Some Reflections on What Might be Needed to Assist People with Disabilities to Become Authentically Included in the Community.

Deb Rouget
Personalised Lifestyle Assistance (PLA)

Introduction

This paper aims to offer some reflections on what has been helpful in PLA's efforts to authentically assist people with disabilities to become active contributing and valued members of their communities. Our reflections stem from the individuals and families we have assisted over many years who have struggled to live a "typical" life in the community. A life that is not extraordinary but ordinarily of community.

What is PLA?

Personalised Lifestyle Assistance (PLA) is a small semi-autonomous community based advisory service/resource that was developed by families in 2003. It aims to inspire and build capacity and knowledge predominantly with people who have a disability and their families to enable individuals to have opportunities *typical of other citizens in the community.*

PLA employs a part time Manager and Assistant. It is directed by a Committee of Management that comprises of a person with a disability and families together with professionals that believe in PLA's aims and principles. In order to avoid duplicating administration resources, PLA is 'hosted' by Melba Support Services. PLA has operated on a series of non recurrent grants from the Department of Human Services (DHS).

PLA's believes that *all* people should have the opportunity to pursue a unique lifestyle in the community that is personally meaningful, relevant and intertwined typically in the community. Its core principles are authentic community/social inclusion, typical opportunities, empowerment and individualisation.

To achieve its aims and principles, PLA provides inspiration, information and education to people with a disability, families and professionals via providing theory, a stream of ideas, and practical (real life examples) that create alternatives to segregation and congregation. This is achieved through information dissemination, sharing stories, courses, retreats, a bi-annual conference and other materials such as a periodical, occasional papers and web site.

PLA also provides one to one advice to individuals/families to enable them to form a vision for a good community life. This may also include assistance to plan, implement, review and safeguard their vision. PLA places an emphasis on strengthening & building people's own

skills and building informal networks around people rather than relying only on paid supports.

PLA has also assisted with reshaping disability support services by assisting people with a disability and their families to re negotiate and reorientate their relationship so that services and supports are authentically driven by the individual/family. This has resulted in a number of arrangements that are individually hosted with various services in which the person/family directs all supports. PLA has also assisted in the establishment of 3 self and family governed collectives in Melbourne (Nightlife, Living Distinctive Lives and One by One.

The following elaborates on our reflections on what might be needed to assist people with disabilities to become authentically included in the community.
The reflections are also supported by the research by Cocks & Boaden (2009) and Carver (2009).

1. **Maintaining unambiguous guiding principles about belonging and social inclusion**

In a world that is filled with conflicting agendas, materialism, business, expedience and other demands, we are continually tempted to pursue quick fixes, easy options and compromise our values. Our values are at the heart of everything we do but are at risk of being most compromised. PLA has worked hard to develop and maintain unambiguous guiding principles around social connectedness. These principles are our guide or our anchor. We refrain adamantly from subjecting people to opportunities that would *not* be available to other members of the community i.e. segregation and congregation based on disability. One of the guide posts that families often use is to ask the question "Would this option be pursued for my son or daughter who doesn't have a disability"?

> *"It's OK to want something better. You don't have to accept only what has just been offered or what has been offered in the past. As parents we need to give ourselves permission to think positively about the possibilities of meeting our son/daughters needs in a normal way – not different to our hopes and aspirations for all our children" Anita O'Brien (parent)*

It is not merely enough to have stated values and principles. They have to be lived in everything we do. It's a path that we practice but like all others we are not perfect. We try persistently to reflect critically with humility and openness. This motivates us to do and seek better. Chris Fyffe (2008) in an external evaluation of PLA, found that not only does PLA have operating principles and values consistent with and aligned to the State Disability Plan and Disability Legislation and arguably any contemporary disability policy but, of its self is less remarkable, than the evidence that PLA is actually assisting people to live these principles.

2. **Understanding and upholding a person's uniqueness - One person at a time**

PLA believes that all human beings, although sharing similar universal human needs are complexly and superbly unique! Thus it is an incorrect assumption to say that people who

have a similar diagnosis or disability want and need the same things out of life. This challenges many of the frameworks and services today that congregate people together based on disability to meet an individual's needs. Such services are not typically designed to create unique supports, one person at a time but are designed to accommodate/support groups of people who share the same label or diagnosis. Kendrick (2009) suggests that one of the major assumptions underpinning the practice of congregating people with a disability is the assumption that people who share a similar label or characteristic should, prefer or want to be with their "own kind". This assumption has an impact on how services are designed and ultimately the impact it has on a person's uniqueness.

