

EVALUATION
PERSONALISED LIFESTYLE ASSISTANCE
(PLA)

*'PLA never loses the vision that people with disabilities
can have a better life.'*

Final report

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1. BACKGROUND

1.1 Purpose of this report

This report outlines the findings from an evaluation of Personalised Lifestyle Assistance (PLA). The initiative for this evaluation came from PLA and Melba Support Services (as host agency for PLA). The report has been written in the first instance for PLA. However the findings will be of interest to a wider audience, including individuals with disabilities and families, service providers and funding sources, notably Disability Services, DHS.

2. ABOUT PERSONALISED LIFESTYLE ASSISTANCE

The following sections summarise material provided by Personalised Lifestyle Assistance (PLA). Direct quotes from PLA source material are indicated by quotation marks.

2.1 History of PLA

PLA emerged in 2003 following some workshops in Victoria by Michael Kendrick (consultant from USA) and others in regard to addressing the dissatisfaction experienced by people with disabilities and families about the dominance of traditional group-based, time-based services. The concern was that these services are not designed to meet the unique needs and wants of each person in the community. Another catalyst for the emergence of PLA was the establishment in 2001 of a family-governed collective in Melbourne, called One by One, that aims to create personalised lifestyle arrangements for a small number of individuals with intellectual disabilities. This collective wanted people with intellectual disabilities to be able pursue their unique lifestyle aspirations and abilities in the community and have opportunities similar to other citizens. This model 'locates decision making in the hands of the person and those who support such empowerment'. As a result of the interest generated, PLA was formed in August 2003 as an experimental project with a non-recurrent grant from Disability Services Division, DHS.

2.2 Vision and aims

'PLA believes that all people should have the opportunity to pursue a unique lifestyle that is personally meaningful and empowering, relevant and typically intertwined in the community. PLA aims to provide advice and consultation to a

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number of people who have a disability together with their families/allies who want to:

- Create alternatives to group-based, segregated options for people with a disability.
- Create 'typical' lifestyle responses and supports that foster community inclusion, typical pathways and a range of freely given relationships.
- Create individualised (one person at a time and unique) lifestyles and supports.
- Be empowered to make decisions over their own lifestyles through self direction.
- Govern their own projects and arrangements and have high degrees of influence over service design and implementation.'

PLA aims to promote the emergence of such advances through seminars, training and discussion with various people, agencies and funding departments.

PLA draws on material from Michael Kendrick (www.kendrickconsulting.org) and others, for example, Jeff Strully <http://www.jaynolan.org/>; Community Resource Unit www.cru.org.au; Jane Sherwin sherwinconsulting@gmail.com; Lorna Sullivan <http://www.imaginebetter.co.nz/>; Janet Klees janet@legacies.ca; Pat Frangelo www.oclinc.org.

2.3 How PLA is organised

PLA has a committee and funding is managed through a hosting arrangement with Melba Support Services. 'Hosting' means that the administrative and legal responsibilities are undertaken by the host organisation. Day-to-day decision making and control for any funds, staff etc remains with PLA.

The committee of five people has an advisory and support role to staff. The operations of PLA depend on one staff member. Committee members have all been personally involved with PLA activities as individuals or parents. There is no PLA membership base; no formal office bearers, beyond the chair person and the committee who undertake limited administrative and management functions. There has been an annual action plan in response to the available funds. Committee members do undertake specific administrative tasks to assist staff such as organisation for the biennial conference.

The hosting arrangement between PLA and Melba Support Services enables PLA to be 'semi-autonomous with delegated authority for policy decisions and

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directions, while legal, employment and legislative requirements are undertaken by the host.' The hosting agreement provides an administrative cover for PLA while allowing the local committee and staff to plan and undertake their activities. The CEO of Melba is a member of the PLA advisory committee.

The principal resource has been one 27-hour worker and some administrative costs. This has allowed employment of a second 10-hour per week staff member in the past, although this latter role has currently been put on hold due to funding restrictions.

There is no PLA office base. Staff work from home and typically travel to all appointments and meetings. There is very limited office infrastructure. There are no ways to disseminate information and materials other than by post and email. There is no PLA website.

