SUNSHINE COAST

CITIZEN ADVOCACY

December 2019

...... Something to Ponder

Australia has become a place where entertainers and professional athletes are mistaken for people of importance..

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I've Needed a Doctor..

I've Needed a Teacher..

I NEED farmers every day..

I have NEEDED an auto mechanic, a plumber, a house painter and a lot of other everyday people.

But I have NEVER, not even once, NEEDED a pro athlete, a media personality, or a Hollywood entertainer for ANYTHING!

Inside this edition

At least the barbed wire has gone now

Bob Lee

Many years ago I was visiting a friend in the small room (more of a cubicle really) he occupied in a nursing home. It was quite a momentous day. It was the last day he was to spend in the institution he had endured for much of his life. We were quietly talking about all the things he would soon be able to do which were not now possible. Not very radical really, not even irresponsible! Just some of the things you can do in your own home. Things like… sleeping in on the weekend, staying up late at night, eating between meals, having a friend over for coffee or a meal, having a garden, and maybe even having a pet cat!

Just as we were getting a little more ambitious with the expectations, some new faces appeared at the door. It was a group of concerned looking people arriving to say farewell.....well not really. We all knew that it was a last ditch effort to talk him out of moving. The leader of the group shuffled in as I shuffled out to make room. She loudly exclaimed about the "lovely" room and said the fatal words.... "I don't know why you want to leave here. I'd be happy to live in a room like this!"

I will never forget the next few moments. He was always so quick to spell out his words on his communication board. This time however he took his time, taking great care to ensure that his response was clearly understood. "GOOD.....YOU CAN HAVE IT....I'M MOVING OUT TOMORROW!

During the rather strained silence which followed this exchange, I reflected yet again on the tension which always seems to exist between two quite legitimate concerns involving people with disability. On one hand there are those whose primary concern is for the safety and security of vulnerable people, and on the other there are those who struggle to assert their legitimate rights to have a regular life as part of their community. Why is it that these things are thought to be incompatible?

There is no mystery about how most Australians like to live. We are surrounded by the evidence. We like to live in houses, or in apartments. Some of us like to live with our families, or with friends, and some of us like to live alone. Some of us like to live in very isolated places, but only a very few. Most of us like to be close to other people as long as we have a little privacy, independence and autonomy. Sometimes we dream of having a farm, a mountain retreat, a penthouse, a beach house, or a houseboat. I've never heard of anyone dreaming of having a bed in an institutional dormitory.

In fact despite the commonly stated belief that institutions offer safety, security and efficiency, they are unlikely to ever be accepted as a mainstream accommodation option. Most of us wilfully refuse to move into one until we are old and no longer capable of resisting the concerted efforts of well intentioned family and medical systems.

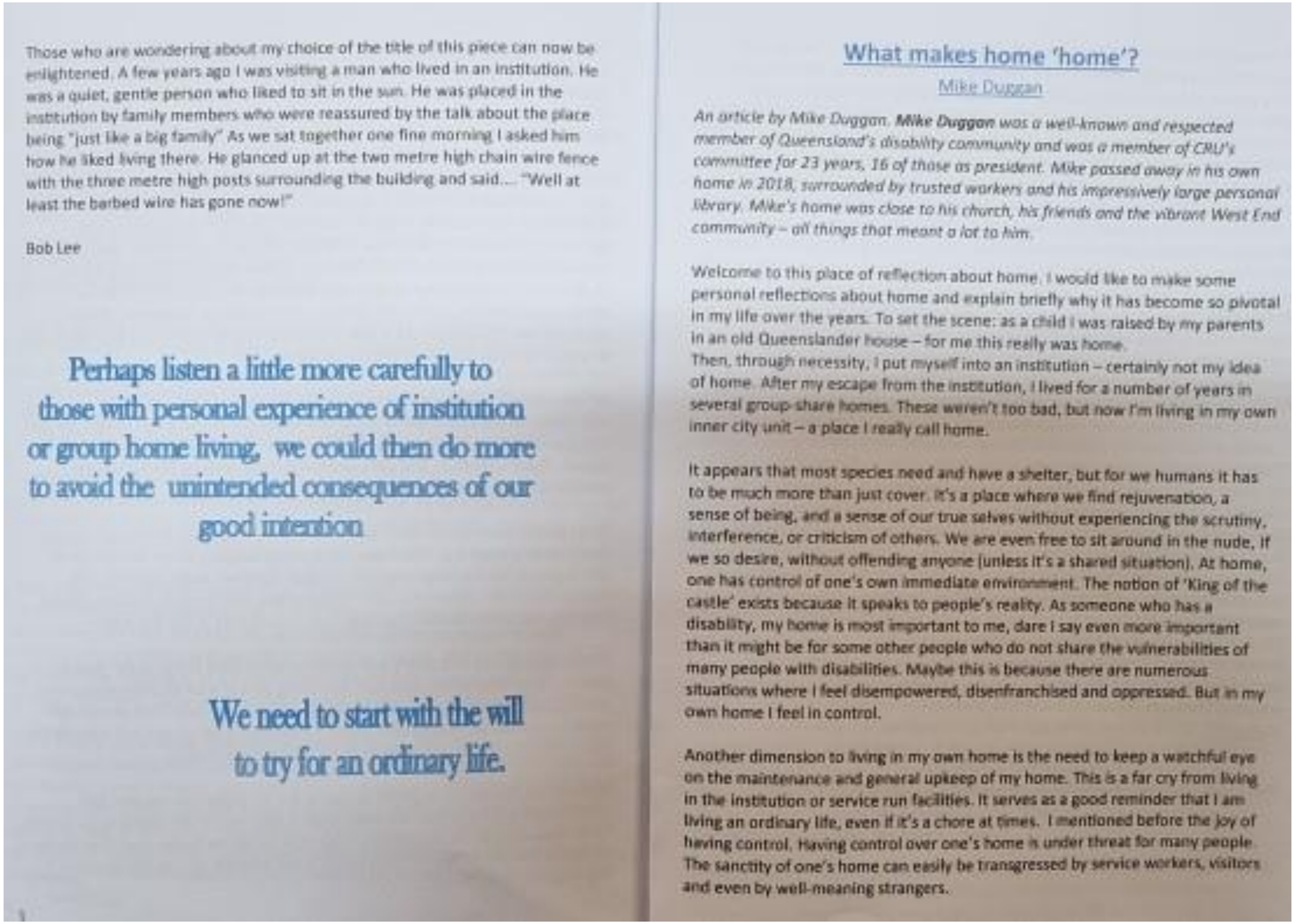
Why do we resist? Well it is probably because, whatever we would like to believe, we know deep down that safety, security and efficiency is not provided by buildings. We know we might be trading off our cherished privacy and autonomy for promises which can't be kept. Those of us who take notice of the reports of abuse and neglect which occurs all too regularly in nursing homes, hostels and institutions for people with disability, know that these can be dangerous places for vulnerable people. *I once visited a "homeless" shelter where people paid the fee for a bed so they could have access to a bathroom, but preferred to sleep outside where it was safer.*

