

# Thinking about...

Periodical of Personalised Lifestyle Assistance

Issue 4 ~ May 2010

## How people with disabilities can be supported to live in their own home



*PLA believes that all people should have the opportunity to pursue a unique lifestyle that is personally meaningful, relevant and typically intertwined in the community.*



## Editorial ~ How people with disabilities can be supported to live in their own home

by Deb Rouget

This edition of “Thinking about...” is an extension of the previous theme of “Thinking about ... MORE than Accommodation”. As we seek equality for people with a disability we uncover a huge disparity in regard to the expectations around the types of accommodation options that are available to people with a disability. Many see that group housing is the only option for accommodation, especially for people with complex disabilities. This is often based on the assumption that it is cheaper, or that people with a disability like, want and should live together.

The Commonwealth State Territory Disability Agreement (CSTDA) 2004-2005 is the third in a series of annual reports advising of the progress and achievements of the Australian Government, and state and territory governments under this agreement, which operated between 2002 and 2007. It states that 31% of service users with a disability were provided with group homes at an average cost of \$92,949 per person, per annum; 14% were provided with accommodation in institutions and hostels at an average cost of \$82,389 per person, per annum; 56% received community based support to enable them to live in their own home or family’s home at a cost of \$17,674 per person per annum. Even a very crude comparison of such figures begins to dispel the myth that living in one’s own place is more expensive! The other question that arises is this, “if individuals with disabilities and their families were allocated the group home cost per annum *with support* to think and do differently, what many more meaningful options may be available to people?”

If the assumption that people with a disability want and should live together is valid, then this assumption could be put to the test with other groups of people who have needs. For example, it’s like saying that all people with glasses want and should live together because they have similar needs. This fundamental assumption is also flawed. Human beings generally do not come to live together based on a label or disability. They usually come to live together based on relationship and the desire to live together. As we listen deeply to people with a disability we realize that they do not want to be “housed”, nor live with people that share the same label, nor have an agency that owns and “operates” their home and governs their lives. Just as this would be abhorrent to other valued citizens!

But, of course we hear you saying “what about people with complex needs? It’s ok for people with mild disabilities,

that could never happen for the person I know or my son or daughter... they need 24 hour support, want company or couldn’t live on their own!” On reflection, generally most people in our society choose to live with others, prefer company and require support. It’s just that other citizens with needs are not expected or forced to cohabit with people who have a similar disability or label to gain support or company.

This issue of “Thinking about... How people with complex disabilities can be supported to live in their own home” explores how people with a range of needs can live in their own place. Jo Walters raises the importance of seeing a home as more than housing, having a positive vision and gathering people around each individual to support their vision i.e. family, friends, allies, neighbours, housemates and support workers. Pat Fratangelo et al explain Kristen’s journey to move into her own place with a flat mate and about the importance of everyone’s efforts. Linda Dawe and Janet Klees tell the story of Tiffany who has lived in her own place for 15 years and the contribution of her family, friends and others that assist her to live in her own home. Kieran Jeff’s talks about how Homeshare is a relationship based way of people living together for mutual benefit. Michael Kendrick’s article provides us with a road map about how people with disabilities can have real homes and how genuinely supportive people and systems can uphold the notion that people with a disability should have sovereignty in regard to their home and lives.

All of these stories have common messages about what *home* should and could be - to live more fully in ordinary and typical ways. This seems a long way from group home living. If all of the people who have contributed their stories to this edition and the last edition of “Thinking About...” have figured out how it is possible for people with complex disabilities to live in their own homes, then our challenge is to figure out options with the people we support and love. This can only be done *One Person at a Time* and with imagination, clear vision, creativity and determination rather than dependence on a system and misguided assumptions!

**Reference:** Commonwealth State Territory Disability Agreement Annual Public Report 2004-05. (2006). Australian Government Department of Families, Community Services and Indigenous Affairs

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Personalised Lifestyle Assistance  
2/18 Floriston Road  
Boronia Vic 3155  
Australia

Phone/Fax: 03 9739 8333  
Email: [laura.sykes@plavic.net.au](mailto:laura.sykes@plavic.net.au)  
Website: [www.plavic.net.au](http://www.plavic.net.au)

## Useful links

Jay Nolan Community Services (Los Angeles): [www.jaynolan.org](http://www.jaynolan.org)

Onondaga Community Living (Syracuse): [www.oclinc.org](http://www.oclinc.org)

Homeswest Association (Queensland): [www.homewest.org.au](http://www.homewest.org.au)

Living Distinctive Lives (Melbourne), email: [ldlcoordinator@optusnet.com.au](mailto:ldlcoordinator@optusnet.com.au)

Michael Kendrick: [www.kendrickconsulting.org](http://www.kendrickconsulting.org) Publication of interest "How Genuinely Supportive Persons, Agencies And Systems Can Enable People To Have Real Homes Of Their Own", Crucial Times, Issue 40, 13-15, Brisbane, Australia, 2008

[www.deohaeko.com](http://www.deohaeko.com)



# The importance of everyone

by Pat Fratangelo, Linda Webb, Erin Edwards, Kristen Webb and Bud Buckhout

Onondaga Community Living is an organization in Syracuse, New York, USA that supports people with intellectual disabilities. Each person's service is designed based upon what a person wants and needs. OCL has moved towards helping people in their home, with jobs of their choice, and with volunteer positions all in their community. OCL also assists people with their social life and their valued role as an accepted citizen. OCL works to support people with their family lives and also with the academic pursuits. The agency has opened its arms to helping people to have typical relationships with community members. Every person service is self designed.

Email: [patfrat@oclinc.org](mailto:patfrat@oclinc.org), [www.oclinc.org](http://www.oclinc.org)

**T**his is a story about a set of people: a family who wanted a normal life for a daughter who was labeled with a disability, a service provider that had to listen, understand and allow life to unfold naturally and community members that had to believe and join in, to make the circle complete.

A circle is just that, it is round. Think of a bicycle wheel. There is a hub, a center point. In this story you will find that to be Kristen. There are spokes all radiating from the hub, all equidistant and all with equal strength. You will find them to be two sets of families, community members, friends, an agency and staff supporters. You will then find the wheel, which holds the spokes intact, which is the dream and value that comes to the life of Kristen that each spoke upholds. The tire on the outside is how it runs against the world and cushions the ride when bumps are hit. Life is never perfect and even though the ride may get harder and the tire may need to be re-inflated or replaced, as long as the spokes are equidistant and with equal strength and there is new air to replace the lost air, the journey will go on.