Kendrick (2009) suggests that many service responses that exist today may be problematic to upholding a person's uniqueness because they are typically deigned before the person arrive by others rather than *with* people, designed around generalised specifications rather than unique or personal ones (one size fits all), are non-negotiable in regard to individual need and variance e.g. they're often financially based on pre set assumptions that can't not be varied to accommodate personal variances, based on service related routines that do not vary from day to day and week to week, usually inflexible and rigid as to model, method & resources and lack authority sharing with individuals and families.

PLA attempts not to make any assumptions about people or begin with preconceived ideas. We do not design anything before a person arrives. Thus when people ask for assistance we have to start to get to know them and those who love and care about them. This takes time as all people are different. They have unique histories, experiences, needs, passions, interests, dreams, routines, priorities relationships etc. Therefore the starting point with each person, their vision, priorities, lifestyle and pace will all be unique to them. No two people we assist pursue the same things.

If assisting people to apply for funding, each person's package is unique and based on their needs. Historically if people have been given standarised funding packages they all use their resources differently and uniquely and for different things. There are no predesigned programs, timetable, activity, lifestyle arrangement or destinations in life. The essence is one person at a time arrangements rather than groups.

If people's visions and plans for the future are unique then frameworks and supports need to also be uniquely tailored. Thus what is created in people's lives is as many models of support as there are people!

3. Identifying people's needs and honouring all aspects of people

We have found that we need to honour all aspects of people, not just their disability. A person's disability is only one part of their identity and should not define their life. If disability becomes the person's defining identity then they are at risk of living, working and recreating in disability settings and their lives become defined by service routines, programs and relationships with professionals and other people with a disability.

Michael Kendrick (2009) suggests a range of universal needs that are common to all human beings i.e. work, autonomy, respect, value and reputation, social inclusion, meaning and spirituality, identity and culture, relationship, respect for and exercise of rights, financial viability, health nutrition, vulnerabilities and safeguards, learning and growth,

communication, leisure, adaptive devices and transport. Incongruously although all human beings share some common human needs the way these needs are met will be complexly unique!

Once people's needs are identified and prioritised the work begins with people on identifying how their needs will be met in a typical or culturally valued manner.

4. **Meeting Needs in a Typical Way: Understanding Social Role Valorisation (SRV) & Using the Culturally Valued Analogue as a Way to meeting needs**

Although a complex theory, with increasing debate as to its relevance today, Social Role Valorisation (SRV) has offered us a remarkable explanation and foundation for why people are devalued or rejected by society and how people can be accepted and valued.

Wolfensberger (1998) defined SRV as "the application of what social science has to tell us about the defence or upgrading of the socially perceived value of people's roles" p58. This can be done through enabling, enhancing, maintaining and defending valued social roles for those at risk by using culturally valued means as much as possible (Wolfensberger,1992).

SRV conveys to us that often people with a disability are devalued in society because of a perceived difference, characteristic or identity. If a person is seen as being of low value then they are at risk of not being treated equally, not afforded the same opportunities as others in society or treated differently i.e. low quality treatment, housing, services, lack of employment opportunities, strange routines determined by staff etc. The person will also be at risk of rejection and then separated and/or exclude and denied the good things in life e.g. respect, supportive relationships, no access to the community/food/holidays or other. Once rejected or excluded from "mainstream" society people's needs are seen as "special" or different, thus needing "special" or "professional" help to meet all of their needs. Once people are segregated from society they are denied the richness that community has to offer or the opportunities that most people take for granted.

One way of overcoming the impact of social devaluation, Wolfensberger (1998) suggests, is by assisting people who are devalued by society to develop valued social roles. "A social role may be viewed as a combination of behaviors, functions, relationships, privileges, duties, and responsibilities that is socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person who occupies a particular position within a social system." p 25.