So what about those people with disability who have found a place for themselves in the community? Those places are just as we would expect. Houses and apartments, shared and single, owned and rented. Life is also as we would expect. There's pleasure and pain, excitement and tedium, friendship and loneliness, gains and losses....in other words, a regular life.

Some people have found they need a little more support than they get. Others find that they need less. Often surprising things happen. When two people go out together, have a meal together, a cuppa together, laugh together, the barriers between worker and client dissolve and they become just two people enjoying life. Other barriers just don't get constructed in the first place

People have found that safety and security comes from knowing the neighbours, having friends and family who visit, and being part of a community whose eyes are watching what happens. A community which has a belief that people with disability should be treated with respect and given a fair go, will not tolerate the abuse, neglect and exploitation of those who are vulnerable.

Nothing has moved me so much as seeing the unrestrained weeping and inconsolable grief of a man who asks what it was that he did wrong to be moved to an institution six hundred miles away from his family home where he has lived as part of a loving family for forty years. What possible answer could soften the rejection this man feels?



Those who are wondering about my choice of the title of this piece can now be enlightened. A few years ago I was visiting a man who lived in an institution. He was a quiet, gentle person who liked to sit in the sun. He was placed in the institution by family members who were reassured by the talk about the place being "just like a big family" As we sat together one fine morning I asked him how he liked living there. He glanced up at the two metre high chain wire fence with the three metre high posts surrounding the building and said…. "Well at least the barbed wire has gone now!"

Bob Lee

Perhaps listen a little more carefully to those with personal experience of institution or group home living, we could then do more to avoid the unintended consequences of our good intention

We need to start with the will to try for an ordinary life.

What makes home 'home'?

Mike Duggan

An article by Mike Duggan. ***Mike Duggan*** *was a well-known and respected member of Queensland's disability community and was a member of CRU's committee for 23 years, 16 of those as president. Mike passed away in his own home in 2018, surrounded by trusted workers and his impressively large personal library. Mike's home was close to his church, his friends and the vibrant West End community – all things that meant a lot to him.*

Welcome to this place of reflection about home. I would like to make some personal reflections about home and explain briefly why it has become so pivotal in my life over the years. To set the scene: as a child I was raised by my parents in an old Queenslander house – for me this really was home.
Then, through necessity, I put myself into an institution – certainly not my idea of home. After my escape from the institution, I lived for a number of years in several group-share homes. These weren't too bad, but now I'm living in my own inner city unit – a place I really call home.

It appears that most species need and have a shelter, but for we humans it has to be much more than just cover. It's a place where we find rejuvenation, a sense of being, and a sense of our true selves without experiencing the scrutiny, interference, or criticism of others. We are even free to sit around in the nude, if we so desire, without offending anyone (unless it's a shared situation). At home, one has control of one's own immediate environment. The notion of 'King of the castle' exists because it speaks to people's reality. As someone who has a disability, my home is most important to me, dare I say even more important than it might be for some other people who do not share the vulnerabilities of many people with disabilities. Maybe this is because there are numerous situations where I feel disempowered, disenfranchised and oppressed. But in my own home I feel in control.

Another dimension to living in my own home is the need to keep a watchful eye on the maintenance and general upkeep of my home. This is a far cry from living in the institution or service run facilities. It serves as a good reminder that I am living an ordinary life, even if it's a chore at times. I mentioned before the joy of having control. Having control over one's home is under threat for many people. The sanctity of one's home can easily be transgressed by service workers, visitors and even by well-meaning strangers.

