tenants to address privacy dilemmas such as how staff can respect tenant privacy while also maintaining oversight of their welfare and wellbeing.
- 14. Peer worker roles at ESCG should be developed to promote connections with people with lived experience and connections with organisations such as the Council to Homeless Persons.

Model of support and care

- 15. Launch should ensure all supported tenants who choose to access support have both a key worker and an individualised support plan outlining their key needs, goals and related support and resource strategies, as well as details about external service providers. Support plans should be regularly reviewed and updated in collaboration with tenants and reflect their changing needs and goals. Tenants should have clarity about when they can meet with their key worker and clear expectations about what to expect from the support contract. Support approaches should be proactive.
- 16. Launch support staff should ensure individualised plans and supports include, where desired by the tenant, community participation and employment goals, voluntary or paid, along with strategies and resources to achieve these. Creative ways of linking tenants to education and employment opportunities should be considered, along with strategies for capacity development in these areas. This could include, for example, links with neighbourhood houses, community-based social enterprises and training organisations which might offer partnership opportunities. NDIS participants could include related goals in their plans and funding could be allocated to these activities.
- 17. Launch support staff should work with ESCG tenants to maintain an up-to-date online resource of community groups, networks and opportunities relevant to their needs and interests, for example, neighbourhood houses in the local area, disability-related support groups (e.g. acquired brain injury [ABI] support groups), free community festivals and volunteering opportunities. Consideration should also be given to inviting guest speakers from these organisations in order to build links and support 'warm' referrals (e.g. accompanying someone on their first visit to a group or community organisation if this would help).
- 18. To promote relationships between tenants and staff, including new tenants and new staff, consideration should be given to the creation of self-authored profiles, where tenants choose

any medium they like to create a representation of who they are and what is important to them. Any art form or medium can be used, such as a poem, short video, photo or painting. These profiles would be available for staff to view and would be particularly valuable for new staff and for staff who had not previously worked with certain tenants.

Communication, roles and relationships

- 19. ESCG should increase staff visibility by, for example, ensuring that new staff are introduced to tenants in several ways such as via a group meeting, through letters and on a poster with photos and names. In addition, support staff could spend more time in shared communal spaces to enhance their visibility.
- 20. Launch staff should partner with tenants in co-developing strategies for building a stronger sense of community and stronger relationships between ESCG tenants with the aim of strengthening social connection and a sense of belonging. Note that some tenants may prefer to keep to themselves; however, others may need proactive support to connect with other tenants in the building.

Workforce

- 21. Consider minimum qualifications for support staff to be a recognised welfare or social work qualification or equivalent as well as relevant experience in the disability and homelessness sectors. It should be ensured that all support staff also have qualifications and experience working with alcohol and other drugs (AOD), with people with psychosocial disability, and an awareness of trauma-informed care.
- 22. Launch Housing should build staff capacity to support tenants in community engagement and participation, including voluntary and paid employment. This could involve additional staff training in strengths-based approaches, as well as building staff networks, knowledge and links to community organisations and opportunities of interest to tenants, including support groups relating to particular disabilities.
- 23. All support staff should have access to regular professional supervision for critical reflection and to debriefing following critical incidents.
- 24. Adequate staffing should be ensured across the 24-hour timeframe and over weekends, and adequate time should be made available for handover between shifts. The recommended proactive model of support is more time intensive and is likely to require additional funding for staff positions.
- 25. Launch Housing should build career pathways for support staff and develop strategies to actively reduce staff turnover.

Sense of home, belonging and community inclusion

- 26. Launch should reinstitute a calendar of in-house activities and excursions to revitalise community connections following the long months of COVID-19 lockdowns. This should be developed in partnership with tenants with the aim of reflecting tenants' interests.
- 27. ESCG should review how challenging behaviours are managed in communal areas and how these impact on other tenants. This should include working with tenants to identify effective approaches which do not discriminate against people with challenging behaviours, but also ensure ESCG is not just a safe place to live but also feels like a home both inside and outside individual units.
- 28. The pet ownership policy should be reviewed, with input from tenants and in line with relevant legislation.

Housing pathways beyond ESCG

- 29. Information and support should be provided about alternative housing options such as scatter-site housing for tenants who choose not to stay at ESCG. This may be particularly relevant for some long-term tenants who have achieved housing stability and wish to leave congregate living; these tenants should be linked to information and supports to enable pathways out of ESCG.
- 30. More tailored information about the portability of NDIS funding and supports should be provided in the move to other housing.

Chapter 1 Introduction and Background

1.1 Project Background

This project was a collaboration between RMIT University, the University of Melbourne and industry partners Unison Community Housing and Launch Housing. The aim of the project was to explore the experience of people living with disability in permanent supportive housing (PSH) and how they can be best supported to access both National Disability Insurance Scheme (NDIS) and non-NDIS support to meet their needs and goals, including maintaining tenancy and avoiding the risk of re-entering homelessness. The project has built on the existing evidence base regarding the support needs of people with disability who also experience homelessness, particularly in relation to PSH settings. The project provides a set of recommendations relating to the interface between Elizabeth Street Common Ground (ESCG) and the NDIS, as well as recommendations relating to the existing model of support and care, and to building internal cohesion as well as stronger connections with community. The recommendations address identified gaps in disability supports to ESCG tenants and aim to enhance collaboration between ESCG, the NDIS and the broader disability service system.

The research arose from an awareness of the lack of research exploring the intersection of homelessness and disability (Beer et al. 2011) and, within this, the limited research focused on the everyday service and support experiences of people with disability living in PSH. People with disability face additional risk factors in relation to homelessness. These include greater likelihood of unemployment, reduced social supports and low income (Australian Institute of Health and Welfare [AlHW] 2019). Tenants living in PSH experience intersectional disadvantage produced by complex needs including disabilities and histories of chronic homelessness, substance use, incarceration and trauma. While there is substantial international and Australian research supporting the PSH approach (e.g. CHP 2018; Parsell et al. 2015), there is little research which more explicitly focuses on disability supports in this context, including the extent to which tenants with disability experience onsite supports, and if and how they meet their diverse and intersectional needs and goals.

This project was designed to explore these experiences in more detail and also included exploration of the challenges and opportunities offered by the NDIS, the national \$22 billion per annum program for people with disability introduced by the Australian Government in 2013. The NDIS has the potential to offer people living with significant and permanent disabilities the supports they need to live more independently and engage in the community; however, little is currently

known about how people with experience of homelessness access and navigate the scheme. Paterson (2017) argues that the NDIS was not designed with people who are experiencing or have experienced homelessness in mind and that this community faces additional and substantial barriers to accessing the NDIS and other disability supports. The NDIS design presents additional hurdles to people with complex needs such as psychosocial disability. Challenges include not knowing about the NDIS, hesitancy to apply, difficulty in making contact, limited capacity to make an application and limited support to assist with them in these processes. There is little research in this area and even less which explores the dynamics, enablers and barriers in the PSH context despite the existing levels of need within this cohort and the potential benefits a more nuanced understanding of the relationships between these systems would offer. This project aims to contribute to the evidence and knowledge in this area, with implications for policy and practice reform.

PSH is an innovative response to supporting people who have experienced long-term homelessness, who have additional complex needs and who face additional barriers to accessing and maintaining secure and stable housing (Parsell et al. 2015). The PSH model reflects Housing First principles, which prioritise, as a first step, safe and permanent housing for people with a history of long-term homelessness, followed by provision of onsite wraparound supports intended to meet a broad spectrum of health, welfare and psychosocial needs, and to support tenancy (Australian Housing and Urban Research Institute [AHURI] 2018; Henwood et al. 2013). These complex needs can include substance use, histories of trauma or incarceration, severe mental illness, intellectual disabilities, ABI, physical disabilities and chronic health issues (CHP 2018). The Housing First model is in direct contrast to a housing-ready approach, which requires someone to be adequately stable and to move through short-term and transitional housing before being offered permanent housing (Launch Housing 2019b, p. 12). The Housing First model is guided by rights-based principles including that everyone has rights to a home, choice and selfdetermination, active engagement without coercion, and social and community inclusion (Dodd et al. 2020). This model is also distinguished by its separation of support and housing services, ongoing and flexible supports, and a harm-reduction and recovery-oriented approach. Rent in PSH is subsidised to no more than 30% of a tenant's income (CHP 2018).

1.2 Elizabeth Street Common Ground

The Common Ground housing model was founded in New York in 2009 and has since spread across the USA and Australia. The ESCG site was identified as the case study for this research due to its Melbourne CBD location and access to 65 tenants who were receiving various levels of onsite support. ESCG was established in Melbourne in 2010 and is a partnership between Unison Community Housing, the Victorian Property Fund, the Victorian and Federal governments and the construction company Grocon. The ESCG model aims to operate according to five key elements: permanent housing; safety; affordability; supportive; and a social mix of tenants (Launch

Housing 2015). It provides onsite wraparound services for 65 ESCG tenants with complex needs and offers 66 affordable housing apartments for low-income earners. In keeping with Common Ground principles, support services and housing services are delivered by separate providers. Launch Housing provides the onsite support services, while Unison manages the property and issues such as accessibility, maintenance, security, rubbish and recycling collection, and auditing of units to ensure adequate maintenance and compliance with hygiene standards. The Launch support team aims to provide support for health, independent living, and emotional and psychosocial needs using a team-based approach. Levels of support are guided by tenants and can range from intense and active to intermittent support. As of May 2021, staff reported that of the 65 tenants eligible for support approximately 20 to 30 required intense and active supports while the remaining tenants required intermittent support. Other regular onsite supports delivered by external providers include counselling, medical and health services. The ground-floor entrance to ESCG includes a reception desk operated 24 hours a day by a concierge.

The Residential Tenancies Amendment Act 2018 made over 130 amendments to the Residential Tenancies Act 1997 (Vic) and came into effect in Victoria on 29 March 2021. These changes affect renters, including those who live in housing designated as 'rooming houses' such as the ESCG, along with the Rooming House Operators Act 2016 (Vic), which governs rooming house operators. Rooming house residents have a range of rights in relation to their residency including the rights to safety and privacy, minimum standards relating to their rooms and common areas, and rights relating to entry into rooms, rent increases and so forth (Consumer Affairs Victoria 2021).

The research on PSH highlights the benefits to individuals of safe, secure and comfortable housing, of onsite flexible supports and of independence and empowerment (Hannigan & Wagner 2003). There are also social and economic benefits to the community of reduced rates of engagement with the health, mental health and justice systems and emergency services (Bullen et al. 2016; Launch Housing 2019b). Successful PSH enables people with long histories of homelessness and additional complex health and disability-related needs to regain some control over their current and future lives, to participate in work, school and the wider community, and to develop and maintain social connections (Kirsh et al. 2009). This supportive housing model offers the opportunity to live independently, enjoy secure and stable housing, and by doing so avoid the recurrence of homelessness (Cohen et al. 2004).

Evaluations of other Common Ground sites in Australia include a 2015 evaluation of the Brisbane Common Ground site (Parsell et al. 2015) and a 2016 evaluation of the Camperdown Common Ground site (Bullen et al. 2016). Both evaluations found that tenants valued the security, affordability and privacy of their housing after years of homelessness and also valued access to flexible onsite support services. Parsell et al. (2015) found that the Brisbane Common Ground had effectively

removed barriers to affordable housing and 'fostered the conditions' to maintain tenancy (p. 4). Both evaluations reported that onsite support services had assisted tenants in various ways to support positive changes.

In terms of gaps and areas for development, both evaluations identified the risks and challenges of housing people with such complex needs, including substance use, in congregate housing. Both evaluations also identified a range of implications for tenant wellbeing and sense of security, as well as for support staff, of this model of care and of resourcing. Bullen et al. (2016) warn that a mix of tenants with highly complex needs could create 'dependency and institutionalisation' (p. 4) and that this can be compounded by support staff attitudes and decision-making. Both evaluations highlighted the importance of clear and close communication and of strong relationships between housing, support and security providers. The importance of a 'unified' supportive housing model, while also maintaining separation between support and housing services, was emphasised as a key success factor (Parsell et al. 2015, p. 3).

1.3 Policy context – disability and homelessness

Policy areas relevant to this research relate to the intersection between disability, housing and homelessness. An intricate framework of legal conventions and declarations make up the international framework defining the right to housing and the responsibilities and obligations of nation states to provide adequate housing and associated support services, including for people with disability. There is no specific international convention on housing rights; however, the right to adequate housing is recognised in both the *Universal Declaration of Human Rights* (United Nations [UN] 1948) and the *International Covenant on Economic, Social and Cultural Rights* – Article 11 (UN 1966). The right to housing applies to all persons without discrimination and extends to all parts of a state without limitation.

The right of people with disability to adequate housing has been increasingly recognised over recent years. The UN (2006) Convention on the Rights of Persons with Disabilities (CRPD) states that people with disability have the right to an adequate standard of living with adequate food, clothing and housing and to the continuous improvement of living conditions (Article 28). The CRPD specifies that people with disability should have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others (Article 19) and have access to public housing programs (Article 28). In the CRPD, the right to housing sits alongside people's other rights to independent living and full inclusion and participation in the community (Article 19).

In 2011, the Council of Australian Governments (COAG) in response to the CRPD initiated the National Disability Strategy (Australian Government 2011). In relation to housing, the strategy states that people with disability should have access to affordable and secure housing across

all types of tenure (Chapter 3). This right to housing is asserted within a broader context of maximising the potential of people with disability and ensuring their participation as equal citizens in Australian society (Foreword). In 2013, the Commonwealth Government introduced the NDIS, providing funding for services, equipment and support for people under 65 years living with a permanent and significant disability. The NDIS has been described as a key plank in Australia's attempts to promote and realise the human rights of people with disability as enshrined in the CRPD (Cukalevski 2019). A key element of the NDIS is LAC, a function provided by partner organisations in the community. The role of LAC services is to provide information about the NDIS, to support access, planning and plan implementation, and to build links between people with disability and community services (NDIS 2020).

In relation to housing support, the NDIS encourages people with disability to live independently; however, it only provides specialist disability accommodation (SDA) to people with severe disabilities and very high support needs, and does not provide funding to assist with private rental costs. Moreover, many people with disability who may be eligible for SDA funding are not receiving it, with SDA funding being paid to only 54% of the estimated 28,000 NDIS participants who are expected to be eligible for SDA (Summer Foundation 2021). The remaining group of more than 12,000 eligible people, if housed at all, are likely to be living in government housing, hostels or residential aged care, or with family (Summer Foundation 2021).

1.3.1 Policy responses - Victoria

In Victoria, several streams of funding resource homelessness services. Key among these are the specialist homelessness services, an umbrella term for a range of agencies that provide support to people experiencing or at risk of homelessness. These agencies are funded under the National Housing and Homelessness Agreement, where Victoria matches the amount of funding provided by the Federal Government (Launch Housing 2019a).