## An introduction

Our agency (Onondaga Community Living – OCL) met Kristen when her family heard of the college service we had. Kristen's family had always felt that Kristen had a lot of potential but they found it as a big let down when she entered into the adult service world. Traditional day programs and grouped vocational programs were plentiful but not at all what Kristen and her family were looking for. Wait lists for any volunteer or work programs were huge.

But, what about this college service? They had an opening. The application and information was on line. It seemed like a normal progression for their daughter. Kristen

was accepted into the Access College service at OCL in August of 07. The transition from the high school setting to that of a University can be challenging for any student with a disability, but with the right supports there is success. Kristen was supported with a college mentor that works with her in a 1:1 relationship. The mentor attends class and aids in whatever area Kristen may need support in from completing assignments to navigating through the campus. She has taken a variety of courses with the help of her mentor. Kristen has chosen now to work with the elderly so her classes are concentrated with that in mind. Kristen meets with an advisor for the University who discusses each class and how it best fits in with her eventual goal of employment.

In the beginning Kristen was shy and did not have adequate study skills but as she became more comfortable with her new life and surroundings, she began to blossom. She began to be more outgoing and entered into class discussions. She began to identify with her new peers and began to enjoy some of the social aspects of going to college. Her family was amazed with the growth they saw in her as she began to expand not only her knowledge but her experiences.

## Ready to move and nowhere to go... or is there?

Kristen continued to live at home with her parents as she got the support she needed to take some classes at the local university. As she became more comfortable in her student role, she began to think about what it would be like to get her own place and no longer live with mom and dad. But once again, mom and dad's survey of the adult service world was not what they hoped for. Kristen's mom states,

"Other agencies that we spoke to regarding a

place for Kristen to live were looking at the group home model. The options discussed were either an established home that had a vacancy, or developing one with other families who were also looking for a place for their daughter(s) to live. Kristen prefers to spend time with a variety of people and we were concerned that she would be limited to spending time only with peers with disabilities and “staff.” We had heard from other families that staff turnover rates are high and change is difficult for Kristen. Kristen likes a schedule, but this was also a concern because she can get too dependent on a schedule and become very upset when something happens to change the schedule. We were worried that in a group home Kristen’s level of ability would be compromised. She is very high functioning and if she lived with others who needed more support she would not be expected to work to her competence.”

Our College Coordinator knew that Kristen was looking to have her own place and thought that it might be good for Kristen and her family to begin meeting with people at OCL. A meeting was set up and slowly discussions arose about what Kristen was looking for. As OCL has no openings or beds to fill, the people at the organization had the opportunity to tailor what Kristen and her family wanted. There was no hurry to fill a vacancy. There was a slow, yet targeted discussion to get to know Kristen, her wants, her personal routines and desires while also getting to know the family and the role that they currently had or wished to have in her future life. Kristen’s mom states,

“Working with OCL was completely different. There were several meetings of discussions about what Kristen (and her family) thought would be the best living situation for her. These Circle Meetings were a process of getting to know Kristen as an individual rather than as “another person with a disability.” We discussed the things that were important to her and things that made her uncomfortable. For example she wanted a cat so we made sure that was a priority in finding an apartment. Kristen, and her sister and I, and sometimes others, met monthly for about a year to discuss and plan for the move.”

There was much to know and find out about. She had many interesting things going on in her life with her art, her studies, her community and her family life. There was much to learn about her family and Kristen’s role as a daughter, a sister and an aunt. There was much to learn about how to keep her safe, while also allowing her to grow.

## Planning

At first it seemed logical that living in the university area might make sense as she was really identifying with the student population. She even would have a connection with her sister and her sister’s family living in the neighborhood. It would probably be easy to find



Kristen Webb and Erin Edwards

college housing and support her within it. Kristen at first thought that to be the best plan. But as meetings went on Kristen became more and more quiet, and eventually, thought she did not want to move.

As we explored more to find what her hesitations were all about, we found that she really identified with her home community and its comfort and was worried about all she would lose if she moved from there and had a completely fresh start in another neighborhood.

As we abandoned the idea of college housing, we asked Kristen what she then wanted.

“...An apartment with a cat, where I grew up, where I can go to see my family, have Sunday dinner with them, continue to work at the YMCA, meet with my art teacher and take my classes....”

Kristen had a life with meaning currently and did not want to lose it. As we figured out the support needs that Kristen had, we folded into the equation everything that she currently had in her life, along with what else could be done to enable her to grow.

The parents were worried about her safety and security, as they felt that Kristen could be vulnerable. They also wanted good role models available for their daughter. The group met monthly for about a year to discuss and plan for the move. Time was taken to explore her needs and desires. As the support needs and weekly routine were agreed upon, goals were determined:

1. Find an apartment in a location that both the family and Kristen were comfortable with.
2. Find the right person to live with Kristen that could share her new home and be a companion and support to her.
3. Ensure we had the right plans in place.

As Kristen and her family knew the home town neighborhood far better than the agency, it made sense for them to do the apartment hunt. The agency gave them some parameters about rental amounts and did little else.

Kristen and her mom then began talking with landlords and rental people in their neighborhood about apartments and visiting them. They eventually found a two bedroom apartment with good space that they were both satisfied with, that also had security, accepted cats and was within the rental amount. The family passed the lease to the agency for another opinion, everything seemed to fit. Kristen then signed her first lease to her own home.

As we began to think about who would live with Kristen, she wanted someone her own age going through similar life changes. So we put an advertisement together.

*Young woman with a disability, going to a local college and moving out of her parent's home for the first time, looks for someone to share her home. Free rent in return for companion and some support. Call xxx-xxxx*

Everyone in Kristen's circle was encouraged to talk with people they knew. An ad was placed in the local newspaper, the Sunday paper and on line at Craigslist. The majority of people who contacted us were young women going to college, looking to move out of their parent's home. The agency sorted through the applicants and did initial interviews. After several interviews, a person was decided on, Erin. Erin stated:

"The biggest thing in the ad that grabbed my attention the most is that I would be helping someone and moving in with them. My parent's thought I was not responsible enough to move out and I wanted to prove them wrong."

Kristen, Erin and both of their families went out to a favorite restaurant of Kristen's for their first meeting. Erin and Kristen got along well from the start. Then about a week later, Kristen and her family went over to Erin's home and met with Erin's family again. It was about the two families uniting on behalf of their daughters in their strong desire to have each of them have a successful life and home.