Since 2002/03, PLA has had a series of non-recurrent grants from central and regional DHS. There has been some 'fee for service' for presentations, workshops and the biennial conference. Most recently (late 2008), funding has been allocated for an 18 month time period in a joint funding agreement with DHS Eastern, Southern and North and West Metropolitan regions. This funding allows the continuation of a part-time worker (27 hours per week), and some additional staff time and administrative costs.

2.4 What PLA has done

a. Work with individuals and families

At the time of the evaluation PLA reported conducting approximately 152 consultations with 55 individuals and families since PLA commenced in 2003. PLA provides information and assistance about:

- Where to start with forming a vision for a person's life with valued roles and a plan to achieve it.
- Developing, implementing, reviewing and renewing strategies using family and community resources, forming circles of support, and not being restricted to paid supports.
- Developing safeguards now and for the future (for example, circles of support, consumer/family governance).

There is no time limit or set sequence for working with families. Some work is intensive, such as setting up and facilitating a circle of support, while at other times there might be phone contact. Some people may be part of information and learning opportunities only. How people are involved with PLA may change

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over time. There is no sense that individuals and families need to cease involvement with PLA unless that suits them.

b. Information and education

PLA is part of a local, national, international network promoting ideas through information dissemination and education. In Australia this includes: Mamre Association Paving the Way Project (QLD), Building Informal Networks project (Queensland), Circles Initiative, Community Living Project (SA), Community Resource Unit QLD, Family Leadership and You (ACT) and Family Advocacy NSW. Through this network ideas are explored. Various people come to Victoria and PLA staff, individuals and families go to other conferences and workshops and present their experiences. PLA has a supportive mentoring role with these interstate organisations and vice versa. PLA contributes to a national network of learning and support for people with disabilities, families and staff, most apparent with the biennial PLA conference. The PLA contributors to these events are individuals with disabilities, family members, service providers and PLA staff. In the last year, this included sponsoring of educational events and development of written materials:

- One Person at a Time Conference (two previous conferences with 300 attendees).
- A Home of My Own – Alison Oullette (Canada), 50 attendees.
- Optimal Individual Service Design 10 day Leadership Course – Michael Kendrick, 30 attendees.
- Family Leadership – Community Vision Building (eight sessions during year) 17 attendees.
- Circles of Support – Marg Rodgers & Jeremy Ward (Mamre, QLD), 45 attendees.
- Contributions to occasional papers ('Challenging the Myth that One Size Fits All' (CRU); 'Small Family-governed Collectives' (TASH); 'Working Towards a Good Community Life' (DSVA); 'What is a Home' (DSVA).
- Various presentations throughout Victoria and interstate.

The various educational events have attracted families, individuals, service providers and bureaucrats from Victoria, but also across Australia.

c. Formation and support to self governed collectives

PLA has provided support to form four individual and family-governed collectives, three of which are continuing at present, Living Distinctive Lives (LDL), One by

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One and Nightlife. (Nightlife is discussed separately below as a support service). The collective members support each other to further the vision of each individual. Each collective is focused on a specific aspect of achieving the vision, namely housing and post school options. This reflects the priorities for the members. A range of formal and informal ways to achieve the goals is explored. In both the LDL and One by One collectives the individual sons and daughters may have individual support packages, and involve the employment of support staff by the individual and family. The fourth collective, EQAL, was formed but has not continued.

Living Distinctive Lives (LDL) aims to develop individual accommodation arrangements for 10 people, with a range of informal and formal supports. LDL is recurrently funded for a part-time coordinator by DHS EMR and hosted through Melba Support Services. Initially the group started with two families. Families wanted to support their sons and daughters to live in their own places, become genuinely included in the community and have more control over lifestyle arrangements, supports and funds. A way was needed to enable them to do this. Only those people who align with the group's principles join LDL. The group is guided by a family governance model suggested by Michael Kendrick and others. There is a consistent emphasis on long term planning to develop typical community living arrangements for each person and leadership by families. The focus has been developing a life for each person with a disability in the community, establishing circles of support and then identifying and how the person can live in their own home considering the potential housing options. The belief is that housing can't be planned if there is no understanding of how each person wants to live and be supported. Governance group members describe a role with each other to 'protect the vision' for each person immediately and over time. Summary of features of LDL:

- Family-governed (individuals not excluded).
- Hosted with an agency for administrative purposes. The host agency is also intended to provide one aspect of sustainability by providing a safeguarding role in the background and acting more or less as needed.
- Aim for people with disabilities living in own homes – not with other people with disabilities ('unless these are genuine friendships'). 'Creating a good life around people'. Pursuing options that would be typically available to other members of the community. The aim is clearly to develop options other than shared supported accommodation and group homes.