There has been a concerted focus in recent years on addressing homelessness in Victoria, including the *Homelessness and rough sleeping action plan* (Department of Health and Human Services [DHHS] 2018) followed by the 2021 Inquiry into Homelessness in Victoria (Parliament of Victoria 2021). The *Homelessness and rough sleeping action plan* recommends a strong Housing First approach and the need to prioritise stable accommodation for rough sleepers as quickly as possible, followed by effective and responsive homelessness support services to retain that accommodation. The plan emphasises the need for 'rapid' accommodation with flexible supports to be provided and that these support services need to be 'tiered,' with differing levels of support provided to the different cohorts of rough sleepers based on their needs. While support for this model is strong, limitations include that the PSH approach is constrained in how many people with complex needs it can support due to housing stock and resourcing issues (DHHS 2018).

The 2021 Victorian Inquiry into Homelessness (Parliament of Victoria 2021) acknowledges the complex challenges facing many people who are homeless, including the intersectional challenges and barriers created by mental illness and homelessness, with poor mental health being a risk factor for homelessness and homelessness likely to negatively impact on wellbeing and mental health. The DHHS submission to the inquiry reported that people with persistent mental illness are 8 times more likely to access homelessness services and 5 times more likely to be in social housing than other Victorians.

1.4 Research design

This project used a case study methodology, focusing on the ESCG, to address the aim of the research. The project was co-designed and informed by the lived experience of tenants and staff practice knowledge, and included analysis of the interface between the NDIS and non-NDIS disability, mental health and health support services. It was guided by a project advisory group that included partner and sector representatives, tenants, staff and the RMIT and University of Melbourne research team. The specific research questions that have guided the project are:

- 1. How are tenants with disabilities and complex needs in permanent supportive housing supported to access information and services in relation to the NDIS?
- 2. What is the lived experience of permanent supportive housing for people with disabilities and complex needs?
- 3. What are the implications for policy and practice?

1.4.1 Ethics review

The project was reviewed and approved through a two-tiered ethics approach: Stage 1 of the project, which involved interviewing staff employed by the two partner organisations, Unison and Launch, was reviewed and approved by RMIT University's Design and Social Context College of Human Ethics Advisory Network and by Launch Housing's ethics review processes; Stages 2 and 3 of the project, which involved ESCG tenant interviews and a tenant workshop, were reviewed and approved by RMIT University's Design and Social Context Human Research Ethics Committee and by Launch Housing's ethics review processes. Pseudonyms have been used throughout the project in seeking to ensure participant confidentiality and privacy. All participants involved in the research received a Participant Information Sheet outlining details of the project and what participation in the project involved, and all signed a consent form before participating in the research.

1.4.2 Methods

The project focused on the ESCG site situated on the outskirts of the Melbourne CBD. Stage 1

participants were staff employed by the partner organisations at the ESCG site. Stages 2 and 3 participants were tenants who identified as having a disability. In total, 12 tenants, 4 Launch, one Unison staff member and one home and community care (HACC) worker who provided support to tenants in Unison housing participated in the project.

A key element of the research design was using co-design principles to understand the experience of living in PSH and to develop strategies for improvements for people living with disability at ESCG. Co-design is an established approach aimed at involving the people who use services in the development of these services. The original project design also aimed to include tenants in the project advisory group; however, despite efforts to recruit tenants to these paid roles through the Launch team, we were unable to fill these positions. We were, however, able to involve two tenants in the workshop (Stage 3) to reflect on findings and develop strategies. Both Launch and Unison staff were members of the project advisory group which advised and supported the research team on recruitment, analysis of the data and recommendations for policy and practice. This qualitative project used several different methods to address the overall aim of the research and the specific research questions. These were an initial scoping review, in-depth interviews with both staff and tenants, a tenant workshop and thematic analysis of the qualitative data collected.

1.4.3 Data collection

The data collection for the project was conducted in 3 stages. The first stage involved a literature review and interviews with Launch and Unison staff. The second stage involved interviews with tenants. The third stage involved a tenant workshop where key findings were discussed, and draft strategies and recommendations identified.

1.4.4 Stage 1: Literature review and staff interviews

The first stage of the project was a literature review on the intersection between PSH and disability. This involved exploring the international literature as well as the Australian context and research related to take-up of the NDIS by people experiencing homelessness. The review of the literature, which is discussed in Chapter 2, informed the research project as a whole and the development of the interview schedules with staff and tenants specifically. The second part of Stage 1 was indepth interviews with 4 Launch support staff (one of whom was a community worker), a Unison manager with former experience of ESCG and a HACC worker employed by the City of Melbourne to provide support to Unison tenants.

1.4.5 Stage 2: Tenant interviews

The second stage of the project involved in-depth interviews with ESCG tenants who identified as living with disability and/or other complex needs. Tenants were recruited through a letterbox drop of a flyer advertising the research into tenant letterboxes onsite at ESCG. Prior to this attempts had been made to recruit tenants with the assistance of the Launch team; however, this approach

was not successful. Interviews lasted approximately one hour in duration and were conducted onsite or online via Microsoft Teams. Twelve tenants who identified as living with disability were interviewed for this part of the project. Length of tenure ranged from two to 10 years and tenants had diverse pathways into ESCG. Two tenants were employed part time. There were 8 males and 4 females. Tenant participants ranged in age from 37 to 59. Of the 12 participants, 6 had NDIS packages and two were pre-planning with Launch staff. Two of the 6 tenants were self-managing their packages and the other 4 employed providers to assist in managing their plans and services.

1.4.6 Stage 3: Tenant workshop

The third stage of the project involved a workshop with tenants and the research team to coanalyse the data from the staff and tenant interviews, and to co-develop recommendations for policy and practice. The researchers presented a preliminary thematic analysis of the interview data and, together with the tenants, identified 8 key themes: the NDIS and interface with PSH/ ESCG; vision and leadership; tenant rights, representation and participation; model of support and care; communication, roles, and relationships; workforce; sense of home, belonging and community inclusion; and, housing pathways beyond ESC. These themes will be discussed in Chapters 4 and 5.

1.4.7 Data analysis

Staff and tenant interviews were recorded and transcribed, and the data was then thematically analysed to develop key themes in relation to the research questions. This involved two members of the research team analysing each interview and then, after initial themes were identified, these were workshopped with the tenants as described above (Stage 3). The final themes were then presented and reviewed with the project advisory group.

1.4.8 Limitations

This research began in mid-2020, shortly before Melbourne moved into an extended 4-month lockdown due to the COVID-19 pandemic. Since then and to the time of writing of this report, Melbourne has experienced 3 further lockdowns. This has caused disruption to various stages of the research and reduced our capacity to engage with tenants and staff onsite, to become more familiar with the site's everyday operations and to recruit more tenants to the research. A limitation, therefore, is the small sample size of 12 tenants. This is below the anticipated minimum of 20 tenants originally planned for and the findings need to be considered in light of this. Close analysis of the rich data produced by the interviews has succeeded in mitigating the small sample size to a degree. The lockdown restrictions also made it more difficult to recruit tenants to the project's advisory group, a key element of the research design, and to enable more tenants to attend the co-design workshop. The lockdowns may also have influenced the data collected due to the impacts on service delivery and the difficulties experienced by staff and tenants during this period, in particular in relation to responses to questions regarding social connections and opportunities to participate in the broader community.

1.5 Outline of report

This chapter has introduced the research project, background and aims, and discussed the context in which it has taken place. The chapter has also outlined the qualitative research design. Chapter 2 will offer a brief overview of the academic and grey literature regarding the experiences and needs of people with disability who have experience of chronic homelessness and policy responses to this. Chapters 3 and 4 will present the key findings identified from the 6 staff interviews, 12 tenant interviews and tenant workshop. Chapter 5 will provide a discussion of the key findings and provide the 31 recommendations for policy and practice.

Chapter 2 Disability, Housing and Homelessness: A Review of the Literature

2.1 Introduction

Existing research demonstrates that people with disability, and particularly those with a cognitive disability and those who experience mental distress, are at higher risk of homelessness. There are particular drivers of homelessness among people with disability including a lack of affordable and accessible housing, inadequate planning for deinstitutionalisation, limited access to disability support funding, social isolation, substance abuse and imprisonment. Housing First PSH programs have been introduced internationally and in Australia and are a response to chronic homelessness for people with complex needs including substance use, histories of trauma or incarceration, serious mental illness, intellectual disability, ABI and chronic health issues (CHP 2018). This literature review explores the intersection between disability and homelessness, and the Housing First PSH programs that have been introduced to address chronic homelessness for people with disability.

2.2 Disability and homelessness: Demographics

The risk and prevalence of homelessness are much greater for people with disability than for those without. Within the broad population of people with disability, those with more severe limitations, intellectual or psychological disabilities are at higher risk of homelessness. In Australia, almost 25% of people with difficulty learning or understanding – indicative of cognitive disability – and 34% of people with mental illness who require intensive support are at the most extreme levels of homelessness risk, compared to only 16–17% of people without these disabilities (Beer et al. 2019).

These Australian results echo studies conducted internationally, which found cognitive impairments are more prevalent in homeless populations (3–40%) than in the general population (1–3%) (Cotman & Sandman 1997; Mercier & Picard 2011; Spence et al. 2004). Focusing on people with intellectual disability, a recent meta-analysis by Durbin et al. (2018) found that estimates of the prevalence of intellectual disability in samples of homeless people varied within and across countries (12–39%). The authors acknowledged that it is difficult to determine whether these differences result from data limitations, methodological differences or indeed different demographics of the homeless populations in different countries. Focusing on psychosocial disability, in the USA it is estimated people with psychosocial disability account for about 30% of the homeless population (Gulcur

et al. 2003). Similarly, in Australia in 2015–16, 31% (72,364 people) of those who accessed specialist homelessness services and were over 10 years old had a current mental health issue. This is double the rate of mental illness among the general population (16.2%) (AIHW 2018; Brackertz et al. 2018).

The 2021 Victorian Inquiry into Homelessness describes mental illness and homelessness as 'intersecting' and 'bi-directional' issues (Parliament of Victoria 2021, p. 140) with poor mental health being a risk factor for homelessness and homelessness being likely to negatively impact on wellbeing and mental health. The DHHS submission to the inquiry reported that people with persistent mental illness are 8 times more likely to access homelessness services and 5 times more likely to be in social housing than other Victorians. People with disability experiencing homelessness present some similarities and some differences to other homeless people without a disability. Mercier and Picard's (2011) study in Montreal, for example, found that the population of homeless persons with intellectual disability differed from the overall homeless population in terms of a higher proportion of women, lower incidence of rough sleeping and higher level of contact with family, albeit still well below those of the non-homeless population.

2.3 Drivers of homelessness among people with disability

The drivers of homelessness among people with disability are varied and complex, and include the following 6 factors.

2.3.1 Lack of affordable housing

Housing affordability stress is prevalent among people with disability because of barriers to participation in paid employment and consequent low incomes. In Australia, only around 25% of people with a profound or severe disability aged between 15 and 64 years old are in the labour force, compared with 83% of the non-disabled population (Australian Bureau of Statistics 2018, Table 8.3). Anglicare's 2021 *Rental affordability snapshot* report found less than 0.5% of rental properties on offer were affordable for a single person with the Disability Support Pension as their primary source of income (Anglicare Australia 2021). In 2020, nearly a third (32%) of private renters receiving both the Disability Support Pension and Commonwealth Rent Assistance, and 72% of those receiving the Disability Support Pension without Commonwealth Rent Assistance, experienced housing affordability stress, that is, paying over 30% of their income on rent (AlHW 2021). A severe shortfall in social housing supply has left many people with disability without any affordable housing options. In July 2019 there were 148,500 people on the waiting list for public housing and an additional 12,100 households on a waiting list for State Owned and Managed Indigenous Housing dwellings (AlHW 2020).

2.3.2 Lack of accessible housing

Due to the exemption of newly built housing from the minimum accessibility standards that apply to public venues, most existing housing stock in Australia is inadequately designed to meet the

needs of people with mobility restrictions. This leaves some people with complex disability and inadequate support at risk of homelessness (Wiesel 2020). The recent inclusion of minimum accessibility standards in the National Construction Code is expected to increase the supply of housing that is accessible for people with mobility restrictions; however, New South Wales, South Australia and Western Australia have not committed to implementing these changes to the National Construction Code. Even in other states and territories, it will take many years for new accessible housing supply to reach the people who need it most.

2.3.3 Inadequate planning for deinstitutionalisation

A haphazard, inadequately planned and under-resourced process of deinstitutionalisation in Australia has also increased homelessness among people with disability. Until the 1980s, institutional care was the major form of supported accommodation for people with intellectual or psychosocial disability. Since the 1980s, most institutions have been progressively closed or redeveloped and their residents rehoused. The research evidence suggests that the availability of smaller scale, non-congregate housing in the community is a fundamental condition for the social inclusion, self-determination and wellbeing of people with intellectual disability (Kozma, Mansell & Beadle-Brown 2009; Walsh et al. 2010). However, inadequate resourcing and planning have meant many people with disability moved out of state-run institutions only to enter other congregate settings such as prisons, nursing homes and psychiatric hospitals, or became homeless (Drake 2014; Wiesel & Bigby 2015). For people with psychosocial disability, discharge from hospitals is a point of significant homelessness risk. Inadequate discharge planning and procedures, a lack of coordination across sectors and limited options for exit into appropriate and secure housing leave people at risk of being discharged from institutions or hospitals into homelessness (Brackertz et al. 2018; Duff et al. 2021).

2.3.4 Limited access to disability support funding

With the closure of institutions, group homes have become the dominant form of government-funded supported accommodation available to people with disability and are used primarily by people with intellectual disability (Wiesel 2021). The supply of group homes (approximately 4000 homes nationally before the NDIS rollout) was well below the estimated need (Productivity Commission 2011). Those who did not wish to or were unable to enter supported accommodation had very few alternative ways to access both paid support and housing, increasing their dependence on informal carers, especially ageing parents, to provide informal support and housing (Wiesel 2021).

The NDIS was designed to fix some of these historical problems, with a significant increase in funding for supported accommodation and a shift to individualised funding aimed to allow NDIS participants to access paid support wherever they live (not only in group homes). However, the NDIS provides funding for only 10% of people with disability in Australia and SDA funding for only 6% of eligible NDIS participants; this leaves the vast majority of people with disability ineligible for NDIS assistance with housing.

Beer et al. (2020) explored the changing distribution of the risk of homelessness among populations with a disability before and after the nationwide introduction of the NDIS. Their analysis shows an increase in the risk of homelessness since the NDIS rollout across all disability categories. People who experience blackouts, fits or loss of consciousness, difficulty learning or understanding, nervous or emotional conditions, or mental illness are especially vulnerable to homelessness in the NDIS era:

already at-risk groups (especially people with disabilities affecting cognitive or mental health) within the population with disabilities have missed out on the potential benefits of NDIS, and may be experiencing the double disadvantage of doing so in a policy environment that assumes they have received protection from the NDIS ... the NDIS unintentionally provides more assistance to those who were least at risk pre-NDIS and, potentially, the least to those in the upper range (Beer et al. 2020, p. 8).