A simple example occurs when a worker has a key to the person's home, and uses that key to enter, without even knocking. For some people, there may be very good practical reasons for this. Nevertheless, there is an impact on the spirit of home. People experience a change of feeling as suddenly the person's home becomes a 'facility'. It is also too easy these days for one's home to become a place where Work-based health and Safety take prominence. Although I definitely wouldn't swap my situation for the world, to say things are easy all of the time would be an overstatement. Firstly, it's difficult to 'fly solo'. One of the challenges for people living alone is of course the potential for loneliness. Please do not misunderstand me. I don't mean that all people with disabilities should live together. I am simply observing that periodic loneliness is a by-product of living alone and that one needs to find ways to have people in one's life. There is also a practical problem. One has to ask for help as there's nobody there to give incidental assistance, and this takes courage. It means putting oneself regularly in the role of dependant and this is not an easy position to be in. So, what can one do for company? I refer to unpaid company, freely given relationships, not paid workers. This is an ongoing challenge for not only the individual, but also for the people who support that individual.

There are broad implications that flow from these brief observations. We must get much smarter and more diligent at providing people with disabilities with the most appropriate supports so that we can live meaningful lives in the community. We must gain a better understanding about what it takes to live in the community. The service and its workers may not appreciate that what they are doing is supporting someone to have their own home. This can deteriorate to a situation of passive 'community minding'; that is, minding someone in their own four walls.

We need to understand that the role of the worker is in the context of helping people to make their home comfortable, meaningful and authentic for that person. Home is part of the person's identity, and the person's identity is expressed through home.

Peace!!

Mike Duggan ***'From the President' article from*** ***CRUcial Times 40 (2008)***

Because it's better (excerpts)

Anita O'Brien

Anita O'Brien *is the Melbourne-based mother of two adult sons. Anita and her husband are committed advocates for her son Warren ,and Anita has served on the boards of numerous organisations. She has been a strong advocate, supporter, presenter and writer for many years. This article is a collection of excerpts from her 2016 book 'Because it's better... to live my life within community'. These excerpts chronicle the changes in thinking that led her to move Warren from a group situation with other people with disability in to a home of his own. Anita also shares the ideas, frameworks and strategies that helped Warren embrace a life embedded in community with a job, friends and opportunities to craft a life of his own.*

In June 2002, we became aware of an 'accommodation' option for our son Warren with other young people with a disability in a home established by a group of parents in 1982. I was excited about the possibility for Warren as I had been working towards a similar initiative for some time.

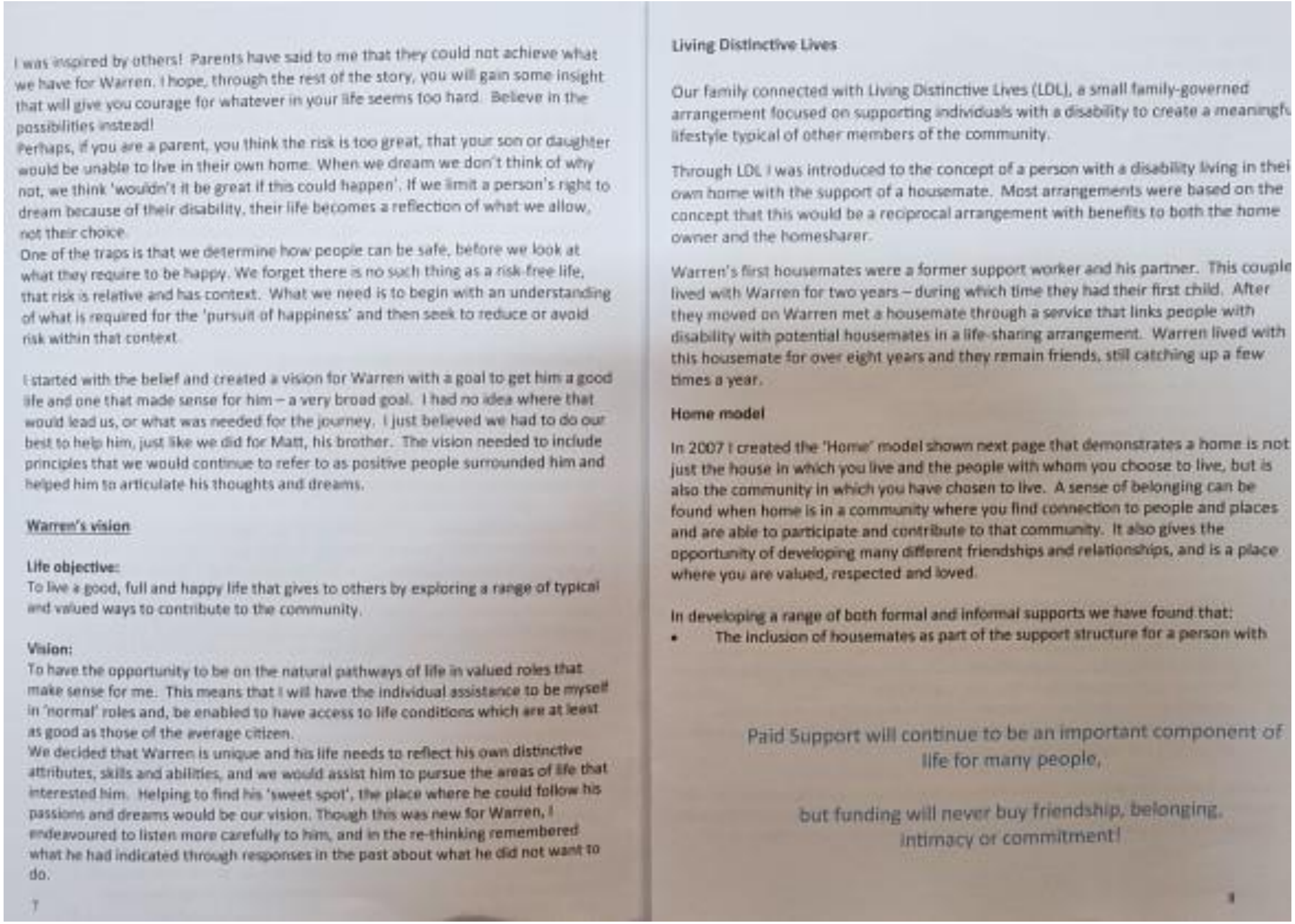
On contacting them I discovered the parents' motivation for creating this place was due to their concern about the lack of community-based accommodation for their children, a universal worry.

