



A YOUNG ADULT'S GUIDE TO

flattening





It has long been evident that the lives of people with disabilities are limited more by the very low expectations that we have held of them, and by a set of assumptions and stereotypes that have built up around them, rather than by any personal limitations they themselves may hold. This has led us to create a social reality for people with a disability where they are assigned to live only with other people who also have a disability, and for that living arrangement to be controlled and managed by paid strangers with no relationship to the household.

The stories contained in this booklet begin to help us recognise that a different reality is possible. If people with a disability are to be supported to live lives that are – in the ordinary sense – full and meaningful, then this can only be done when they are truly engaged in the shared life of our community.

I am hopeful that this booklet will encourage other young people and their families to imagine better for their lives. For if we can imagine better, we can become better and seek out those who will walk with us towards what we know is possible, and away from the doubters and naysayers whose own fears and apprehensions would stand in the way of what is both possible and achievable in the lives of others.

Lorna Sullivan



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key elements



Vision, safeguards, circles of support, planning, future and funding.

Vision

A vision that clearly identifies your family member's rightful place in the world is essential in the pursuit of an inclusive life and a good life in the community (*Pocket Guide to Advocacy AACL*), where he or she is living alongside neighbours and friends. When you are very clear about that vision, then talk about it, write it down, explain it to others and occasionally review it. If our sons and daughters have led inclusive lives, then they're more likely to develop their own vision and begin to hold this vision for themselves.

Safeguards

Know the person well through listening, so there is a strong awareness of what their vulnerabilities may be. We know that it is people who keep people safe, therefore we recommend that you support the development of friends and family to be a part of your son or daughter's life.

Be seen in your local community on a regular basis. Always have a 'Plan B' and don't leave anything to chance. It's also important not to be risk averse because, when things go wrong, it can be a learning opportunity for everyone – providing the person is not exposed to real danger. It's often through taking risks and the mistakes we make that we learn a little about ourselves.

Circles of support and intentional networks

Bringing people together to provide advice, support and friendship is one strategy to maintain a successful living arrangement over the long term. A circle of support is also seen as 'The Dream Carriers', as this group of people hold the dreams you have for your family member, both now and when you're no longer around. There are many ways to support an individual, and unpaid and natural supports will develop over time if effort is put into building the relationships.

Planning

Planning is at the heart of helping people move toward lives of self-determination, connection, companionship and contribution. Robust planning, coupled with the development of personal support networks, is crucial in developing strategies that define vision, invite collaboration and build energy and commitment. (*Planning For The Good Life Using PATH 2013, Imagine Better*)

The future

Start to plan for when you're no longer around. Nurture and support the development of enduring relationships for your child, and safeguard against loneliness and isolation is through establishing a circle of support. Our sons and daughters are going to change and grow over time, as would be expected. Therefore, it's quite likely that their living arrangement today will look different in 10 years' time.

Funding

Thinking about funding is important. However, it's not necessary to have it in place before you start your planning and move out of home. Always start with the vision and, often, the rest will fall into place. If you begin with the funding and how much you have, then there is a greater likelihood that you'll restrict your thinking to what support can be purchased, rather than what's truly possible for your family member.





planning

A vision is all about having a clear picture of what a good life looks like from the individual person's perspective. This can involve listening deeply to a person. Of course, it's also important to listen to other people who care deeply about that person. In our society and in our family, we believe everyone has the right to personal autonomy, choice and control in making decisions that impact on the way they live their life, with all the responsibilities that come with being an active, responsible adult.

Thinking, talking and listening are important components of planning, but what's critical is having a vision for what a good life is for your son or daughter. As parents, we want to do the right thing for our family and, in particular, for our most vulnerable family member. In our household, we fought very hard for a fully inclusive education from kindergarten through to college. A direct result of an inclusive life for our son is that he has the same ordinary dreams and aspirations as his peers. By the time he was ready to leave home, we felt that all the hard work was now coming to fruition. He wanted to leave home on his terms and he had the full support and love of his family and friends.

Over a period of weeks, we explored what it was that we wanted for Alex when he left home. We also gave him plenty of opportunity to think and talk through his concerns (of which there were a few), so we listened and responded accordingly. Time was taken to check out what was being said so that we could get a good understanding of what he really wanted. If we had not gone through this process, there was potential to not be true to him. He remained at the centre of all decisions.

Sometimes, in a process of discovery, our children surprise us with what they want and, at times, it may be things that we consider not to be appropriate. Often this is the 'big stuff' that doesn't align with a family's values. It may be useful to think about how you might respond and how you might manage the situations that take you by surprise. If it is an 'ordinary life' we're seeking for our sons and daughters, then they're going to enjoy the rights and responsibilities that sit with that.

What he wanted

Action and no more talk

Flatmates who respected him

No support workers

A young people's circle of support

Near Mum and Dad

To be 'in charge of my life'

Close to church, train, bus, gym and friends

'Just ordinary flatmates'

Freedom from Mum mostly

To be happy and not lonely

What we wanted

To find courage to move forward

People who would respect him

To have governance of the arrangement, and definitely NOT to be the managers of his life or staff

A safeguard against loneliness and social isolation

To be no more than a five-minute drive away

For him to have control over his living situation and authority over with whom he would live

For him to live in the community he knew best and where he is known

To live with people who held similar values and who would have respect for his values. To be seen and treated as an equal

Freedom and liberation

To be happy and not lonely

By Alex's mother

Person-centered planning

Person-centred planning is a way of helping people to think about what they want now and in the future. It's about supporting people to plan their lives, work towards their goals and get the right support. It's a collection of tools and approaches based upon a set of shared values that can be used to plan **with** a person, not **for** them.

Person-centred planning is built on inclusion and looks at what support a person needs to be involved in their community. Person-centred approaches are different from how traditional planning is carried out, which typically assesses need and then allocates services.

Person-centered planning is about listening and asking questions to draw out from the person their desires, gifts, interests and talents, and using that information to better support real outcomes for the individual.

Planning tools

There are a number of planning tools available for person-centred planning and the principles followed are:

- the person is at the centre
- family and friends are partners in planning
- the plan focuses on gifts and capacities, and looks to the future
- planning builds a shared commitment to action

Planning is an on-going process and requires facilitators who have experience and are skilled in drawing out what is being said by the individual and the group. Where graphing or artwork is used, there is also a graphic facilitator whose role it is to listen carefully to what's being said, in order to capture and design the graphic story.

PATH – *developed by Jack Pearpoint and Marsha Forest*

A PATH is a seven-step process. It starts with the dream and covers the what's happening now, who you need to get on board, what gets in the way of where you want to be, what actions are going to be taken so the dream becomes a reality and clear time frames around this. It's the dream that guides and gives direction to the rest of the meeting. When used in person-centred planning, PATH requires the person (and the people he/she wants to invite) to meet together with two facilitators to work through the process.

PATH works well when an individual has a group of people around him/her which is committed to making things happen. Using the PATH process enables people to understand and take control of the situation.

MAPS

MAPS is a useful planning tool for making action plans. This tool creates a joint commitment to help focus the person on making progress towards their dreams and aspirations. The 'focus person' and other significant people come together and follow a process to discover who the person is, what their dreams are, what their fears are, what their gifts are and what it is that the person needs, followed by an action plan.