Wolfensberger (1992; 1998) also described the Culturally Valued Analogue (CVA). This is a useful way of thinking about meeting a person's needs i.e. what valued ways do other citizens in our society or culture meet this particular need? It may be a certain practice, pattern or custom. For example, if someone needs money in Australia they get a job in much the same way as other citizens by using their networks, word of mouth, newspapers, community adds (e.g. in shop windows), starting a small business based on their skills, volunteering to develop skills, studying etc. They do not automatically seek welfare or attend a sheltered workshop!

Along with the valued role of work comes many other valued roles e.g. colleague, contributor, friend, social organiser, shopper, wage earner, tax payer etc! The common

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

assumption though is that people with a disability can't work as they're seen as different and often denied this opportunity. Thus special work places have been developed for people who have a disability which do not offer the same richness of opportunity.

The constant question we ask in our practice is "if any other citizen had this certain need or want, where would they pursue it"? This way of thinking prevents us from thinking "special group" for people with a disability and thus helps to prevent the continued segregation and congregation of the people we assist. It has become an automatic response in our thinking which from the onset steers us to community belonging and connectedness.

For other needs the same thinking is followed - If a person needs a home they might use a real estate agent not disability services. If they need financial assistance to rent a house and can't afford it they might find a flat mate. If they need assistance to live in their home they live with a friend or housemate. They don't tend to live in a group home that is controlled by an agency! If they want to make friends they might join the local Rotary Club. If they have a spiritual need they go to the local Church or Buddhist retreat. If they want to learn ceramics they go to the local potter's studio or community house. If they need to further their education they go to the local university or school and so on. For example articulating Rachel's need for work was clearly articulated in the following manner:

> *Rachel needs to have a paid job which is based on her interests and abilities, respectful, local and in the community (not segregated, in "special" disability settings, with other people who are vulnerable or have disabilities). The work place should be friendly, organised, spacious, not too crowed and enhance Rachel's valued roles. Rachel wants to do something that "is challenging and meaningful".*

There are so many opportunities in the community that we fail to notice because of thinking "disability" rather than thinking in terms of the Culturally Valued Analogue. The community is awash of prospects waiting to be engaged and taken advantage of!

Once people are in such valued roles, community members are more likely to see people for what they contribute rather than their disability or label. The practice of meeting needs in a typical manner can have many positive effects e.g. reduces social isolation and increases engagement with the rest of the community, increases positive role models, various and multiple learning opportunities to develop and reach one's full potential, the development of a wide range of associations and friendships other than disability professionals and other vulnerable people, broadening of secondary interests that lead to further opportunities, increased safeguards as people are known in the community, increased community support and acceptance, less reliance on paid support etc.

> *Cameron is employed part time by a local business. It is an award paying job. Recently the Manager at Cameron's workplace said that not only did he do a wonderful job but the workplace had a different feel and some staff reported looking forward to coming to work on the day that Cameron worked! Cameron's shared interest of sport also led to a weekend away with his boss and work mates to the International Cricket in Tasmania. On his birthday, to Cameron's delight, his*

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

workmates organised an autographed Collingwood Football Club jumper as a gift. Cameron's work mates were invited to his 30th birthday party. When there were job losses at his work place he was retrained!

It is not to say that community can meet every need but it should be our starting point to think about every need. If it can't be found in community then perhaps it a specialised service may be useful e.g. a person with Cerebral Palsy may need a physiotherapist with specialised skills however the therapy could be carried out at the local gym rather than at a special day service for people with Cerebral Palsy. In addition this is only one need. The other needs of the person could be met entirely in community.

5. Understanding & strong ideas of what inclusion is & is not (i.e. not a program)

As we advance into the age of technology and materialism, it seems that community inclusion and community belonging is not just an issue for people with a disability but for all of human beings.

Often what makes it more difficult for the people PLA assists is that they have often journeyed unwittingly into an unfamiliar culture. A culture that has a heightened tendency to believe services, experts or professionals are the only way to meet one's every day needs rather than looking to their neighbour, friends, family or community to meet their needs. For example an interest in art can only be supported in a specialised art service for people with a disability.