## Living life

Once the decision was made that Kristen and Erin would live together, each woman, with their families, began gathering what they would each need to live in their new place. They both were so excited to be moving out and sharing a home together. Both sets of parents helped to move their daughters into their new home and threw a wonderful housewarming party that brought family, friends and agency staff together in celebration of their new home and life together.

Kristen's mother states, "Kristen now lives happily in the apartment with the roommate. She comes for a family dinner every Sunday, sometimes bringing her roommate with her. We continue to be involved in her day to day life, but from a distance. We meet to discuss how things are going, help to monitor her finances and help with doctor's appointments. We see tremendous growth in Kristen's independence. She now plans meals, cleans her apartment, shops and does her

laundry sometimes with minimal assistance. She balks when we act too much like parents and don't treat her as an adult."

Kristen and Erin have a great relationship and enjoy poking fun at one another. They enjoy each others company and are very fond of one another. They do allot together. Erin often goes with Kristen to Kristen's family gatherings or for Sunday dinner. Erin stated that, "Kristen's mom is a great cook!" Kristen often goes with Erin to Erin's family gatherings and birthday celebrations. Erin says her mom loves Kristen and Kristen also loves her mom. Both women feel that they now have an extended family. They both love living together and say they are learning more and more from each other every day.

## Life goes on

Everyone feels that this situation went beyond what was originally expected. Kristen has fun with her staff and because she enjoys them is better able to do the work around her home. Her mother says, "When someone other than a parent is the one offering guidance, she takes it so much better." She seems to have fun while living up to her responsibilities.

It is a big step for any person to start out on their own and when it is your child with a disability, it can be very scary. It is scary when you want something but only find closed doors. It is easy to become shoe horned into taking something that does not fit and then give up so much control to an organization.

Having an organization take the time to discuss all aspects of the dreams and desires of the individual, as well as the family, not only helps to alleviate the worries, but it also helps the organization to understand the story and their role within it. Too many times organizations come up with standardized answers before they even know the questions... and the tire goes flat. When you let the story unfold, an organization may find that there may not be much from them that is actually needed, beyond cooperation and filling in the gaps....and new air inflates the tire to make the ride comfortable again.

Having a solid circle of people around you working towards the common good makes life's harder times more bearable. And not having the answers before the planning is done is the key. It is not about residential support. It is about helping Kristen to have the life of her choice given in a way that helps her to mature and grow over time.

Kristen is very much the hub of a very solid wheel that keeps turning with relative ease because she has so many equal and strong spokes in her wheel that help to keep moving in the right direction.

# A home of her own

by Linda Dawe with Janet Klees

Linda Dawe is Tiffany's mother and Janet Klees has been coordinator with the family-governed Deohaeko Support Network for the past 15 years and has been deeply affected by the lives of the people that she has come to know. Janet is the author of two books which are directly rooted in the Deohaeko experience, ("We Come Bearing Gifts; Our Presence has Roots") as well as numerous other reports, documents, tools, and writings. Janet also works closely with other Scarborough, Ontario families, and several family groups and projects across Durham Region. All of Janet's work focuses on individually-designed arrangements and she is especially concerned that families are well-supported to think through practical, principled ways to ensure that their family members live meaningful, involved and secure lives within their communities. Her work is rooted in a social role valorization framework and she is involved with valued-based initiatives, writing, and training across the GTA, Ontario, throughout Canada, and internationally as well.

Email: [janet@legacies.ca](mailto:janet@legacies.ca)



Tiffany Dawe

**T**iffany Dawe is a Canadian woman in her thirties who has had a home of her own within the Rougemount housing co-operative for the past 15 years. She is an artist who works in natural watercolours and increasingly in vivid, lively acrylics on larger and larger canvases. She is a long-time environmentalist as head of the Butterfly Garden in the Rouge Valley, home of the largest urban park in North America. Tiffany also volunteers with the local pioneer museum, sits on the local art guild, is an active church member and supporter of her church choir.

At Rougemount, Tiffany is known as a great host to many parties, events and gatherings. Along with other co-operative members she upholds Rougemount's tradition of being good neighbours to one another, thereby creating an intentional community of possibility and welcome. Tiffany has often, but not always, shared her bright, spacious three-bedroom apartment with a room mate – typically, a young working woman of her own age who pays her share of the rent and shares time and

space with Tiffany in natural and unpaid ways.

Tiffany graciously embraces the support of her parents, dear friends, and others in paid and unpaid roles to help her build and maintain a home that reflects her truest nature and is a stepping stone to the rest of her life. This support looks natural and comfortable, and yet is intricately planned to ensure that Tiffany is safe, well and actively involved in her life.

Tiffany is a woman who does not speak, and requires a significant amount of thoughtful and sensitive support for almost all aspects of her personal grooming, her diabetes and other health-related care, the planning of her day, moving around her community, contact with others, and all of her household management. In getting to know Tiffany, both paid and unpaid assistants and support people come to understand how she communicates and thereby directs her own support in many ways.

Tiffany and her family are one of seven families that form Deohaeko Support Network, a family-governed individualized and supportive network in Pickering, Ontario. The families initially came

together about twenty years ago to think about how and where their adult sons and daughters with disabilities would live in the future. Since that time, they designed and had built a 105-unit housing co-operative that is now home to about 225 ordinary people looking for housing



in the region. Most, but not all, of the seven individuals who receive support have chosen to call this co-operative home. The families form a tight, supportive and thoughtful unit as they continue to plan and figure out both day-to-day life and the future for and with their sons and daughters and each of their circles or networks. At the same time, the seven individuals live very separate and unique lives – each with homes of their own, their own separate support funding, various support arrangements and a variety of ways that they choose to be connected with their neighbours and greater community.

Linda, Tiffany's mother is a thoughtful woman who maintains the vision of a good life for and with Tiffany. She has many wise and insightful thoughts to share about the impact of how home and support work for Tiffany and those around her.

### **What does Tiffany's home and lifestyle mean for her?**

I think Tiffany's home means several very important things. First of all, a home of her own means ownership for Tiffany and this has a ripple effect in her life. When people have their own home, it enhances their competency and their confidence. This is very evident for Tiffany – people see her as more competent, and she has grown in her confidence as she receives and welcomes friends, guests and visitors into her home.

Secondly, having a home of her own allows Tiffany to live her own life more fully. She loves people to come into her home, her space. Having her own place allows this to happen. It cannot happen in

a group home, in her parent's home or even in a shared arrangement, but it can happen in a home that is fully hers. She can invite and entertain and celebrate and welcome as much or as little as she likes. People can't really interfere with that.