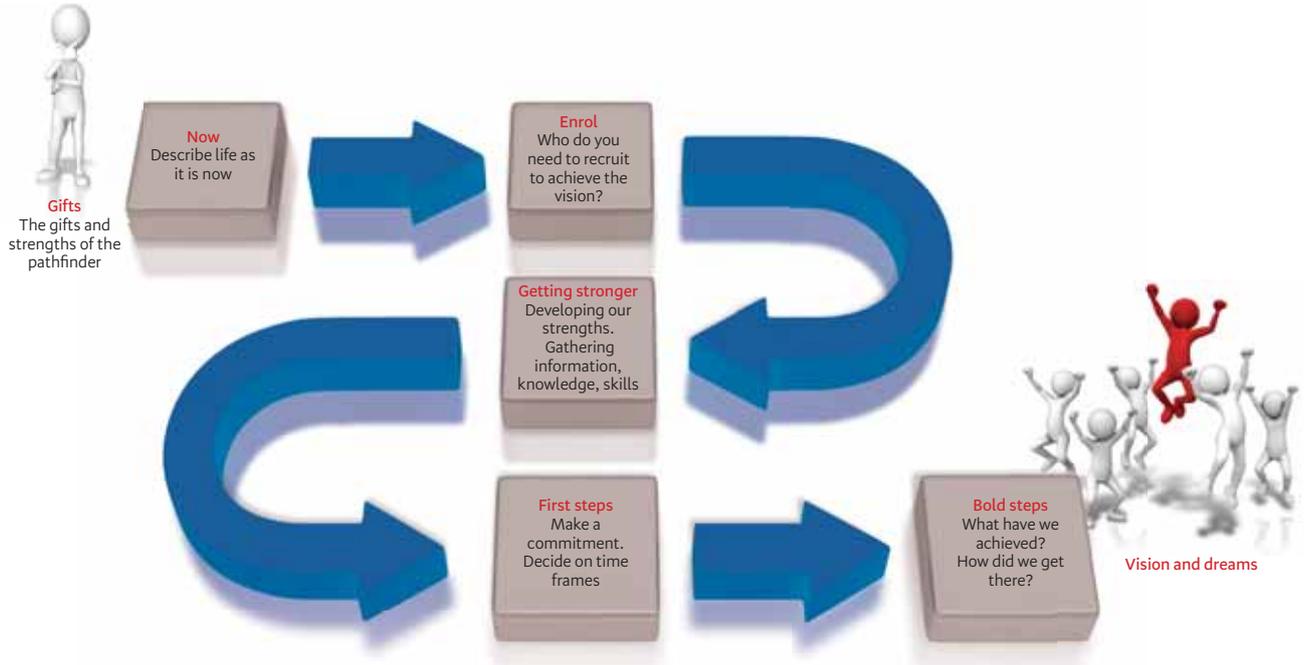
One-page personal profile

- People who are important in my life
- My gifts, talents and interests
- My hopes and dreams
- Paid people in my life

This is a very easy process and places the focus on some of the things that can so easily be forgotten when plans are being developed. A personal profile is always a work in progress, as lives change. It's useful if you don't want a more in-depth planning process or, at least, it can be a place to start and then move to the other, more detailed planning tools.



PATH *Planning alternative tomorrows with hope*



(J O'Brien, J Pearpoint and L Kahn, The path and maps handbook. Inclusion Press)



Damien, 25, is an only child and has always shown determination to act independently. When he completed his education, Damien found employment three days a week at a large printing company, where he carried out various tasks in the warehouses.

At first, Damien was very apprehensive about moving out of home. However, after visiting a friend who'd moved into a flat herself and was thriving on the experience, he quickly took to the idea.

Encouragement and positive discussions led Damien to become eager to move from the family home to a more central, but close-by, location in Onehunga.

Damien appointed a Lifestyle Coordinator (LC) to facilitate flatting life for him. At the time, it seemed his only requirement was to have a house with French doors! Damien's family fully supported his dream to have his own home, as it was always in his 'life plan'.

Damien likes architecture, writing, rearranging or organising, and takes an interest in things of beauty wherever he finds them. He loves going to cafés, restaurants and shopping. Damien's room is full of books, DVDs, stationary, bags, shoes and magazines – all the things that make him happy. Damien also inherited the cooking gene from his parents and he loves to entertain.

The flat hunt in early 2012 was difficult. There were few houses available, so it took several months to find the right place. Damien needed to be the leaseholder, so that he was in control. The real estate agents he met throughout this process were extremely open to Damien taking on a lease. All they wanted was someone to pay the rent and keep the house well looked after.

At the same time as house hunting, Damien advertised for a support person/mentor for a few hours each day to help him stay motivated, and to assist with budgeting, planning and cooking. He was fortunate to employ Tom, who started a few weeks before Damien moved. Tom's been a very calming, fun and realistic influence on Damien, and this solid support has really kept his life on track.

Initially, Damien explored the possibility of finding flatmates who'd then help him rent a house, but this proved difficult as most were under time pressure. Once a house was secured, an ad was placed on TradeMe and the Christian Accommodation website. It took many weeks and Damien's family had to cover the full rent of the house until the other two bedrooms were filled.

A week after Damien decided to move into his flat, two male engineers took the other rooms and seemed to be good sorts. However, over the following months, Damien's tidy standards began to slip into line with these two extremely untidy men. The house always smelt, food was left out and flies lingered. While this situation is pretty typical of early flatting experiences, it wasn't a good environment for Damien. Consequently, the two flatmates were given their notice (as per their flatting

agreement) and moved out. Again, there was little response to the online ads, so other avenues were used, such as local notice boards at the supermarket, library, universities and cafés.

The next two flatmates were a talented male artist and a female early childhood teacher. Both were lovely characters and got on well with Damien, but they didn't get on with each other! It emerged that one had a drinking problem which, alongside some language and culture differences, proved to be problematic. The situation concluded with both moving out, which caused more disruption for Damien.

Currently, Damien's flatmates are a lovely young couple and a great guy who all get on well with each other. The flat is stable, clean and peaceful. The flatmates all live busy lives and mostly keep to themselves, but have passing conversations and generally keep an eye out for each other.

Flatting certainly hasn't been plain sailing for Damien. An incident in the flat saw trust broken by Damien and the flatmate involved was truly hurt by his dishonesty. This good-hearted flatmate simply requested a sincere apology and afterwards said, "I like you Damien and really want to stay your friend." Damien learnt very quickly that honesty and trust in the flat needs to be reciprocal.

Damien has support to manage the flat expenses. As the leaseholder, he's in charge of making sure the bills are paid. He collects the paper bills and files them away to be looked at and paid with his LC at the end of each month. Damien also goes through his receipts and online bank statements on a regular basis. He divides his spending into 'social', 'food' and 'personal', then logs it in an expense journal. This helps him to understand money priorities, while still enjoying his passion for spending!

As well as the difficulties with flatmates, Damien's had a rough time with family loss and job redundancy, due to his company going into receivership. Just like other people who experience these setbacks, it's been hard for Damien not to fall into a slump of inactivity and lack of motivation. One of the greatest impacts on Damien's life is having a job that pays and he keeps meeting harsh hurdles associated with being out of work.

A great hotel job, that Damien loved and worked hard to attain, was lost to him because the employer wanted to be assured that Job Support funds were in place. However, Workbridge wouldn't confirm these funds until Damien was actually employed. By the time the issue was worked through, the job was lost to someone else.