The house had been set up by parents and was financially independent of government funds and control. Basically, we decided it was perhaps a first step and maybe the only opportunity for Warren to move to a 'home of his own'. It was certainly worth a try and to be honest, would give Allan and I some time to reconnect without some of the worries of Warren being unhappy and extremely anxious. We thought having day-to-day company would reduce his loneliness.

Moving out of our comfort zone

Warren was showing us by his behaviour and reactions that he was not happy living where he was. He was becoming more and more anxious to the point of vomiting and would not get out of the car when we arrived back after a day out. Allan and I had a conversation with Warren and asked him if he wanted to stay in his current 'home', return to live in the flat on the lower level of our home, or live in a unit of his own. He wanted to come home to his community and on asking him why he said "because it's better".

So I moved out of my comfort zone when I was 59 and Warren was 30 to embark on a journey with Warren towards discovery of who he was created to be. I looked at the lives of others who had achieved a good life for their child with a disability and decided it was possible.



I was inspired by others! Parents have said to me that they could not achieve what we have for Warren. I hope, through the rest of the story, you will gain some insight that will give you courage for whatever in your life seems too hard. Believe in the possibilities instead!

Perhaps, if you are a parent, you think the risk is too great, that your son or daughter would be unable to live in their own home. When we dream we don't think of why not, we think 'wouldn't it be great if this could happen'. If we limit a person's right to dream because of their disability, their life becomes a reflection of what we allow, not their choice.

One of the traps is that we determine how people can be safe, before we look at what they require to be happy. We forget there is no such thing as a risk-free life, that risk is relative and has context. What we need is to begin with an understanding of what is required for the 'pursuit of happiness' and then seek to reduce or avoid risk within that context.

I started with the belief and created a vision for Warren with a goal to get him a good life and one that made sense for him – a very broad goal. I had no idea where that would lead us, or what was needed for the journey. I just believed we had to do our best to help him, just like we did for Matt, his brother. The vision needed to include principles that we would continue to refer to as positive people surrounded him and helped him to articulate his thoughts and dreams.

Warren's vision

Life objective:

To live a good, full and happy life that gives to others by exploring a range of typical and valued ways to contribute to the community.

Vision:

To have the opportunity to be on the natural pathways of life in valued roles that make sense for me. This means that I will have the individual assistance to be myself in 'normal' roles and, be enabled to have access to life conditions which are at least as good as those of the average citizen.

We decided that Warren is unique and his life needs to reflect his own distinctive attributes, skills and abilities, and we would assist him to pursue the areas of life that interested him. Helping to find his 'sweet spot', the place where he could follow his passions and dreams would be our vision. Though this was new for Warren, I endeavoured to listen more carefully to him, and in the re-thinking remembered what he had indicated through responses in the past about what he did not want to do.

Living Distinctive Lives

Our family connected with Living Distinctive Lives (LDL), a small family-governed arrangement focused on supporting individuals with a disability to create a meaningfu lifestyle typical of other members of the community.

Through LDL I was introduced to the concept of a person with a disability living in thei own home with the support of a housemate. Most arrangements were based on the concept that this would be a reciprocal arrangement with benefits to both the home owner and the homesharer.

Warren's first housemates were a former support worker and his partner. This couple lived with Warren for two years – during which time they had their first child. After they moved on Warren met a housemate through a service that links people with disability with potential housemates in a life-sharing arrangement. Warren lived with this housemate for over eight years and they remain friends, still catching up a few times a year.

Home model

In 2007 I created the 'Home' model shown next page that demonstrates a home is not just the house in which you live and the people with whom you choose to live, but is also the community in which you have chosen to live. A sense of belonging can be found when home is in a community where you find connection to people and places and are able to participate and contribute to that community. It also gives the opportunity of developing many different friendships and relationships, and is a place where you are valued, respected and loved.

In developing a range of both formal and informal supports we have found that:

- The inclusion of housemates as part of the support structure for a person with

Paid Support will continue to be an important component of
life for many people,

but funding will never buy friendship, belonging,
intimacy or commitment!

support needs is most beneficial and renders the budgeting of available funding affordable.

- The natural support of housemates can be targeted at the times and in the way that is required.
- The arrangement provides opportunities for the development of natural relationships and friendships.
- Housemates can be a pivotal link to the other supporters (both natural and paid), and they can provide invaluable insight when participating in the Circle of Support that is a crucial element in the support plan.
- Whilst it may not be for everyone, this is one of the most valuable ways to support an individual with a disability in their own home, so they can live a life that is typical of others in the community.