The report "SHUT OUT: The Experience of People with Disabilities and their Families in Australia" outlines the continuing challenges for people with disabilities to be included in community life. The Executive Summary states:

> *"Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard."*

PLA stemmed from the struggle of individuals and families who felt that they had been "shut out" and did not belong to the community even with countless services, strong policy direction, good intentions, aspirations and Person Centred Plans! Individuals felt marginalised, segregated, congregated and rather than being seen as citizens they were seen as clients attached to services. Often a person's every need and movement was determined by professionals and services.

Inclusion means different things to different people. Vanier (1988) suggests that community is a place of struggle and sometimes of conflict but also it is a place of celebration, joy and

ultimately of human fulfilment. Historically congregate services have been built around people with a disability to protect them from the struggle and conflict that arises in community. But in doing so services often prevent the celebration, joy and human fulfilment that community brings.

PLA does not see that inclusion is a fantasy, an idealist place, somewhere you belong a bit, a choice, a panacea or a beautiful place where nothing goes wrong. Neither is it access, a program, a bus trip, a group outing to a park, "special" groups for "special" needs at the local neighbourhood house or time filling activity. It does not view social inclusion and belonging as a need only of people who have a disability but for all community members.

In ordinary terms "inclusion" is what the human race wakes up to everyday. It's our neighbours, families, schools, associations, friends, businesses and governments. It's an intricate web of experience and opportunity where we belong, learn, love and grow from the moment we are born. It's very "ordinary" and very familiar.

Wills and Jackson (1996) suggested that inclusion in regard to mainstream schooling includes being physically included, socially included and included in regular curriculum. Thus, social inclusion is more than physical presence – it's also a sense or *feeling* that you belong, are welcomed, connected, have something to offer or reciprocate and are surrounded by a range of relationships other than those which are paid or based on diagnosis. Janet Klees (2005) suggests that we can't force relationships to happen but we can build a context for relationship to grow and flourish with other community members. Thus enabling and supporting people with a disability to also experience, contribute, learn, problem solve and belong to what is good and difficult about community, can only happen through every-day or typical opportunities. If other citizens cannot participate on equal terms in an experience then we believe it is not genuinely "inclusive" or "of community".

6. Finding people's "hook" into community life

We have found it important to discover what might "hook" people into community life. This is done by discovering and harnessing people's unique interests or abilities. For example what is the person passionate about, what makes the person "tick", what gets the person up in the morning, what does the person enjoy most, what is the person good at doing etc. Once a person's "hook" is found it offers an opportunity for the person to share their common interest, cause, desire or skill with other members of the community. Once people share their interest it also provides an opportunity for people to get to know each other in terms of the interest. In addition if people contribute their skill then others see the person as having ability rather than disability. This highlights that people are more than their disability. Fear of the unknown often subsides as people see people as having interests and skills not that different from their own.

> *Lauren was passionate about TV and soap operas. Her passion was her "hook" into community life. It was harnessed by her family and she became an usher at a large theatre in the city. This was a great opportunity for Lauren and her self esteem and skills began to flourish. However her family really wanted her to belong and develop friends at her work place. Being a Melbournian Lauren is also passionate about*

football. Her family then used her passion for the Kangaroo's Football Club to "hook" her into her work place. They discovered many other passionate football followers! Lauren then went on to attend various football matches with a co worker who even went to the Footy Show with her!

7. The power of positive expectations and assumptions about people

If one is surrounded by positive expectations and assumptions then they will have a chance to live up to them. Alternatively if they are surrounded by negative expectations and assumptions then they will live up to those too! This is not only about people with a disability but also fellow community members.

Positive expectations and assumptions and high expectations about people are vital to imagining better as it frees one up to countless possibilities i.e. believing that *all* people seek happiness and fulfillment; have the ability to learn, grow and develop regardless of their age or disability; can love and be love; are equally as important as each other; have strengths and weaknesses; can contribute and become valued; belong to the community; live in their own home with a range of supports.

8. The "right" support

Many of the people we have assisted have complex disabilities. Thus they need personally tailored support to participate in the community. Support workers that have been engaged are more like social networkers or community connectors rather than "Disability Support Workers". They need to be able to not only research and know the local community but keep their eyes peeled for opportunity and nurture possible relationships and friendships.

