Meaning of Home

Best practice for people with disability in home and community living

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

by the National Alliance of Capacity Building Organisations

NACBO

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Introducing NACBO

The National Alliance of Capacity Building Organisations (NACBO) is a national network of not-for-profit, values-based, capacity building organisations. We have a shared vision and belief that all people with disability are valued citizens and have the right to contribute to society through social and economic participation. We have worked together over the last 30 years building the capacity of people with disability in Australia to have a home of their own and a good life in their community.

We acknowledge that many people with disability are shut out from the richness of many ordinary experiences through outdated practices that limit people's lives. To shift this paradigm, members of NACBO provide information, education, mentoring, planning, peer support and leadership development. We provide:

Education

We provide information, education, and workshops to people with disability, families, and their allies on the importance of a positive vision, inclusive life, valued roles, home, and self-direction. Opening people up to what is possible and building the confidence, skills and knowledge is at the core of our work.

Follow up

We empower people with disability and their families to do this for themselves and with each other, rather than someone else doing it for them. We mentor people with disability and their families to identify their needs, implement their plans and identify what resources are available.

Leadership

We develop the leadership of people with a disability and families directly through development courses and workshops, and indirectly through opportunities to present, write, lobby, and collaborate on projects.

Purpose of the document

This document is our submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

We define the meaning of home and what we consider to be best practice in home and community living. We list what each sector can do; people with disability themselves, families, allies, services, or government. We then consider how best practice for a few can become accepted practice for many. We offer three take-home messages from our work and offer four recommendations for government action.

Finally, we share twenty-three stories which illustrate that people with disability can have a home of their own, establish networks of family and friends and contribute to a community where they belong.

Summary

Our experience has shown that everyone, regardless of their level of disability, can have a home of their own, and belong in community. Everyone, regardless of their level of disability, can decide where, how and with whom they live.

People with disability consider the meaning of home in the same way as other people do. Home is a place of safety, rest and renewal. It is our doorway to community life. It is a place to be truly oneself. Best practice in home and community life enables people with disability to live, work and play as everyone else does.

Best practice in home and community life for people with disability is everyone's responsibility. The starting point is for people with disability to know what sort of home they want, and what they do not want. When people with disability are not clear, others will make decisions that are well-intentioned and often wrong.

People with disability across Australia have demonstrated best practice in home and community living for over 30 years. For this to become accepted practice for many, we offer governments three take-home messages and four recommendations.

Three take-home messages

1. Significant gaps in knowledge, expertise, innovation and leadership has cemented traditional congregate care models as the default. Without commitment and investment in innovation and leadership, conventional services will, as in the past, maintain the status quo. Governments will ultimately determine the speed and extent to which adoption of best practice occurs.

2. People with disability, their families and allies have demonstrated what is possible in home and community living in the past and will continue to strive for best practice in the future as they have the most to gain. Their leadership needs to be acknowledged, supported and built upon.

3. People with disability, with their families and allies, can now have authority over their funding. Ongoing investment is needed to build their capacity over time to use this authority well.

Recommendations

Four recommendations

If The Disability Royal Commission (DRC) want to promote a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation then their recommendations must ensure a rapid and profound shift to adopt best practice in home and community living.

The National Alliance of Capacity Building Organisations calls on the Disability Royal Commission to work strategically and respectfully with 'on the ground' leaders as agents of this change. Specifically we request that the DRC recommendations:

1. **Reflect the objects and principles of the conventions and legislation that support social inclusion and define best practice**
2. **Outline the leadership role required by Government departments**
3. **Support the continuation of investment in the capacities of people with disability, their families, and allies over a long period of time**
4. **Support investment in human service capabilities to undertake the required reform.**

To achieve this we ask the DRC to convene a National Roundtable on housing and individualised supported living arrangements for people living with a disability, tasked with mapping out a 5 year plan to implement meaningful and lasting reforms.

The DRC should invite 'on the ground' leaders to be part of a longer term steering group to ensure the voices of people living with disability are paramount.

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Contents

Meaning of home

What do we mean by home?

We each have an individual understanding of home; yet some things are universal [1]. They are:

1. **We feel safe**

   A secure home enables choice and control over our living circumstances. When we wake up in our own home day after day, with control over where, how and with whom we live, we have a sense we are in charge of our lives.

   When our home is secure, we invest in ourselves, in others and in our surroundings. We can trust others and learn about intimacy and reciprocity.

2. **We decide who comes in**

   Our home enables us to 'open the door' to others. We can also 'shut the door' when we want privacy, to rest and renew for another day, and to feel safe.

   Home is also the doorway to our community. We can choose who from our community we want in our home, and when we want to step out to be with others.

3. **We can truly be ourselves**

   Home is where we can truly be ourselves. We can express who we have been, who we are and who we hope to become. Home is where we do things that give us meaning and purpose on our own terms.