Another thing is that Tiffany has her own belongings around her and her home is truly hers. That's huge. When you live some place and the things around are not really yours, you feel some

restrictions on using it – even if it is living with family, or someone of your choice. For Tiffany, right now, it all belongs to her and she decides where to put things, and what to have around her.

Living as she does gives Tiffany all kinds of freedoms she would not otherwise have. She can decide to do something or to do nothing. She decides how to use the rooms she has. For example, she is currently using the spare bedroom as a small art gallery. She decides on décor and furnishings – with the same financial limitations and possibilities that any of us on a fixed income feel. She decides when and how often to have shower, do the laundry or just hang out. Although daily life falls into a pattern that makes sense for her, she can change her mind about doing any of those day-to-day things in her home as she feels like it.

### **What has Tiffany gained from her home and lifestyle?**

Well for one thing, she does not have to live with her parents! As much as she loves us, it is clear that she loves to live away, fairly independent of us. Of course, because she requires assistance with many things, she now, in some respects, relies more upon other people than she used to, but interdependence with a wider circle of people gives her a much greater sense of independence overall. Also, just to be absolutely clear – people who support Tiffany do so at her direction, relying on her for advice, guidance and detailed feedback.

And she has gained in many other ways as well. She has more excitement in her life, more fun, more freedom, more opportunity to welcome

other people and be welcomed. In addition, she has influences from a wider range of people, and therefore she has tried things her father and I could not have thought of. She has relationships with other people that are separate from her parents.

It is also very obvious that others have also gained by Tiffany's presence in our co-operative and community. Because of Tiffany and the kind of home that she wants to have, other people have had lots of fun, good food and companionship. They have shared in her excitement in the ordinary, wonderful things in life. They have gained insight and understanding of how Tiffany can live in her own home well. I think that many people feel better about themselves

by being a part of Tiffany's life. They are involved in giving and receiving and that just feels right. They gain a deep understanding that if we can figure things out for Tiffany to live well, we can do so for almost anyone. This expands people's ideas of community and what is possible.

I think that Tiffany also contributes much to her neighbours, friends and family. She always takes up opportunities to be a good co-op member and neighbour. She chats and keeps up with her neighbours, attends regular co-operative meetings, and helps to plan and attend social events. She greets visitors and others in the lobby and shows them the friendly, welcoming face of her community. With her family, Tiffany is usually kind, cheerful and thoughtful. She is patient when life is imperfect and things need to happen in unusual or unexpected ways. This attitude contributes to our ability to figure out the problems – Tiffany keeps us focused. Her friends know that a greeting from Tiffany is a hearty, joyous welcome that they receive from no other. To be chosen by Tiffany in this way feels like an honour and a blessing.



## What does having a home of her own mean for the rest of Tiffany's life?

Tiffany shows us that living in her own home in this way is very satisfying for her. It provides her with variety and access to many things just as they happen. Each day is different from the one before, and yet there is a strong rhythm so that much is also familiar and knowable and something to look forward to.

Having her own home in this way means that Tiffany can live in similar ways to many other people. Like other women of her own age across the city, she can have a good deal of control over many aspects of her life. She can share her home, her

space with others, and her time as she chooses. She can stop and start things, and try out many different opportunities as they come across her path.

I think that having her own home also keeps Tiffany safe from less desirable situations. If others think that she just occupies a bed, then that can happen in

many places. But if she can keep her home, and others see her as having a home of her own, then no one will say she has to go someplace else.

When other people see Tiffany in her own home in many ordinary ways, they can imagine how she could then be a part of the rest of her community in similar ways. It begins at home. When home is typical and makes sense for people, they can believe that it works in similar ways beyond her home.

Finally, I think that Tiffany having and fully enjoying a home of her own is inspiring for other people, especially families. When people see that a home and this lifestyle are possible for Tiffany, they begin to believe it can be possible for anybody. When people first see Tiffany, they cannot immediately see her gifts and competencies, and yet they see that life is working well for her. When they begin to see that it works because we focus on her interests, passions and gifts, they realize that this can be done for and with anybody. That is the power of a good model and Tiffany provides this for many people.

# How genuinely supportive persons, agencies and systems can enable people to have real homes of their own

by Michael Kendrick PhD

This paper was published in the *Crucial Times*, Issue 40, pp 13-15, Brisbane, Australia, March 2008

Michael Kendrick is currently an independent consultant in human services and community work with a focus on both national and international work in the United States, Canada, Australia, New Zealand, and the United Kingdom. He has a passionate interest in the provision of quality services to people with disabilities and other marginalised people. With over 25 years of experience, he has made a significant contribution to the field as an educator, consultant and advocate.

A listing of his various publications and training he offers is available at [www.kendrickconsulting.org](http://www.kendrickconsulting.org).

Email: [kendrickconsult@attglobal.net](mailto:kendrickconsult@attglobal.net)



It is not always the case that what ordinary people may think of as a “real home” is necessarily shared by agencies and systems. This is because everyday people exist in the world of normative culture in which a home can mean much more than simply having a place to live. 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 ourselves and reflects our deep identity, values and preferences for a good life.

Agencies and systems are not impervious to such concerns about home, but they may often come under the sway of other intentions and preoccupations that can help distort how “home” becomes interpreted in practice. What follows are some initial guidelines as to how supportive persons, agencies and systems can define their role in such a way that they can become a help rather than a hindrance to its achievement in the lives of those who may require support in order to obtain a home of their own.

- **Supportive persons, agencies and systems should recognize that people should have sovereignty in regards to their homes and lives**

It is quite normal for people to want to be “captains of their own ship” and to have the dignity of being master in their own lives. Often, when such persons require assistance in their lives, this dependence upon others can often act to undermine this

autonomy, should the supporters act in ways that assert their dominance of the person life and home. On the other hand, should such support persons, agencies or systems be deeply appreciative of the person’s need to preserve and assert their personal sovereignty, then it would help create the “right relationship” between such persons and those who seek to support them. In most instances, the ideal result is that one’s home is one’s castle.