Those relationships which have flourished have taken intentional effort. For example invitation, building moments for reciprocity e.g. giving a person a lift to art class, collecting a person's mail while they're away, encouraging and enabling community members to support the person (even in small ways), sharing secondary common interests such as Cameron had with cricket. This gradual and thoughtful work of drawing community members into people's lives will not just happen by chance. It's a skill that is vital but is not always fostered or recognized and fostered in support workers.

9. Being in the Driver's Seat: Control & directing one's own life & supports with assistance support from family &/or other trusted people

PLA believes people should determine their own lifestyle and if people require support to do this then it needs to respond in a way that is enriching, life enhancing and supports their decision making. This means that people should have choice over where they live, who they live with, what they do, where, when and how etc. People should also have say-so over resources and supports if required. Although this is quite complex for people with communication difficulties they can generally let people know in some way what things, people or places annoy or delight them. The art is in tuning in to people! It is also about engaging and harnessing the knowledge and strengths of those who love and genuinely care about them.

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

However, PLA avoids defending the choice of segregation or congregation of people with a disability. Until people have had the opportunity to pursue a typical life of inclusion the choice of segregation/congregation is not a choice but one of limitation based on a set of assumptions about what people want and need and often an inability to think beyond such arrangements.

Most people PLA has assisted have experienced a lack of authentic control over their life and supports. For example people were unable to determine what they did through the day, where they lived, who they lived with, selection, direction and scheduling of support workers amongst many other things. They also lacked knowledge or control of their funding budget. Predominantly such decisions were made by services. As a result people had many restrictions placed on their lives or a limited menu of options.

At a systems level, Fyffe (2008) states that the outcomes of PLA are impressive as it places individuals and families in the driver's seat and reduces the demand on services and government by reshaping the locus of control from services and DHS to individuals and families, renegotiates relationships and expectations and has assisted people to become more resourceful and to see the value of informal/natural/community supports rather than see funding as the only solution to a good life. In addition Fyffe (2008) states that PLA has also had an impact on re-orientating services through the development of individual and family governed collectives, hosting arrangements with traditional providers and assisting with the identification and engagement of natural and informal supports.

The shifting of the locus of control from services back to the hands of people themselves has predominantly been achieved by PLA through "recrafting" traditional congregated, program, centre based or service driven decision making processes. One method has been through assisting people/families to establish Individual Arrangements in which the person (with the assistance of their family/advocates if necessary) is empowered to make decisions over their own lives. To achieve this PLA has assisted people to negotiate an agreement with a service provider to "host" their individual funding. In this arrangement the service delegates conditional authority to the person and family to direct their supports and resources and make decisions over their life. The service takes care of the administration requirements and other components of importance as requested by the person. Such delegation, although having conditions that are mutually negotiated and agreed upon (e.g. meeting legal requirements of employing staff, duty of care, reporting on funds etc), means that people have high degrees of transparency over the use of their funding and authority to use their resources in a personally tailored manner that meets their needs within funding guidelines and other legal limitations. It also means people are able to chose what they do, when, how and who with. This includes selecting and directing support workers if necessary. An additional benefit is that people have not had to operate a "business" to have their needs met as the agency takes care of tedious administration requirements. Melba Support Services Inc in Melbourne, is an example of a service that has hosted such arrangements with individuals and families for nearly 10 years.

Another method PLA has used is to assist people and families is to create consumer or family governed collectives. Such examples are a means in which people and families who share similar values (of individuality, empowerment and typical pathways) come together in a collective. Collectives have often developed from people coming together to solve a problem or from a lack of service options. The advantage of a collective is that although getting on

with their own lives, people have the support of each other, can share some resources e.g. a shared coordinator, knowledge, information and guest speakers etc. Members often inspire and support each other in a manner that is unlike typical service provision. Examples of collectives initiated with the assistance of PLA are One by One, a family governed service to enable its members to gain the support needed to live personally tailored community lives; Living Distinctive Lives, a family governed collective to enable its members with disabilities to live in their own place away from the family home; and Nightlife, a consumer governed flexible, on call night-time service for people who live in their own home. These collectives also have a "hosting" arrangement with a service provider who delegates conditional authority to the collective in regard to day to day operation, membership, resource allocation, staff etc. The benefit of such collectives is that people are genuinely empowered at both an individual level and at a service design and implementation level, while gaining assistance from a host agency in regard to administration. Collective membership can also be a useful safeguard to ensure what is being provided is actually needed and wanted. The collectives although useful to people and families are not for everyone. People and families who join them need to be able to work together and share the same values.