Home and community

Home as "a place" differs from the broader sense of community as "a place. Home is local, familiar and nurturing. Home is in our control. Community is expansive, changeable, and full of opportunities. Yet, many things are not in our control.

We need home and community. Without them both, we feel lost, isolated, and as if we do not belong anywhere.

These concepts of home and community challenge many housing and support solutions for people with disability. Specialist solutions which group people with disability may be cost-effective and convenient for support services, but they deny many social, cultural and emotional opportunities that community living brings and other people take for granted [2,3].

A good place to start is to think about how, where and with whom other people live.

Best practice in home and community living

We are guided by the research [3,11,13] and the objects and principles of the following conventions and legislation that define what is best practice:

- The United Nations Universal Declaration of Human Rights [4]
- The UN Habitat principles of adequate housing [5]

- The Convention on the Rights of People with Disabilities [6]
- *The Disability Discrimination Act 1992* [7]
- *National Disability Insurance Scheme Act 2013* [8].

Evidence-based research into current and past practices informs our position on what is poor practice [9,12,16,21]

We use Social Role Valorisation theory [11] as a theoretical framework in our discernment on why poor practice occurs, and how to achieve best practice.

What is best practice?

Best practice [3,4-8,11,13] is evident when:

People with disability:

- have a positive vision and a plan for their life [8,13]
- have a home to call their own in an established community where they are known and feel they belong [4,5]
- maintain their personal relationships, and develop new ones [8]
- participate in meaningful work, play and creativity as a valued community member [8]
- have the same rights and responsibilities as other citizens. [6]

Their home:

- is a place of safety, rest and renewal, provides privacy and where they can truly be themselves [4,5,13]
- is ordinary housing in regular streets and neighbourhoods, near transport and amenities [11]
- is designed for them, to meet their needs and preferences
- provides secure tenure, that is not contingent on support arrangements.[7]

Their support:

- understands, respects and upholds the sanctity of home [8,13]
- meets their individual and changing needs as they change and grow [3,8]
- assists them to reach their full potential as home maker and community member [8]
- works respectfully and adaptably with them, to build and maintain their community connections and relationships.[8,13]

What is poor practice?

Poor practice [9,12,16,21] is evident when:

People with disability:

- do not know or have not experienced what most people take for granted in home and community life [12]
- are expected to live with others that they have not chosen, do not know or do not like [9]

- have no control over who comes into their home, what they do there or when they leave. [21]

Their home:

- does not feel like their own [21]
- does not feel safe, private or a place of rest and renewal [9]
- offers no security of tenure and is contingent on decisions of support providers [9]
- is designed to look different or "special" [16]
- is assumed to be where they "are housed" for the rest of their lives. [12]

Their support:

- is primarily provided by paid staff who establish routines and standards of care that primarily benefit themselves [9,21]
- does not encourage visits by neighbours, family, or friends [21]
- is unable to adapt to people's changing needs and relationships, and opportunities for development and growth [21]
- is compromised because of the needs of other people in the home [12]

What have we learnt?

People with disability and their families have shown us that:

- Everyone, regardless of their level of disability, can have a home of their own, and belong in community life. Everyone should be able to choose where, how and with whom they live.
- People with disability, given the chance, take their own path in life, and will develop over time. This means they change their homes and how they live along this life journey.
- Group homes, cluster housing and special disability facilities limit people's lives and do not guarantee safety or quality of care. Arbitrarily grouping people with disability makes them less safe and more susceptible to neglect, abuse and exploitation.
- Community living does not guarantee safety or freedom from abuse; however, it does provide opportunities for valued social roles, community connect ions and real relationships. These relationships provide the best safeguard.
- Maintaining natural social connections, informal networks and relationships is particularly difficult in specialist, segregated residential settings.
- People with disability need a strong vision for their home and community life, a plan, and people who want to help them. People with disability without family or friends also need someone committed to their vision and plan, and to find a place they can truly call home.
- Thoughtful planning takes time and exposure to a wide range of options and possibilities. Readymade housing and support solutions, such as a room in a group home, lead to compromises that people later regret.

There are many examples of people with disability living good lives in a home of their own across Australia. *(See Individual stories on p. 10.)* These people have shown that everyone can contribute to best practice (see p. 5) and what needs to happen for best practice to become accepted practice for everyone (see p. 8).

Everyone can contribute to best practice

Everyone has a role to play in the best practice enabling people with disability to have a place they call home and a community where they belong.

What can people with disability do?

Get clear [8]

It is important for people with disability themselves to choose what sort of home they want, and what they do not want. This might take some time if the opportunities to envision a better life thus far have been limited. A good place to start is to think about how, where and with whom other people live.

Like other people, their first home is unlikely to be their last. Every life opportunity and challenge clarify what is important and what is not. When people with disability are not in charge, others will make decisions that are well-intentioned and often wrong.

