



Barriers to engaging Younger People In Residential Aged Care. Observations from the My Future My Choice Project

The Alliance has undertaken extensive work with younger people living in residential aged care to develop and trial a choice making process that supports younger residents to articulate their wishes and preferences regarding their current and future living arrangements.

We have also designed and successfully implemented a collaborative transition methodology that ensures a younger resident's move from residential aged care to community living is safe, healthy and successful.

To do this, we have worked intensively and collaboratively with the following groups. We have also provided extensive capacity building and secondary consultancy to individuals in these groups

- younger residents living in residential aged care, their families and informal supporters;
- support coordinators working with these younger people;
- residential age care management and staff;
- allied health practitioners;
- public advocates and trustees
- health, disability, mental health and housing service providers;
- NDIS planners and other NDIS staff.

The observations below are drawn from the project's initial surveys with these groups; feedback from workshops; conversations with younger people (YP); other extensive stakeholder engagement the project has undertaken, and are offered to inform the successful delivery of the Younger People In Residential Aged Care (YPIRAC) Strategy.

They reveal a significant lack of understanding of the younger people in residential aged care cohort; their journey into residential age care; and the impact that placement in residential age care has had on these younger people and their families. They also expose the lack of service design and service integration that younger residents needing concurrent service responses from multiple programs confront when making such a decision.

Of particular concern is that younger people living in RAC do not see themselves as decision makers or with agency to interact in a decision making process. The project has undertaken wide-ranging capacity building work with these individuals that has confirmed the critical importance of providing proactive supported decision making assistance; and the time needed for a younger person to consider and articulate their wishes and preferences, as well as the impact of any decision they may make.

These observations also confirm that support coordinators and NDIS planners lack the appropriate skills and orientation to work collaboratively with aged care, housing and health programs; and to organise the integrated service responses their younger clients living in residential aged care may need.

The Alliance is committed to the successful delivery of the YPIRAC Strategy and achievement of the YPIRAC Targets and is keen to discuss these observations further to that end.

| Younger people living in residential aged care (YP) | Family & significant others | Residential Aged Care (RAC) Services | Other formal supports - support coordination (SC) & allied health |
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| <ul style="list-style-type: none"> • Have diminished understanding of their decision-making capacity • With few opportunities to make decisions and take ownership of their lives, do not see themselves with agency to make decisions about living arrangements • View the RAC as safe because <ul style="list-style-type: none"> • system failed me previously • previous negative housing experiences • RAC’s health management/ nursing care • RAC service’s connection to health services • staff familiarity • “a roof over my head & 3 meals a day” • reliability of daily services: food, water, shelter, care • people know me, know my name, recognise my birthday etc • better the devil I know... • Unaware there may be other options | <ul style="list-style-type: none"> • Fear & anxiety about change • See RAC as safe. YP can’t get out and other people can’t get in therefore RAC is secure. • System has failed them & loved one before. Don’t want the stress of another poor experience & difficulties with other living arrangements • RAC was only option offered previously; abandoned by system before; why trust now • Assume they know best. Don’t trust the YP’s capacity to make decisions or be supported in making decisions • Don’t always consider the YP’s agency, or defer to/consider YP’s wishes and preferences • Don’t always understand what options are possible • Not open to learning about changes and options or to discussing any concerns & risks • Acknowledgement of cultural needs and connection to country | <ul style="list-style-type: none"> • Under resourced & time poor. • Have competing priorities where service orientation is to supporting older people • Know the YP better than most NDIS funded services • Have taken YP on when no other options existed. Feel their care and commitment not valued and dismissed • Because they have taken YP in when no other option existed, initial response to YPIRAC Strategy & Targets often seen as criticism of RAC’s care • Responsibility for clinical management, providing a supportive care role • Less understanding of YP’s disability & impact • Not included by SC in NDIS planning meetings with YP • Can facilitate conversations with YP but time poor • Very concerned about dual regulatory requirements & | <p>Support coordinators</p> <ul style="list-style-type: none"> ▪ Lack knowledge of YPIRAC Targets and Strategy ▪ Lack knowledge of other service systems: health, aged care, housing, justice et al ▪ Lack connection, rapport with YP ▪ Lack knowledge of the YP and capacity to support them with NDIS questions & planning processes ▪ Lack ability to collaborate, particularly with other service systems ▪ Don’t engage with RAC provider ▪ Fail to include RAC provider with YP in NDIS planning meetings and reviews. ▪ Have limited understanding of the benefits in bringing stakeholders together to collaborate ▪ Have little if any capacity to bring diverse stakeholders from multiple programs together to collaborate • Need the skills to understand and translate the support the RAC provides to the YP’s community living setting |