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- Using a housemate approach – arrangements where someone without a disability lives with a person with a disability. Daily support is exchanged for subsidised rent. (This does not preclude specific formal support arrangements).
- Aiming for a high degree of choice and flexibility.
- Development of unpaid supports e.g. community members, circles of support.
- Support workers are used as community connectors e.g. links to community clubs and groups, volunteering options, possible work experience options, development of friendships, shop keepers (Material from the *Evaluation of the Accommodation Innovation Grants, 2007.*)

One by One is aiming to develop individualised post-school options and living arrangements for 8-10 people. It is funded through individual support packages and hosted through Melba Support Services. The One by One pamphlet describes One by One as 'an intentionally small arrangement which supports people with a disability.' The group was formed in 2001 by parents wanting to help 'provide their sons and daughters with the best chance of enjoying lives of purpose, meaning and value in the community'. The features of One by One are:

- 'Each person, with family and advocates, develops their own vision for the future.
- Each person has influence over the allocated funding and other resources to craft a unique support arrangement... towards a typical lifestyle in the community that is personally relevant and fulfilling.
- Activities of One by One are overseen by a governance group.
- One by One employs a host agency to take care of legal and financial requirements while delegating necessary authority to individuals and families to create their own arrangements and lifestyles.
- Governance is not by the host agency but by the people who use it. There are high degrees of influence at an individual and collective level'. (From the One by One pamphlet)

d. Re-shaping disability support services

PLA has contributed to the formation, establishment and ongoing implementation of a personalised support service, Nightlife. In October 2003, PLA hosted a think tank day facilitated by Michael Kendrick. From this seminar a small working party of people with physical disabilities was formed. Members of the Working Party were experiencing frustration and desperation at the lack of

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evening and overnight flexible support by service providers. This included constraints on the hours in which support was provided during the night; restricted, set bed times (generally no later than 10pm), leaving people with little choice when it comes to undertaking a meaningful social life in the evenings.

After more than three years of research and planning by people with disabilities a proposal was submitted to DHS. DHS agreed to fund a pilot project in the Bayside Suburbs of Melbourne to enable people living with a disability to have a better quality of life. Nightlife Disability Services was formed and is hosted by Melba Support Services Inc. In mid 2007 a Project Worker was employed to assist the Working Party to develop Nightlife. The working party remains an essential part of the new service until a governance body, comprising mainly of people who use the service, will be formed to direct and form the core structure in which the vision, goals and principles of the service are determined. Nightlife supports 14 people by providing flexible overnight attendant care support.

Through PLA's work, a small number of traditional services are re-orienting and changing their relationship with individuals. Host agency roles are being negotiated so that agencies are more flexible and able to re-define their roles and relationships with individuals and families. The two principal examples are:

- Melba Support Services now hosts three personalised individual/family-governed arrangements, the PLA and 18 individual service arrangements.
- Milparinka following presentations and mentoring to families, staff and management, has defined its role based on the pursuit of inclusion, individuality and empowerment. There are now more than 50 examples of meaningful community participation enabled by the day service staff and largely maintained through natural supports.

2.5 Who is involved

PLA places no restrictions on people with disabilities who might ask for assistance and support in terms of where people live and the nature or extent of the disability and support requirements. The only limitations arise from the finite capacity of PLA staffing resources and families and individuals' preparedness to align with PLA principles.

Most work by PLA has been with parents and their younger adult sons or daughters with an intellectual disability. In these instances family members,

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usually parents, but including siblings have been closely involved. PLA has also supported people with physical disability, mental illness and multiple disabilities; and has been involved with individuals in their own right. In many instances individuals have been living with their family, perhaps attending an ATSS (day program). Some individuals were living in shared supported accommodation. When PLA has worked through organisations to effect changes for individuals, family members have not necessarily been involved. Everyone has in common the desire to live more independently and uniquely.

People have come to PLA from all over Victoria, although most people are from the metropolitan areas, inner, south, north and east of Melbourne.