Get informed [17]

There is a lot of information and stories available; however, this is just noise until people with disability can decide where they are going and what they need to know. Then information and stories can become powerful tools for making good decisions.

Get connected [17]

There are many people with disability who have a similar vision, plan, and experiences. It can be useful to have a mentor or coach who can give courage and hope for a better life, and to guide what to do.

What can families and allies do?

Make an enduring and personal commitment [8]

People with disability, like everyone, need others who believe in them, encourage them to dream and to take risks. Families and friends have a role in making that enduring and personal commitment to the wellbeing and potential of people with disability.

Encourage reasonable risk-taking, self-determination and personal growth [8]

Families and allies know there is benefit in just getting started, and not waiting for the approval of others. They also know the benefits of thoroughly considered vision and plan, rather than opting for a compromising ready-made service solution.

Families usually have known the person with disability for the longest and have a well-rounded understanding of their desires and needs. It follows they will know what safeguards are needed and will encourage reasonable risk-taking that leads to self-determination and personal growth.

Think succession [13]

Families and allies can assist the person with disability to be resilient and able to manage inevitable life events, such as the death of a parent or a breakdown in relationships. Parents can plan for when they are gone, document what others should know, and intentionally share this knowledge with others.

What can service providers do?

Go person by person [8]

Service providers can commit to a vision for people to live in their own home and to let go past practices. They can learn from people who are leading the way and work with one person at a time. Supporters, both paid and unpaid, can regularly invest in each person's vision and plan to ensure best practice continues over time [13].

Service providers can be careful, humble, and trustworthy, think 'journey' rather than 'solution' and respect and follow the vision and plan of each person with disability. These measures can ensure they do not recreate the past.

Respect families and informal networks [4]

Service providers can also work respectfully and collaboratively with the families and allies who have made enduring personal commitments.

They can build the capacity of people with disability to envision and plan better, and to design and direct their own supports.

Honour the sanctity of home [1]

They can honour and safeguard the sanctity of people's home life. They can reflect on how people normally live, how people's relationships, community connections and roles flourish and not be eroded or overtaken by paid service.

What can governments do?

Support

Commit to social and economic inclusion [4,8]

Governments can commit to every person with disability being included in community life, having "real" paid employment and being able to choose where, how and with whom they live. This requires sustained political will at all levels of government and willingness to confront discrimination and poor practice at both a systems and individual level.

Respect families and informal networks [8,16]

Governments can respect and support the role that families, community connections and relationships play in achieving good lives for people with disability. They can seek out best practice examples and consult those people "on the ground" who have shown leadership.

Invest in innovation and build capacity in people with disability and families [8]

Governments can actively invest in innovation and build the capacity of people with disability and families to envision a good life, to demand better, and to plan and direct their own lives. They can provide technical and practical assistance to turn the vision and plan into a safe and workable reality.

Enable people with disability without families [16]

Governments can acknowledge that people with disability who have no family or allies are most at risk of abuse and neglect, and provide for:

- independent advocacy to safeguard their self-determination and wellbeing
- independent life planning so people are not solely reliant on service providers
- initiatives that find citizens to make enduring personal commitments to them
- the closure of congregate living facilities in favour of ordinary homes in the community.

Separate housing from support [8]

Governments can ensure that the management of housing is distinct and separate from support arrangements to safeguard the authority and self-determination of people with disability [14].

Housing

Build inclusive and accessible residential neighbourhoods [15,16]

Governments can enact policy supporting accessible and inclusive residential neighbourhoods with a mix of housing types, and access to transport, leisure, and work. This would include housing policy that:

- **Mandates a basic access standard in all new housing construction**
  Governments can amend the National Construction Code to provide accessibility in all new housing construction; thereby reliably increasing.

- **Ensures housing assistance is equitable**
  Governments can ensure people with disability have the same access to housing assistance programs as other people. This includes being given the same rights and responsibilities regarding housing tenure.

- **Increases the supply of affordable and social rental housing**
  Governments can increase the supply of social and affordable rental housing which enables social inclusion and participation in work.

- **Expands home purchase assistance to people with disability**
  Governments can expand established State direct lending programs to assist people with disability, to enter and sustain home ownership.

- **Adequately funds and standardises national home modifications programs**
  Governments can adequately fund and bring together the many home modification assistance strategies under one standardised and data collection framework for optimal use of funds

Best practice to accepted practice

Many people with disability have lived in a home of their own and a community where they belong for many years. How this happened for some and not for others informs how best practice can become accepted practice for all people with disability.