Family, friends and enthusiastic supports are helping Damien to actively seek new employment. While it's time-consuming and slow, everyone's determined to stay positive and not become reliant, least of all Damien, on government agencies - two of which have badly let him down in the past.

Damien volunteers two mornings a week at the local food bank. He catches the bus and, on Friday, walks from there to his church, where he helps set up for the weekend services and events. Damien also has a micro business at the markets and is being encouraged to turn it into a small money earner. Damien is proud to show off his products and loves the opportunity to engage with people, to create conversations and networking relationships. Sharing with people helps Damien overcome any reluctance to do the hard work.

Damien's devoted parents have a governance role in his flatting life. They encourage him strongly to embrace good values, to develop an understanding of and empathy for other people, to have an active and purposeful involvement in the community, and have a 'reciprocal' way of living. They've always wanted Damien to succeed in the 'real' world and are incredibly grateful that he can live the way he wants to, but they're always conscious of his vulnerability to become withdrawn and isolated. Damien's parents don't want to manage their son's life

or provide the hands-on supports. They've put trust in others to help Damien make healthy choices, stick to a planned and purposeful routine, and to continue learning good habits in order to live a regular (interdependent) life.

Damien's had a circle of support since he left school, which consisted of family friends who'd been a huge support in achieving his flatting goal, and many others. Damien and his LC have recently formed a new circle of trusted, similar-aged friends around Damien, who'll become a great network for social, educational and safety needs.

Damien goes to a local dance and exercise group each week with one of his friends, and has met lots of young people who really appreciate his company. He's also recently taken up archery, which is developing into a true passion – he lights up when he talks about it! Damien attends the social groups 'Recreate' and 'Phab' on a regular basis. It's a social life made up of independent, community and agency events. This is vital to Damien's social wellbeing and his links to a more inclusive life.

As you can see, Damien's path to a greater, more autonomous life is far from perfect and always in movement. He took control too fast in those initial stages and now has to let his supports

lead more directly, until he can become more responsible for himself. It's important for Damien to have people at his side who believe in him. He needs constant reassurance that he's not 'this person with a disability' but simply 'Damien' – a smart young man who must show the world his caring personality and all the skills he has to offer.

"For as long as I can remember envisaging Damien's future, it's always been a future of purpose, self-determination and independence, as much as the constraints of Damien's abilities



would reasonably permit.

“Having attended workshops about what’d been achieved with regard to living arrangements for family members in Australia and Canada – being supported completely independently in their own homes – it was an attractive idea for Damien.

“However, the prospect of us finding the supports to make this happen was daunting and seemingly prohibitive. So, when considering what opportunities there were for him to live away from home, I initially started to screen for organisations that offered the most independent supported living environment.

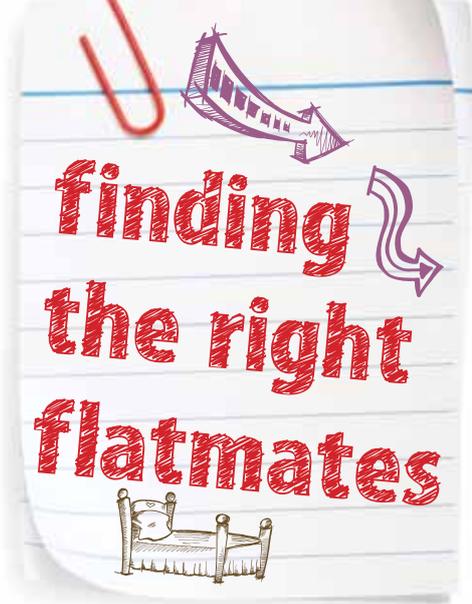
“In the meantime, we’d become part of a parent initiative set up in response to these workshops, with the hope of achieving similar outcomes for our family members here in New Zealand. Networking with the members of this group provided us with the necessary contacts and Damien was, therefore, able to move into his own home.

“Despite many questions, the misgivings we have regarding some of the things we witness Damien doing and the apprehensions we have over not intervening on occasions,

we’re still deeply committed to doing it this way and working continually towards making it as dependable as possible.

“The increased maturity Damien exhibits, and the pleasure and joy he expresses at having his independence in his present living arrangements, is immeasurably more valuable than any conceivable alternative. I hope and trust this can be maintained throughout his life.”

Damien’s mother



When setting up a flat, you need to be open-minded and intuitive. The individual going flatting must be involved with the whole process, alongside a trusted and knowledgeable assistant. This assistant may be a vibrant and strong-minded friend or a paid support. They need to be confident to back-up the person they're supporting. The individual with a disability will be the leaseholder or head tenant, and should have an advocate or facilitator to assist with this responsibility.

If you're considering a flatmate who'll also have a paid support role, be careful to fully understand the difference between these two positions. It's best to keep rent and support costs separate, so it's not recommended you pay for support with reduced rent.

Plan and advertise

- Understand exactly what qualities you're looking for. Be clear and detailed about the personality traits that will complement the head tenant
- Think about the possibility of having a flatmate who's paid for a support role of some sort
- Have a discussion about what to do if it takes a long time to find the right people
- Create a flatting agreement, consisting of realistic requirements of the flatmates. See example overleaf
- Place an advertisement on Trademe (or whichever avenue you may choose). Look at other 'flatmates wanted' for examples. Make sure good features of the house and the local area are promoted
- Only disclose relevant information about the head tenant, eg works at Bunning's, enjoys sport, likes to be social etc
- Ask for a brief account of personality, character and lifestyle
- Screen applications: look for good writing style, language and mood. Invite those who seem fitting to a house viewing

House viewings

- The head tenant should host viewings with someone who's going to show off the 'could be' environment of the flat
- Introductions and discussion about the house should come before the head tenant's disability and support requirements. It might be helpful to say something like, "So, now you've seen the place, I need you to know that Sally has an intellectual disability. She has a personal assistant who'll help her become an integral part of the flat and she hopes to find flatmates who'll enjoy the same things she does. Of course, you'll have no other responsibilities other than to be respectful, honest and compassionate towards the other flatmates."
- Make it clear that flatmates can and should contact the people who provide the supports for any advice or if they're concerned about anything to do with the head tenant
- Paid support people and friends need to be connected with flatmates as a way of making sure the flat is safe, but also to help the social environment

Sample advertisement for flatmates





Rachel is in her late twenties and has lived in her own home for six years. She loves people, has a photographic memory, a gift for dates and days, is artistic, loves the garden and is a great housekeeper. She is a persistent and patient communicator.

Rachel's family established the vision for her life through a realisation that the best path for her couldn't be found within the disability sector. For the first three years of Rachel's life, her family held no particular devotion to the inclusion movement. Early on, they deliberately chose to base all life choices and decisions on embracing foundational values expressed in SRV theory and what was 'ordinary' for people of Rachel's age, culture and their family culture. As Rachel grew older, she also made it clear that being 'special' did not meet her needs or desires.