3. ABOUT THE EVALUATION

3.1 Terms of reference

The evaluation was designed to:

- Describe 'what is PLA?' including history, distinguishing features, activities, achievements, outcomes and products.
- Identify the strengths of PLA and the contribution PLA can make within the current support options for individuals with disabilities and their families. This may include which individuals and families are most likely to choose the PLA approach.
- Identify the obstacles and issues arising during the implementation of PLA, including, but not limited to, possibilities for replication or expansion; viability; and cost effectiveness and value for money.
- Identify PLA's outcomes and achievements which are relevant to current Victorian disability policy, funding program and legislation.
- To make recommendations about the future directions of PLA.

3.2 Method

The reference group for the evaluation process comprised: Deb Rouget (PLA staff), Delia Fisher (Chair, PLA committee), Therese Morgante (DHS, Access, Planning and Pathways), Anthony Kolmus (CEO, Melba Support Services), Jackie Holmes (PLA committee).

The evaluation method involved:

- Interviews (face-to-face and phone) with 30 family members, typically parents, and five people with disabilities. This included group meetings with Living Distinctive Lives, Nightlife, One by One and the PLA committee, and their coordinators.
- Interviews (face-to-face, phone and several written responses):
 - Seven DHS regional and central staff.
 - Five Victorian-based service providers.
 - Eight interstate and international government or non-government service providers or consultants.
- Attendance at part of the PLA conference 2008.

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- Review of PLA material: submissions, training events, conference brochures. PLA provided a summary of activities and outcomes (between 19/10/06 and 14/4/08) which had been collated as part of the recent funding submissions.
- Review of relevant Victorian policy and legislation.

The method was able to compare the activities of PLA with the roles of planners and case managers in DHS and other organisations. A high percentage of the families interviewed had had experiences with both PLA and staff in other planner and case management roles. However, in general the method adopted was not a comparative evaluation with other approaches.

Throughout the report people's direct quotes are used to demonstrate the points raised. These quotes are shown in *italics and quotation marks*.

3.3 Policy context

The Victorian State Disability Plan 2002-2012 outlines three goals so that people with a disability can live and participate in the community and have opportunities that are equal to those experienced by other citizens. The goals are:

'Goal 1: To enable people with a disability to pursue their own individual lifestyles.

Goal 2: To strengthen the Victorian community so that it is more welcoming and accessible, so that people with a disability can fully and equally participate in the life of the Victorian community.

Goal 3: To lead the development of a more inclusive community for people with a disability by developing more inclusive and accessible public services, and promoting non-discriminatory practices'.

The principles of the Disability Act (2006), which apply services funded to support people with a disability, include that disability services must 'assist families to support people with a disability, where they can; and support people with a disability to make choices and be independent; make choices and get support if they need it; and take part in their local community'.

All of these policies recognise the importance of people steering their own lives as much as possible, having appropriate support including informal supports and developing new ways of working for disability support providers. DHS is involved with monitoring funded services, while at the same time recognising that not everyone's supports come exclusively from government.

4. FINDINGS ABOUT PLA

In addition to discussions with PLA staff and committee members, the following findings are based on discussions with individuals, family members and various service providers and government representatives here, interstate and internationally.

4.1 How do individuals and families become involved with PLA?

The families and individuals currently involved with PLA started with their dissatisfaction with the offerings of the traditional service system. The only services available were described as inflexible and group-based rather than individually-based. Many parents reported being unhappy with what was on offer for their young adult son/daughter soon after finishing school, special school or completing TAFE (with FFYA funding) and being left wondering, *'then what'?* Some parents said they had a belief in something better, *'not segregation, more normal'*. Some expressed disappointment that the TAFE experience had effectively meant segregation. Parents said they started to imagine other ways FFYA funds could be used rather than, *'just giving the funds to an ATSS'*, and were clearly disappointed when any, *'funds available were for placement or for shared supported housing but not home-based support'*.

For some parents, their distress with traditional services was more acute because of the reaction of their son/daughter. There were examples given of several young people's deteriorating behaviour while attending day programs or living in group housing. Parents said the only suggestions offered were for increasing medication and progressively limiting possibilities and daily experiences through more restrictive practices. Service responses were described that had resulted in individuals being moved away from home and their local community. Many families described a history of wanting to get the system to be more adaptable. Some families were told that their child (young person) was too disabled, and that the disability support programs were unable to meet the young person's needs.