Three take-home messages

1. **People with disability, their families and allies led the change in the past and will lead the change in the future**

The major changes to policy and practice in the past 30 years has largely been instigated by people with disability, their families and their allies, rather than by large formal services [17,18,19]. Change typically started through small best practice initiatives across Australia, which demonstrated what was possible. In turn, these initiatives were replicated in three steps:

- People with disability and their families shared their experiences with their peers who wanted similar best practice
- Community and service leaders championed, publicised, and demonstrated what was best practice through their networks, then
- Service organisations that are ready to try new ways of doing things, integrated these innovations with what they already knew, and used their capacity and influence to replicate them [17]

Conventional services were slow to initiate or replicate best practice in the past and continue to rely on traditional models. They now require investment in contemporary best practice.

Because people with disability, their families and allies have most to gain, they have led the change in the past and will continue to strive for best practice in the future.

2. **Government policy and leadership will decide on the speed of change**

The adoption of best practice in the past has been variously helped and hindered by government policy and leadership. Where governments worked collaboratively with people with disability, families and allies as change agents, (such as the individualised cash payments) change was rapid, profound and lasting [20]. When governments put their faith in congregate care models and used top down measures, change was slow, marginal, and not sustained over time [11].

The speed of replication of best practice[12] depends on how it aligns with:

- current funding policy
- the level of risk-taking and experimentation that a government can tolerate
- the personal values and principled leadership of people in authority

Although people with disability, families and allies have demonstrated best practice, government leadership and policy will ultimately decide on the speed and extent to which adoption of best practice occurs.

3. **People with disability, their families and allies will build their capacity over time**

People with disability, with their families and allies, now have authority to varying degrees over their funding through the NDIS. We have seen many people build their capacity over time to use this authority well.

We are also aware that there are many people with disability and their families who have not had capacity-building investments, are socially isolated, and/or have come to accept a less than optimal life after years of struggle and disempowerment.

Given what we know and have experienced, capacity-building in people with disability, their families and allies deserves on-going investment.

Three recommendations

If governments want rapid, profound, and lasting best practice in home and community living for people with disability they must:

1. **Work towards the objects and principles of the conventions and legislation that support social inclusion and define best practice**
2. **Invest in innovation and the capacities of people with disability, their families, and allies over a long period of time**
3. **work strategically and respectfully with ‘on the ground’ leaders as agents of this change.**

We now offer twenty-three stories of people with a wide range of disability and life experiences. They illustrate best practice in home and community living and have been sustainable for more than five years.

Individual stories

The twenty-three people with disability, listed below, have generously shared their story in short films, and these are currently available via a website link. We have also provided a short summary.

The stories are a snapshot in each person's life, which is likely to have changed to some degree, just as everyone's life changes and evolves over time. What was filmed may not be an accurate picture of the person's life now.

What is important is the message behind the story. Together, the stories support our position that everyone, regardless of their level of disability, with the right supports, can have a home of their own, and belong in community life.

Everyone, regardless of their level of disability, can decide where, how and with whom they live.

The critical role of family and allies

Luke: leading the way

A short film about Luke (Courtesy: Community Resource Unit Ltd.) (https://www.youtube.com/watch?v=gYGQe30blr8)

Previous:
Luke lived with his family until he was in his early 20s. His parents realised that they needed to start then to assist Luke to build his own life and community as they would not always be around.

Current:
Luke does not speak and uses facilitated communication to communicate. He is a poet and assists at the local school once a fortnight in the poetry class.

Best practice in home and community living:
Luke rents a small public housing home. When Luke was settled, his parents relocated to be close to him. Luke receives support through a small personalised service, which allows Luke to employ, train and direct the support-workers.

Cameron: home and belonging

A short film about Cameron (Courtesy: Belonging Matters)
https://www.youtube.com/watch?v=h9N_3x6YMec

Previous:
Living in a small rural, country town, Cameron felt isolated and unable to find work when he was living with his parents. He wanted to work and started making plans with his family to find a good neighbourhood to move to in a regional area.

Current:
Cameron has his own home and has previously lived with non-disabled housemates for company and to help home learn the skills of living in his own home. He has developed the

skills and confidence with managing his home and has lots of connections in the community. He has a part time job as a Receptionist. The family acknowledged that much of the success of Cameron's home is the planning that happened beforehand.

Best practice in home and community living:
Cameron rents a simple, timber house in the private market in a regional, country town. The family chose the neighbourhood because it was in a good community, where Cameron felt safe and it was close to his new job.

Cameron has some formal support. The housemate assists him to learn daily household tasks and manage his bills in return for free rent. Cameron and his family had support from Belonging Matters to build his vision and plan for moving into his own home together with, self-directing his funding package and supports.

Dee: my place

A short film about Dee (Courtesy: Australian Human Rights Commission)
(http://www.humanrights.gov.au/twentystories/video-dees-place.html)

Previous:
Dee has mild cerebral palsy, intellectual disability, and mental health needs. Her family were advised to place her in an institution as a baby. Instead, they raised her to want a life like her brothers.

Dee lived with her parents and attended a day program. When Dee decided to move out in 2003, she was told the only option was a group home. But Dee did not want to have to live with other people with disability, so she and her parents spent time considering alternatives.