10. **Some thoughts on safeguarding and sustainability: Balancing formal and informal supports**

Individualisation based on costly paid supports is not only unsustainable but does not enrich people's lives in freely given relationships that safeguard people. Individuals with disabilities can be extremely vulnerable if the only supports in their lives are paid. Paid supports are problematic and can be more prone to disappear as their primary motivation is financial remuneration.

Fyffe (2008) argues that PLA has assisted people and families to see the value of informal/natural/community supports rather than see funding as the only solution to a good life. By building people's awareness and motivations to gradually and thoughtfully build unpaid supports, people have not only had the opportunity to build a wider network of friendships and associations but also build a more reliable safeguard around their lifestyle that is not paid.

Another vulnerability of people with a disability is what happens when their family is no longer around. Fyffe (2008) found that PLA has assisted with changing risk by assisting families to answer the question "what happens when I die" through Circles of Supports. Ward, Rodgers and Lys (2007) describe Circles of Support as a group of unpaid citizens who come together to support and share a relationship with a person who is vulnerable because of having a disability. For many individuals Circles of Support have been an intentional strategy of PLA to draw unpaid people into people's lives to think about and safeguard their vision. Circles of Support require good facilitation and clear articulation of purpose, roles and responsibilities. Circles of Support have been useful to people but are not a magical answer. They take intentional thoughtful assistance, perseverance and good values based facilitation. However often Circles of Support can increased links to community. For example one member of Warren's Circle of Support goes to the gym with him, another takes him to Salvation Army Band practice every week and another has helped him with contacts to exhibit and sell his art work.

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

11. **Good community lives don't necessarily cost more when the right supports are in place**

As we live in a climate of scarce resources, PLA has a philosophy of thinking "how could we do differently" with available resources. Resources are never our starting point but once we assist the person's to develop their vision, it is then a matter of assisting them to tailor their resources in a different manner. People often save resources via hosting arrangements as they avoid costly overhead fees. As people seek support from the community and build in informal supports and relationships they also become less dependent on paid supports. Thus the staff people employ need to be good community connectors who can research local communities, discover opportunities, foster valued roles and encourage and foster relationships between people with a disability and other community members.

> Originally Cameron received a Support and Choice funding package to support his vision of finding work and living in his own place. Through a hosting arrangement Cameron and his family employed a job and community seeker. Six years on he is now employed by a local business and supported at his work place by his co workers. He is also supported to live in his own place with the support of a housemate of his choosing (who receives free rent in lieu of support). His funding package is now only approximately ¼ of the original package and significantly less than the cost of living in a group home.

12. **Capacity building & exploration & consideration of options through value based training, mentoring & networking**

We have found that one of the greatest catalysts for creating change in ourselves and others is through building the capacity and knowledge. Often people with disabilities, families and professionals can't imagine or see past the current way of doing things. Thus they continue to walk the same path unaware that a different, more liberating and inclusive path might be possible. Often when people become discouraged they may become dismissive and thus even less likely to seek a new path. People need to be inspired, informed and assisted. We have found that it's more likely that when people see that something can actually be done that they will actually believe it to be true.

> *"Many thanks for a great w/end - very inspirational especially the realisation that even families who struggle with severe disability have achieved what seems to be impossible. Also the wealth of practical knowledge & the realistic informative way it was delivered - a building of layer upon layer which I felt catered to everyone's interests in the room, so our thanks again. I have worked out an action plan in my head & I hope you don't mind if I briefly run it by you - I would appreciate any feedback you may have & assistance" (SE – parent from Community Vision Building Retreat, 2009).*

Such capacity building investment needs to be multiple and frequent. PLA has used a number of methods to build people's capacity as one method on its own is not enough. We have found one of the most powerful ways of inspiring people is when individuals and families share their own stories of community belonging and connectedness. Fyffe (2008) found that

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

PLA has assisted individuals, families and service providers to "think differently and re think" with an emphasis on assistance and examples.

People's personal stories of struggle and achievement bring such richness and truth that is difficult to dismiss.