From all the parents' comments there was a pattern of dissatisfaction to distress with the available service offerings and eventually finding PLA following many disappointments. People, *'heard about PLA from another family or worker ... almost by chance'*. Often people approached PLA following an education event.

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Each family and individual then became involved with PLA on a one by one basis initiated by the efforts of the family.

The striking point was that these families wanted more typical lifestyles for their sons and daughters and they reported struggling to get any recognition that this was a desirable goal and failing to get assistance to enable it to happen. Finding PLA, which is a very small organisation, depended on the individual and family being sufficiently determined to keep exploring possibilities.

Case study 1: (Based on a telephone conversation with a parent)

Mother described the situation in disability services as 'awful'. 'They were making us a disabled family.' T used to go to a day program, he was hurt, sad and learning to hurt people. His speech deteriorated and we were learning nothing as a family. T doesn't fit usual services as he is very able and independent and has autism. He grew up in the local community. Mother believed in community involvement and looked everywhere for assistance. Mother eventually located PLA through a case manager. T has been involved with PLA since about 7 years ago. Initially Deb (PLA) just had a chat, gave information, and the mother followed up with Melba Support services. Eventually T was part of an Arts Project, which proved too unstructured, but there was a lot of contact with artists and art work. This all started with Deb identifying the potential for T as an artist. We had first thought government would get us through this, but now we know the family has to do it. With other families we received a grant for a family-governed group: a group of families who met together to share ideas and information. Deb has been the facilitator of our support group. She may suggest to other families to make contact.

Now there are no 'services' for T. He is a full time community member. He has two support workers during the week as art workers. The art workers are funded through Support and Choice and employed via Melba Support Services, but the family directly hire the workers and determine what is needed. Melba takes responsibility for the administrative and regulatory requirements of employment. PLA sends out lots of emails about what I can do as a parent. Melba and Deb are the glue that holds it all together. The aim is independent living for T – we have a long way to go. However, none of this would have happened for T through normal disability services: T now uses public transport to go to four 4 local communities.

4.2 Features of PLA

The features of the 'PLA approach' were described as:

- Guiding principles
- Informing and educating
- 'Bottom-up' assistance
- Emphasis on network and relationships

a. Clear goals, unambiguous role and based on a guiding theory

PLA always emphasises that the aim for PLA is that each individual with a disability has a better life in the community, with an emphasis on inclusion, empowerment and individuality. People who approach PLA for assistance must want to pursue these directions. A feature of PLA is a strong, unwavering belief in what is to be achieved and delivered which is not to be compromised by other organisational priorities. These directions are consistent with the Victorian State Disability Plan.

b. Informing and educating individuals and families

PLA's approach uses education and information as the foundation to thinking about possibilities and the future. An education event or conference was often the trigger for people approaching PLA for an individualised consultation. Individuals and families noted that it is difficult to think or choose future possibilities when little is known about different ways people with disabilities can live and be supported. The examples provided at educational events introduced people to the practicalities, obstacles, possibilities and variations of individual lifestyles. Information and education programs auspiced by PLA are also available to service providers.

Case study 2: (Notes from phone interviews with parent and son)

Son has severe physical disability, limited speech, no intellectual disability. At 18 he said he wanted to move into his own house. He has always lived a very normal lifestyle and this to him as a very normal request. We started looking around. Public housing not possible without support funds; looked at cluster units; M didn't want a group home; we contacted various support agencies. Then M started to question living with other people with disabilities. After about 18 months, it was suggested to contact PLA. Everything seemed possible. I attended a family leadership course. There were great stories of determination and persistence. Practicing

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brainstorming was great. M and I went to an overseas speaker who gave us the courage and belief that it can happen.

We've always had good case managers, but we still always hit brick walls about what is possible.

M is now living in a unit with the support required. There is Support and Choice funding for packets of support throughout the day, but not enough for sleep overs. We are thinking of housemates – need to think outside the square. We are just starting to think about a circle of support. Transition funds give M an extra support for three months.

M is so happy. He uses the computer phone; can make his own arrangements with people; he is doing so much more than living at home with us.

c. 'Bottom up' assistance, advice and consultation 'one by one'

PLA begins a 'bottom up' process where individuals and families drive the process for change at their pace. Individuals and families are helped to think about possibilities over years and in many ways. PLA supports the development of a vision rather than developing a plan, implementing support or arranging an immediate response. This is different from a response which aims to provide something tangible for the individual or family, such as a written plan or hours of direct support in order to reach certain results or outcomes.