Current:
Dee lives in her own flat. Each week she goes to her local gym several times and runs her own business in which she develops and sells artwork and greeting cards. Dee has a Circle of Support, enjoys community fun runs/walks, volunteers and is well-known and liked in her community.

Best practice in home and community living:
Dee lives in a privately rented property. Dee has a mix of paid support and informal support from her family and Circle of Support. She has previously lived with a non-disabled housemate, who provided skill development and company. She now chooses to live by herself and through her NDIS funding, chooses and directs her own support workers with the assistance of her family.

Joe: taking charge of Joe's future

A short film about Joe (Courtesy: Community Resource Unit Ltd.)
(https://www.youtube.com/watch?v=DLbqqsyhZow)

Previous:
Joe has always had a large, loving family, who live in a country town. After he left school, he went to a group home because the family thought this was the best solution for Joe at the

time. Over time this was found not to be the case. Joe's parents were concerned about who would look out for him when they were no longer able to.

Current:
Joe's parents asked his brothers and uncle if they wanted to be involved in helping Joe manage his life. They appreciated being asked and, after some discussion, created a company as a legal entity to support Joe. Joe has his ongoing connection with his family as well as his own independence. Joe has many activities in the community. He also has a small mowing business.

Best practice in home and community living:

Joe's family have bought the house across the road. The family renovated it and Joe is now living there. Joe uses computers with assistance to communicate with his extended family.

Joe has a mix of formal support, which the family direct, and informal support from his extended family. Joe has a small stable team of workers from the local community who have become close to him.

Julia: this is my home

A short film about Julia (Courtesy: Community Resource Unit Inc.) (https://www.youtube.com/watch?v=5n_CDX682mI&index=8&list=PLqk23A8wz4yZ7_2BUM42LlJpoWdatCVFC)

Previous:
In her mid-twenties Julia moved out into a group home but she was not happy or well. Julia found out that her residence was closing and said she wanted to live in the city near her sister, so the family decided to relocate. They worked with friends and a service provider to plan how Julia could have a home of her own.

Current:
Julia lives near her sister and enjoys her friends and freedom. She is taking more responsibility for managing her home and life and is less reliant on support.

Best practice in home and community living:
Julia rents a public housing unit. She appoints and directs her own support workers, with the help of her family. She also has informal support from her parents and her sister, all of whom live nearby.

Jonathan: a trusted team of workers

A short film about Jonathan (Courtesy: Western Australia Individualised Service (WAiS) / AVIVO) (https://www.youtube.com/watch?v=C49VUKkVQOA)

Previous:
Jonathan, who has autism, lived at home with his family; however, they were worried about what would happen in the future when they were no longer around. They planned for him to move into his own home with a flatmate and a team of trusted support workers.

Current:
Jonathan's family have seen a significant transformation in Jonathan. He has matured emotionally and in his communication. He has developed life skills by hanging out with his peers and this has empowered him in making decisions. His family have hope for Jonathan's future because they see him feeling safe and secure in his new home. He now has people his own age that share time with him, not just do things for him.

Best practice in home and community living:
Jonathan's family acquired a house to be big enough to have a flatmate plus support workers. Some modifications were made for Jonathan to chill out and de-stress with some safety measures.

Jonathan shares his home with a flatmate who is chosen from his team of support workers. This flatmate provides companionship and overnight support most weekdays.

Matthew: anything is possible

A short film about Matthew (Courtesy: Belonging Matters) (https://www.youtube.com/watch?v=56a6s-gJyKs)

Previous:
Matthew has cerebral palsy and uses a motorised wheelchair. He comes from a supportive family. Despite significant disability, Matthew went to a mainstream school and tertiary college. He always had a strong vision for himself as an independent person. His family were surprised and concerned at his plan to move to a larger nearby town. However, they wanted him to achieve his goals, so they supported him to that end.

Current:
Originally, different options were considered, one of which was the idea of cluster housing with shared support. Matthew preferred the idea of a regular home in a regular street. He did not want to be defined by his disability. In the end they followed Matthew's wishes.

Best practice in home and community living:
Matthew and his family rented a small home that was suitable Assistive solutions have also been helpful.

Matthew has a mixture of paid support and some is provided by his family. Originally the family thought they would manage the support service. When they found a local service that was very flexible and responsive to Matthew needs, and that allowed him to choose and train his own workers, they happily chose to work through them.

From institution to community

June: never too late for a good life

A short film about June (Courtesy: Community Resource Unit Ltd) (https://www.youtube.com/watch?v=wjtIprd3DKI)

Previous:
June lived in an institution for about 40 years and then in a private hostel. There was a lot of abuse in the hostel system and June had lost contact with all her family. It took a long time for June to trust anyone but with the help of some advocates who remained faithful to her, she was able to find her family and to set up a home of her own.