2.3.5 Social isolation and breakdown of informal care relationships

Both social isolation and strained relationships with carers increase the risk of homelessness for many people with disability. A study by Nishio et al. (2017) in Japan found that within a sample of participants experiencing homelessness, those with cognitive disability were more likely to consider difficult relationships as the cause of their homelessness, compared to non-disabled participants who were more likely to focus on financial difficulties (e.g. debt). Relationship breakdowns with carers, often triggered by so-called 'challenging behaviours' associated with unmet support needs for people with severe cognitive and psychosocial disabilities, can lead to relinquishing of care by parents and consequent risk of homelessness (Office of the Public Advocate 2020).

2.3.6 Substance abuse and imprisonment

Substance abuse problems are prevalent among people with cognitive and psychosocial disability, and significantly increase the risk of homelessness (Mercier & Picard 2011; Padgett et al. 2006). People with psychosocial and cognitive disability are also at high risk of involvement with the criminal justice system, which is also closely associated with high risk of homelessness (Office of the Public Advocate 2020).

2.4 People with disability in permanent supportive housing

Until the 1990s, in many countries few programs were equipped to successfully address the needs of people with disability and other complex needs such as substance abuse problems who were experiencing homelessness (Osher & Drake 1996). With the establishment of PSH and Housing First programs, a number of studies sought to examine outcomes for people with severe mental illness in these programs, although the term 'disability' is often not explicitly mentioned in these studies, indicative of the challenges of diagnosis in the homeless population. The evidence suggests Housing First programs provide a superior response to the needs of homeless people

with severe mental illness and substance abuse problems, compared to treatment-first approaches to homelessness. Peng et al.'s (2020) meta-analysis of studies examining outcomes for people with disability in treatment-first or Housing First programs found that Housing First programs decreased homelessness by 88% and improved housing stability by 41%. Housing First residents experienced better quality of life and reduced hospitalisation and emergency department use (Peng et al. 2020, p. 408). Holmes et al. (2016, p. 1) also report that 'the accommodation of chronic homeless persons with psychosis in a "housing first" permanent supported accommodation leads to increased housing stability and optimism, improved continuity of care and reduced psychiatric admissions'.

People with intellectual disability experience unmet needs that exceed those of the wider homeless population (Van Straaten et al. 2017). Although PSH has been identified as a potential solution to the persistent unmet needs of homeless people with intellectual disability, very few programs have been designed to support this group (Mercer & Picard 2011) and only a very small number of studies examine outcomes for people with intellectual disability in PSH. Durbin et al. (2018) identified elements of such models that are applicable to the needs of people with intellectual disability, such as the emphases on self-determination, strengths and increased community participation embedded in the Housing First approach, which is consistent with the current philosophies that underpin services and supports provided to adults with intellectual disability.

2.5 Conclusion

In conclusion, the lack of affordable, safe and appropriate housing, uneven formal and informal support available to people with disability and poor integration across housing, health and disability support systems all generate pathways where people with disability are 'cycling through a number of inappropriate accommodation options' (Office of the Public Advocate 2020, p. 12) including homelessness. PSH has been identified as one model that could potentially address the needs of homeless people with disability through provision of integrated housing and support services while taking a Housing First approach whereby stable housing is prioritised and not made conditional on use of support services. Although there is a growing literature that indicates positive outcomes associated with PSH, very limited information is available in these studies on the disabilities of residents, which are often implied rather than explicitly acknowledged.

Chapter 3 Experiences of Life and Support Services at ESCG

3.1 Introduction

This chapter presents the key findings related to the support experiences of 12 tenants living with disability at ESCG. The focus of the interview questions with tenants and staff related to supports for their disability and/or chronic health conditions; however, this experience is interlinked with everyday life at ESCG and, as such, the findings also include more general themes. Analysis of the data developed 8 themes representative of common patterns in tenant and staff participant experiences as they related to the research questions. The 8 themes are: the NDIS and interface with PSH/ESCG; vision and leadership; tenant rights, representation and participation; model of support and care; communication, roles, and relationships; workforce; sense of home, belonging and community inclusion; and, housing pathways beyond ESC. This chapter discusses 7 of these themes and the next chapter will be dedicated to tenant and staff participant experiences of the NDIS and disability services and the interface with ESCG systems and processes.

3.2 Vision, leadership and management

In keeping with the Housing First principle of separating the provision of support and housing services, either internally by the same organisation or by two different providers, at ESCG Launch provides onsite support services while Unison manages housing services (as a social landlord). Participants appeared to understand the different functions of these two organisations; however, several participants identified problems relating to practice and decision-making produced by the separation of functions and communication gaps related to these. These problems were most apparent in relation to persistent issues such as the management of challenging behaviours and drug use in the building. Several tenant participants identified the need for Launch and Unison to work more closely together to address these issues and to have more transparent decision-making processes:

so you've got Launch and Unison, the real issue with that from my perspective is there's no terms of reference set down for decision-making. So it actually causes problems, you know, bottleneck ... So you'd be better off having just one organisation there or at least one that you, from the outset like, be transparent about the power, who's the decision-maker of this and who's not ... you know, it's just a mess and there's no agreement on who will do what, it just makes these two parties go head to head over issues (Eli – tenant participant).

I don't think that helps either to have a landlord and everything to do with the structure and the tenancies are handled by Unison and everything to do with the physical personalities of the people handled by Launch. That's crazy, it doesn't make sense (Peter – tenant participant).

The separation of building management and support provision, and the gaps in support and risk management this created, meant some tenant participants felt they were falling through the cracks of the support system. Noah felt that persistent problems such as security issues and difficult behaviours at the front of the building went unaddressed due to management and accountability gaps:

So, what happens is Unison do not supply any front-of-house staff to this building, so the people who've manned the front reception are either private security hired by Unison or private security hired by Launch or they're Launch housing staff, so it's not in their job description. They're social workers, they're not security guards. So Unison put all of the front-of-house maintenance and management of people's behaviours and expectations of the behaviours in the common areas onto Launch staff. It's not in their job description, they're social workers (Noah – tenant participant).

These findings suggest the need for clearer lines of communication between Launch as the tenant support provider and Unison as the housing service provider. This reflects previous Common Ground evaluations pointing to a 'unified' management approach as a key success factor (Bullen et al. 2016; Parsell et al. 2015) (see Recommendation 9).

3.3 Tenant rights, representation and participation

This section discusses findings from tenant and staff interviews related to tenant rights, representation and participation, including the right to a safe living environment, and findings regarding complaint mechanisms and safeguarding. The research has found that most tenant participants were concerned at some level about the perceived risks of living at ESCG, about the behaviours, drug use and violence they saw and heard, and at times felt unsafe beyond the walls of their unit.

Many of the tenants interviewed also identified a lack of opportunity to participate in decision-making processes at ESCG and spoke of a desire for opportunities to contribute to more collective decision-making about issues impacting their housing and quality of life in the broader ESCG complex. There was a strong sense that tenants' lived experience was not being engaged in any systematic way and that decisions about policy and practice were largely being made in the absence of their input. Related to this is the finding that understanding of tenant rights was mixed and processes related to complaints and safeguarding could be improved for greater clarity and responsiveness.

While not all tenant participants were interested in contributing to policy and practice decisions, those who were offered a range of ideas for change and showed an interest in being more involved. Although there had, over the years, been processes for consulting with tenants, the findings suggest that these were often limited and not well resourced or facilitated. It was reported that they sometimes quickly degenerated into a complaint and personal grievance forum, rather than a productive space for discussion about more systemic change in the building. These processes had subsequently broken down and stopped running.

Existing avenues for tenant representation include a Unison-run tenancy advisory group and the Launch Lived Experience Advisory Program (LEAP), which was established in 2016 (Launch Housing 2021a). There is, however, no consumer participation process such as a tenants' advisory group specific to ESCG. Several tenant participants suggested that a specific ESCG tenants' advisory group could be a potentially powerful forum as it could focus exclusively on the needs of ESCG tenants and would acknowledge the unique nature of the ESCG site. For example, Finley suggested the following type of tenants' meeting would be useful, together with follow up from staff about actions on agreed decisions:

Having a really big meeting with all the residents, having afternoon tea and sitting down and talking about what needs to be done and actually acting on it, and not brushing it off.

If the workers organised a summary, shared some of the things [raised] at one meeting, and then have another meeting a month later and say "This is what we've decided".

This type of consultative process would, however, need to be adequately resourced and facilitated (see Recommendations 10 and 11).

Conditions regarding pet ownership is another example raised by one tenant as a process which needs to be reviewed to promote tenant wellbeing and autonomy and reduce the sense of living in an institution. Finley described the comfort her cat provided but was scared her cat would be taken away following a comment by a staff member that this would happen if it was seen in the hallway. This tenant referred to the lack of autonomy she felt as making her 'feel homeless even though I am not'. The sense of living in an institution is further explored below under the theme of home.

For tenant participants who described the institutionalised nature of living at ESCG, the perceived limits to their sense of choice and control in the building were reinforced by the ways in which communication about rules was sometimes managed. While the security of the building was

valued by many tenants and provided some comfort, the presence of the security guard, concierge, CCTV and locked doors, combined with congregate living, further contributed to the institutionalised feeling of the building, rather than it feeling like a home.

3.3.1 Right to a safe living environment

While many tenants described being 'grateful' for permanent, affordable supported housing, many also described the significant challenges of living at ESCG. Of the 12 tenants interviewed, most described it as a difficult place to live due to the chaotic, unpredictable but persistent culture of violence and problematic behaviours produced by housing many people with complex needs in the same building. Several tenants felt this situation was exacerbated by what they described as limited management oversight, not enough staff to provide adequate support and limitations in staff skills, particularly the skills required to manage challenging behaviours. Several participants suggested that problematic behaviours were not adequately managed due to limited staff resourcing, staff often being overwhelmed and ill equipped to manage such complexity or volume of need. Participants felt that at times the needs and rights of tenants with the most problematic behaviours were privileged over the needs of those with less complex needs and behaviours, and that staff resources were stretched across the cohort:

Unfortunately, there's a few individuals that sort of take a lot of the staff's time and it's just unfortunate because it means other people are missing out because these people just aren't managed very well (Michael – tenant participant).

My perception, my opinion, is the worse you behave, the more you get here. I have asked. I have a pacemaker. My legs are still damaged, I need bone scans, you know. I also have, my discs are damaged from that fall, I am so physically injured. Thank god it happened because they discovered I had a heart problem, but I've asked to be taken shopping, doesn't happen. But that guy, he'll get taken shopping. The people here that are violent and threatening, they get taken shopping. They get taken to appointments, they get time with staff, and I just ... (Daphne – tenant participant).

Episodes of violence and harassment were described as 'prolific' and exhausting. Male participants spoke of being physically confronted by certain other tenants and having to exercise great control not to protect themselves by hitting back. Some participants felt relatively unsupported when reporting issues to staff and that the lack of consequences enabled problematic behaviours of tenants with significant AOD and mental health issues. For example, Noah noted that he was tired of being told to 'look away' when he felt he was being harassed. He also felt that problematic behaviours of tenants with significant AOD and mental health issues were enabled by a lack of consequences and being allowed to stay in the complex.

Participants spoke of needing to be 'vigilant', particularly in the common spaces such as the lounge room, foyer, mail room and lifts, and on the front steps, and of the need to avoid certain tenants. The behaviours at the front of the building caused distress and this was noted by many participants. Several spoke of a sense of shame and stigma about these public behaviours, particularly when they had visitors. Participants were also concerned that, from their perspectives, these behaviours were not being addressed:

I get really bothered by the issues going on in the building, like the front of the building is chaotic anyway because the residents have nothing to do but sit on the front steps of the building, drink, smoke, piss their pants, shit on the front steps, smoke cigarettes, leave dirty cans, rubbish, food, and they beg on the front steps. (Noah – tenant participant).

The mix of tenants was identified as problematic, with one tenant, Eli, describing the mix of tenants as a 'pressure cooker' and 'vulnerable' neighbours as 'the greatest risk to your tenancy':

But really the greatest risk to your tenancy is someone else in a vulnerable position that's desperate, that's struggling and is set up there. You're placing an incredibly and, you know, acute amount of people with acute symptoms all together and you don't have the management in there and you don't have the flow to other forms of housing and you don't have the proper staffing levels for people to have proper care (Eli – tenant participant).

Female participants described being harassed and feeling generally unsafe due to the lack of safeguards in place. Longer term tenant participants seemed more fatigued and distressed by ongoing challenging behaviours and described being worn down by repeated exposure to these:

I'm just really tired, because it's the same people doing the same terrible things, and I find it quite shameful to come here, because there'll be people out the front, and I'm not judging anybody, drug and alcohol affected, throwing all of their rubbish and stuff, spitting everywhere, smoking. The signs, you're not allowed to smoke there, ever, but nobody has ever come out and said, 'You need to move'. People are just let do what they want, it's shameful, it's embarrassing (Daphne – tenant participant).

The ESCG site was established to support people with significant and complex needs; however, participants' experiences of living in this environment raise the dilemma of how the support provider and housing organisation can best meet needs that occur on a very broad spectrum. These findings raise the issue of competing rights and the trade-off some tenants feel they must make in order to maintain secure PSH. Longer term tenant participants seemed most impacted

and weary of the environment but felt that they had significantly limited housing options and believed they would be very low priority for social housing because they currently had housing. This suggests the need to provide more information and support about alternative housing options to tenants who have maintained stable tenancy and choose not to remain at ESCG (see Recommendation 30):

Well, look, I'd love to have my own place again. I'd love to own a place one day ... so I don't have any of these hassles. It's just not possible, you know, like I'm not going to go back to private rental and into that cycle again. Not when I've got this. As bad as some of the things are, it's a lot to trade off (Michael – tenant participant).

Participants also spoke of the trauma of either witnessing or hearing about deaths on their levels or in the building. Witnessing police interventions was also discussed. These events were disturbing and, for some, retraumatising. The risk and pervasive sense of vulnerability experienced by tenant participants in the common spaces of the building amplified the sense of security and privacy offered by their private units. Having control over who came in and what happened in their private space was identified as very important.

Some participants felt that the standards they were expected to accept were different to those that would be acceptable in the general community and in private rental. Several noted that in other settings police would be called in more often to deal with similar issues:

Okay, so ... something I've thought of a lot over the last ten years is this. If this was a normal or, like a private rental apartment complex, none of this stuff would be happening (Daphne – tenant participant).

Similarly, Eli also referred to the different standards and level of risk tenants were expected to accept compared to staff, commenting that it seemed current staff were not willing to take the lift:

and, you know, I also think the staff won't come up the lift ... how dare you place everyone else at that risk but you won't? ... you know, if it's not good enough for you to walk into as a staff member, like if there's an occupational hazard there for you, then it is there for all of the people, you know (Eli – tenant participant).