The thought of Rachel living in her own home came out of the need not to be placed in a group home. Rachel herself chose not to be in 'special' care, most dramatically noted when she refused to get in the taxi to go to her special school when she was 17. That was her way of saying she'd had enough! Rachel's behaviour at this point had become difficult and she was putting herself and others at risk. It became very clear that the philosophy for Rachel's life was one of inclusion and to be involved with people with whom she chose to have relationships. Along the way, a number of advanced thought leaders helped to craft creative and inclusive ideas for Rachel's life. Her family has found it essential to have these influential, thought-provoking people to inspire a vision for the best life possible.



Rachel and her family concluded that a house needed to be found that could be called Rachel's own. As part of the preparation for Rachel moving from the family home, a psychologist observed her and her mother on a typical day of errands. This was to help create a picture for transferring support skills to the people who would assist Rachel to live in her own place. After this day, for no known reason, Rachel refused to leave her home again. She would only venture as far as the letterbox. After careful consideration, and in response to this unusual predicament, Rachel's parents and younger brother moved out and left Rachel in charge of the family home.



Rachel's arrangement had to be funded through a residential contract because Individualised Funding (IF) criteria at the time were restrictive and Rachel was not eligible. Rachel's sister lived with her as a flatmate for a long time and then she got on with her life, as people do. Rachel's family became unhappy with the way the provider was managing her life and, as IF became more readily available, they began to rethink the arrangement. It was not until a fire started in the house in 2012 that they were shocked into ending the residential contract and decided a much better job could be done by taking on the support arrangements themselves.

The assessment for IF was not easy. In the end, Rachel's mother asked for assistance from knowledgeable advocates to assist in the process. Even now, IF does not fully meet Rachel's identified needs. She requires loving and freely given relationships to cover the short fall. With no support from extended family, the immediate family provides the unpaid roles. Freely given relationships are lacking and this is an area of Rachel's life that needs to be expanded. Her parents, especially, deserve to claim back their lives. Financially, they're burdened by the cost of owning Rachel's house and are charging less than market rent from Rachel's benefit. They also pay for Rachel's food and expenses because her benefit doesn't stretch that far. The budget doesn't account for public holidays, so Rachel's

parents spend these days with her. They also cover some of the sleepover shifts in order to save money. This saving is reserved for a 'Partner' from Imagine Better, who meets with the support team for two hours every month and facilitates the constant movement towards a greater life for Rachel. Rachel's family asserts that this is a much-needed role for maintaining and opening opportunities that are forward thinking and interesting.

Rachel's supports are called 'project managers' because, despite the IF regulations, their roles go far beyond household management and personal care. They are responsible for managing the safety and creativity that keeps Rachel in control. When hiring project managers, a shortlist is made and then Rachel determines who'll work for her. If she isn't interested, her intuition kicks in and she'll not let them through the door. If she thinks they're great, she'll disappear to change her top several times throughout the interview just to impress them! Rachel is her own best self-advocate, but it took a while for this to be understood by her family. She's always communicated in her own way how she wants her life to be directed and is most happy and secure when she's in control. Decisions are influenced by Rachel's behaviour. If she begins to show distress and anxiety, then obviously something in her life isn't right.

Rachel tracks the weekly roster which she insists stays pinned to her fridge, and she has a diary to keep dates and information about all her supports. Managing rosters for support is a difficult job and requires a lot of patience and negotiation. Ideally, this job should be held by a facilitator to take the pressure off the family and, in time, Rachel's mother would love to relinquish her job as the glue in Rachel's life. Despite the difficulties and time involved for Rachel's family, they're all much happier being in control because they see authentic evidence of Rachel making her own decisions, which show her for the competent adult that she is. Rachel is an employer and an effective manager of her team, and a competent property manager. Never, say her family, has the backyard looked so tidy! Rachel displays an attitude in her home that shows an appreciation for life and a feeling of true autonomy. She has even recently begun venturing out shopping with her Mum, a sure sign of becoming more relaxed!

The government funds day services that could provide relief to Rachel's family involvement, but these funds do not support normality nor integration. Besides, Rachel chooses not to go. Instead, there are measured risks that need to be taken to open up the possibilities for enriching and advancing Rachel's life. Rachel loves the time she spends alone, and the family is upfront about the risks involved, but the budget has been stretched as far as it can go and natural support involving the family has been exhausted.

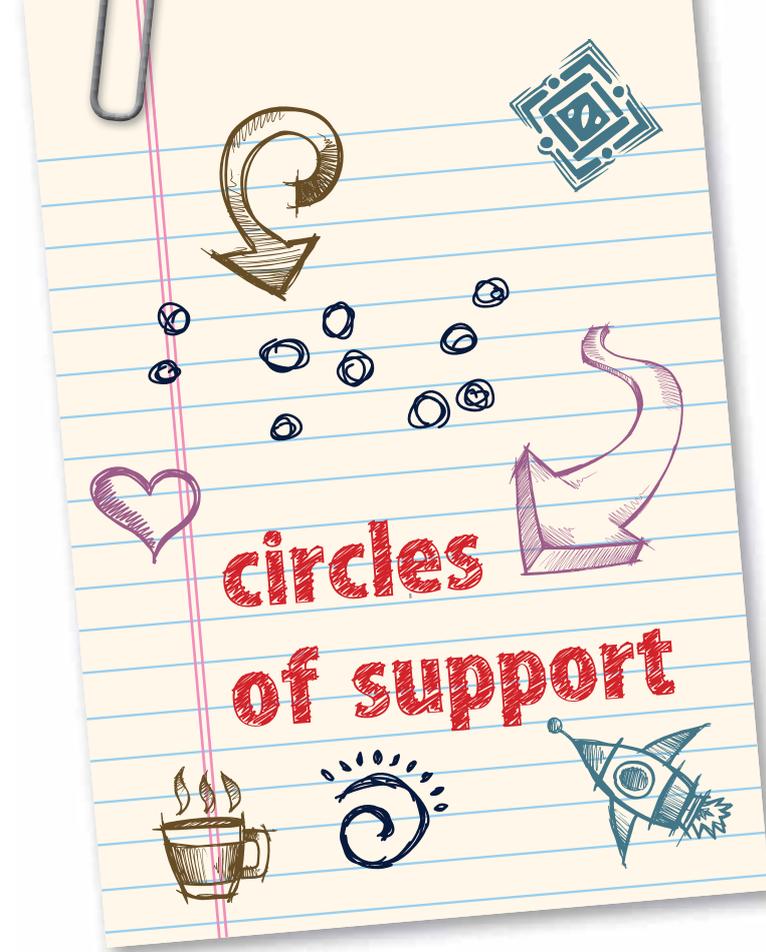
Technologies to support sustained 'alone time' need to be explored. The electronic monitoring systems currently on the market are not a good fit, or require responses from the person which are, for the moment, outside of Rachel's abilities to manage.

Rachel has intense interests that can take over her thinking and lifestyle choices, and need to be strategically managed so she can still enjoy what they bring to her life. But who should ultimately be responsible for risk, should anything happen to Rachel? At what point can families expect to evolve their own adult relationships with their disabled adult family member, and be free to enjoy active citizenship in their own right?

The intent for the future is to build a diversity of people into Rachel's life, so her day-to-day lifestyle will continue along an inclusive and exciting path. Her family wants her to be secure after they're no longer here.