Looking from a very personal perspective, the success in recruiting housemates for Warren has involved prayerful belief in the possibility, and trust, especially through difficult and often painful adjusting to relationship building, and when 'life happens'.

The housemate model has not, and will not always be smooth sailing, and there will be changes, as we have all experienced. But this is just mirroring life for everyone.

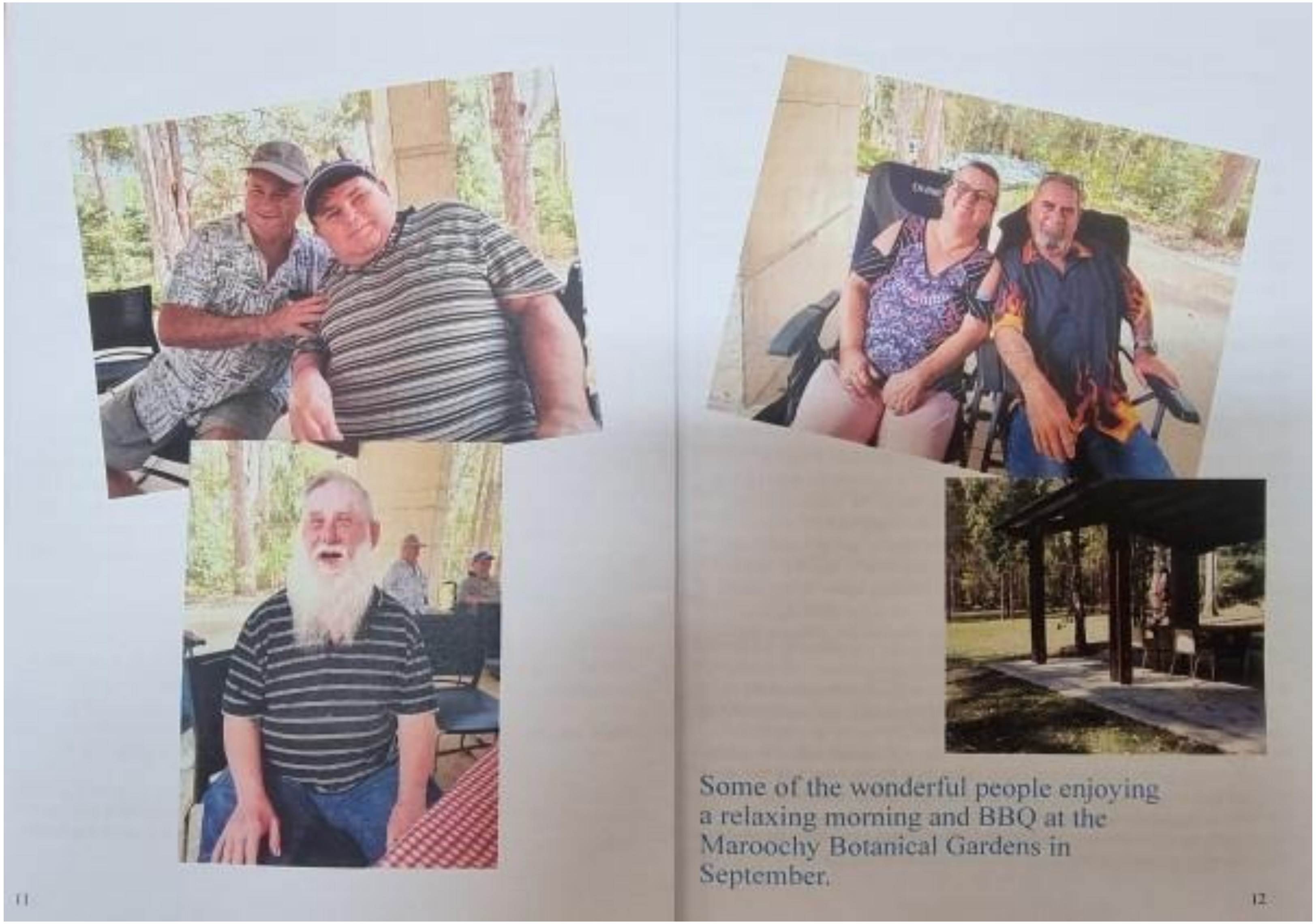
Living Distinct Lives (LDL) learnings on housemates

Over the years, LDL families have been inviting housemates to become an integral part of making this vision come alive for them.