The Rooming house residents guide identifies the right to privacy, peace and quiet. Powers available to rooming house operators include issuing a 'Notice to leave' if tenants are violent and risking others' safety (Consumer Affairs Victoria 2021). Police can also be called to intervene. The above findings suggest the need for more proactive intervention and support from onsite support workers, including conflict resolution and mediation services which could be offered before

issues and behaviours escalate (see Recommendations 23, 27). Some participants described what they saw as a gap between the formally espoused rights-based vision for ESCG and their everyday experience. As noted earlier, for some long-term tenants the reality of living at ESCG was fatiguing. For these residents, congregate living and the institutionalised feeling of the building were consistently challenging and difficult:

At times it's sort of felt like this is like a nursing home, like they're not apartments, they're rooms. This is a boarding house. These are not apartments, this is a boarding house. And they're little rooms. And I've just had moments of real fear, thinking, 'Oh my god, I'm going to die here'. Just the atmosphere of the place and ... they're not home ... I've not ever been happy here, but I was certainly always grateful, always, you know, every day's a new day and da da da, but it was just, for some time I've become aware I'm seriously not happy (Daphne – tenant participant).

The physical design of the building was also noted as contributing to tensions, particularly the single thoroughfare and just two lifts. A Launch support staff participant noted that more privacy was needed at the front desk to allow tenants to discuss issues and be supported less publicly. Launch staff participants also agreed that more needed to be done to ensure communal areas were safe and secure. They observed that some tenants became isolated or 'shut down' in their units for days due to not always feeling safe in common spaces. This made it difficult for staff to engage with them in meaningful ways and offer necessary support:

Leading on from that point too about people feeling safe in their own space ... people can become quite isolated then and shut down because they don't like to leave as well. Yes, they feel safe in their space, but then they may not exit that space for days or long periods, which in itself is problematic, and then they shut down and they isolate, and they're harder to engage with as well. So all of those things have a trickle effect on how you can engage and how you can support people, and the better producing and hopefully getting better outcomes for them. It's really important, that sense of being able to provide a sense of safety and security, not just in your own space but through the building is critical, and so how do you manage that in the best possible way (Staff participant 4).

Related to the right to a safe place to live was the need to live with dignity and respect, including through respectful communication. Several participants raised the issue of communication from Unison to tenants and focused in particular on breach notices. Examples given related to notices which appeared in the laundry if someone left their washing there too long or in the hallway when rubbish was left there. It was felt that such messages could be conveyed more respectfully. Requests for assistance and complaints not being followed up or responded to were also interpreted as signs of disrespect (see Recommendation 12).

3.4 Model of support and care

The third key theme relates to the model of support and care provided at ESCG. ESCG is a PSH initiative which aims to address long-term homelessness in Melbourne by providing 'ongoing support [24-hours a day] to improve residents' health, wellbeing, and lifestyle' (Launch Housing 2021b, para. 2). The support component of the Common Ground model is a key feature of the PSH approach. However, findings from the interviews with participants and the tenant workshop have identified that although participants valued access to onsite support, they had some concerns about the particular model of support and care. Three subthemes were identified. The first is the value of the support provided at ESCG, the second is a lack of clarity as to the exact nature of the 'support contract' made with tenants, as well as the philosophy and values underpinning this model of support and care, and the third subtheme relates to the crisis-driven approach to support provision, as opposed to a more proactive approach to support. Each of these subthemes is discussed in turn.

3.4.1 The value of the support provided at ESCG

As noted previously, tenant participants unanimously valued the affordability and permanence of the accommodation that was provided by ESCG and the onsite and externally provided supports that were provided alongside this. As Michael noted:

I think that having the staff on hand, like not just the reception staff but the social workers ... the Launch staff ... and the doctor coming in once a week ... and massage therapist and the nurse, all these services, you know, give a ... good umbrella. You know, like it gives us the services that we really need (Michael – tenant participant).

So, since I got here, I got support and got medication and back on track. It was such a relief (Finley – tenant participant).

ESCG tenants can access in their units, or within the building, a range of health, counselling and social support services provided by ESCG and a number of external organisations. Tenants can choose the extent to which they engage with these services, unlike crisis homelessness accommodation where residents are required to engage with support staff if they wish to keep their tenancy. At times, however, tenant reluctance to access support can be a barrier to providing needed supports, as explained by a Launch support worker:

Our role is linking people to those sorts of supports and help, but one of the barriers is always willingness and consent to us doing that (Staff participant 1).

When relationships with support staff were strong, they were highly valued and supported good outcomes in terms of social connections:

[Support worker's name] checks on me every day basically. It's not necessarily his job, like he genuinely wants to see me and I enjoy seeing him ... because of my disability the furthest I can walk is to the shop up that way, there's one just up there ... so I'm basically either stuck here or [support worker's name] will take me out for a coffee or just some interaction, go to an art gallery or appointments, more than anything else ... Yeah, I'd be lost without Launch, without [support worker's name] I'd just be sitting in my room basically and that's not much of a life (Alex – tenant participant).

The ground-floor entrance to ESCG includes a reception desk which is operated 24 hours a day by a concierge. Beyond the added security this provided, which tenants valued, the presence of a concierge around the clock meant there was always someone tenants could speak to or call at a time of urgent need. One participant, for example, recalled that the concierge was there to call an ambulance when he had an epileptic seizure:

Yeah, they called the ambulance straight away ... Oh yeah, yeah, yeah. They've got good support workers that have helped me and I could honestly say that the majority of all the workers helped me (Dominic – tenant participant).

it's managed in a lot different way to a boarding house ... in that even though this is classed as a boarding house, you've got a reception area ... where it's manned all the time, so if people have got a problem they can come downstairs and talk to the staff and not hassle their neighbours (Michael – tenant participant).

Launch employs ESGC support workers whose role involves responsibility for the 'development, implementation, and ongoing monitoring of support plans as well as work in close partnership with other ESCG and ancillary staff, using a team-based approach to ensure the effective coordination and delivery of serviced for ESCG tenants' (Probono Australia 2021). Support workers offer support, assist with connecting tenants and other services (including taking them to appointments if required) and provide assistance with shopping and other needs. These services were valued by most participants:

It's really good; you get a worker who is assigned to you and they're great, I mean, they're really great ... And there's just people you can talk to here about whatever and they'll support you, like if you've got any problems, no matter what it is, it seems, legal, financial, anything like that, they'll support you and advocate for you and things like that, just give you information that you may not have had before (Harley – tenant participant).

And most of the staff are fantastic. You know, they're really dedicated and they'd do just about anything for you (Michael – tenant participant).

Many tenant participants also received support services delivered by external organisations such as medical and counselling services and, for those receiving NDIS funding, NDIS disability support services. These were delivered independently of ESCG, but often ESCG support workers assisted tenants in connecting with such services, for instance, in choosing or hiring a disability support worker as part of their NDIS plan. A service frequently used by many participants was the weekly visits by a GP, a nurse and a massage therapist. Participants particularly valued the continuity of a relationship with the GP and nurse, being treated by a familiar person who knew them and their medical issues well:

the doctor, you know, being able to talk to a familiar face when you've got a medical issue rather than going through a bulk billing place. You know, he's like our doctor (Michael – tenant participant).

You know, they're fantastic. You know, the social workers (Michael – tenant participant).

It's just easier. If I don't need to see him, I can wait until he [the doctor] comes here (Harley – tenant participant].

For many tenant participants with psychosocial disability, the ongoing connection with another person allowed for continuing monitoring of their mental health. Participants appreciated that they could have casual conversations with support workers or turn to them when in need of help with practical matters such as connecting with other services or if they needed something explained:

they're just here ... do you know what I mean? ... I can't put a finger on it ... Like small things, having someone there to immediately call ... But to me, like they're big things because, like I was at Coles at Spencer Street with a [wheelchair] puncture once ... What do I do? Who do I call? ... So if you're stuck, even outside, like in the supermarket there, you can call someone here and they'll come (Jason – tenant participant).

Yeah, I think it's great. No one harasses you here, the staff or anything. You're free to do whatever you want, but they check in on you, just make sure you're okay, which I think is a good thing. I'm in my fifties and I live on my own, and so it's nice to know that if they don't see me for a little while they ring up, and they'll eventually come in if they don't hear from you. That's nice to know (Harley – tenant participant).

Several tenant participants expressed a sense of trust in individual Launch staff and highlighted the invaluable support they provided:

for me the support that I take from there is from a staff member again [name] ... she's a senior social worker and she works as the coordinator on the weekends. And she's still, she's one of the people that probably keeps everyone going too, like on the weekend she's flat out, booked out nine to five, and keeping people going, you know, in terms of just, like their loneliness (Eli – tenant participant).

Staff participants also recognised the difference the support made in many tenants' lives and supported the ESCG model of providing both housing and support:

I just knew in my gut that this is what we need to do to get outcomes for long-term homeless complex people, the mix of the housing stability with the support, the 24-hour support is, it is critical. It does make the difference, but of course how that's done is also important (Staff participant 4).

3.4.2 The support contract

While most tenant participants were appreciative of the support that was provided alongside their permanent housing, some also expressed some significant concerns particularly regarding a lack of clarity as to the exact nature of the 'support contract' made with them. For example, some were not clear whether they had been assigned to an individual support worker or the 5 support workers were shared by all tenants. There was also some confusion among tenants in relation to the boundaries of the support worker role. There was considerable variation among the participants regarding levels of engagement with support workers, with some having daily contact and others more infrequent contact every 3 weeks or even less frequently. For the latter, interaction with support staff had become primarily a channel to raise complaints or safety concerns, rather than more positive interactions based on their support needs:

You know, I only go to report things (Eli – tenant participant).

While the model of support is intended to be guided by tenants, the interviews revealed that some participants would like to have received more support than they were receiving. This is further discussed in 3.4.3 below.

Tenant participants were unable to describe the philosophy or models of care that underpinned the support model operating at ESCG and several suggested that, given the cohort and complexity of need, there needed to be a stronger more recovery-oriented and more proactive support approach to support tenants' needs:

there's no kind of recovery-oriented stuff, no one's being proactive like in [name of previous support worker] days, you know, where it was a proactive, you know, really advanced recovery model and it's like trying to find people's strengths, helping people to learn how to read again, really assertive, respectful intervention (Eli – tenant participant).

Reflecting the above comment, several participants suggested that the model of support in use when ESCG first opened was more strengths-based and person-centred compared to the current practice.

3.4.3 Proactive versus crisis-driven responses

The third subtheme relates to the perception of most tenant and several staff participants that support provision was crisis-driven, caused primarily by a low staff-to-tenant ratio and the challenges produced by the mix of tenants with significant and complex needs. Despite the challenges experienced in the first 18 months of operation (Launch Housing 2015), the long-term tenant participants felt that the support provided in the early years had been more proactive and less crisis-driven. Participants felt that staff were now too thinly spread and that this impacted on the quality of interaction and capacity for more proactive support. It was noted that higher staff/ tenant ratios in the first years of ESCG operation had allowed more positive personal relationships to develop:

ESCG was in a very different place. So when it was proactively seeking to support people, you know, I suppose in a more contemporary, ground-breaking way to really help people, and it was a very different situation to what it is now (Eli – tenant participant).

For some participants, access to support workers had become more limited over time and less equally distributed among tenants. These participants felt most support workers' time was now consumed by a minority of people with the highest and most complex needs, leaving little support available for others:

But support on a personal level very much goes to the difficult people, of which I'm not one ... But yeah, I don't think they've got time to deal with me or somebody who's not in constant crisis. It's an interesting situation and I found it both really understandable and then other times really frustrating. There's a bit of both (Peter – tenant participant).

One participant, Daphne, noted that she was unable to get support for simple tasks like completing paperwork and wondered if this was because she was perceived to be 'too competent'. Similarly,

Michael noted that some tenants were not getting the support they may need due to a lack of staff:

No, there's some great people but, you know, unfortunately there's a few individuals that sort of take a lot of the staff's time and it's just unfortunate because it means other people are missing out because these people just aren't managed well (Michael – tenant participant).

Several staff participants agreed that low staff resourcing coupled with the complexity of need was driving a more crisis-oriented response and that this was at the expense of more assertive support and time to work more proactively with tenants towards goals:

One of the fundamental concerns for people in this environment, and with disabilities and complex needs, is isolation, disenfranchisement, a sense of value, a sense of purpose, a sense of meaning in their day ... we need to have the resources, like the staffing resources, to ensure that we have a lot of assertive contact with people, reaching out, because people will shut down in their rooms and live their life that way, and it can become guite a disturbing existence (Staff participant 4).

Staff participants also spoke of the professional challenge of having to make choices about the most pressing needs at any given time, juggling demands, and of the costs to those who were not well enough supported because of this. They spoke of the tension between attending to crises and doing more proactive work with tenants in a context of limited resources. Staff also reflected tenants' concerns regarding congregate housing and the complexity of having so many people with complex needs living together (see Recommendation 15).

3.5 Communication, roles and relationships

Participants identified scope for increased staff visibility and improved communications between support staff and tenants. It was also noted by some participants that there had been a shift in these elements over recent years. Participants also described limitations in communication about onsite services and arrangements. One tenant participant, for example, noted she had not known about certain available services such as counselling until someone had told her:

So, I think sometimes it's more like communication, you know. There's a barrier in communications too ... If there's something going on, you know, like they should let everyone know, have a letter put in the letterbox. I didn't even know there was a counsellor, to be honest, until someone told me (Fleur – tenant participant).

The data from staff and tenant interviews also suggests the need for different forms of communication to meet different tenant needs. For example, several tenant participants said that a notice in the

lift was ineffective as it could easily be torn down and suggested letterbox communications as better. In contrast, a support staff member believed notices in the lifts were the best form of communication. This suggests the need for closer collaboration between tenants, Launch and Unison regarding different and effective communication methods (see Recommendations 10,11).

Tenant and staff participants also spoke of the importance of communication built on relationships and collaboration, and that there was room for improvement here. This applied to both Launch and Unison:

but building relationships with people here is really important. I don't see relationships between staff and tenants here, and relationships are really important ... if there's no relationship, it's like you're alone and you're on your own (Daphne – tenant participant).

just a little bit more transparency from Unison and maybe also more of a collaborative thing, instead of just 'You do things our way because we own the building', you know (Justin – tenant participant).

Support staff concurred that effective communication was vital in managing and working in such a complex environment and that staff needed to be proactive in this:

There needs to be a dedicated focus on all this communication stuff, absolutely, on a day-to-day basis. This is people's day-to-day lives. If something changes in that hour, then they need to know that, if it's relevant ... you [other staff] don't just go home and go, 'Well, the afterhours will tell them' or whatever (Support staff 4).

A lot of people don't have phones ... for us [Launch support staff], we communicate with our clients when and how they choose to engage with us. So ... if they don't have a phone, I'll try the intercom. If I can't get in that way, I'll leave a message at front of house for them to ... let them know that I need to speak with them and let them come to me ... unless it's actually an emergency. It's not appropriate for me to go and knock on someone's door. If they want to see me, if they don't want to see me, that's perfectly okay. It's their home, I shouldn't be in it. It's not my workspace (Support staff 5).