There is a lot of work to be done to facilitate social relationships, in order to bring the community to Rachel. One of the ways this'll be initiated is through advertising for local creative individuals, interested in being part of a craft group to assist Rachel with her micro enterprise. A group may also be found to surround Rachel in her love of gardening. These groups will bring together people with similar interests creating trusting social relationships. Rachel and her family have wrestled with the 'no one will be interested' demon, but have resolved that – in order to move forward in life – a leap of faith has to be taken every now and then. The dream is for Rachel to become part of the fabric of her community, even if she never wants to leave her garden again.





circles of support

People keep people safe.

*Not services, not funding, not governments, people...
Ordinary people, people who understand and people
who are committed.*

Sharon Bourke

What is a circle of support?

‘Circles of support’ or ‘intentional networks’ are different names but have the same meanings. Circles are a group of people who are intentionally invited to come together in friendship and support of a person with a disability, for the purposes of protecting their interests into the future. They can also be there to support the focus person to achieve their dreams and aspirations in leading a full and inclusive life. A circle of support is about making positive change by taking action, and about sharing ideas and a strategy to move a vulnerable person’s life forward. It’s about safeguarding a vulnerable person from the isolation and loneliness so common among people with a disability. Most importantly, they’re about developing enduring relationships with people who love and care about the disabled person and their family.

Why have a circle of support?

The reasons people would choose to have a circle of support are many and varied, and would often be because there's a need to bring more people into a person's life, so that they can be supported to have a fully inclusive and good life. It's important to be clear about the purpose of bringing people together, as this'll help when thinking about whom to invite to be in the circle of support. Be clear about who's at the centre of the circle of support. Is it the parents or is it for the person with a disability? Either is okay, but being clear is what's important.

People in circles can change over time, because life is constantly evolving. New people also join the circle as new lifestyle goals emerge. Having allies to walk alongside the family and/or the person with a disability gives a strength that is otherwise hard to find on your own.

Who would be in a circle of support?

This depends on the purpose of the circle of support, and is closely aligned with the dreams, aspirations and interests of the person at the centre of the circle. For example, the focus person may be interested in folk music, so find someone who is part of a folk music club and ask that person to join the circle. It is asking that we find the right people to join the circle of support and people are often very willing to be there when asked.

“For me to be happy and not lonely, I need help from good friends. So I have a circle of support and they're called ‘The Young Champs’. The Young Champs is a group of very special people who're there for me. Every two months, we have a meeting and I organise them. I wrote them a letter asking if they could help me with my goals. I wanted people who were funny, helpful, friendly, honest, supportive and smart. We have dinner that I cook and then have our meeting and talk about ME. I'm very blessed to have good people in my life. They're all there for me and it feels good. My Champs make sure that I'm in charge of my life and are there to help me. My Champs and my family are all behind me so that makes me feel very strong. They really listen to me.”

Alex Snedden

A few facts

- A circle of support is made up of people who care about the person with a disability and their family
- They can range in size from three to a large group of 10
- The members of a circle of support are not necessarily paid to be there
- **YES**, it is hard for all parents to ask people for help. But when you do, the rewards are worth it
- **YES**, most people are pleased to be asked, some may have even been waiting to do something in support of you and your family member
- Circles of support, intentional networks or support networks all have the same meaning, which is to bring people together that will support the vision of a good and ordinary life for the person in the community
- A circle of support can assist a person to create a positive vision for their future, and identify and work towards the person's dreams and aspirations
- Every circle of support is different, as is the purpose for bringing people together

Circles can be excellent sources of support. A circle can really help with planning and making stuff happen.

A circle of support

- Meets regularly (often once a month, but more or less depending on what you feel works best for you)
- Has members chosen by you
- Helps you plan things in your life
- Helps problem-solve
- Helps get stuff done
- Provides support, encouragement and, generally, the help you need to meet your goals and dreams

(Neighbours Inc, High School Transition Project 2006)



“Charlotte’s 21st birthday was really the time we seriously started thinking of her transition away from home. To qualify that, I think it’d always been the plan. We were emphatic that Charlotte wouldn’t be living at home with us – that she needed to live her own life, independent from her parents – as we won’t always be there.”

We were talking to many, many different people and that’s when Nicola (from Recreate) suggested we watch the article about Alex Snedden on Attitude TV. That blew us away, and a lightbulb went on – could that be an option? The effort was huge to put things in place.

I can honestly say that, for three years prior, we actively pursued our goal and met with various organisations. It was hard and we felt we were being continually roadblocked – that Charlotte was ‘too good’ or that her home life was ‘not bad enough’ for anyone to help us.

Having management/facilitation for Charlotte’s [flattering life] is the best bit. All the minutiae of day-to-day stuff, which we’ve dealt with for 24 years, is now the domain of others. Charlotte remains very much at the forefront of our minds and, after two-three months away from the family home, we’re still focused on Charlotte’s wellbeing. Charlotte living independently will always feel scary – she’s a vulnerable member of our society – but things are going so very well and we would recommend this type of living situation to anyone.”

Charlotte’s mother

Charlotte is 25 and an impressionable, but smart and sensible young woman. She has an older sister, who is about to be married, and a younger sister and brother who still live at home. Charlotte is open to learning new things and always ready to engage more with life. Her interests are singing, reading, cooking and the occasional puzzle. She works five days a week at a local high school, keeping on top of a busy staff room. She works in the library and carries out other office jobs. While Charlotte has worked hard to retain full-time employment, her life outside of work was previously limited to camps and 'outings' with social agencies. She needed to make changes for her life to become more purposeful, rewarding and inclusive.

Charlotte and her family began looking for options for her to move out of home when she turned 21, and the family had initially decided that residential care in a group home was their only option. However, funding for this was declined.

In retrospect, her family regards this as a blessing. Charlotte remembers thinking she didn't want to have a 'parent' type figure in her flat, but thought there were no other options for a young person like her. Charlotte's parents knew they wanted an adult relationship with their daughter, one where they didn't have to monitor her every move and where she would be safe.

In late 2012, Charlotte and her family met with a Lifestyle Coordinator (LC) and were excited by the prospect of regular flatting life. Charlotte was initially very quiet as possibilities for the future were discussed, but eventually she confirmed, "I really love the idea of making my own flat". There was little apprehension on her part to begin with, Charlotte always thought she would leave home, "Everyone else does!". She just didn't know if she had the option to follow that 'norm'.

Charlotte's parents found the process stressful, as it was a struggle to get Charlotte's needs met through their local NASC. Initially, Individualised Funding (IF) was denied by the NASC and only after many negotiations was a thorough plan completed and Needs Assessment carried out. Eventually, the IF was put in place and a move out of home was soon arranged.



While lengthy Needs Assessment processes are being done, Charlotte – along with her family – was supported to establish a circle of support. Charlotte’s circle is made up of her siblings, cousins and friends. Charlotte wrote an email that explained her venture and her need for committed support. She invited everyone for pizza and a casual group discussion about what it meant to be part of this team, now called the ‘A-Team’.

As with all groups of friends, it’s an effort to get everyone equally involved. It requires facilitation to uphold the main drive and purpose of the group. A critical element of Charlotte’s circle has been the role of facilitator and they’re striving to make these connections reciprocal and long-lasting.

Charlotte and her family decided that they would buy a house in the community she grew up in, close to her place of work and other places of interest. She now lives very comfortably with two female flatmates. This was not easy to achieve, as some potential flatmates didn’t even turn up, though this had nothing to do with Charlotte’s disability as it was not stated in the ad.