Current:
An advocacy service set up a group of people to help her move into her own home. June now has her family and friends around her. She is now confident in her own home and directing her support workers. She has a lot of community activities.

Best practice in home and community living:
June has a public housing unit which is accessible for a wide range of people. June has a mix of formal and informal support. She uses a small service, which assists her to think through what she needs and how best to use her support. June, with her friends, appoints and directs the support-workers; the service manages the employment of the staff.

Greg: a supported independent life

A short film about Greg (Courtesy: Summer Foundation) (https://www.youtube.com/watch?v=TQ_qJWsDVoI&t=5s)

Previous:
Greg acquired a traumatic brain injury following an unprovoked assault when he was 18 years old. Prior to the assault, Greg was living with his father. After being discharged from hospital Greg lived with his mother for a period of 18 months. To move toward more independence, Greg moved into a nursing home. Greg recalls knowing immediately this decision was a mistake. During the four years Greg spent living in a nursing home, his independence and recovery deteriorated.

Current:
Greg eventually moved into public housing. Greg lives alone in this home with 24-hour on-call support. While the home is not in the location Greg would choose, he rates highly his ability to live a supported independent life. Greg now focuses on his rehabilitation and is an active volunteer in his community.

Best practice in home and community living:
Greg's public housing is an older dwelling that has been modified to suit Greg's individual needs. Greg uses an electric wheelchair for mobility but remains strongly focused on his goal of walking again. Greg receives 24-hour support in his home.

Paul: home is best

A short film about Paul (Courtesy: Summer Foundation) (https://www.youtube.com/watch?v=pOwk74RprdY&list=PLElxlnPqnmznEs4TxzEQuo4fGkbBH6gjk&index=7)

Previous:
Just before Paul turned 18, he acquired a severe brain injury. Paul's family were advised the only place Paul would receive the level of support he required would be in a nursing home.

Paul's family refused to send Paul to a nursing home. With minimal preparation they brought Paul home and commenced providing the 24-hour support he required.

Current:
Paul still lives with his parents and continues to make progress through rehabilitation. Paul still requires 24-hour support.

Best practice in home and community living:
Paul's family built a new home, designed with Paul's support needs in mind. Paul uses an electric wheelchair for mobility and a room in the home has been dedicated to Paul's equipment and rehabilitation. Paul is supported by workers in his family home, and the shortfall in funded support hours is made up by Paul's family.

Amidu: reconnecting with children

A short film about Amidu (courtesy: Summer Foundation) (https://www.youtube.com/watch?v=bBGDCOrMk54&list=PLElxlnPqnmznEs4TxzEQuo4fGkbBH6gjk&index=8)

Previous:
Amidu migrated from Ghana with his young family. In his early 40's Amidu experienced a stroke, resulting in an acquired brain injury. Amidu lived in the nursing home for five years, where he was generally referred to by his room number, rather than his name. His young children found it difficult visiting him in this environment. Amidu spent most of his time going out, simply to avoid the nursing home.

Current:
Amidu finally secured an apartment where he now lives on his own. Living independently was an important goal for Amidu, not only for himself, but so he could provide an environment where his children felt comfortable visiting and spending time with him.

Best practice in home and community living:
Amidu's apartment is accessible for his manual wheelchair. Amidu relies on a motorised wheelchair when he is out and uses a computer for correspondence and to augment his communication when necessary.

Amidu is supported in the mornings and evenings and can access off-site 24-hour support in the event of unplanned support needs. Amidu's preference is to minimise his reliance on paid support and do as much as he can for himself.

Tania: family means all

A short film about Tania (Courtesy: Summer Foundation)
(https://www.youtube.com/watch?v=53L7OoNI048)

Previous:
Tania experienced a series of strokes that left her requiring a high level of support. Tania's husband was committed to bringing her home, but in the absence of funding for support, living at home with her family was not sustainable. There was no choice for Tania other than a nursing home. Tania moved between nursing homes for a period of two years.

Current:
Tania had one goal and that was to return home to live with her family. Tania received an electric wheelchair and her husband rented a home for them to live together as a family. The solution was not perfect, with Tania being placed in the dining room so she could stay connected to her family. Tania rarely moved around the house in her wheelchair for fear of damaging the property, eviction would mean a return to the nursing home.

Best practice in home and community living:
Despite the limitations of the rental home, support from the NDIS enabled the purchase of a motorised wheelchair, some equipment and home support for personal care. This funding provided the necessary support to enable Tania to continue living at home with her family.

When design makes the difference

Kate: a creatively customised home

A short film about Kate (Courtesy: Opening Homes by the Julia Farr Housing Association)
(https://vimeo.com/168865716/72daa56292)

Previous:
Kate, who has a significant physical disability, moved out of her parents' home to live alone. She found a house in a community with lots of people, parks, and cafes nearby, but the design was not suited to her current and future needs.