3.6 Workforce

The complexity of need among tenants at ESCG requires a workforce experienced and skilled in working with people with histories of chronic homelessness, who live with complex health issues and disability, and who have experienced trauma and loss. The data identifies that participants

valued support staff and the additional health and medical services they could access onsite at ESCG. However, a theme in the participant interviews was that there is scope for improvement in staff support with a focus on more specialised skills and experience in approaches such as trauma-informed care and recovery-oriented practices. Participants spoke of the cumulative impact of living with and watching people with significant behavioural issues, mental distress and AOD issues 'go round in circles' and 'just die'. Several tenants spoke of regular deaths in the building, including people dying by suicide, and noted the need for more support following such events:

So I don't think homeless, housing staff, they understand mental health to the degree that they need to (Eli – tenant participant).

I've become aware I'm seriously not happy and I really think I've reached my tether ... I can't deal with this violence (Daphne – tenant participant).

Tenant participants also noted the problems of burnout and high staff turnover, resulting in valued staff members leaving, which made it difficult to establish long-lasting, trusting staff-tenant relationships. A values clash was also identified by several participants as an issue:

And also the staff that are there, the changeover is huge because they burn them out. There's not a lot of support from what I can see ... The ones that really care have to leave because their values are keeping them in the job and then they have to probably get to a point where they're like 'I'm either going to compromise my values in the way I provide care or I'm going to have to leave because I'm not going to be supported', you know (Eli – tenant participant).

but my case worker, it has changed. I've had a few [laughs] since I've been here because people just moved on (Harley – tenant participant).

and a lot of good workers, they've moved on. Now there's only new workers here. I don't really know much (Dominic – tenant participant).

There was a general recognition that there was not enough staff (as discussed in 3.4.3):

There's ... not enough one on one (Finley – tenant participant).

I mean, I really wouldn't go to any of the staff there for any manner of support, they're too run off their feet (Eli – tenant participant).

Although some staff participants felt resourcing levels were adequate, others highlighted the need for increased staff resources to provide a secure environment, given the complexity and mix of tenants:

The ability to provide a safe, secure environment, you require resources for that ... because sometimes you've got not just one thing going on, you've got two or three things going on, and so how do you manage that with limited resources? ... and as always, a sense of providing security because sometimes, well, we do have to call the authorities on a fairly consistent basis to manage stuff that gets pretty out of control and so [that can be] intimidating and frightening (Staff participant 4).

These findings reinforce the need to ensure a well-resourced, supported and skilled workforce with the relevant experience and qualifications required to support people with complex needs living together in the ESCG environment (see Recommendations 21, 22,23,24,25).

3.7 Sense of home, belonging and community inclusion

This section discusses findings regarding participants' experiences of 'home', community and belonging at ESCG. Tenants' units provided a sense of home, of security and of privacy. All tenant participants spoke of gratitude for having secure and affordable housing, and some spoke with pride of their efforts to decorate and enhance their apartments. These elements are all important in promoting ontological security and a sense of wellbeing (Stonehouse et al. 2021). Home meant different things to different tenants and was relative to their previous experiences of homelessness and precarious housing. Many were grateful for 'a place to lay your head', to safely keep their belongings and to be able to close and lock their door. For some tenant participants, the benefits afforded by ESCG far outweighed the limitations, as explained by Harley:

It's fantastic. It's really close to the city, my rent gets automatically taken out of my payment, it's improved my mental health being here. I've had some really good opportunities since I've been here (Harley – tenant participant).

However, while their apartments offered security and privacy, almost all tenant participants described feeling more vulnerable and at risk in communal areas such as the elevators, lounge rooms and the mail area, and on the front steps. These communal areas were not homelike but rather were described as messy, sometimes dirty, sometimes unsafe and often occupied by tenants using drugs and behaving in threatening ways. This was not conducive to staying in these spaces and contributed to participants spending more time in their rooms than they may have preferred.

Congregate living and the institutionalised feeling of the building also prevented the complex from feeling more homelike. Several participants also spoke of the stigma of living in the building, of

a sense of shame or embarrassment of living at ESCG due to the culture and environment, the presence of the security guard and concierge (even though these were also valued for security reasons) and the drug use and behaviours on the front steps. Several noted that they did not invite friends to visit because of this but instead would go out to meet them.

The following quote from Eli further demonstrates the mixed feelings about being ESCG tenants as expressed by many participants:

home, no, stability, yes ... from the beginning I was grateful, absolutely grateful. Home is a house, animals. This is just existing. Home? No. I got to a point, some point, of being here because I've just been existing for so long, I'm just trying to get through, and I just thought, what is a home to me? To me it's like, it's a house! And it's animals, like I love animals ... And at times it's sort of felt like this is like a nursing home, like they're not apartments, they're rooms. This is a boarding house (Eli – tenant participant).

Related to the above was a sense of a lack of community, social connection and positive social networks in the complex. While several participants spoke of neighbours they were friendly with, this was not the case for most participants, who predominantly spoke of 'keeping to myself', 'keeping my head down' and not mixing with others in the building. Similarly, there is no evidence from the interviews that participants actively mixed with affordable housing tenants, despite this being an aspiration of the Common Ground model.

While tenant participants spoke of largely keeping to themselves, some participants also spoke with regret about the lack of organised social activities within the building over the past few years, as well as lack of support to link to community networks and activities. Participants acknowledged the impact of the COVID-19 pandemic on opportunities to mix however several also made the point that the calendar of organised social activities had been diminished for several years prior to 2020. Longer term tenants recalled periods prior to this when there had been a range of inhouse activities such as cooking, gardening classes, bingo and barbecues, as well as excursions, and that these had been well received. Several participants suggested that reduced investment in social activities was due to staff resources being consumed by crisis management. Peter described this as follows:

It takes time in this place to get anything happening. Yeah, I think there needs to be a hell of a lot more of that and less of the putting out the fires, that stuff, which they do a lot. Fair crack to Launch, they haven't got a lot of time to do a lot else because there is so much, it's difficult. Difficult things that are going on most of the time (Peter – tenant participant).

Consecutive COVID-19 lockdowns in Melbourne between March 2020 and October 2021 had a significant impact on social activities and engagement within ESCG and opportunities to pursue community activities. This period of rolling lockdowns from March 2020 until October 2021 had significant impacts on tenant participants' wellbeing with several participants expressing frustration at the lack of opportunity for discussion with tenants regarding how to best handle the lockdown requirements. For example, Noah suggested more needed to be done to manage the hard lockdowns and impact on tenants:

And the fact that we've been locked in our apartments and we're not allowed to have anyone in the front door that we reasonably recognise or want to share a significant moment with means that Launch and Unison need to sit down, work out a set of proposals in case another lockdown happens, put that to the Department and get some legal aid around that or some legal advice to advocate for the human rights for people living in here. (Noah – tenant participant)

While services were still allowed to enter the building, tenants were not allowed visitors. This, in addition to only being able to go into the community for essential purposes, had significant impact on tenants' social isolation:

Well, no visitors were allowed so that stopped people coming to visit, which was my only real social interaction apart from [Launch support worker]. But then even going places like to the supermarket with [Launch support worker], like I had to wear masks and sit in the back of the car, not the front, which was really weird. But yeah, the COVID really hit home, like not being able to go places, cafes weren't available and it was less social than what I used to do ... Yeah, very isolating (Alex – tenant participant).

Alex also noted that the impacts of the lockdown experience in Melbourne would be felt once restrictions lifted, suggesting that additional measures should be put in place to support tenants to emerge and connect:

Yeah, I think it's had a big impact on lots of people and still continues even though we're coming out of it. Yeah, I mean and hopefully the vaccinations are going to make a big difference, obviously (Alex – tenant participant).

See recommendations 26,27,28 in relation to the above findings.

3.8 Housing pathways beyond ESCG

The interviews suggested that although all participants placed a high value on permanent and supported accommodation, longer term tenants (6 years or longer) were more likely to express an

interest in moving out to an alternative housing option. As noted previously, this was mainly due to the fatigue of living in the environment, a desire not to live in congregate housing and, for some, a sense of stigma attached to living at ESCG, as described by Justin:

I don't have any visitors simply because I feel weird about being in there. It's like how do I explain this with somebody that doesn't understand it? I guess maybe I am a little bit embarrassed, maybe I don't want people to think that I live in an institution, because technically it is not but it feels like it at times (Justin – tenant participant).

The sense of being worn down by the environment and shifts in experience over the years was noted by several and is demonstrated in Peter's comment:

Initially it was great, because it's so wonderful to have your own place. But yeah, it's tough and the longer you stay, the tougher it gets ... But as I said, when I started, people who had been here for a while said, 'You'll get sick of it'. I said, 'No, I won't. It's so good'. And it is. They do try, don't get me wrong. But yeah, it has, it's worn me down moving into my sixth year (Peter – tenant participant).

Similarly, Eli spoke of feeling 'trapped' and needing to move out:

I feel trapped. I stay there because of the rent amount, to be honest. And also, I've gotten stuck there, you know. It would've been better to transition out years ago. I need to move out (Eli – tenant participant).

Several participants also spoke of the challenge of being exposed to substance use when they were in recovery and the need to move away from this, including a desire to move away from the city:

Up and down, up and down. It's not smooth, because I think I've been here too long, to be honest. I want to move from here ... because I'm a drinker, trying to recover from alcohol while I'm here, I don't think I can last sober because of the environment ... (Fleur – tenant participant).

A key issue for participants who wanted to move out of ESCG was a perceived lack of options and support to do this. For example, tenant participant Finley noted that although they were trying to find alternative housing, they had not 'had any support with it at all'. Most participants shared the view that it would be very helpful to have clearer pathways out of ESCG and that it was not necessarily a place to live for the long term except for people with the most complex vulnerabilities and needs:

The idea to stay here is not a good idea for long term unless you're right at the end of your life. I don't mean age wise. I've had three deaths in my floor in five years. I know of another eight or ten in the building in that period. That's not the fault of the building as such, but it's a difficult place to live long term (Peter – tenant participant).

These findings suggest the need for more information and support to be offered to tenants who feel ready and able to move to alternative housing arrangements such as, for example, scatter-site housing (see Recommendations 29,30).

3.9 Conclusion

This chapter has described 7 of the 8 key themes that were identified in the analysis of tenant and staff interviews: vision, leadership and management; tenant rights, representation and participation; model of support and care; communication and relationships; workforce; sense of home, belonging and community inclusion; and housing pathways beyond ESCG. The findings indicate some clear themes about the benefits of the ESCG model and the value participants placed on 24-hour support, good relationships with support staff and the importance of permanent and affordable housing. The findings also highlight areas for improvement relating to workforce skills and development, workforce resourcing, the model of support being provided, and clearer information and support for pathways out of ESCG for tenants who feel ready and able to move towards a different housing option. The next chapter will present findings related to the interface between the NDIS and ESCG services and supports.

Chapter 4 The NDIS and Interface with PSH/ESCG

4.1 Introduction

This chapter discusses the key findings related to tenant participants' mixed experiences of accessing and navigating the NDIS, the benefits and challenges of using NDIS-funded services and some of the complexities for staff and tenants at the interface between the NDIS services, housing management and onsite support systems.

Six of the 12 participants were NDIS participants. The findings highlight benefits for tenants of having individualised NDIS funding, as well as the challenges and costs for some of navigating a complex funding and service system. NDIS funding promises more personalised support and for some participants this promise was realised with enhanced wellbeing, independence, community participation and support to maintain stable tenancy at ESCG. In addition, the flow of NDIS-funded services was recognised by support staff as important in going some way towards addressing resourcing and service gaps. While several participants were actively benefiting from their NDIS funding, others faced barriers to accessing the scheme or, if they were participants, spoke of difficulties in navigating the scheme, poor service quality and limited understanding of how to address service quality issues. These participants did not feel in control of their NDIS funding and were frustrated with the system. These findings reflect broader research which highlights scheme complexity as a barrier to access and choice, particularly for those with reduced capacity and resources, advocacy or support to engage with complex systems and complete required tasks. The findings indicate significant scope for improvement in the provision of more accessible information and support which are tailored to the particular needs of ESCG tenants, as well as more advocacy support to guide participants in complaint and review processes where necessary. The findings also point to the need for NDIS service providers that are skilled and experienced in working with people with complex and fluctuating needs.

Support staff played an important role in supporting access to the NDIS and liaising with NDIS services where required. There were challenges, however, related to lines of accountability for tenants with NDIS funding, issues related to liaison and coordination with external NDIS services, and managing the fallout when NDIS services were poor or failed, impacts on workload and navigation of tenant privacy.

An important finding is very minimal engagement with the NDIS LAC, despite their role being to help people understand and access the NDIS, to help plan and to help implement and review NDIS plans (NDIS 2020). Recommendations related to these findings suggest the potential benefit of stronger relationships with the designated LAC team and the provision of in-reach support whereby LAC services engage more proactively with ESCG and develop relationships with tenants and staff. The findings also highlight the need for NDIA planners and disability service providers, including support coordinators, to have more specialist skills and experience in supporting people with complex needs including psychosocial disability and histories of homelessness and/or substance use (see Recommendations 1,2,3).

4.1.1 NDIS participation – ESCG tenant participant profile

As outlined in the methodology, 6 of the 12 tenants interviewed had NDIS packages and two others were currently pre-planning with Launch staff. Two of the 6 NDIS participants were self-managing their packages and the other 4 employed providers to assist in managing their plans and services. Of the 4 tenant participants not in the NDIS, key reasons included not wishing to engage with a new system/bureaucracy and being discouraged by hearing from others about the complexity of the scheme. These tenants reported that they were satisfied to continue being supported by Launch services. Launch staff had completed NDIS pre-planning for 4 of the 6 tenant participants, while the other two had had pre-planning support prior to coming to ESCG. While at the time of the study staff advised that approximately 12 supported tenants were NDIS participants, it was suggested that many more tenants should be eligible for the NDIS but needed additional support to engage in the application and pre-planning process. Staff participants also noted that some tenants, despite eligibility, had chosen not to apply.

4.2 Experiences of accessing and navigating the NDIS

Participants with NDIS funding revealed mixed experiences of accessing, navigating and participating in the scheme. Interview analysis revealed the importance of access to clear information and having the skills and knowledge required to navigate the very complex bureaucracy that is the NDIS. These findings reflect the broader literature highlighting the differential impacts of the NDIS and the importance of timely and responsive advocacy and support for those who need assistance at all stages of the NDIS journey.

Most tenants were frustrated with the time it took to test eligibility for the NDIS, the pre-planning process and the work involved in finding service providers and establishing relationships and schedules with them. Beyond this phase, however, 4 tenant participants reported satisfaction with their NDIS packages, while two continued to have frustrations and difficulties in using their funding. For these participants, inadequate support coordination was a key issue and barrier to optimising the potential of their funding. Launch support staff participants echoed tenants' experiences, referring to problems with some support coordination services including underutilisation of funds or fees taken without tangible results for tenants in terms of service provision.

Tenant participants had heard about the NDIS from a range of sources, including doctors and allied health services, and through Launch staff. Launch staff participants noted that they actively tried to support tenants to apply for NDIS funding for both tenant and staff benefits. As noted by a staff participant, supporting tenants to access the NDIS produced good outcomes for tenants, for staff and for ESCG more broadly:

Previous to NDIS there was staff shortages and resource shortages, so not everything could be done ... there was not enough time because of not having enough staff. Then the NDIS arrived, at least we could get the client on the NDIS and then fill the gaps that the regulars could not fill ... so in the last two years there has been a lot more linking of clients with the NDIS (Staff participant 2).