- **Recognize that supportive persons, agencies and systems should “idealize” what is a “real” home and be guided by this**

It is unlikely that supportive person’s agencies and systems can properly help uphold the fullest potential of what might be a “real” home of one’s own without first taking the step of defining what ideals should guide the creation and thriving of people in their own homes and lives. Such ideals, if they are properly understood and appreciated, can then help guide their conduct, roles and perspectives relative to people and their lives. In this way, they may move from possibly undermining “real homes of one’s own” to becoming champions of this purpose. Nonetheless, they will fail in this task if they do not first thoroughly clarify and sincerely embrace what are the ideals that best represent “real homes of their own”. Should this occur, then it then becomes possible to help people to optimally obtain and sustain “authentic homes of their own”.

- **Supportive persons, agencies and systems should recognize that one's home should be principally a private and personal setting rather than a public one**

There is much to be lost when one's home has become a public rather than a private space. For this reason it is necessary that supportive persons, agencies and systems intentionally start from the premise that people's homes ought to be kept private and personal rather than to be converted to places that are no longer private. By "public spaces" it is meant settings that are not controlled by the person but rather are dominated by other impersonal entities operating in the public domain such as agencies and systems. This tendency may be further strengthened by laws, regulations and practices that assert more authority over what happens in one's home than the person whose home it is. This intention to keep the home to be principally that of the person does not mean that it cannot be supported by public funds. Rather, it simply means that having a home of one's own can also be the goal of public funding authorities.

- **Supportive persons, agencies and systems should recognize that designing, establishing and sustaining a home of one's own should be principally done by the person whose home it is**

Though many individuals may require assistance to fully design, establish and sustain a home of one's own, this is no reason not to have them be unambiguously central to helping a home become their home. When a home becomes dominated by persons and entities other than the person whose home it is and should be, it raises the quite legitimate question of whose home it actually is. The only way to know for sure is to eliminate any other possible rivals for dominance of the home and to entrench the person as the undisputed sovereign of their home and their lives. Further, such individuals should have the opportunity to explore and pursue all of the rich and diverse options for what home life can be such that their eventual "home of their own" is as fully developed as could be.

- **Supportive persons, agencies and systems should recognize that whenever a vulnerable person requires safeguarding or supervision that this should be accomplished without subordinating or weakening the person's sovereignty in their home and life**

The tendency to "take over" a person's life can readily be justified by many if the person's conduct is

wanting or if the person is facing consequential harm or damage and has not taken appropriate action to prevent such outcomes. Though in moments of panic or anxiety on the part of supporters, it may not always appear this way, supporters can readily undermine people's sovereignty by refusing to approach personal supervision and safeguarding from the view point that supervision, protection and safeguarding of people need not come at the expense of their sovereignty of their homes and lives.

- **Supportive persons, agencies and systems should assist the person to personalize their home and lifestyle**

A person's home is an expression of who they are and it is expected that the home of a person should reflect the personality of the person whose home it is. It should not be assumed that this personalizing of home is always immediately possible, as with some individuals it may be harder to do this and such individuals may simply require more support in order to do as well as might be feasible and optimal. Further, since each person is unique in their needs and requirements to succeed with making a home of their own, the type and extent of support should be adjusted to best address the person-by-person nature of "home" and lifestyle.

- **Supportive persons, agencies and systems should not own and control people's homes**

The argument for a separation of housing from support has been made on many occasions and has much merit. However, simply separating these functions alone may not entirely resolve this issue, as even in exclusive support roles, many persons and agencies could still exert control and dominance of the person and their lifestyle. The advantage of agencies not "owning" the person's actual home is to both emphasize the person as holding unambiguous home ownership or tenancy and narrowing the question to one of whether the supportive person or agency undertakes its support duties within the proper framework of respect for the person, their home and lifestyle.

- **Supportive persons, agencies and systems should adopt approaches to management that shield people from unhelpful or invasive bureaucracy**

While not all bureaucracy is noxious and invasive, there are variants of bureaucracy that are. Increasingly, many conventional residential services are awash in bureaucracy of all kinds that is largely imported into them due to the requirements of the agencies that either support or fund such settings.

This invasive bureaucracy can radically turn one's (private) home into a regulated site such that it begins to become the agency's home due to the agency's ability to impose its requirements on the home. Though many people may not realize it, much of this bureaucracy can be diverted from people's homes or otherwise minimized in terms of the amount, noxiousness and level of control that has an effect on the person and their home. To do so will require that the agency take intentional measures to bring this about since it is the principal vehicle for both the imposition of such bureaucracy as well as its withdrawal.

- **Supportive persons, agencies and systems should not compel nor coerce people to live together**

Though coercion of this kind is not a practice that agencies like to acknowledge, it is nonetheless quite widespread for agencies to assemble and modify the composition of households. This is in contrast to the occupants of homes largely deciding with whom they wish to live with including opting to live alone. These practices can be overcome by simply relinquishing sovereignty back to people to themselves decide with whom they wish to live. Put another way, it means that all relationships of home sharing must be entirely voluntary and the specific terms of these negotiated between the parties rather than household composition being imposed by other parties outside the home. This also applies to supporters that may either reside on the home or visit. These relationships should also be voluntary in nature and respect the shared and individual sovereignty of the persons who reside in a given home.

- **Supportive persons, agencies and systems should welcome, respect and cooperate with the person's relationships and personal networks**

Part of making a home of one's own is to integrate one's home life with one's web of relationships and one's lifestyles. This task will be thwarted if the supportive people or agencies in one's life lack suitable regard for the people in one's life. Relationships are an integral part of home life and personal lifestyle and it is important to uphold the relationships and networks that are important to a person. Relationships can also be very private and personal and therefore may need to be respected with this in mind by supportive persons and agencies. It may also be true that some individuals would like to strengthen and expand their relationships and networks and may benefit from competent and thoughtful assistance.

- **Supportive persons, agencies and systems should utilize arms length governance mechanisms that enable people to have directive authority over shaping the supports they receive**

Many agencies are unaware that they can fashion ways to partner with people to ensure that such persons are placed in a directing role relative to the supports they use. Such empowered options can include various mechanisms such as hosting of service user governed projects, providing administrative, financial and other back-up to self directed or self-managed individual supports arrangements and even cultivating and spinning off new mini-agencies or projects. To do this would require that agencies cease their preference for authority to rest only with those in elite agency positions and to delegate decision-making about the design of services downward and outward to the service user and their allies. This would make agencies champions of the empowerment of people and extensively reduce their role as an obstacle to people directing their own supports, including those that come from unpaid sources.