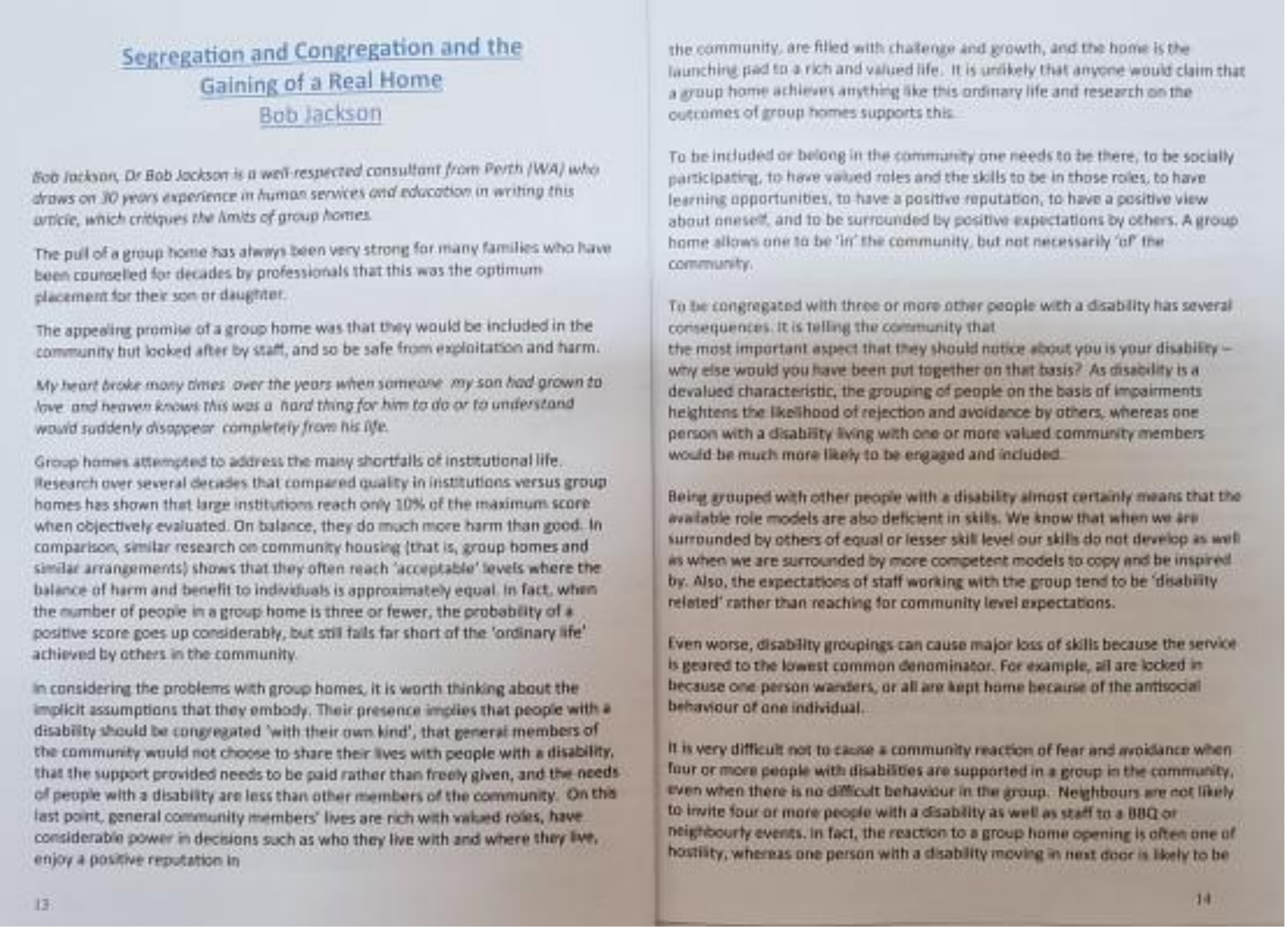
- By sharing a home, housemates are given an opportunity to come to know someone with a disability in a real way. They learn about their trials and triumphs, their hopes and dreams, what struggles they may have and what successes they achieve each day.
- They get to know someone for who they are, and not for whom they assume them to be.
- This is the same for the person with disability. As they share with a housemate, they come to realise who they are and what it's like to live in their own place, with all the responsibilities this entails.
- They relate with a housemate in everyday, normal ways.
- They are no longer just in relationships with their parents or paid staff.
- They get the opportunity to step out of a preconceived or long-existing role and discover what it is to be 'them', in their own place, sharing with another.
- All the regular housemate things occur: sharing, arguing, discovering about each other, working out rules and who does what chores, etc. Added to that is a unique and rich experience of interdependency, acknowledging the importance of belonging, friendship and genuine care, discovering and acknowledging strengths and weaknesses, and of working together to make a home that works for all.

This has not necessarily been an easy road for many, but it is one that LDL families continue to choose as they value real relationships, of giving and sharing and of regular community life. This outweighs the time, energy and effort it can take to make these arrangements a success.

Anita Obrien 2016 book 'Because it's better...



Some of the wonderful people enjoying a relaxing morning and BBQ at the Maroochy Botanical Gardens in September.



Segregation and Congregation and the Gaining of a Real Home

Bob Jackson

Bob Jackson, Dr Bob Jackson is a well-respected consultant from Perth (WA) who draws on 30 years experience in human services and education in writing this article, which critiques the limits of group homes.

The pull of a group home has always been very strong for many families who have been counselled for decades by professionals that this was the optimum placement for their son or daughter.

The appealing promise of a group home was that they would be included in the community but looked after by staff, and so be safe from exploitation and harm.

My heart broke many times over the years when someone my son had grown to love and heaven knows this was a hard thing for him to do or to understand would suddenly disappear completely from his life.

Group homes attempted to address the many shortfalls of institutional life. Research over several decades that compared quality in institutions versus group homes has shown that large institutions reach only 10% of the maximum score when objectively evaluated. On balance, they do much more harm than good. In comparison, similar research on community housing (that is, group homes and similar arrangements) shows that they often reach 'acceptable' levels where the balance of harm and benefit to individuals is approximately equal. In fact, when the number of people in a group home is three or fewer, the probability of a positive score goes up considerably, but still falls far short of the 'ordinary life' achieved by others in the community.