Tenants with NDIS funding had reduced need for Launch support services. While participants understood this, for some it had taken a little while to get used to the withdrawal of support, given existing relationships with Launch staff. The following comment by Justin demonstrates this readjustment to the transition but also the benefits of NDIS funding:

I used to have more support from the staff here, but when I got onto the NDIS they basically told me they were going to withdraw most of my supports they were giving because I would get it through the NDIS, which is true and it is fine ... I don't know, it made me sort of feel a little bit ostracised, sort of thing, it was sort of a little bit like, 'Okay that's it, we sort of like done', you know? I've got all people through my NDIS to help me, so it's like 'Do I need another meeting with a Launch person this week? No' ... so yeah, so I'm kind of moving away from it, you know, now (Justin – tenant participant).

Participants who had decided not to test their eligibility shared a view that it was too difficult and that perhaps the payoff might not be worth the effort. Although it was acknowledged that ESCG might be able to help if they had asked for help, there was a sense from this small group of participants that it felt too difficult. One participant also highlighted the particular challenges for people with mental health issues in accessing the NDIS, particularly in relation to the criteria of permanent and significant disability being inconsistent with fluctuating mental health and the recovery model:

I think NDIS as well, in terms of mental health, you've got to go and declare permanent disability, which no one wants to do, and that's totally in contravention with the current Mental Health Act that obviously would've come out of the Royal Commission in terms of recovery-oriented language and strength-based language, is kind of completely at odds with that. So anyone in the mental health space is

reluctant to go through that, it's become very hard, as you know, to get into that (Eli – tenant participant).

4.2.1 NDIS services – benefits and challenges

NDIS funding was used for a range of services and supports including equipment such as push and power wheelchairs, therapy supports such as physiotherapy, psychology, exercise physiology and occupational therapy, personal training and remedial massage, cleaning, personal care and independent living skills, to access the community and health product supplies.

Support staff participants noted the clear benefits to some participants of joining the NDIS, describing outcomes related to health and general wellbeing, maintaining independence and stabilising their tenancy at ESCG through provision of unit cleaning and general support. For some participants, the NDIS had provided equipment, personal care and community access supports for which they had been on waiting lists for years under the previous disability funding system. For some participants, NDIS funding and access to regular support services also meant the difference between having food in their fridge and clean apartments and not having these basic essentials. The range of outcomes were described by a support staff participant:

we've got one of my clients ... Got a brand new wheelchair that's motorised. Has got a new specialised bed for him. He's kicking goals and getting a lot of stuff through them [the NDIS]. Another one has stabilised on their medication because they've got a routine in place for the support worker and they've got cleaning. Their tenancy is not at risk anymore because they've got three days a week cleaning, getting prompted and reminded that medication is important daily and eating their meals. And for me, some of my clients aren't changing their lifestyles at all, but the fact that I know they've got food in their fridge now means that some things are getting better for them. So they don't need to change their drug use, they don't need to change their behaviours that they've got going on, risky behaviours that they've got going on, but to know that previously they were also doing that and being hungry. Now at least that's there and I know that that's one thing that's helping their mind and body at times (Staff participant 5).

But there were mixed levels of satisfaction among tenant participants regarding their NDIS plans and service access and quality. While several participants, particularly those who were now using their second or third plan, felt in control and were satisfied with what their services were enabling, others struggled to understand their plan, how to use it and how to ensure quality services, and were frustrated by unresponsive support coordinators.

There was negligible mention in participant interviews of advocacy and support to review plans or make complaints. Two tenant participants called for greater transparency in how their funding

was being used and regarding the costs associated with the administration of their plans. Two participants also raised the issue of episodic unwellness and were unsure about how flexible their NDIS plan could be in relation to this and extra supports that may be needed, or whether these extra provisions had been included in their NDIS plan already. These findings overwhelmingly highlight the need for better information, education and support about the scheme. Stronger relationships and onsite engagement with LAC could assist with this (see Recommendations 1,2,5).

4.2.2 Support coordination performance and quality issues

A key finding relates to the variability of support coordination. Support coordination is intended to support NDIS participants in setting up and implementing services, and can involve support to choose services. Participants who self-manage have greater control over the services they choose (i.e. they can choose services which are not NDIS registered) and can also include support coordination in their plans. Satisfaction with support coordination was mixed, with several participants very satisfied with the service but others describing more negative experiences. These findings raise questions about support coordination quality and how to best promote NDIS participants' choice and control.

The two participants who had had poor experiences with their support coordinators noted that they had not been provided with adequate support to select or coordinate their services and felt they had not been kept informed. For example, Daphne was very concerned that most of her \$50,000-plus package seemed to have been spent on support coordination, with minimal supports to show for this. She had received her first plan in 2018 and at the time of the interview was with her fourth support coordinator due to dissatisfaction with previous providers. She felt that her funds had been drained away and that the support coordination service had consumed most of the funding in phone calls and administration. She recalled that her plan had funding for education, daily living, support, a psychologist and community engagement, but she said that these services 'never happened'. It was not obvious to Daphne how her package had been spent and it also appeared that she did not know how to address this or who to complain to:

Yeah, yeah, so I was getting billed for all these things, but nothing was happening. I didn't get engaged into anything. As I said, it took her seven months to arrange one person to come and do one session of cleaning ... they were putting in like every month, you know? Even to this day, no classes, no social activities. I haven't even met the support coordinator of the place I'm with now (Daphne – tenant participant).

Daphne described the administration of her NDIS package as 'damaging', suggesting that she might have been better off never having it. She was also concerned that her support coordinator had at one time suggested transferring funds from her core supports to cover support management costs, something which should not happen in the NDIS.

Similarly, Finley spoke of support coordination which had failed to adequately deliver the service it should have. She spoke of having a significant NDIS plan but was confused about the contents of the plan and its management. She claimed that despite having this level of funding, she had only received two hours of weekly support for shopping. She said that she wanted to understand more about what was in her plan, but was unsure how to do this or who to speak with:

yeah, I'd like to know what is in that plan. I haven't been told. So that's why there's a gap there ... I really need to know my finances ... [there's] a lot of bullshit, but I got \$149,000, which is actually extreme, but I only use it for shopping. I only go shopping with the worker, to take me shopping on a Monday (Finley – tenant participant).

For another participant with a relatively large NDIS plan, a main challenge was finding a service provider who understood his needs. He had sought help from ESCG staff to achieve this.

Launch staff participants echoed these negative experiences with some support coordination and plan management services, describing some examples of funding underuse coupled with fees that did not seem to produce tangible results in the form of services. Staff also commented on the variable quality of some services, including cleaning, and of NDIS service providers which seemed unskilled and inexperienced in meeting the needs of ESCG tenants. While support coordinators may have had legitimate reasons for the delays in services, particularly during the successive COVID-19 lockdowns in Victoria, it appears that this may not have been communicated to tenants.

These findings highlight the importance of advocating for more specialist NDIS services which are skilled in working with people with histories of homelessness and who experience intersectional disadvantage and complex needs, including substance use. A short list of suitably skilled and experienced service providers would be a significant resource for ESCG tenants and staff, and would help prevent issues raised in the interviews regarding NDIS services being ill-equipped to work with people with complex needs (see Recommendation 3).

In contrast to participants who felt they did not have enough control over their NDIS funding, two participants had chosen to self-manage their plans as a means of gaining greater choice and control over their services. Self-management allows NDIS participants to choose their own providers, in contrast to plans that are managed by the NDIA and who can only choose from a list of registered providers supplied by the NDIA. For example, Noah explained his choice to self-manage as his way of maintaining control over his services and choices:

[if I wasn't self-managing] the NDIS would choose my physio, they would choose my personal trainer, they would choose my support workers, and I think that is absolute, that is totalitarian control over people with disabilities and it's like, why should I have

to be locked into [that]? ... I don't want some NDIS worker in a building in Geelong picking my support workers for me or my physio or my doctor or anything, so I went with self-manage (Noah – tenant participant).

But self-management also carries a high administrative burden and requires participants to have the capacity to manage this. Noah described the work involved in self-managing his funds:

Yeah, it's a lot of paperwork, like I uploaded two invoices yesterday and one this morning and I've got to get up early before work and pay it all and take screenshots so I know I've got a transaction receipt and save it to my computer and file it away and all of that and then email everyone. That's a lot of work (Noah – tenant participant).

Participants' perceptions of choice and control in relation to NDIS funding and services were influenced by whether tenants were self-managing their plan or were being plan-managed and by the responsiveness and quality of their support coordination. It was also clear that there were both benefits and challenges associated with different types of plan management. For example, one tenant participant who did not self-manage his NDIS plan felt 'ripped off' by the costs of plan management, while those who were self-managing enjoyed greater choice but carried the load of the high administrative burden.

4.2.3 The relationship between knowledge, choice and control

The findings reflect the broader literature regarding the relationship between choice and control in the NDIS and the experience, knowledge and capacity to navigate complex systems. There was significant variation in participants' basic knowledge about how the NDIS and their funding package worked, about their own level of funding and the content of their plans, about how to access and manage supports and services, and about their rights in the scheme and the complaint and review processes. Participants with previous experience of disability systems and who had already had several NDIS plans were more confident and able to navigate the scheme and services more effectively. These participants also had a better understanding of their rights in the scheme and how to make changes, including knowing that they did not need to wait for their next annual review to adjust their plan if needs changed.

In contrast, several other participants had only a vague idea of the contents of their plan and funding. Finley, for example, reported that she had not been told what was in her NDIS plan and was confused between the boundaries and relationships between her NDIS plan and the State trustees (and her legal guardian/pension). Similarly, Alex, who had just joined the scheme at the time of the research, was also unclear about the contents of his plan:

the proposal to the NDIS suggested some things like physiotherapy, but how the budget was allocated, it was all so vague and wishy-washy, and very generic terms

... I think that was intentional, so it wasn't specific saying 'and I require \$20,000 for this and I require \$5000 for this' (Alex – tenant participant).

Related to the above was the confusion, for some participants, about the difference between internal support and external roles, and regarding multiple NDIS service providers. Alex reflected this role confusion when discussing his services:

That's the NDIS coordinator, which I think in this area is the Brotherhood of St Laurence. She came here and told me a bit more about the NDIS and then I got a support coordinator and now I've been issued a support worker. But it's a lot more levelled than I thought, I thought it was a one-stop-shop as in 'Okay, so I'm dealing with you now' but no, no, this person, hang on, there's a fourth person. So I'm dealing with this person and you and you (Alex – tenant participant).

4.3 Support staff roles in relation to the NDIS

Support staff played an important role in supporting tenants to access and participate in the NDIS. Staff highlighted the benefits of NDIS funding for tenants, but also noted the challenges of supporting tenants to access the scheme as well as the challenges of liaising with NDIS service providers and, related to this, issues regarding lines of accountability when, for example, services failed to meet tenant needs. Each of these additional tasks also had workload implications.

Staff also spoke of being unsure, at times, about their role in supporting tenants in managing their NDIS services without having access to their NDIS plans due to privacy. This issue was highlighted in several staff interviews and highlights the tension between tenant privacy and Launch staff responsibilities to NDIS-funded tenants. This needs to be clarified if staff are to play a more proactive, rather than reactive, role in supporting tenants to make the most of their NDIS funding (see Recommendations 4,5,6). How to best navigate and provide sufficient oversight of the complex network of NDIS services coming into ESCG, as well as intervening when quality issues arose, was a consistent theme. The following outlines staff experiences in supporting tenants to access the NDIS and issues relating to external service providers.

Support staff took on the work of informing tenants about the NDIS, supporting NDIS applications, gathering documentation, pre-planning and liaising with NDIS service providers, including support coordinators and plan managers. Support staff also spoke of contributing to annual NDIS reviews and providing some oversight of onsite NDIS services such as cleaning. The observation from a support worker that 'you can't just put the client on to NDIS and forget about them ... the service providers are looking to Launch for that engagement' (Staff participant 1) describes the expectation for Launch staff to support this work. It was also apparent that some tenants with NDIS funding still required ongoing engagement with and support from Launch workers.

Support staff also spoke of the emotional labour involved in supporting tenants' disappointment when their NDIS application was rejected and in supporting repeat applications. For tenants with a history of marginalisation and struggle with institutions, being rejected, sometimes repeatedly, was difficult. For example, Staff participant 4 referred to the experience of one tenant who they felt was worse off after applying:

You've got a client who is actually worse off because they have become so disillusioned, they've had expectations set for them, they haven't been met, they've actually regressed potentially into depression and distrust, and said at times, 'I couldn't be f**ked. I don't want to do this anymore'. So it's really the antithesis of what it should be doing, so it's really frustrating and disturbing (Staff participant 4).

Supporting tenants to reapply relied on tenants having the energy required to keep trying. For at least one tenant, it took 3 applications before he was finally accepted:

One gentleman with significant complex issues, ABI cognitive impairment ... he really needed the NDIS ... it took us three attempts of putting in an application until he was finally accepted (Staff participant 1).

The complexity of the NDIS was identified as a key barrier to some tenants being willing to apply. Staff participants referred to different types of behaviours, such as not attending appointments, not completing required paperwork properly and not answering phones, which made the application and pre-planning process very difficult. One staff participant emphasised that the 'hard work of getting onto the NDIS' was something that not all tenants, despite potentially eligibility and benefits, were able to engage with. Part of this was a 'psychological' reluctance to deal with yet another bureaucracy:

they refuse, either they neglect themselves or whatever reason ... we think a person should be linked with the NDIS but for whatever reason they can't do it and we can't do it – some just can't do it (Staff participant 2).

Staff also identified problems associated with health professionals providing limited assessment documentation and missing key details regarding cognitive functioning, resulting in tenants having issues with eligibility. This suggests the need for improved understanding on the part of health professionals of the impact of 'hidden' and fluctuating impairments such as cognitive impairment and of the need for tenants to have support, advocacy and existing health reports when attending assessments:

The GP did a functional assessment and the client was quite functional ... but his particular issue was with memory and remembering to do tasks and to get to appointments etc ... but NDIS looked at the paperwork and thought he looked quite functional so didn't give him a package, claiming he was quite independent, not addressing other limitations (Staff participant 2).

While some staff cited the paperwork and NDIS administrative burden as a key access barrier, the need for additional staff development and training to enhance understanding of the NDIS and its systems was also identified as important. Similarly, staff noted the importance of being able to explain the benefits of the NDIS to tenants, of believing in their potential and of 'bringing them along on the journey' (Staff participant 3). (See Recommendations 4,7)

4.3.1 ESCG and NDIS services interface

Staff interviews provided nuanced insights into interactions with external NDIS service providers and the complexity of service provision at the ESCG site. External service providers, providing services such as personal support for independent living and/or community engagement or cleaning, should be responsible for organising staff and doing this in liaison with the NDIS participant or support coordinator. But where NDIS participants use online hire platforms such as Hireup to recruit staff and organise shifts, it is up to them to coordinate these things.