- **Supportive persons, agencies and systems should avoid support arrangements that unduly commercialize relationships with supporters in home sharing arrangements**

The sharing of home with "ordinary" people with whom one is compatible is clearly an option for many people. The voluntary nature of these relationships can become obscured whenever people are paid to live with a given person, such that the money becomes the rationale for home sharing rather than that the people involved are compatible with each other and choose voluntarily to share a home. In many instances where the amounts of money are sizable enough the paid home sharing essentially becomes a job and the home a place of work. In extreme instances, the paid person quits their former employment because they can make comparable money doing "home sharing". While such homes may preserve much of what makes a home a home, it is nonetheless a return to homes being a part of agencies and systems.

Genuinely supportive persons, agencies, and systems can become welcome allies for people who want to have genuine homes and lives of their own. At the same time, they can also be an obstacle if they do not appreciate the many ways that they can get in the way of this goal. It is no "accident" to become a useful ally of people and it is important that people, agencies and systems that want to be genuinely supportive carefully study the differences between what helps and hinders, so that they can make and hold to the decisions and principles that matter most.

# Some reflections on homeshare ~ a more natural way of support

by Kieran Jeff

Kieran Jeff has worked for Wesley Mission Victoria for 5 ½ years with people of varying disabilities within the residential and day services and is currently enthusiastic about people's independent living choices. Having experienced 12 years within the traditional disability service provision model he has become aware of its shortcomings. He is committed to the establishment of individual, person centred approaches for people with disabilities and is currently working with Homeshare (Wesley Mission).

Wesley Homeshare phone: 03 9666 1231

**H**aving nursed my wife during her battle with cancer it was my introduction into what it is like to support someone in a carer role. After she passed away I was a single parent with 3 young children. I gave away my profession as a musician and started a journey of learning and self reflection.

I then met a young lady with Cerebral Palsy, and her family. Jane's (not her real name) mother, was a single Mum with two other daughters. Jane's Mum was one of the most inspirational people I have met. Jane's support needs are very significant. Jane had no obvious communication skills or aids and most people treated her in a patronising, fearful and very uncomfortable way. I became this beautiful young lady's support worker and friend. After 12 months of support I began to understand the signs and signals of Jane's communication and her sense of being, her humour, her grief, her compassion and her anger. It was one of the most inspiring times of my life.

I then went on to coordinate a program supporting young adults to integrate into adult life. Supporting people to independence through vocational, educational, training and skill development leading onto employment. Through this I formed strong relations with the people I supported and their families. I have personally witnessed the trials, tears, laughter and love, family persistence and fortitude in navigating the minefield of service provision and funding requirements to achieve the best possible outcomes for their children. I have witnessed family struggles with a seemingly unjust system of government and service provider rhetoric.

Over the next ten years I managed a day service

supporting 35 people to live in community residential units, supported residential services and supported employment.

When the new Victorian Disability Act 2006 took effect the focus shifted from the service provider to the person with a disability. Person Centered Planning and similar approaches were now the vogue. As a person providing a service to people with a disability I was expected to support people individually within a group structure. How was I supposed to do that? It did not make sense to me.

Things changed in the way I perceived the disability sector when I attended a forum where Dr Michael Kendrick spoke. Dr Kendrick made a statement which has stayed with me, "you can't make apples out of oranges." This is in reference to supporting an individual in a group environment. You can't do it. If you think you can you are fooling yourself.

After much soul searching and reflection I decided to leave the day service and took a role with a program called Homeshare. This program is supported by Wesley Mission Victoria. Disability Homeshare is an innovative shared living arrangement where two people come together for mutual benefit. The program matches householders who are looking for companionship and some practical help around the home with home-sharers who are able to provide this assistance and contribute to household expenses in return for free accommodation. The real essence of Homeshare, I believe, is the creation of informal support, forming a natural system of relationship, breaking down the stereotyping and preconceived ideas. I have witnessed this process and have seen these relationships bloom.

Home sharers come from a wide and wonderful array of backgrounds and experience. For example, some of the home sharers include a chef, a PHD student from India, an accounting student from China, 2 nurses, a commerce student, and other people from all walks of life with no disability background. All forming very close and personal relationships with the people they live with who have an array of disabilities.

As the Wesley Disability Homeshare continues it is becoming much clearer how amazing the outcomes are for Homeshare people living with a disability. The matches being monitored and supported by the Homeshare coordinators are proving without doubt the importance and potential of Homeshare.

I believe the more natural supports in place within someone's life the more viable and secure that life becomes. The idea that paid supports are fulfilling the wholeness of a person's life is unsubstantiated. Paid supports directing a person's life is not always what the person really wants. Yes, the physical needs are supported, and as well meaning as support services are, the real wants and aspirations cannot be met. This is why Homeshare can be the missing link in introducing and providing wholeness, wellbeing and natural supports into a person's life.

Here is an example of an elderly gentleman living with an Acquired Brain Injury. This person (I will call John), has been living in the family home alone for the past 10 years after the death of his parents. John has no family support, and as such has become significantly dependant on his paid supports, including Case Managers, who have changed four times in 12 months, and on his Personal Care Attendants. He calls his Case Manager "the boss" which is indicative of how he feels toward his paid supports. Ironically both the Case Manager and Support Worker consider each other to be the cause of this person's emotional dependence on paid supports, leading to an uncomfortable situation. The Case Manager has just resigned and has organised for the new Case Worker to locate a new Personal Care Attendant leaving the householder confused and angry. Again, the breakdown of the paid support mechanism is demonstrated.

Recently Wesley Disability Homeshare has matched a Homesharer, Allan, to move in with this gentleman. Allan is a male psychiatric nurse who started nursing at the age of 59. Allan has great empathy for people in general and particularly people living with mental health issues or have a disability. This empathy is something Homeshare

looks for when recruiting a potential Homesharer.

John had interests in farming and horses, as he worked on a farm as a horse breaker and jackaroo before his injury. Allan grew up on a farm and was a farmer for much of his adult life and had great interest in horses. Both John and Allan had similar interests. Allan's experience in psychiatric nursing supports him in understanding some of the complexities for someone living with an acquired brain injury.

The trial period of one month was reasonably successful for both people as they got to know each other. John's carers were suspicious of Allan, making this quite obvious by insisting Allan abide by the rules. This type of control shown by John's carers, always well meaning, was very disconcerting for Allan. Allan chose to stay out of the home, or stay in his room when John's carers were present. His behaviour changed, becoming submissive and compliant around his carers. When the carers asked John if everything was ok John would always respond in a positive way, even if this is not true. For example, John's serious migraines went undetected because John wouldn't tell anyone. Only having Allan in the home has made the frequency and severity known. As the match progressed Allan has become aware of John's behaviour and the complexities of daily living that no-one else is aware of. Only having someone live with John have these issues come to light.