The rental market is hard to predict and the house was unavailable to view until settlement. However, Charlotte is very communicative and promoted her flat well to those who did come to look.

She moved into her house in Ponsonby as planned, having found one amazing flatmate and the second moved in about a month later. The three of them get on really well, sharing expenses, cooking for each other on a weekly basis and occasionally joining in with each other’s get-togethers. Charlotte has an amazing personal assistant who was found through student job search. Charlotte is supported with planning for the week ahead, shopping, cooking and her share of the cleaning.

Four months after her move, Charlotte said that living with non-disabled people made her feel more independent and secure in herself. With this growing feeling of confidence, Charlotte decided that she would get a cat from the SPCA. She loves having a cat to come home to in the afternoons, while the others are still at work. Maisie (the cat) is good company and Charlotte is a very devoted owner.

One of the other worries for Charlotte's parents was managing the unknown. Their daughter was going into the big wide world, where they could only hope people would receive her with kindness and support. They've been surprised at how much Charlotte's siblings have stepped up, as well as the ease and inclusion offered by her flatmates. Taking chances can be pleasantly surprising when the right supports and vision are in place.

Charlotte's parents are happy to now concentrate on the more important aspects of her adult life. Charlotte still has her parents nearby to take her to doctor's appointments and the like. She still goes home for dinner once a week and needs occasional emotional support when life becomes overwhelming (as we all do!).

Charlotte's older sister recently imparted that the everyday challenges of flatting life are what push Charlotte to learn by example, by trial and error, to use her initiative, to make her own choices and to believe in herself. She's learning to make her own arrangements where she can. She's coming to terms with the new relationships she has with her family, and making the most of her friends and supports. She's adapting to using her own knowledge to make good decisions. There's so much more to do, such as investigating the local community to create natural safeguards, and using school holiday periods to extend her work/life experiences. Consistent learning in a regular and constructive living situation is helping Charlotte to become an aware, valued and very happy member of society.



Each of the people in our stories have their paid support needs met through Individualised Funding. Without access to this type of funding arrangement, they wouldn't be able to live the great lives that they do in their communities of choice.

Having the flexibility of Individualised Funding is important as it better meets people's changing needs. As they develop skills in one area, additional support can be put into other areas that need development. For some people, their paid support needs are not exactly the same each week, so having the flexibility of Individualised Funding is one way of meeting a person's needs. People can also choose to forgo some specific supports and use that funding to attend leisure pursuits – for example, the cost of a support person to attend a rugby match.

We are using Manawanui In Charge as the host provider of our individual funding package as they specialise in Individualised Funding. Manawanui In Charge has been the pioneer of Individual Funding, and has developed skill and expertise over a number of years in this specialised area. Each month, every client receives a comprehensive statement detailing where and for what the Individual Funding has been used, providing a balance so that the client and the agent knows exactly how much can be used for supports going forward.

There are other host providers and people are given the opportunity to choose who they wish to use by the NASC.

Individual Funding rate as of October 2013

Personal Care	\$25.63 per hour
Household Management	\$23.83 per hour

Speak to your Individual Fund provider to get a recommended rate of pay, as each of the agencies charge slightly different fees for processing and reporting to the Ministry of Health.

Enhanced Individualised Funding (EIF) takes this idea of personalised budgets one step further. It allocates funding so a disabled person can choose to spend it on disability supports that help them achieve their goals, rather than have to spend it on a specific service. EIF is currently (October 2013) only available in the Western and Eastern Bay of Plenty. In time, it's expected to roll out through the country as part of the 'New Model' of providing disability support services. EIF gives disabled people and their family/whānau choice and flexibility to do more with their budget. The Ministry of Health has developed a set of guidelines that will show how this funding can be used.

(Ministry of Health website)

How does EIF work?

It's an easy three-step process:

- 1 Disabled people living in the Western and Eastern Bay of Plenty talk to Support Net or their NASC agency to find out if EIF is an option for them.
- 2 If it is, the disabled person works with their family/whānau and people such as a Local Area Coordinator to develop a life plan that includes goals.
- 3 Finally, the disabled person works with NASC and their EIF host provider to allocate the dollar amount available for the supports that help them achieve those goals.

(Ministry of Health website)

Budget based on actual hours allocated

Individual Funding budget for 2014 = \$25,719 (gross) or \$18,924 (net)*

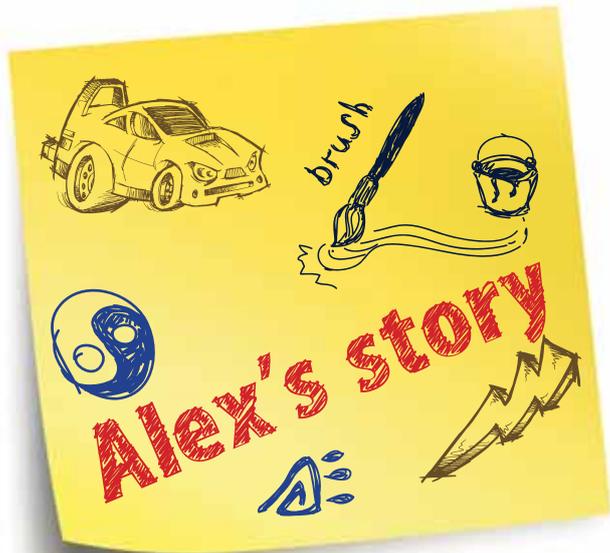
	Hours per week	Contract/Payroll	Hourly rate	Weekly	Annually
Personal Care allocation 520 hours per year or 10 hours per week					
Support person 1	5hrs per week	Payroll	\$18.96	\$94.80	\$4,930
Support person 2	2hrs per week	Payroll	\$18.96	\$37.92	\$1,972
Support person 3	3hrs per week	Payroll	\$18.96	\$56.88	\$2,958
Household Management allocation 520 hours per year or 10 hours per week					
Household Management	10hrs per week	Payroll	\$17.43	\$174.30	\$9,064
				TOTAL	\$18,924

*NOTE: The highest recommended rate to pay staff (with no 'extra hours or expenses' built in) is \$18.96 for Personal Care and \$17.43 for Household Management. These rates allow for the extra costs of employment such as KiwiSaver, ACC, holiday pay and Manawanui In Charge fees for processing and reporting to the Ministry of Health.

Alternative budget

Individual Funding budget for 2014 = \$25,719 (gross) or \$18,924 (net)

	Hours per week	Contract/Payroll	Hourly rate	per week	per annum
Personal Care allocation 520 hours per year					
Personal Assistant	5hrs per week	Payroll	\$22	\$110	\$5,720
Support person	5hrs per week	Contract (expense claim)	\$19	\$95	\$4,940
Household Management allocation 520 hours per year					
Contract cleaner weekly		Expense claim	\$65	\$65	\$3,380
Annual cost of entry tickets for support person ONLY		Expense claim	\$395		\$395
Training of support personell		Expense claim	\$300		\$300
Petrol cost reimbursed to support personnel		Expense claim	\$200		\$300
Podiatrist bimonthly \$65		Expense claim	\$390		\$390
Other costs, eg training/planning/facilitation		Expense claim	\$3,500		\$3,500
					\$18,925
Any overspend to be paid by family or individual				overspend	\$1



Alex is in his mid twenties, with a supportive, charismatic older sister and an encouraging, vibrant younger brother. He's a keen follower of rugby and WWE wrestling, and goes to karate three times a week, where he's been a member for a number of years. Alex is very much a part of the karate family. He goes to the gym on a regular basis and enjoys going out with his mates for a beer. He's animated and invigorated when on a podium speaking in public and he has a big heart.