Current:
Her house has been modified because Kate has moved from a manual to power wheelchair and now uses a ceiling hoist. The kitchen is designed so that she can cook and entertain. The home is big enough for Kate to have housemates. Kate has regular visits from her family who help her solve day-to-day problems. Although the family was not sure of Kate's capacity to live on her own, she has successfully maintained her own life for the last fifteen years.

Best practice in home and community living:
Kate was able to purchase a home and to modify it to her needs. Kate relies on assistive technology to answer the door and let people in, to open and close the curtains and turn on the lights, to get in and out of bed and to bathe herself. Kate uses a motorised chair to get about in the house and community.

Lisa: supporting a good life

A short film about Lisa and her son. (Courtesy: Community Resource Unit Ltd.) (https://www.youtube.com/watch?v=LgwAQaiWPPI)

Current:
Lisa uses a wheelchair and assistive technology for communication. Lisa has a busy life looking after her son, attending university, and managing her support. Lisa enjoys these roles and has immersed herself in the community. She has a good informal support network that can assist her if she needs some help. Lisa loves family time with her son. With friends, a great home and the right amount of support she considers she has a good life.

Best practice in home and community living:
Lisa lives with her son in a purpose-built public housing family home. Lisa relies on a motorised wheelchair, assistive technology to speak, and her computer to manage her service.

Lisa has formal support to assist her in her role as mother and homemaker. She has also developed an informal network of support in her community. Lisa is careful not to have the formal support replace her friendships and the important mutual support they provide.

Tony: making style functional in my inner-city abode

A short film about Tony (Courtesy: Opening Homes by the Julia Farr Housing Association) (https://vimeo.com/177663208/20232776b5)

Previous:
Tony was born with vision impairment and became blind in mid-life.

Current:
He and his wife enjoy many good things of life together, cooking, music, art, and dancing. He lives with his wife in a modern apartment. He has chosen and set out his furniture to make his home attractive, useable, and safe for him to move about and be as independent as possible.

Best practice in home and community living:
Tony has a simple well-designed apartment that accommodates his extensive assistive technology and allows for him to move easily around. Tony has set up his home with assistive technology so that he can do most things for himself, including choose his own music, enjoy reading and organise his own clothes and personal care.

Bree: the sanctity of home

A short film about Bree (Courtesy: Summer Foundation) (https://www.youtube.com/watch?v=Z5jL0E-JLHM)

Previous:
At the age of 19, after a period of prolonged hospitalisation Bree made the decision to move out of her family home and live independently. The only accommodation option available to Bree when she was discharged from hospital was a bed in respite accommodation. Bree occupied this bed during the weekdays, then vacated it and moved to a different respite home for the weekends.

Current:
Bree moved into an accessible supported apartment where she has fully embraced, living independently. Bree has done some volunteering in her local community and has enthusiastically taken on all the responsibilities associated with living independently. Bree enjoys the freedom to make her own choices, even the simple ones, like what she will eat and when.

Best practice in home and community living:
Bree's apartment is an accessible apartment, accommodating both her manual and electric wheelchair. The apartment features smart home technology designed to minimise the need for reliance on paid support, such as tablet/smart phone-controlled doors, blinds, lights, and temperature.

Bree functions with a high level of independence but is supported by a combination of planned and 'on-call' 24-hour support which is co-located in the same apartment complex.

Kirby: the importance of a vision and plan

A short film about Kirby (Courtesy:Summer Foundation)
(https://www.youtube.com/watch?v=eVE_N2QcORg)

Previous:
At 28 years old, Kirby had a career as a teacher. She had also purchased her first home. In 2014, Kirby was diagnosed with a brain tumour and was operated on within 24 hours. While the surgery went well, Kirby suffered a series of strokes shortly after the operation, resulting in an acquired brain injury.

The only place where Kirby could receive ongoing rehabilitation was a nursing home which was co-located with a rehabilitation facility. Kirby spent twelve months living in the nursing home and focusing on her rehabilitation.

Current:
Kirby moved out of the nursing home into her parents' home. Since this move, Kirby's physical recovery has progressed significantly. Aside from ongoing physical recovery, Kirby's goals include moving out of her parents' home and living independently. Kirby also has her sights set on returning to work.

Best practice in home and community living:
Kirby's family home had to be modified, including widening of doors and changes to the bathroom. Kirby currently uses a motorised wheelchair and takes advantage of assistive technology to support her communication. Kirby uses paid support, which is currently augmented by informal support from her parents.

Trudy: my forever home

A short film about Trudy (Courtesy: Opening Homes by the Julia Farr Housing Association)
https://vimeo.com/164210647/dd4cc97cc9

Previous:
Trudy did not realise how good design and a home of her own would enhance her life. Trudy came from a family of gardeners, so she wanted a garden, a home for her dogs and a place to entertain friends.

Current:
Trudy moved into a purpose-built house that is accessible for her friends using wheelchairs, and for her dogs.