> *"We really enjoyed it [the retreat] and it gave us the opportunity to speak with other families in similar situations and with similar ideals... [it] also gave Chris[husband] and me a rare chance to talk together and mull things over on our minds, not that we got things sorted, but we got things STARTED...the highlight was listening to the personal stories, and I dream of the day when we can tell W's story". (LC- parent from Community Vision Building Retreat, 2009)*

> *"I found the 2005 One Person at a Time Conference inspirational, a catalyst for some significant changes in thinking and planning around our 21 year old daughter 'K's' life who has significant multiple disabilities. One of many direct benefits since has been the formation of a Circle of Support around 'K'. The Circle has been successfully active for over 18 months now and has added fun, community, complex planning and many practical benefits for 'K' and all involved. 'K' had some challenging health issues during this time and the support from the Circle also proved invaluable. We have now become members of Living Distinctive Lives which was initiated with the assistance of PLA. This enables planning for 'K' moving out of the family home into her own place which is based on her personality, passions and needs. The shift to **planning around 'K's' dreams** instead of being paralysed into inaction by the lack of suitable services has been very liberating". B.S*

Capacity building should be offered through a range of ways but the underlying factor is that the methods articulate the multidimensional values of uniqueness, community belonging and connectedness and empowerment. Fyffe (2008) describes the outcomes of PLA as impressive as it places individuals and families in the driver's seat, builds knowledge and informed choice through training and education events, has encouraged and supported significant lifestyle changes for people, supports the personal development of individuals and families (by increasing confidence, leadership roles and building informal support so people do not feel alone or isolated e.g. people become part of a larger local/national/international network or through localised/personalised supports such as Circles of Support).

Following is an outline of the methods used to build capacity in people with a disability, families and also professionals.

- Values based trainings such as Social Role Valorisation
- Seminars for individuals, families and professionals on particular topics e.g. Connecting to Community; A Home of My Own; Circles of Support; Optimal Individual Service Design, Ethical Leadership, When Dreams Become Reality, Consumer & Family Governed Services
- Family Series on Community Vision Building
- Family Retreat on Community Vision Building

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

- Bi Annual "One Person at a Time Conference"
- Networking and connecting individuals and families who are just starting out with those who have gone before who can provide good sound leadership, ideas and successes
- Investing in individual and family leadership e.g. national and international networks; sponsorship of visits or attendance at inter/national conferences; developing individuals and families as speakers
- Distributing reading material
- Development of a values based periodical
- Conversation!

PLA makes a strategic commitment to offer capacity building to individuals with disabilities and families as such opportunities are often only available to professionals.

13. Opening people up to dreaming

Once people are inspired we have found that people often ask "where do I start"? Thus people often need assistance to develop a clear vision for the future. This often involves freeing people up to dream about their own life and letting go of the limitations. This begins the process of imagining and thinking about the life they would optimally like to live. It is important not to start with funding, available services, money or past experiences. Dreaming is not about fantasy but opening up possibilities and imaging a good life. Many people dampen people's imagining or dreaming as being unrealistic i.e. it's only possible for certain people. However often the essence of a dream is quite possible.

Often when people get the chance to dream they really want a life with similar opportunities to other citizens' i.e. to get real work, live in their own home, have friends etc. Such dreams are realistic as we witness people achieving such dreams every day. Often we have found its not people's disability that limits them but rather the restriction imposed by many services and systems. So perhaps the real question is do we believe it's possible and do we have the creativity, flexibility ability and stamina to craft the supports people may need to achieve their dream?

Warren, for example, had a strong interest in the police force. Some may have viewed his interest as an obsession and the congregated service arrangements originally supporting him stifled any advancement on his aspiration. However, by enabling him and supporting him and his family to dream, Warren's interest was harnessed into what has been a life fulfilling dream that was once thought of as unachievable.

> *After spending many years in disability settings, Warren's family came to the realisation that authentic change was needed for their son and that would only happen if community members became involved in his life. The journey started in 2005 after his mother had been to an event hosted by PLA. With some assistance from PLA and Living Distinctive Lives, Warren's family began to create a vision for a typical, yet unique life for Warren that is lived in community, and that focused on his skills, abilities and passions. To ensure his inclusion his family believed it was important not rely to on human services to do the asking, so claimed back authority. Warren moved out of a group home and now lives in his own place with the natural*

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

support of housemates. Rather than attending a day service for people with a disability he now enjoys a rich community lifestyle that includes volunteering at The Police Museum, St Vincent's Hospital, The Salvation Army Café, membership of a gym, contributing to his church, and pursuing his interests in art.