Alex works four days a week in three different jobs, having recently negotiated an extra day for one of them. He also spends one morning volunteering at the foodbank. Alex has a major focus in life that keeps him strong and on track, he's deeply committed to his Catholic faith. He's interested in helping others with and without disabilities to appreciate life and to respect those around them. Alex is proud of who he is and doesn't let having Down syndrome define him. He does his best to be a role model for others.

Alex is one of four flatmates in his home and life has been pretty good since he moved in. This is largely due to having a very detailed plan that focuses on his dreams, aspirations, gifts and interests. He knew exactly what he wanted, including non-disabled flatmates, a home in the area that he knew and a place that gave him separation from his parents, but not too much! Alex wanted to have supportive flatmates who would enable him to live without 'caregivers', because he doesn't think of himself as being 'sick' or a 'child' that needs to be cared for. Alex's parents met this vision with their own, which made sure he wouldn't be lonely or isolated, would be securely supported by intentional networks and sufficiently included in his community. As well as the support Alex had from his family, there was much discussion and thinking done together with his circle of support, that had formed a few years before he left school.

There was so much planning and thinking, in fact, that Alex became frustrated with all the talk about his moving out of home and started to demand some action! His mother felt like she needed to be in the right space to let things move forward and, when she was ready (pushed by her eager son), everything fell nicely into place.

Alex employed a Personal Assistant (PA) to help find a flat and flatmates, and to guide him towards becoming a competent member of his own household. Together, they searched very hard for a suitable home in a mapped-out area close to his local hub in Remuera. Everything was expensive and there were few choices of houses that would attract the type of flatmates for which Alex was looking. Alex's parents came up with the incredibly generous idea of taking on the rental market themselves, so that Alex could remain where he was. Within a few months, it was transformed into a comfortable four-bedroom house, ideal for a young group of professionals to live together.

While all this was going on, Alex and his family came up with a list of names for a group to take over from his previous circle. A more appropriate set of young people was required, who had flatting and social knowledge to help Alex become a more included member of society. A letter was written by Alex and

his PA to invite these energetic and thoughtful people to be a committed part of an intentional friendship network. They all responded with extreme positivity. This group, the 'Young Champs', is now (after a few subtractions and additions) an intricate part of his life that freely gives of their time to inspire, motivate and support him. They come together every six weeks to enjoy dinner at Alex's flat and to discuss the goals for the near and distant future.

When Alex's house was ready to become his flat, it was quickly listed on Trademe for flatmates. His parents held their breath and, at times, were quite overwhelmed with what was happening. They certainly didn't do this without questioning whether they'd done the right thing, even though they'd always imagined his life would look like this. Within days, there was a response from two sisters who were moving from Tauranga for university and flight attendant training school. They sounded perfect, so a reply was sent with some details about the flat and about Alex, and a house viewing was arranged. They were bubbly, warm and genuinely nice people, similar in age to Alex and a great match for the flat.

It was around this time that the family decided to have a Needs Assessment, so they could get an Individual Funding package in place based on his needs. Now that he was no longer living

with them, it became apparent how much was being done for him by family. There is nothing that his family would do differently. He has an Individual Funding package that works for him, and the host provider (Manawanui In Charge) has been there in the background and available when needed. The service they've provided has been second to none, both in advice and information.

As his new flatmates were not able to move in immediately, it was agreed that Alex's PA would move in for the two weeks between his parents moving out and his flatmates moving in. It was a good transition period for Alex to settle into the change and prepare for new housemates that weren't his family. He quickly had to learn some courtesy rules, such as not carrying his radio around the house blaring loud music early in the morning and making sure he knocks on others' bedroom doors. These were all things spoken about clearly before he started flatting, but these things need to be learned in situ. There are still moments when he needs to be reminded how to be a good flatmate and what that actually means. Part of this is teaching Alex to understand the different ways people live their lives.

Soon after the girls moved into the flat, a young man viewed the fourth room and got on really well with Alex. He moved up from Cambridge the next weekend to start a new job and completed

this great flat. There have been two new flatmates, where lives have changed and they've moved on, but someone's always been found to fit in, either through friends of the flatmates or using TradeMe. Two of the original flatmates remain and are solid friends with Alex. It is the responsibility of Alex's PA to help everyone connect, so there is a cohesive understanding and friendly feel to the house, as well as making sure behaviour in the house is appropriate.

Alex's mother has learnt that it's perfectly okay for Alex to spend time alone and his family have absolute trust in him that, if he is lonely or bored, he'll call them. Alex also trusts that his family will be there whenever he needs them.

So that his family could get a 'look in', his sister was paid to carry out some household chores for Alex and, consequently, she could get to know the flatmates a little. After a few months, she felt things were working out just fine and a different arrangement to support Alex was set up.

At the outset, one of the girls offered to help Alex with household chores, so she was paid to help with his shopping, washing, ironing and cooking three-to-four nights a week. This has been amazing, but things change and her job has become more time-consuming, so she's now no longer in a paid support role.

In the past two years, Alex has grown and matured in many ways and is taking greater responsibility for some household tasks. He began flatting with very little knowledge of how to cook or clean and, in many ways, was no different from other young males living at home. He needed his parents to transport him wherever he needed to be and had become used to having everything done for him. Alex is now in charge of doing his washing, vacuuming his room, cooking once a week and seeing if any flatmates will be home to join him. He also catches buses and organises his own social life. He walks up to the supermarket to restock the necessities (milk, Weet-Bix, bananas etc) whenever needed or if he feels like a friendly chat with the security guards at the local supermarket. His weekly meeting with his PA is what keeps him on task and is the glue keeping things in place for him.

His neighbours keep an eye out for him, as do the many people in and around his community. His parents have learnt that it is okay to let go and have trusted what he's been taught throughout his childhood. The local gym encourages getting fit and healthy three days a week, and karate has always been a place that he learns an inner discipline and self control. Needless to say, he can defend himself if need be.

Alex thrives on routine and lives very much by a repetitive structure. However, with the help of his flatmates, PA and Champs, he's learnt to be a lot more flexible, making the most of social and independent opportunities. He's proud of these achievements, knowing that each step, as uncomfortable as it might be at the time, is making him stronger and more autonomous. He's showing how he can be a valuable member of his community, which brings him respect and security. He naturally presents commonalities with others instead of difference and he thinks nothing more of himself than an ordinary guy living a great, but ordinary, life.

"It's finally happened! We're moving out of the house and Alex will live in it, and share the house with flatmates. I cried for two days. Alex told me, "Mum don't look back, just forward!" (bless him) so that's what I'll do.

"My biggest fear for Alex is that he'll be lonely. However, I have to trust that he'll be okay and that we've done as much as we can to safeguard against loneliness. He has a wonderful circle of support in his Champs, who'll walk alongside him as he moves away from the security of his family.

"No one told us when he was born that this would be possible. I'm so glad we developed a vision for his future early on in his life."