The number of different NDIS service providers entering the building during the COVID-19 lockdowns presented challenges for some tenants and also for staff in terms of maintaining oversight of traffic through the building and interaction with tenants. There seemed to be a lack of clear communication regarding the movement of so many different people through the building and lack of clear identification. This caused several tenant participants some distress and concern given their family members could not visit during the COVID lockdown periods.

Staff suggested high numbers of providers moving through the building had implications for safety and security, and that some tenants had felt a level of intrusion from these services and the traffic of unfamiliar faces. For example, Staff participant 4 noted the following:

they're [tenants] going, 'Who are these people?' because they are aware of who's in their space, absolutely, and they're mindful of, 'Is this a safe person? Is this person supposed to be here? Why are they on my floor?' even though staff advise other tenants that somebody's NDIS staff might be there (Staff participant 4).

Launch staff also reported acting as intermediaries and liaison between tenants and providers. When problems arose with NDIS services, Launch staff were often called in to support the tenant and intervene with services, ostensibly taking on the role that support coordination should be doing. Staff participant 1 gave the following example of calling a service provider to assist a tenant find a service:

I rang one of the service providers and they said 'We don't have anyone to work in your area' and I'm like, 'We are in the City of Melbourne!' ... and maybe Launch could help with that sort of recruitment, because they are sort of linked into the area and the field and know people ... but clients choose to engage with whoever (Staff participant 1).

Problems also arose when NDIS providers lacked the skill and experience to understand and adequately support ESCG tenants and the complexity of their presenting support needs. Support staff suggested that some NDIS providers seemed to have little if any experience in working with people with histories of chronic homelessness, mental health issues or AOD use. Staff participant 5 explained the problem as follows:

They keep sending me young people who have no knowledge or experience with mental health. I cannot be more clear about what I need and the support coordinator has been doing the same thing, and we are banging our heads against the wall because no one is listening to what we're saying. We're not saying it for the sake of saying it. We're saying it because it's not going to work if it's not (Staff participant 5).

Another issue was the hesitancy on the part of some NDIS providers to work with ESCG tenants because of assumptions about the risks involved with working at the site:

Another client was rejected by [an] NDIS provider not because she was an IV drug user, but because they were aware of IV drug users in the building and it actually took them about three weeks for them to tell us that she was declined ... so we were hearing things like they're just organising the paperwork and staff, and then when nothing had happened, I [Launch worker] rang them back and they told me that they had decided not to work with her ... so that was a lost month, and we understand their safety concerns as much as we understand ours, overall the building is pretty secure (Staff participant 1).

Lack of provider accountability to NDIS participants, and the increased burden this placed on tenants and Launch staff, was a significant and ongoing challenge. Although staff had provided feedback about the quality and skills of some NDIS services, staff did not believe there had been any noticeable change or improvement in this regard. Staff were concerned about the lack of accountability of NDIS service providers and the cost of this to both tenants and Launch support staff:

because I have certainly assisted some of my clients to have to try numerous times to find an appropriate person because the people that they've engaged have

not been, I would suggest, not trained or skilled adequate to do the roles ... the whole accountability framework around the NDIS providers is problematic, really problematic, and the standards of practice and engagement, and their ability to actually work with people is questionable (Staff participant 4).

The challenge of finding suitably skilled and reliable services for people with very complex needs, such as ESCG tenants, reflects the broader evidence regarding challenges for the disability support workforce and this will be discussed in more detail in the conclusion and recommendations chapter. ESCG tenants should be able to access a list of NDIS service providers with the necessary and relevant skills and experience. It is also suggested that some NDIS planners should develop specialised skills and knowledge in understanding needs related to people with complex histories of homelessness and social marginalisation in addition to their disability (see Recommendations 3.8).

4.3.2 Information, privacy and consent

Staff highlighted a tension regarding tenants' right to privacy and the need for their choices to be respected while also acknowledging the responsibility Launch staff felt to monitor wellbeing and ensure NDIS services and other external services were adequate, responsive and accountable. ESCG tenants can access in their units, or within the building, a range of medical and social support services provided by ESCG and external organisations. Launch staff participants described the challenges of navigating these roles and the blurred lines of accountability without clear guidelines or additional resourcing to do this work. These findings highlight the need for consideration of the relationship between onsite support staff and NDIS services providers, particularly where NDIS support coordinators and services are inadequate (see Recommendation 6). The tensions at play here were described by Staff participant 5:

They [the tenant] don't want us involved ... then there's people turning up and their clients aren't here, that's not actually something we can control because we can't enforce our engagement onto them ... Clients will take over their own planning and then all of this stuff gets put into place and it falls away. They call us and they want to know what's going on. Well, the client didn't want us involved, so we can't be involved (Staff participant 5).

This tension was raised a number of times in relation to cleaning. Housing staff were concerned about the condition of some tenants' units and whether cleaners funded through the NDIS were providing adequate cleaning. Housing staff expressed a belief that onsite support staff should be taking a more proactive and assertive role in overseeing the services tenants were getting. As noted above, this has implications for resourcing and clarity regarding the roles and the responsibilities of onsite and external NDIS service providers.

Support staff identified examples where they had intervened such as cases where health was endangered, there was a security risk, the unit was becoming unhygienic and/or there were cognitive issues, meaning tenants were forgetting important appointments. Staff participants spoke of needing to carefully navigate these circumstances and needing to make a judgement call regarding the balance between privacy and safety while being 'conscious of the surrounds' and that they worked in a building that was the tenants' home (Staff participant 1). It was also noted that in cases where NDIS support coordination had failed, it often fell to onsite Launch staff to find a new provider and the supports that tenants needed. Staff participant 1 explained this tension as it arises from the distinction between supported and crisis accommodation:

ESCG is supported accommodation, not crisis accommodation, so the tenants are not 'required' to engage with staff if they don't wish to, whereas in crisis accommodation they do have to engage with the coordinator to be able to stay there ... we're not an IAP [Initial assessment and planning], there are general privacy issues ... if they've got an appointment either in the building or somewhere else that we know of, we will send them a reminder call or try and attend the appointment with them to help them (Staff participant 1).

One suggestion from staff was to centralise the tenant information system so that onsite support staff and external NDIS providers could access tenant information such as care plans, goals, staff rosters, progress notes, particular issues at that time and appointment times on a single centralised platform. While the need to address privacy issues in such a system would be critical, the staff member who raised this approach argued that it would reduce problems created by onsite and external providers not having access to an overall view of tenants' services networks and circumstances:

I think for all parties, and everybody that lives in the building, it provides a broader sense of stability, consistency, knowledge, safety, all those things [because at present] ... I've got no idea. I don't know who works with who because it's not listed anywhere on their [Launch] files or on their record systems. There's no one centralised [system saying] ... 'Yeah, so and so's hooked up with the NDIS. This is their support worker. They come on these days' or whatever, or 'they do this' ... that information's not accessible to me [as a Launch worker], which is problematic (Staff participant 4).

This staff member felt that a centralised system would provide parties with a sense of knowledge, a 'kind of collaborative consistency', working as a team, and felt this approach together with strong communication and knowledge-based systems within a privacy framework could be workable.

This suggests the need for clearer guidelines regarding tenant information, privacy and consent, and the need to develop a system which offers enough information about tenants' services and needs for all involved services in order to function collaboratively while also ensuring safeguards for tenants' privacy (see Recommendation 6). Staff participants also raised this need in relation to other funding systems in addition to the NDIS, such as My Aged Care, City of Melbourne cleaning services, homelessness outreach mental health teams and co-health teams.

4.4 Conclusion

This chapter has presented the project's key findings regarding tenant and staff experiences and perspectives of accessing and navigating the NDIS and of using and managing funded services. The next chapter will conclude the report, highlight link to existing research and present the recommendations for policy and practice that have been co-designed with the tenants and the project advisory group.

Chapter 5 Conclusion and Recommendations

5.1 Conclusion

This research project arose from the need to better understand the support and service experiences of people living in PSH who, together with histories of chronic homelessness, also live with differing levels of disability, chronic health conditions and mental health issues. The ESCG site was identified as a case study which, as an example of one approach to PSH, could contribute to our understanding of the intersection of these identities and needs, and of tenants' experiences of the onsite supports the Common Ground model aims to provide as well as external support service including those funded by the NDIS. The broader context of the NDIS and the potential opportunities afforded by increased and more personalised funding and supports, as well as potential barriers to access, was a critical area to understand from the perspectives of both tenants and staff.

As such, the study has aimed to better understand the support needs and experiences of tenants with disability and complex needs living at ESCG, the extent to which these needs are being supported internally and via external service providers, and to identify areas for development and improvement. Interviews with 12 tenants with a disability, 6 of whom had NDIS funding, and 6 staff (4 Launch support staff, one Unison staff member and one City of Melbourne HACC worker) were conducted, followed by a workshop with tenants to discuss the key findings and develop recommendations. These recommendations, together with a short summary of the key findings for each of 8 thematic areas, are given below. Tenants who participated in this study identified as having a disability, mental health condition and/or chronic health issue, as well as a history of homelessness and other complex needs. Some tenants had previously been in prison and some were managing substance addiction. Length of tenancy at ESCG varied from two to 10 years.

The recommendations are specific to ESCG and the support services at this site. While these recommendations primarily address issues in relation to disability support needs, it was impossible to isolate these from tenants' broader experiences of living at ESCG. As such, the recommendations also refer to experiences of this environment as they impact on mental and physical health and wellbeing and on social and community participation and opportunities. While many of these key findings reflect those of other relevant studies such as the Parsell et al. (2015) Brisbane Common Ground evaluation, further research is needed in order to understand the extent to which these findings and recommendations may be applicable to other sites.

Key findings regarding access to and engagement with NDIS services show mixed experiences ranging from significant benefits to high levels of frustration with aspects of service quality, responsiveness, access to tailored information, and support to navigate complex NDIS processes. These findings suggest the need for stronger links between ESCG and LAC services, including in-reach LAC visits for provision of information and support more closely tailored to the particular needs of tenants. Recommendations also include providing access to specialist NDIS support coordination and personal support services, and greater clarity regarding privacy and lines of accountability between in-house and external services for tenants with NDIS funding.

Key findings relating to onsite support services also identify mixed experiences, with some tenant participants feeling very well-supported over many years while others spoke of difficulties in getting consistent and timely support. These findings suggest a crisis-driven model of support rather than a more proactive approach. High levels of need and complexity of need across the tenant cohort left some tenants with less urgent needs finding it difficult to access the support they felt they required. The implications of these findings relate to workforce resourcing and support, skill development and the model of support offered at ESCG.

Key findings relating to tenants' desires for stronger links with community, and for more opportunities to build capacity for employment or voluntary work, have been important in drafting the recommendations. Similarly, findings relating to what makes a home, social activities in ESCG, and the importance of feeling safe have found these issues are inextricably related to experiences of support, and frustrations about the volatile and challenging behaviours of some fellow tenants. Drug use and abusive behaviour on the front steps of the building and in communal areas were common complaints in the interviews. For many long-term tenant participants, despite them placing a very high value on permanent and affordable housing, exposure to difficult behaviours of other tenants, coupled with the challenges of congregate living over the long term, had resulted in the desire for an alternative housing option beyond ESCG. These findings reflect other research exploring conceptions of home in PSH settings, the importance of safe spaces, connections to normal everyday routines and opportunities to pursue personal goals (Chan 2020; Parsell et al. 2015). Similar to Parsell et al.'s (2015) evaluation of the Brisbane Common Ground site, these findings also point to the need for more effective methods of managing challenging behaviours for the benefit of all tenants.

An overarching recommendation consistently informed by the findings and relating to many of the other recommendations is the need for closer collaboration between tenants, Launch and Unison in key decisions impacting on tenants' experience of home, wellbeing and support. The interviews highlighted the need for a more robust and coherent approach to working with and beside tenants in order to engage with their lived experience so as to co-develop key decisions about life at ESCG. This could be addressed in a number of ways over time, including developing

sustainable rights-based processes which respect tenants' experiences and perspectives, and which promote stronger partnership approaches to policy and practice decisions. Related to this in the need for stronger tenant advocacy and peer worker opportunities.

The wide-ranging effects of the COVID-19 pandemic and consecutive lockdowns and restrictions in Melbourne since March 2020 should also be acknowledged in terms of impact both on this research but, more importantly, on the mental health and wellbeing of ESCG tenants and staff. The lockdowns did not just prevent visitors and outings in the community, but also halted in-house activities and interaction thus increasing the negative impacts of social isolation. For tenants with disabilities, there were additional impacts in terms of capacity to access external services and the effects on health conditions. These implications have been identified in Chapters 3 and 4 and have informed some of the recommendations. These recommendations address each of the 8 key theme areas discussed in Chapters 3 and 4 and include short, medium and longer term recommendations.

5.2 Recommendations

5.2.1 The NDIS and interface with PSH/ESCG Summary of findings:

The findings identify mixed experiences for the 6 tenants with NDIS funding at the time of the research. While all 6 tenants noted the difficulties of navigating the NDIS, of managing funded services and of the administrative burden of engaging with the scheme, there was a marked difference in satisfaction. Those with more NDIS experience (e.g. those onto their second or third plan) and with more general experience with disability services were more confident and able to optimise the value and potential of their packages. For those reporting good outcomes, having good quality and responsive support coordination services was critical, as was being clear about their goals, being able to exercise choice in service providers and understanding the review system. For other tenants, engaging with the scheme was problematic and stressful. For these tenants, there seem to have been difficulties in accessing information and support to address NDIS service-provider problems and no sign of independent advocacy to support their choices. Some tenants were also unsure about levels of funding and what exactly their funding was being used for. Poor support coordination was a key problem for several tenants with concerns about how their funds were being spent. Underutilisation of plans was also reported. In addition, there were gaps noted in the activation of funding for community engagement despite tenant participants stressing the importance of this for them. These findings highlight the problem of service providers who are not experienced or skilled in working with people with complex needs. Launch staff noted the benefits of NDIS funding for individual tenants and for overall resourcing levels, but also described the impacts on their workload of supporting tenants in accessing and navigating the NDIS and in liaising with external service providers. A compounding issue was the proliferation of NDIS service providers moving through ESCG and the difficulty for Launch staff of providing a reasonable level of oversight.