Best practice in home and community living:
Trudy's house has spacious rooms and specially designed fit-out to cater for her large motorised wheelchair. She has several friends who also use wheelchairs and she can invite them to visit because it caters so well to every need. Trudy describes her home: "*This is my forever house! I am never leaving this place.*"

Life my way

Stephen: living blind and free in the country

A short film about Stephen (Courtesy: Opening Homes by the Julia Farr Housing Association)
(https://vimeo.com/173573295/2ffb6915d7)

Previous:
Stephen has always lived in the country and continued to do so after losing his vision and ability to walk because of multiple sclerosis. This was where he raised his family.

Current:
Stephen considers remaining in his own home important to his identity and is determined to stay there for as long as possible. He hopes his home will contribute to his role as a father and perhaps one day as a grandfather.

Best practice in home and community living:
The house has been modified so that he can prepare simple meals and move about the house both inside and outside. He uses computers to communicate and to manage his daily business.

Thao: the Vietnamese way

A short film about Thao and Trevor (Courtesy: AMPARO Advocacy)
https://www.youtube.com/watch?v=HD8Uoh81OJY

Previous:
Thao is the mother of Trevor, who has autism. She has a strong vision of a good life for Trevor within her Vietnamese family and culture. When Trevor was younger, Thao found it difficult to ask for help, because this was not the Vietnamese way.

Current:
Trevor continues to live with his family and Thao has started planning for his own future, what sort of work he can do and where he will live, and the support he will need to enable this. Trevor is interested in IT, so he is likely to optimise his use of assistive technology for his education, to communicate and to develop his interests as an adult.

Best practice in home and community living:
Now that Thao understands the value of support, she assists other Vietnamese families to understand too. She hopes that funding from the NDIS will assist her to keep her family together, as well as support Trevor to be more independent. An important part of Thao's and Trevor's support will be access to an interpreter so that she can communicate their plans for Trevor.

Willie: the yarning circle

A short film about Willie (Courtesy: Queenslanders with Disability Network)
https://www.youtube.com/watch?v=QCdsNetxkno

Previous:
Willie is an indigenous man with cerebral palsy, who uses a wheelchair

Willie spent much of his youth living in an institution. He could not go outside the gates and had little control over everyday decisions. He worked in a sheltered workshop and sold newspapers on the street.

Current:
He has lived in his current home for more than 10 years and is well-known in his community. He worked at the state library for 30 years, resourcing members and the public about aboriginal history.

Best practice in home and community living:
Willy lives in a public housing unit that has been designed to be wheelchair accessible. Willie uses a motorised wheelchair and relies on accessible public transport to get to work.

Scott and Daniel: living together works well

A short film about Scott and Daniel (Courtesy: Uniting Care Community)
https://www.youtube.com/watch?v=bPLmZf10x7s

Previous:
Scott and Daniel are brothers who have Duchenne Muscular Dystrophy. Scott and Daniel moved out of the family home in 2007 to a state–run group home.

They quickly found they were incompatible with the other residents, who had very different needs. Their needs were not being met and they had no choice in who supported them. Their health, community connections and trust in the service deteriorated.

Current:
The public housing authority offered them two options: two adjacent apartments or a 2-bed house. They chose the house, preferring to live together. With a well-designed house and

the capacity to direct their own service, their life has improved significantly, and they are now looking forward to their future.

Best practice in home and community living:
The house was designed to be fully wheelchair accessible, so they were able to move in with little delay. Both Scott and Daniel use Sip Ventilators during the day so they can breathe properly. They use personal computers to organise their daily affairs, including directing their own service.

Scott and Daniel have individual funding packages and direct their own support. They use a large service which specialises in a personal and collaborative approach to support and encourages people to make their own decisions about the life they want to live and to follow their dreams. Scott and Daniel share some support and use other support individually to follow their separate interests.

Warren: life with a flatmate

A short film about Warren (Courtesy: Belonging Matters)
https://www.youtube.com/watch?v=u4kaIGxjiVA

Previous:
In his late twenties, Warren moved from living with his parents into a group home where he lived for three years. His mother noticed by his actions and anxiety that he was not happy. In 2006, Belonging Matters encouraged her to imagine something better for Warren; a life where he had a home of his own and choice as to who lived with him.

The first step for Warren's mother was to believe it was possible. Warren's transition to live in his own home commenced by moving from the group home to the flat on the lower level of the family home with the support of a housemate.

Current:
Warren has lived in his own home for since 2015 with a housemate who provides support where needed in exchange for only a small rent contribution. Warren also has a keyworker who coordinates a team of support workers.

Best practice in home and community living:
Warren lives in a regular home in the community and is supported by a mix of formal (paid) and informal (housemate, family, friends) support. The family, who originally directed the paid support, has now delegated this to his Key Worker. Warren continues to articulate his choices and direct his life, as much as possible.

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