In considering the problems with group homes, it is worth thinking about the implicit assumptions that they embody. Their presence implies that people with a disability should be congregated 'with their own kind', that general members of the community would not choose to share their lives with people with a disability, that the support provided needs to be paid rather than freely given, and the needs of people with a disability are less than other members of the community. On this last point, general community members' lives are rich with valued roles, have considerable power in decisions such as who they live with and where they live, enjoy a positive reputation in

the community, are filled with challenge and growth, and the home is the launching pad to a rich and valued life. It is unlikely that anyone would claim that a group home achieves anything like this ordinary life and research on the outcomes of group homes supports this.

To be included or belong in the community one needs to be there, to be socially participating, to have valued roles and the skills to be in those roles, to have learning opportunities, to have a positive reputation, to have a positive view about oneself, and to be surrounded by positive expectations by others. A group home allows one to be 'in' the community, but not necessarily 'of' the community.

To be congregated with three or more other people with a disability has several consequences. It is telling the community that the most important aspect that they should notice about you is your disability – why else would you have been put together on that basis? As disability is a devalued characteristic, the grouping of people on the basis of impairments heightens the likelihood of rejection and avoidance by others, whereas one person with a disability living with one or more valued community members would be much more likely to be engaged and included.

Being grouped with other people with a disability almost certainly means that the available role models are also deficient in skills. We know that when we are surrounded by others of equal or lesser skill level our skills do not develop as well as when we are surrounded by more competent models to copy and be inspired by. Also, the expectations of staff working with the group tend to be 'disability related' rather than reaching for community level expectations.

Even worse, disability groupings can cause major loss of skills because the service is geared to the lowest common denominator. For example, all are locked in because one person wanders, or all are kept home because of the antisocial behaviour of one individual.

It is very difficult not to cause a community reaction of fear and avoidance when four or more people with disabilities are supported in a group in the community, even when there is no difficult behaviour in the group. Neighbours are not likely to invite four or more people with a disability as well as staff to a BBQ or neighbourly events. In fact, the reaction to a group home opening is often one of hostility, whereas one person with a disability moving in next door is likely to be accepted and even welcomed.

Overall then, the group home continues the processes of the institution in many ways. The congregation of people by disability is highly likely to cause rejection as it causes focus on this devalued characteristic and so feeds the stereotypes that exist. It continues the problems of loss of control over major life decisions, vulnerability to unreasonable demands of staff, stereotyping around negative roles such as incompetent or childlike, low expectations, and lack of community belonging. If we think of the goal of an ordinary life – and surely that is not an unreasonable goal, then it is clear that the group home model will have great difficulty making this a reality.

We now have many examples of people who, in their own homes, in work places and in other places in ordinary life, have made substantial gains in their development. They are surrounded by more competent role models and normative expectations that do not seem to occur in disability groupings.

All around the world we see people achieving an ordinary life in the community with natural support from ordinary members of the community. I cannot believe that we are incapable of achieving what others have managed. We need to start with the will to try for an ordinary life. Then with creativity and focus on what is ordinary and valued, we can start to build ordinary lives for people who will otherwise continue to exist in lonely and unstimulating environment.

We need to start with the will to try for an ordinary life.

Bob Jackson CRUcial Times 55 (2019)

A 'real' home is not solely one's dwelling place, but rather a key crucible in life that helps sustain and uphold much that is deeply personal, private, and intimate about us.

Social Role Valorisation

Roles are so powerful that they largely define who we are, what we do and who and with whom we act, and even what we wear (Wolfensberger 1992).

Society will attribute certain qualities to particular roles. If roles are generally perceived as positive then the attributes and qualities which help define these roles will be positive and how one is treated and perceived by society will be positive, reinforcing competencies and confidence. Conversely if a person is not in a valued role, then certain assumptions about their competencies and attributes will be made which are usually negative.

Our society perceives a disability to be a negative attribute and consequently people with disability are treated in a negative and devalued manner with little or no regard of their personal attributes, competencies and potential to develop.

In order to counteract this cycle, people's roles can be enhanced through: enhancement of their social image/appearance so that they are perceived in a positive manner; and enhancement of their competencies so that they can fill valued roles.

How can we increase people's image?

- Personal Appearance
- clothes that suit the individual
- clothes that are age appropriate
- haircuts which are flattering
- clothes bought at valued shops (not at second hand or charity shops)
- Language and Labels
- people should be referred to in age appropriate ways eg. "Mr and Mrs" for adults rather than "Timmy or Joey"
- people referred to as human beings (this will be more likely to result in people being treated as human beings.
- services which have positive names (like Northside Employment Service")