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| <ul style="list-style-type: none"> • Didn't feel supported to explore other options (too hard to conceive alternatives, conceptualise anything different, better to stay with what I know) • Become institutionalised very quickly. • Considering a move out of RAC provokes heightened stress and anxiety for many • No certainty that disability providers understand and can support their needs appropriately | <p>/community – indigenous and CALD</p> | <p>adverse financial & resource implications</p> <ul style="list-style-type: none"> • Dual regulatory requirements causing some providers to not renew NDIS Commission registration • Don't always understand/consider the YP's agency • Limited engagement with NDIA/planners & support coordinators & working relationship around YP • Know of the NDIS but little knowledge/understanding of scheme processes • Third party disability providers can cause upheaval & frustration through disability providers' lack of knowledge of aged care sector/processes; & application of disability lens only to RAC structures & processes • Lack of access to YP NDIS plans and awareness of funded supports | <ul style="list-style-type: none"> • Have insufficient hours/funding to participate fully in transition process, both before, during and after move to community living from RAC • Do not understand importance of a transition process to ensure successful move from institutional setting to community living • Many are still unaware of the YPIRAC Strategy and Targets • Feel pressured to provide information they don't have to the YP, their families and Aged Care facilities about the YPIRAC Targets/Strategy <p>Allied health professionals</p> <ul style="list-style-type: none"> • Lack of integration of RAC and NDIS supports to provide consistency of care & support • Have insufficient hours/funding to participate fully in transition process: before, during & after move to community living from RAC • Many Behaviour Practitioners lack knowledge of the aged care environment; have limited understanding of the adverse financial & resource impacts of |
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| | | <ul style="list-style-type: none"> • Lack of inclusion in planning and plan review meetings. • RAC support contribution not valued by SC other than providing paperwork related to RAC funding. • RAC support contribution not valued/understood by third party disability providers • RAC provider is regularly the default body providing consent for services after a guardianship order has lapsed/ceased. | <p>strategies recommended in behaviour support plans on RAC provider.</p> <ul style="list-style-type: none"> • Expectation that behaviour support & other strategies can be implemented without consultation and adequate training and review. |
| NDIS aged care team | Appointed guardians /trustees | Other | |
| <ul style="list-style-type: none"> • No communication with participants or RAC re questions about exploring alternative accommodation options • Engagement & questions about current & future living options are not happening at the right time; should not happen in the planning meeting when YP is not prepared; planner doesn't understand YP | <ul style="list-style-type: none"> • Large caseloads • Inconsistent communication from all actors • Don't know YP • Different jurisdictions have different rules • Key stakeholder & should be able to bring parties together • Request for input & engagement often missed | <ul style="list-style-type: none"> • Lack of confidence in the NDIS decision making • Inconsistent NDIS decision & funding outcomes • SDA vacancies do not match YP housing & support needs • SDA decisions made by the NDIS Home and Living Team do not take account of YP's particular needs | |

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| <p>background, their pathway to RAC prior to engagement.</p> <ul style="list-style-type: none"> • No transparency of process • Extensive length of time to get decisions /outcomes • Inconsistent planning decisions • NDIS aged care planners lack delegation to make decisions around supports • Planning team’s lack of engagement with RAC providers • Have limited history, background of the YP and requirement for communication and decision support • Lack of accountability by the NDIS of support coordinators • Lack of recognition of the need to fund transition activities to supports the YP | <ul style="list-style-type: none"> • Gaining consent to engage with guardians & trustees can be difficult and irregular | <ul style="list-style-type: none"> • Need for all stakeholders to understand the RAC environment, the important input they can provide in supporting the YP & their support network. • Lack of formal support for YP with decision making and capacity to give consent. | |
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