Recommendations:

- 1. Launch Housing support staff should develop a stronger relationship with the LAC service designated to the City of Melbourne and organise regular in-reach visits offering onsite information and NDIS advice and support to ESCG tenants. Regular LAC visits to ESCG should aim to provide tenants with accessible information about accessing the scheme and pre-planning as well as tailored advice regarding principles for selecting and using NDIS services, about rights as NDIS participants, and review and complaint processes. These visits should aim to build tenant confidence and awareness of the NDIS and its benefits. Regular onsite LAC presence and more robust relationships would also benefit ESCG support staff and build their capacity. LAC staff could also use these regular site visits as an opportunity to gain insights into the needs of ESCG tenants and how NDIS services can be developed to cater for the needs of people living in PSH, particularly in relation to social isolation, lack of community engagement, psychosocial disability and the impacts of chronic homelessness on health and wellbeing.
- 2. LAC staff should offer onsite tenant-focused NDIS information seminars on relevant topics such as choosing an external service provider, the role of support coordination and plan managers, what to expect from an NDIS disability worker, choosing NDIS disability workers, your rights as a tenant and dealing with service providers. In addition to building knowledge, these seminars may help build confidence and self-advocacy skills.
- 3. The LAC team should develop a short list of specialist services skilled in working with people experiencing intersectional disadvantage and complex needs including psychosocial disabilities, histories of homelessness and substance use. A short list of suitably skilled and experienced service providers would be a significant resource for ESCG tenants and staff, and would help prevent issues raised in the interviews regarding NDIS services ill-equipped to work with people with complex needs. Ensuring that tenants are more informed about the experience and skills of providers, including support coordination, would not limit choice but in contrast build capacity for more informed choice. Likewise, the National Disability Insurance Agency (NDIA) should ensure that NDIA planners keep tenants' complex needs in mind when supporting service choices. It is hoped this model will build a more relational approach and reduce the transactional way in which some NDIS services are currently being provided to ESCG tenants.
- 4. Launch staff should receive training and up-to-date information about the NDIS process to build and maintain their knowledge and capacity.

- 5. Information should be provided to tenants about independent disability and mental health advocacy organisations in order to build their capacity and assist in navigating service systems including the NDIS; for example, the Disability Advocacy Resource Unit, Victorian Advocacy League for Individuals with Disability, Self Advocacy Resource Unit, and Victorian Mental Illness Awareness Council. These organisations could be invited to ESCG as guest speakers.
- 6. The interface between in-house supports and external service provision should be reviewed in consideration of how to balance tenant privacy issues with Launch staff responsibilities for tenant welfare and Unison's responsibilities. This should include reviewing tenant documentation and guidelines regarding access and privacy.
- 7. Creation of a dedicated NDIS support role onsite at ESCG should be considered. This role would support tenants to access and navigate the NDIS, support selection of services and address support coordination issues if this fails. This role would assist with tenant concerns and complaints regarding NDIS services as well as with plan review, promote active and effective use of NDIS plans, and act as the key ESCG liaison with the LAC team.
- 8. Development of a tenants' group to share information about NDIS experiences should be considered with the aim of sharing information about preferred service providers, including support coordinators, as well as tips for increased choice and control in the scheme.

5.2.2 Vision, leadership and management Summary of findings:

In disability housing literature and policy, there has been a strong emphasis in recent years on the need to separate housing management from support provision in order to reduce uneven power relations between tenants and support providers who are also their landlords. However, the findings from tenant interviews suggest that some issues may be falling through the gaps created by the separate roles, accountabilities and responsibilities of place management (Unison Community Housing) and in-house support services (Launch Housing). From tenant participant perspectives, the most pronounced issues related to overlapping areas which might not sit squarely with either site management or tenant wellbeing such as, for example, disruptive behaviours and substance use on the building's front steps and in communal areas. These findings strongly reflect related research which has highlighted the importance of a unified supportive housing approach where support, housing and security providers work in partnership and have a clear and coherent vision for the site (Parsell et al. 2015).

Recommendation:

9. There should be clarification of place management and support service roles, responsibilities and accountabilities about the most problematic issues, such as those relating to the occurrence of challenging and volatile behaviours in communal spaces. It is recommended that Unison and Launch work with an ESCG advocacy group to gain insight into the most problematic issues at ESCG and, together with tenant representatives, develop understanding about lines of accountability and responsibility regarding these issues. This information needs to be clearly communicated to tenants in accessible formats, for example, written information, tenant meetings, one-on-one conversations, an updated charter of responsibilities.

5.2.3 Tenant rights, representation and participation Summary of findings:

The interviews with tenants revealed an organisational culture which separated tenant lived experience from professional expertise and in which there were insufficient processes for tenants' experiences to be shared and to inform policy and practice development at ESCG. While Launch has the LEAP process, this is an organisation-wide group that spans many sites and is not exclusively for ESCG tenants. Attempts to develop a robust and sustainable ESCG tenants' advisory group have been mixed and not well-resourced. Tenant participants suggested these tended to become a complaint forum rather than a productive space for working together. The interviews highlighted tenants' valuable lived experience and ideas about how to develop and improve life at ESCG, but also revealed frustration at the lack of organisational processes for them to participate in decision-making. Some tenant participants also noted the need for more transparent and responsive complaint and suggestion systems.

Recommendations:

- 10. Launch Housing and Unison should work with tenants to develop a more collaborative culture and strategies for co-design approaches to policy and practice development at ESCG.
- 11. There should be development and resourcing of an ESCG tenants' advisory group with codesigned terms of reference and resources for skilled facilitation to promote sustainability. This group would feed into Launch's Lived Experience Advisory Program (LEAP) but remain specifically focused on ESCG matters and experiences. Information about the advisory group and tenant representatives should be disseminated widely to promote visibility of the process and encourage tenants to engage with their representatives regarding issues to be raised.

- 12. Existing complaint and suggestion processes should be reviewed together with tenant representatives to ensure that these processes are accessible, transparent and responsive, the processes are well advertised and the actions arising from complaints are clearly communicated both collectively and to individual tenants who have raised complaints.
- 13. Links with disability and housing advocacy groups (e.g. Tenants Victoria) should be reviewed to ensure tenants are provided with clear and accessible information about their rights at ESCG. This should include working with tenants to address privacy dilemmas such as how staff can respect tenant privacy while also maintaining oversight of their welfare and wellbeing.
- 14. Peer worker roles at ESCG should be developed to promote connections with people with lived experience and connections with organisations such as the Council to Homeless Persons.

5.2.4 Model of support and care Summary of findings:

The findings suggest that housing large numbers of tenants with complex needs in a congregate setting can produce a crisis-driven and reactive model of support and care which leaves some tenants feeling vulnerable and with needs unmet. For some tenant participants, it appears that the support contract with Launch lacked clarity and was experienced as inconsistent and subjective. This resulted in tenants with what might appear less complex or urgent needs feeling overlooked. The findings suggest support staff often had insufficient time to engage in more proactive, forwardlooking and strengths-based support work with individual tenants such as building capacity for independent living and community participation goals, or collectively in terms of community building and belonging work. The findings highlight the needs for more individualised, consistent and responsive support for all tenants wishing for it and for good systems for monitoring and review of services provided and of tenants' progress towards their identified goals. Tenant participants stressed the importance of meaningful activity in their daily lives and having more opportunities to participate in the community through recreation and employment, both voluntary and paid. There appeared to be, however, a lack of consistent support for accessing and engaging with community groups and networks. This was, of course, exacerbated by COVID-19 restrictions over 2020 and 2021. The model of support and care at ESCG needs to shift from crisis management to one which more proactively addresses self-directed goals and builds capacity for social and community participation. This approach needs to be underpinned by awareness of the additional challenges arising for tenants with complex physical, neurological and psychosocial disabilities.

Recommendations:

- 15. Launch should ensure all supported tenants who choose to access support have both a key worker and an individualised support plan outlining their key needs, goals and related support and resource strategies, as well as details about external service providers. Support plans should be regularly reviewed and updated in collaboration with tenants and reflect their changing needs and goals. Tenants should have clarity about when they can meet with their key worker and clear expectations about what to expect from the support contract. Support approaches should be proactive.
- 16. Launch support staff should ensure individualised plans and supports include, where desired by the tenant, community participation and employment goals, voluntary or paid, along with strategies and resources to achieve these. Creative ways of linking tenants to education and employment opportunities should be considered, along with strategies for capacity development in these areas. This could include, for example, links with neighbourhood houses, community-based social enterprises and training organisations which might offer partnership opportunities. NDIS participants could include related goals in their plans and funding could be allocated to these activities.
- 17. Launch support staff should work with ESCG tenants to maintain an accessible and upto-date online resource of community groups, networks and opportunities relevant to their needs and interests, for example, neighbourhood houses in the local area, disability-related support groups (e.g. acquired brain injury [ABI] support groups), free community festivals and volunteering opportunities. Consideration should also be given to inviting guest speakers from these organisations in order to build links and support 'warm' referrals (e.g. accompanying someone on their first visit to a group or community organisation if this would help).
- 18. To promote relationships between tenants and staff, including new tenants and new staff, consideration should be given to the creation of self-authored profiles, where tenants choose any medium they like to create a representation of who they are and what is important to them. Any art form or medium can be used, such as a poem, short video, photo or painting. These profiles would be available for staff to view and would be particularly valuable for new staff and for staff who had not previously worked with certain tenants.

5.2.5 Communication, roles and relationships Summary of findings:

The findings suggest room for improvement in communication systems between Unison, Launch and tenants. Some tenant participants described communication as often inconsistent and

sometimes disrespectful, particularly when relating to compliance issues and warnings about breaching of rules. It was felt that a more stepped approach towards communicating problems that might lead to breaches would reduce the need for more formal disciplinary communication and reduce the worry such communication often produced. Communication often relied on just a few methods such as formal letters or notices in communal areas, but this can be limited, particularly if letterboxes are not regularly checked or people do not frequent communal spaces. There was no mention of technology such as group messaging or email to facilitate communication. Tenant participants discussed the need for more effective and personalised forms of communication between Unison, Launch and tenants via more accessible formats including face-to-face conversation, both planned and casual. Related to this were suggestions regarding the needs to develop a more welcoming and comprehensive induction for new tenants and to find ways of promoting staff identity and visibility. High staff turnover sometimes led to tenants not knowing the names of staff members they saw walking through the site.

Recommendations:

- 19. ESCG should increase staff visibility by, for example, ensuring that new staff are introduced to tenants in several ways such as via a group meeting, through letters and on a poster with photos and names. In addition, support staff could spend more time in shared communal spaces to enhance their visibility.
- 20. Launch staff should partner with tenants in co-developing strategies for building a stronger sense of community and stronger relationships between ESCG tenants with the aim of strengthening social connection and a sense of belonging. Note that some tenants may prefer to keep to themselves; however, others may need proactive support to connect with other tenants in the building.

5.2.6 Workforce

Summary of findings:

Launch provides onsite support to tenants with diverse and significant needs and complex histories. This is a demanding job and requires a range of skills, knowledge and experience. The findings suggest that key limitations to providing the type of proactive wraparound supports envisaged in Housing First and Common Ground philosophies include resourcing, staff turnover and access to regular professional supervision. As noted in 5.2.4, tenant and staff participants reflected on the impact of staff resourcing on capacity to move beyond a crisis-led support approach, with the limited capacity to engage in more tenant-led support related to the lack of community engagement and participation. The consequence was that those tenants with the resources and capacity to independently pursue these goals would do so but those who required

additional support might not be able to progress their aspirations in these areas in the absence of other supports such as the NDIS, thus perpetuating their social isolation. The findings also suggest the need for more systematic and accessible professional supervision and debriefing for support staff, as well as the need to ensure staff skills and experience match the complexity of the tenant mix and intersectional needs presenting at ESCG including chronic homelessness, problematic substance use, disability, incarceration, family breakdown and mental health issues.

Recommendations:

- 21. Consider minimum qualifications for support staff to be a recognised welfare or social work qualification or equivalent as well as relevant experience in the disability and homelessness sectors. It should be ensured that all support staff also have qualifications and experience working with alcohol and other drugs (AOD), with people with psychosocial disability, and an awareness of trauma-informed care.
- 22. Launch Housing should build staff capacity to support tenants in community engagement and participation, including voluntary and paid employment. This could involve additional staff training in strengths-based approaches, as well as building staff networks, knowledge and links to community organisations and opportunities of interest to tenants, including support groups relating to particular disabilities.
- 23. All support staff should have access to regular professional supervision for critical reflection and to debriefing following critical incidents.
- 24. Adequate staffing should be ensured across the 24-hour timeframe and over weekends, and adequate time should be made available for handover between shifts. The recommended proactive model of support is more time intensive and is likely to require additional funding for staff positions.
- 25. Launch Housing should build career pathways for support staff and develop strategies to actively reduce staff turnover.

5.2.7 Sense of home, belonging and community inclusion Summary of findings:

The findings reflect previous research in revealing the importance of having a sense of home and security, and of feeling safe in PSH settings (Bullen et al. 2016; Chan 2020). Gratitude for secure tenure was a key finding in this research but parallel to this was a weariness, particularly for long-term tenants (8 years plus), that was produced by long-term living in a congregate environment,

the institutionalised nature of the ESCG site, the complex mix of tenants and related behaviours, and the reduced agency in key life choices such as having pets and being able to entertain friends and family. For some, there was also a sense of stigma in living at ESCG and this was exacerbated by some behaviours of other tenants. The findings consistently identify a tension for tenants between their sense of home and safety in their apartments and the challenges of behaviours in the communal spaces beyond their doors. There was also a tension for some tenants in being grateful for the onsite security and concierge while at the same time feeling that this added to the institutionalised nature of their home. For some long-term tenants these factors resulted in a strong desire to leave ESCG for an alternative housing option; however, they felt there was minimal information about such options or how to secure them, thus adding to a sense of feeling trapped. The other key finding relating to this theme was the diminished sense of community at ESCG. Tenant participants generally felt they had one or two others that they connected with but there was not a greater sense of community or connection beyond this. In-house activities seem to have diminished over the years, impacted further by COVID-19 and resource limitations, and the curtailment of activities such as cooking classes, barbecues, gardening and excursions was noted as a loss.

Recommendations:

- 26. Launch should reinstitute a calendar of in-house activities and excursions to revitalise community connections following the long months of COVID-19 lockdowns. This should be developed in partnership with tenants with the aim of reflecting tenants' interests.
- 27. ESCG should review how challenging behaviours are managed in communal areas and how these impact on other tenants. This should include working with tenants to identify effective approaches which do not discriminate against people with challenging behaviours, but also ensure ESCG is not just a safe place to live but also feels like a home both inside and outside individual units.
- 28. The pet ownership policy should be reviewed, with input from tenants and in line with relevant legislation.

5.2.8 Housing pathways beyond ESCG Summary of findings:

As noted above, long-term tenants participating in this research discussed a desire to move on from ESCG and the fatigue of semi-institutionalised and congregate living. Some tenants wanted smaller scale supported housing and some also expressed a preference to live in the country. However, tenant participants interested in leaving ESCG reported a lack of information

and awareness about housing options outside of ESCG and also believed that given they were in PSH, they automatically went to the bottom of the list for other housing options. Private rental was a potential option for only one tenant participant. Living with disability was seen as an additional barrier to finding alternative but equally secure and supported housing.

Recommendations:

- 29. Information and support should be provided about alternative housing options such as scatter-site housing for tenants who choose not to stay at ESCG. This may be particularly relevant for some long-term tenants who have achieved housing stability and wish to leave congregate living; these tenants should be linked to information and supports to enable pathways out of ESCG.
- 30. More tailored information about the portability of NDIS funding and supports should be provided in the move to other housing.

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