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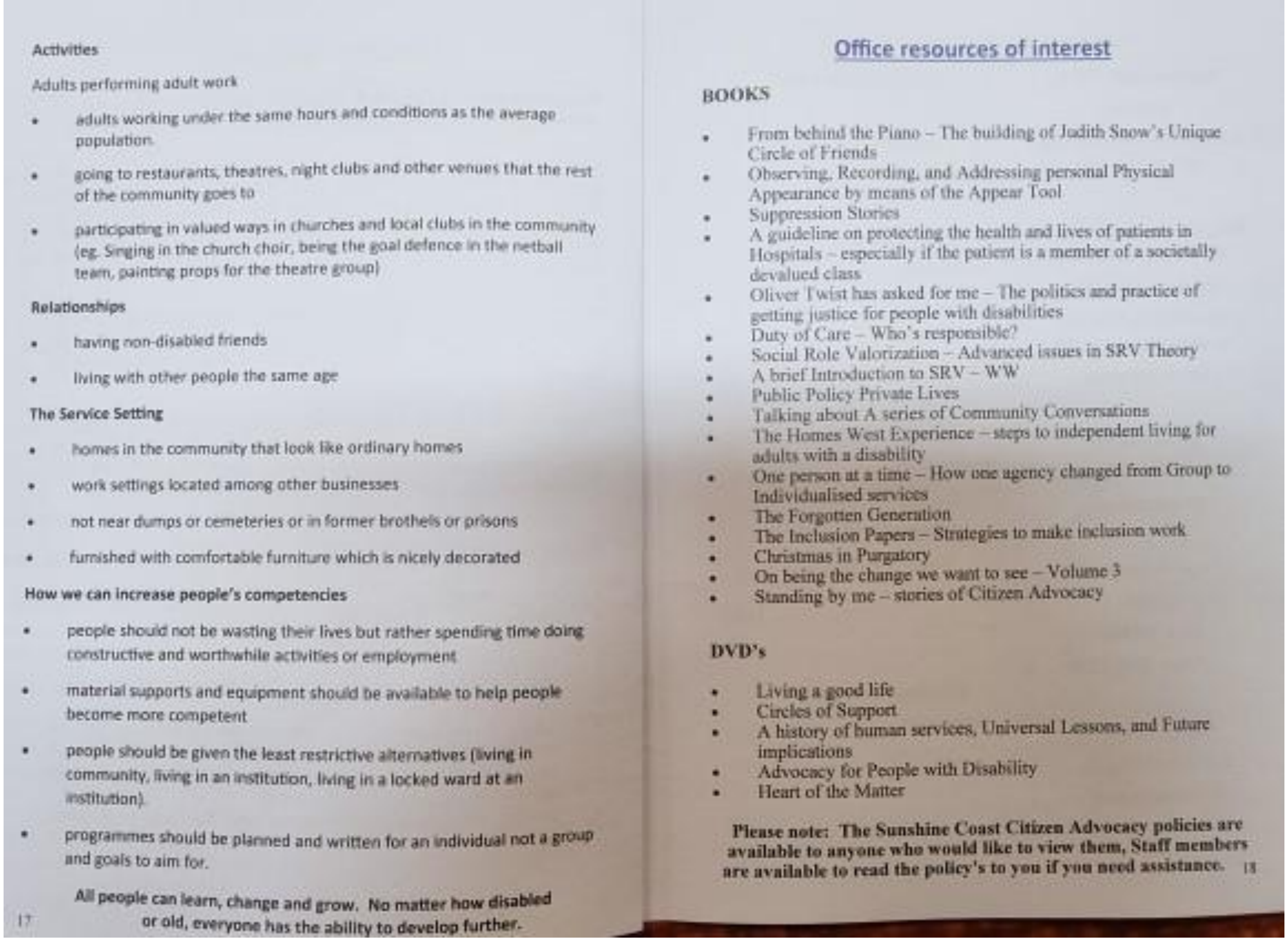

Activities

Adults performing adult work

- adults working under the same hours and conditions as the average population.
- going to restaurants, theatres, night clubs and other venues that the rest of the community goes to
- participating in valued ways in churches and local clubs in the community (eg. Singing in the church choir, being the goal defence in the netball team, painting props for the theatre group)

Relationships

- having non-disabled friends
- living with other people the same age

The Service Setting

- homes in the community that look like ordinary homes
- work settings located among other businesses
- not near dumps or cemeteries or in former brothels or prisons
- furnished with comfortable furniture which is nicely decorated

How we can increase people's competencies

- people should not be wasting their lives but rather spending time doing constructive and worthwhile activities or employment
- material supports and equipment should be available to help people become more competent
- people should be given the least restrictive alternatives (living in community, living in an institution, living in a locked ward at an institution).
- programmes should be planned and written for an individual not a group and goals to aim for.

All people can learn, change and grow. No matter how disabled or old, everyone has the ability to develop further.

Office resources of interest

BOOKS

- From behind the Piano – The building of Judith Snow's Unique Circle of Friends
- Observing, Recording, and Addressing personal Physical Appearance by means of the Appear Tool
- Suppression Stories
- A guideline on protecting the health and lives of patients in Hospitals – especially if the patient is a member of a societally devalued class
- Oliver Twist has asked for me – The politics and practice of getting justice for people with disabilities
- Duty of Care – Who's responsible?
- Social Role Valorization – Advanced issues in SRV Theory
- A brief Introduction to SRV – WW
- Public Policy Private Lives
- Talking about A series of Community Conversations
- The Homes West Experience – steps to independent living for adults with a disability
- One person at a time – How one agency changed from Group to Individualised services
- The Forgotten Generation
- The Inclusion Papers – Strategies to make inclusion work
- Christmas in Purgatory
- On being the change we want to see – Volume 3
- Standing by me – stories of Citizen Advocacy

DVD's

- Living a good life
- Circles of Support
- A history of human services, Universal Lessons, and Future implications
- Advocacy for People with Disability
- Heart of the Matter

Please note: The Sunshine Coast Citizen Advocacy policies are available to anyone who would like to view them, Staff members are available to read the policy's to you if you need assistance.

Sunshine Coast Citizen Advocacy
is funded by the Department of Social Services

The program operates in and around Maroochydore, Nambour, Caloundra, Mooloolaba, Buderim, Coolum, Noosa and the Hinterland areas.

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