Alex's mother



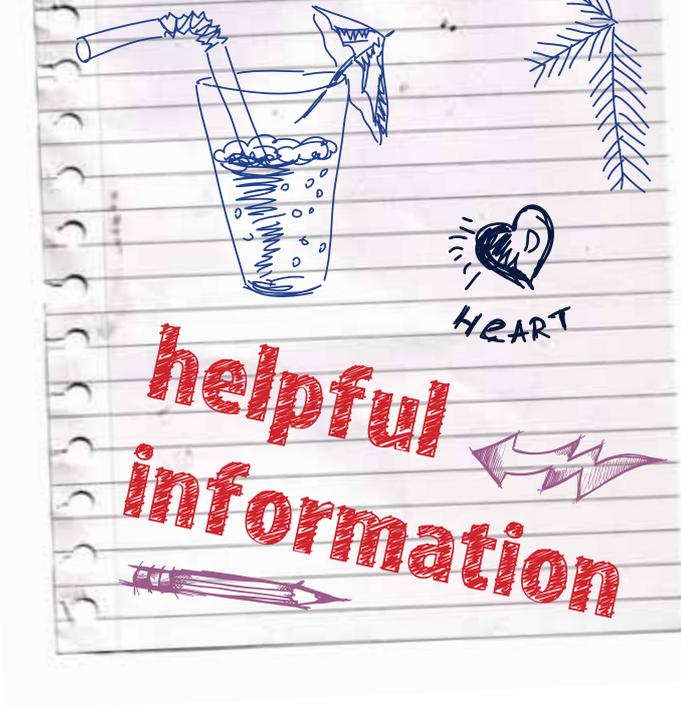
budgeting

The following is based on an actual budget for a young man sharing the rent and utilities with three others. It's important to note that transport remains an on-going issue and, so that their son can continue to do the things he enjoys and is committed to, his family have chosen to transport him to these activities – often up to three times a week. They also understand that, as he gets older, he's likely to choose to live with fewer people so, at that point, there'll be an impact on his budget.

Reality for some families is different from others

In one of the personal accounts in this booklet, the cost of rent totals the amount received in the Supported Living payment from Work and Income. So that their family member can have the quality of life they always envisioned, they're willing to contribute all of the other weekly expenses, ie food, utilities etc. This family is able and prepared to do whatever it takes so their family member has a good quality of life at the expense of their own. They acknowledge this approach is not sustainable in the long term.

Sample budget		
Income		
Work and Income	Supported Living payment and Accommodation Supplement	\$342
Wages		\$96
	Total weekly income	\$438
Less expenses		
Food and groceries	Groceries	\$60
	Bought lunches	\$10
Housing	Rent	\$190
Utilities	Power/Water/WiFi/Sky	\$20
Transport	Bus/Train/Taxi Using Total Mobility subsidy of 50%	\$45
Entertainment	Bar/Club/Café	\$20
	Movie (average one per month)	\$20
	Gym (annual membership)	\$25
	Clothing	\$20
	Haircut (one per month)	\$20
	Events/Tickets	\$10
	Total per week	\$438
	Balance	\$0
Weekly family contribution	Medical/Mobile phone	\$40



Work and Income

Supported Living payment

This benefit is for people who are severely restricted or unable to work on a long-term basis because of a health condition or disability, and for people who are caring for someone who needs significant care.

Accommodation Supplement

How much you will get on the Accommodation Supplement will depend on:

- your income
- your assets
- your accommodation costs
- where you live – this is important as the cost of rent is much higher in central Auckland than what it would be in west Auckland or even central Hamilton. Therefore, the accommodation supplement is not the same in both cities

Disability Allowance

You may get a Disability Allowance if you:

- have a disability that is likely to last at least six months
- have regular, on-going costs because of your disability which are not fully covered by another agency
- are a New Zealand citizen or permanent resident
- normally live in New Zealand and intend to stay here
- **Note:** The Disability Allowance also depends on how much you and your spouse or partner earn

Transport

Total Mobility scheme

Total Mobility scheme (TM) is used for buses, trains and taxis, and is a national scheme that assists people with impairments to enhance their community participation by accessing appropriate transport. This assistance is provided to eligible, registered individuals in the form of subsidised door-to-door transport services, wherever TM transport providers operate.

The TM scheme offers registered individuals a 50 percent discount (up to a maximum subsidy of \$40 in the Auckland region) on fares charged by contracted transport providers. To receive the discount, the individual must present their TM photo identification (ID) card to the driver at the start of the trip, so the correct tariff is selected for fare calculation. The individual is then required to have their TM ID card swiped at the end of the trip, and pay their portion of the fare to the transport provider.

It is recommended that you set up an account with a reputable taxi company. Therefore, your family member will always have access to reliable transport to get to and from social events at short notice, and to work if buses and train are not an option.

More information on how to access the TM scheme go to
www.ccsdisabilityaction.org.nz





A few learnings and suggestions

- We are parents first and foremost, not service providers
- Our role is to provide good governance in support of our family member's life
- We are very clear that we do not want to manage the lives of our sons and daughters, and have no desire to manage day-to-day supports needed so they can have a good life. This is the domain of the Personal Assistant (PA)
- The role of the PA is invaluable and can support/guide you and your family member in developing a lifestyle that is right for them. The PA can also have the role of negotiating with agencies on your behalf
- **Always start with the vision**
- **Never start with the funding**

- We recommend that the Needs Assessment process is used to look deeply at your son/daughter's support needs. Keep in mind that the support to do even the most simple of tasks or personal cares is no longer going to be done by family members. You're not going to be there to do the things that prop up their lives when they're living at home. This, in reality, can be far more than what you're conscious of doing for them
- Don't fall into the 'readiness' trap
- Attend to the legal issues such as your will and guardianship, if your son/daughter doesn't have the capacity to make supported decisions and understand the outcomes
- Ignore the naysayers and be wary of those who say 'Yes, but...'
- Trust your instincts and be courageous – it's truly worth it
- Think about and plan for ways that will safeguard the arrangement before you look at funding
- Most importantly, be prepared to do whatever it takes to craft a good life in the community for your family member

Useful websites

- www.paradigminitiative.co.nz
- www.parent2parent.org.nz
- www.imaginebetter.co.nz
- www.incharge.org.nz
- www.dbh.govt.nz/flatting-101
- www.sorted.org.nz



This publication was made possible through the willingness of the families who shared their personal stories. Although they held a vision for a good and ordinary life for their family members, they've been courageous in making that vision a reality.

The four young people in the stories are stunning individuals. They've all matured in ways that even their families didn't envision. We're indebted to them for allowing their stories to be told, so others can learn and be inspired by what they've achieved.

Thank you to Sarah Ferens, who wrote the four stories and who is the glue (Personal Assistant) to three of the young people. Thank you to our editor Justin Walsh and Finity Design – to whom we are very grateful. This publication was a result of a partnership between Paradigm Initiative and Parent to Parent NZ, with funding from Ministry of Health – Disability Support Services.

Bridget Snedden
Paradigm Initiative

Paradigm Initiative

Circles of support and bespoke living arrangements

The Paradigm Initiative is a not-for-profit agency based in Auckland, and established to walk alongside and assist families in creating and sustaining a good life for their family member with a disability. Our purpose is to work with a person with a disability and his or her family to enable their full inclusion in all aspects of community life. Our primary work is on the development of circles of support and the establishment of bespoke living arrangements.

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