John's quality of life has improved significantly due to Allan living and sharing with him. His social skills have improved and he is communicating his feelings more openly. Allan has created strategies to support John when his inability to cope with a situation causes anxiety. These strategies have occurred naturally rather than the previously experienced service driven strategies which sometimes lead to a power imbalance.

Recently Allan was asked by one of John's carers "what are your future plans?". John responded "I am not sure". The carer responded "you can't leave, because John really likes you". John "liking" someone who is not a paid person is a significant breakthrough as Allan is the first person in many years to become a friend. The formation of friendship is the ultimate outcome for any person moving from a life of isolation into the community. Homeshare is proof that with the right planning and support any vulnerable person can live a life without loneliness and fear of community exclusion.

# Accommodation ~ it's more than a matter of housing

by Jo Walters

Living Distinctive Lives (LDL) is a small family governed group with a focus on supporting each person with a disability to move into and to live in their own home. However, the members of LDL believe that a house alone does not equal a good life, so rather than looking at accommodation in isolation a whole of life approach is taken and each individual is supported to connect to and entwine with the fabric and life of the community that they are a part of.

Jo Walters is the coordinator of Living Distinctive Lives. She has worked with this group for the last 2 years as they support their sons and daughters to live in their own homes and to develop meaningful lives in the community. A member of the PLA committee Jo is also currently studying a Masters in Transformative and Integrative Studies at Oases Graduate School. Through her study she is exploring community as a dynamic living organism which, in order to be sustainable and healthy, requires each and every individual to express their intrinsic Self and fulfil a vital role. In this way she is looking at how best to work with individuals with a disability, their families and the wider community to support this process.

Email: [ldlcoordinator@optusnet.com.au](mailto:ldlcoordinator@optusnet.com.au)



**T**he desire for home is a desire for comfort, safety, security and self. Home beyond all other places is where we can really express who we are, a place where we belong, as this quote states, “A house is made of walls and beams; a home is built with love and dreams” (Author unknown). This is why on the topic of accommodation options for people with a disability it is important not to start with the question of a house, but with the question of a life. This is why in my role as Coordinator with Living Distinctive Lives I find myself focusing not on housing alone, but working with families on the creation of a vision, a dream of what sort of life it is that their son or daughter wants.

This is done by supporting each individual and their family to develop a positive vision for the future; they are supported to think about what it is that they want, the type of home, who they would like to live with, social connections and work roles, and then what supports they will need to achieve these goals. It is then a process of co-creation, and planning. Each individual is also supported to identify those who are around them who support their vision; this can mean building upon existing relationships, and developing new ones. These allies may be in the form of family, friends, neighbours, support workers, housemates, and disability support services that are willing to help hold the vision for a good life, lived in the community.

As well as the development of a vision, the families in LDL are also committed to the following principles. These principles form a foundation for planning and action and act as a reference point as people move towards their vision of a good life.

- A circle of supportive people is essential to the well-being of individuals in the community.
- All individuals have the right to a meaningful life in the community.
- All individuals have the right to decide where they want to live, who they want to live with, and how they want to live.
- Home is about being connected to community and having valuable roles and relationships.
- Life planning should be creative and driven by the individual and those closest to them.
- The needs and preferences of individuals change over time and they should be supported through these changes to ensure a satisfying life.

In my role I have come to believe that the following points are of great importance in achieving positive outcomes, and a good life for individuals in their own home in the community.

- A plan should be a living story of somebody's life, and the life that they wish to have. It should include all aspects of the person, from personal care needs, and health concerns through to goals

around personal relationships, spiritual needs and safeguards for the future.

- The planning and actioning should be driven by the individual and/or their family and those closest to them.
- It is important for each individual and their family to have all the information and knowledge that is important to them. This includes information on funding dollars, funding applications, and to know the true cost of the supports that they have in place.
- Individuals and families should use this information to decide where their funding is held and what it is used for.
- Individuals and families should be supported to decide who works with them and direct the workers themselves.
- For many individuals and their families this is a process of regaining the authority to make some of the most important decisions in their lives, such as where they live, who they live with and who will support them.
- The role of informal supports cannot be understated; these allies can help through the planning process, through providing social supports and by reinforcing the goals and vision that has been developed.
- A home of one's own is not about independence but of meeting each individual's needs with a range of supports and striving to achieve the vision that they have for their future.
- Any person, regardless of their disability is able to be supported to live in their own place, and with individualised support they will be much more likely to have their own unique needs met.

In 2009 LDL also established the Community Inclusion Initiative; this was made possible by a grant from the Scanlon Foundation, and means that LDL also has the resources of a Community Inclusion Facilitator. This project is focused on building inclusion and social cohesion, by connecting individuals with their communities and increasing the communities' ability and interest supporting the inclusion of people with a disability. This is done one person at a time, building on each relationship to establish strong and meaningful community connections. Another key aspect of LDL is in supporting families to build their capacity, to take on leadership roles in the community, and to share their stories with others.

The individuals and families in LDL are on a journey, and whilst the goal is for a home of one's

own, along the way members are also looking for and finding

- ways of meeting each individual's unique needs
- of achieving inclusion
- of pulling back from a reliance on services
- and are stepping out of the role of client and into the role of community member

Living Distinctive Lives is not a service, it is if anything a mechanism for individualised vision building, planning and support. LDL does not have clients, it has group members, individuals with a disability and their families, it also includes the support workers, the circle members and other allies, and is interested in looking at how to further involve and connect these people to the group. LDL doesn't do things for people; rather it gives people the support and structure to make significant improvements in the lives of their family members, as a group LDL helps to inspire and to facilitate change.

### **Colleen's story**

At the end of 2009 Colleen moved into a two bedroom unit in Ashburton. She lives there with her housemate Wen and her dog Danya.

During the day Colleen volunteers at a children's music group, she attends swimming lessons and water aerobics and is part of a local drama group. Colleen has also started working at Coles part-time.

Colleen's life wasn't always this ordinary. Ten years ago Colleen had a stroke, from which it was thought she would never recover. Colleen continues to live with the effects of the stroke; she has an Acquired Brain Injury, which impacts on her in a number of ways but with much planning and a range of innovative supports Colleen has been able to realise her dream of having a home of her own.

After an extensive period of rehabilitation Colleen moved into supported accommodation. However she wasn't happy in the group home so moved in with her parents. To help her maintain her independence as much as possible her brother built her a flat out the back of her parents' house. However she was in effect still living with her parents and they were still providing the majority of support.