We have found that a dream may begin with a few moments. It then has an anchor to gather momentum. The path seems clearer and thinking differently about people and community becomes a natural evolution. It also suggests that anything is possible and people can have a better life.

14. Articulating a clear vision for the future

PLA has found it important to anchor people's dream into a vision statement so it remains on track. This is often done through trying to encapsulate the dream in a few words by being precisely descriptive! For example the following is Warren's vision statement:

"To have the opportunity to be on the natural pathways of life, in valued roles that make sense for me. This means I will have the individual assistance to be myself in typical roles, and be enabled to have access to life conditions which are at least as good as the average citizen" (Warren's vision statement, 2009)

This helps to steer all that is done and acts a point to check ideas or opportunities. It becomes a guide for further action. Thus if an idea is raised e.g. a work opportunity in a segregated setting it is avoided as the experience is not ratified by the vision statement.

15. Staying with people over time

In our lives we rush from person to person, task to task, meeting to meeting hoping that within an instant or a few months we will have a quick fix or a solution to people's lives and it seems that genuine inclusion in the community has eluded us. People and communities are an intricate web of uniqueness, complexity and information. It is an impossible task to "get the job done" in a few months as much of the detail around people and who they are and can be is unseen and unknown by a fleeting visitor. If we are going to connect people sincerely and genuinely to the community and build typical lives then we must be committed for the long term. This does not always mean people, families and communities will need the same intensity of support as their skills will develop and strengthen. However as life throws it challenges and changes, people need champions to be *with* them over time.

Conclusion

Our learning about community would not have been possible without the efforts of the individuals, families and professionals involved in the community living movement. They not only dreamed of an ordinary life typically abound in community but have worked with vigorous determination over many years to make it a reality. Our work is not a panacea but we have found some key ingredients that are helpful i.e. maintaining unambiguous values and

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne

ethics about social inclusion, inspiring and educating people with information and "real" life stories and giving them assistance over time to craft a unique lifestyle. We know that it is possible and we dream of the day we will not have to argue and write about what should naturally occur just because you were born!

References

Cocks, E. & Bowden, R. (2009) *The Personalised Residential Supports Project*. Centre for Research into Disability and Society. School of Occupational therapy and Social Work. Curtin University of Technology.

Carver, J. (2009) *A Home That's Right For Me. Valuing Choice, Evolving Individualized Residential Options*. Summary Report of Policy Forums. Ministry of Community and Social Services.

Fyffe, C. (2008) *Evaluation: Personalised Lifestyles Assistance. Final Report*. December 2008.

Kendrick. M. (2009). *Optimal Individual Service Design*. Unpublished Course Material. St John of God Accord: Melbourne

Klees, J. (2005). *Our Presence has Roots: The Ongoing Story of Deohaeko Support Network*. CA. Resources Supporting Families and Community Legacies Inc.

National People with Disabilities and Carer Council. (2009) *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*. National Disability Strategy Consultation Report.

Vanier, J. (1988) *From Brokenness to Community*. Lecture. Harvard University

Ward, J., Rodgers, M and Lys. C. (2007). *Circles of Support*. Unpublished Workshop Notes. PLA. Melbourne

Wills, D & Jackson, R. (1996). *Inclusion: Much More Than Being There*. Interaction, 10 (2), 19-24.

Wolfenberger, W. (1992). *A Brief Introduction to Social Role Valorisation as a High-Order Concept for Structuring Human Services*. (2nd Edition). Syracuse: NY

Some reflections on what might be needed to assist people with disabilities to become authentically included in the community.

Wolfensberger, W. (1998). *A Brief Introduction to Social Role Valorization: A High-Order Concept for Addressing the Plight of Societally Devalued people, and for Structuring Human Services* (3rd ed.). Syracuse NY: Published in Australia under license by Community Resource Unit, QLD

Deb Rouget, Personalised Lifestyle Assistance (PLA), Melbourne