The family recognised the need for change and so started to look for ways for Colleen to have her own life, but with the supports that she needs. In 2008 the family met Deb Rouget of PLA and over a period of months started to plan for the kind of life that would

met Colleen's needs, and fulfil her goal of moving out of home. Through attendance at conferences and workshops put on by PLA they got to listen to other people's stories and became inspired to find a way for Colleen to achieve her goals.

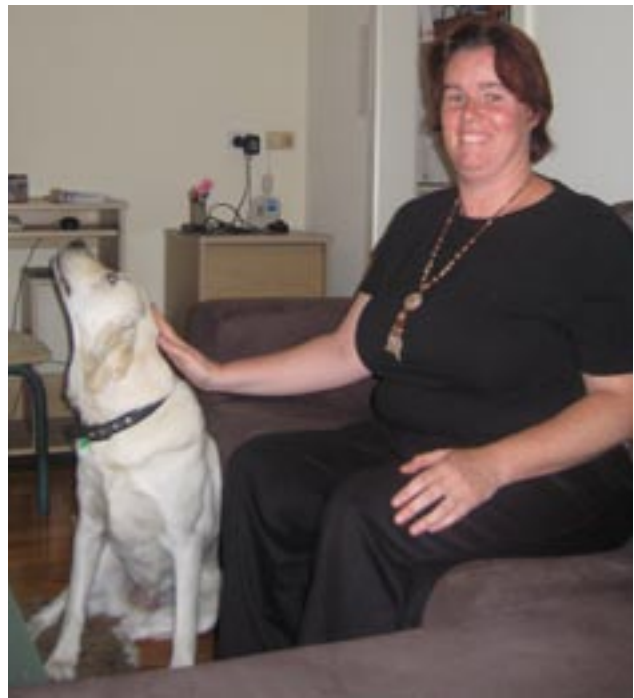
Deb introduced Colleen and her family to Living Distinctive Lives, a small family Governed group, who with the support of a Coordinator, and community inclusion facilitator, plan, and create ways for individuals with a disability to live an ordinary life in the community, a life outside of the disability service setting.

Part of this process involved establishing a Circle of Support around Colleen; Colleen and her parents also decided to have the funding Colleen receives from DHS hosted by a service. This arrangement gives the family the autonomy to select, supervise and direct the support workers in Colleen's life.

To support Colleen in her own home her family looked for a Housemate, who would get along well with Colleen and also be able to provide some support. Arranged through Wesley Homeshare Colleen's housemate Wen helps her out by preparing some meals and assisting with other tasks. In return for this Wen receives her accommodation rent free.

Today Colleen has the responsibilities and the choices that for most of us take for granted, this has only been possible because her family wanted to find way for Colleen to live her life her way.

The story shared here is a part of the journey that Colleen and her family are on, the starting point was recognising that life could be better, then Colleen was supported with her family to voice what it was she wanted, to develop her vision of a future, and to think about what arrangement would meet her needs, increase her independence, and allow her and her family to retain authority and choice. This paved the way for planning and the steps that have been taken so far. But Colleen's journey continues, new ideas are born, needs change, interests vary, support workers move on and more need to be found, all of this is a continual process of change, of listening, of looking, of always keeping your eye on the vision, and slowly and steadily moving towards it. Colleen's story is unique, it is hers, and hers alone, it is also however an example of how LDL works. It demonstrates that by coming together around core values, by sharing strong principles, and holding onto hope for the future, each person with a disability can be supported to move into and to live in their own home.



Colleen with Danya

## Personalised Lifestyle Assistance (PLA)



2/18 Floriston Rd Boronia, VIC, AUS 3155. Phone/FAX: +61 03 97398333

### APPLICATION FOR ANNUAL SUBSCRIPTION TO THE PLA PERIODICAL "THINKING ABOUT..."

PLA is a small community based advisory service developed by families. It aims to inspire and build capacity/knowledge predominantly with people who have a disability & their families to enable them to have opportunities *typical of other citizens in the community*. PLA is people/family friendly & value driven. PLA believes that all people should have the opportunity to pursue a unique lifestyle that is personally meaningful, relevant, empowering and intertwined typically in the community. This membership entitles you to receive all notices about PLA events and receive the PLA quarterly periodical "Thinking About...." (4 editions during one year). It also helps to support the work of PLA.

### **TAX INVOICE: Melba Support Services Inc. ABN 39 848 842 276**

*If Requiring a TAX INVOICE please copy this form for your records. Receipt issued on payment*

FIRST NAME	SURNAME

INTEREST e.g. Person with a Disability/Family/Worker etc	ORGANISATION NAME (if applicable)

POSTAL ADDRESS:		
STREET/ROAD	TOWN/SUBURB	
STATE	COUNTRY	POSTCODE

PHONE	MOBILE	FAX	EMAIL

TYPE	EMAIL COST PA	PRINTED PA (INCLUDES POSTAGE WITHIN AUS)	EXTRA PRINTED COPIES (ADD \$40.00 PA PER EXTRA COPY)	TOTAL COST PA (AU\$ - INC GST)
Health/pension card holder/families <b>not</b> sponsored by an agency (no copying or further distribution permitted)	\$30.00	\$50.00	\$	\$
Student (no copying or further distribution permitted)	\$50.00	\$70.00	\$	\$
Professionals (no copying or further distribution permitted)	\$80.00	\$100.00	\$	\$
Small collectives/agencies (copying or distribution permitted up to 5 members/staff)	\$100.00	\$120.00	\$	\$
Agencies (copying or distribution permitted)	\$160.00	\$180.00	\$	\$
Donation				\$
<b>TOTAL</b>				<b>AU\$</b>

**Cheques Payable to:** Melba Support Services Inc. ABN. 39 848 842 276

**Credit Card Payment:** Please complete **all card details** **ALL PAYMENT MUST BE IN AUSTRALIAN DOLLARS**

Please Tick - No other cards accepted		Card Number		Expiry Date
Mastercard	Visa			

Card Holder's Name	<b>Card Holder's Signature (We cannot accept if not signed)</b>

**Post Membership Application to:** **PLA Periodical & Membership**, Suite 2/18 Floriston Rd Boronia, VIC, 3155  
 Or Fax: (03) 9739 8333, or **Email:** [laura.sykes@plavic.net.au](mailto:laura.sykes@plavic.net.au)  
**Further Info:** Phone (03) 9739 8333