'You walk away from that meeting with PLA with fresh hope...and the journey with PLA imparts empowerment, re-invigoration... we can go about this another way... and she (PLA) stays in touch in that journey as a resource... even after other contacts start to build...'

PLA does not take responsibility for making the vision or the support happen. There is a strong sense of individuals and families being in control and having ways to respond to things not going as planned.

'PLA gave us the courage to try things. .. it didn't work this time... but try next time.'

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This process was often described as changed thinking ('*to State Plan thinking*'): an external process (to organisations, families people with disabilities) to enable change through introducing new ideas about the meaning of community living and practical examples of what is possible.

'He's no longer going to be a client.'

'I always assumed that the pattern was special school, ATSS, CRU. PLA led us to a re-think.'

This support from PLA had additional aspects. Many people praised PLA's response to the individual with a disability and to family members. This response was praised for being quick, reliable, and available over time. PLA took on roles such as advocate, mediator, interpreter, problem solver, assistance with negotiations, and mentor.

'PLA modelled problem solving eg 'What is the most important thing needed now?'

'I don't need PLA daily, or weekly, it's over time to 'stay on focus.'

d. An emphasis on building relationships and networks

PLA emphasises building relationships and networks as a basis for long term support and safeguarding for each individual. This means PLA:

- Gets to know each family and the individual with a disability.
- Encourages links between families to share ideas, compare experiences and solve problems. This link might be with one other individual or family in a similar situation; a group of people with similar goals via a collective or a course; or participating in or attending a conference.
- Encourages links to community members and with the service system to build supports and protections around an individual to achieve the vision.

The effect of this approach is meaningfulness and relevance to each person. Through contact with PLA individuals and families have developed support solutions. Some of these solutions include:

- Two families decided to organise respite from each other and flexible ways of employing support staff were devised.

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- Individuals and families know more about different ways people with disabilities can live, learn and work in the community.
- Individuals and families support each other and don't feel as isolated as before.

Arising from PLA talks, visits, courses, individual and group processes a ripple effect of increasing informal and formal connectedness was described.

Case study 3 (Notes from telephone call with parent)

We were invited by DHS to attend a Michael Kendrick seminar, about 5 years ago. Our son had significant health conditions, behavioural issues and lived in shared supported accommodation. Other parents didn't want him from the start. He had to leave the CRU because of his behaviour despite 24 hour and expensive support arrangements and medication. Next he lived in a two bedroom house on his own with his usual carers. It worked well but it wasn't the usual DHS response. Deb (PLA) was at the Michael Kendrick seminar about personalised living arrangements. Over the next 12 months we worked with Deb to put in a submission – she has been a great back up all the way. She guided the submission process with DHS. For the first two years 'she was there often, whenever we wanted her'. We've even had her come and talk to our staff and make suggestions about staff selection criteria.

Now W lives in his own home. Initially funding was via a service provider but the annual funds were spent in six months. He is now supported though an individual/family-governed arrangement, which is hosted by a support provider. He is now well and supported with fewer staff. Now we manage the funds ourselves. His health conditions have improved markedly, having 'deteriorated when in shared supported accommodation'. Now we might ring Deb two to three times a year if something crops up. 'Can I bounce this off you? There is nowhere else to go.' Case managers don't have the experience and they still try to change the concept usually based around saving money.

We do still see old CRU residents- they haven't changed. Our son has changed. He has so much more in his life. He is a library member, a well recognised local identity, shopper, restaurant patron, and church goer. We have gone from daily health concerns over medication and restrictions due

to behaviour to monthly health checks and outings with our son sitting in the front seat with the driver. We are now training other people to know how to keep this going when we can't – the behaviour management, the food and nutrition, medication and health requirements.

4.3 Comparisons with planning processes

One interpretation of PLA is that it is a model of planning. All individuals and families who had experienced other case managers and planning staff said these planning processes were fundamentally different in process and result from being involved with PLA.

'PLA offered a chance for people to develop their vision. It all took longer than expected but the result (Nightlife) is one of the best in the state.'

'PLA takes the emphasis away from planning. Simply talk to people about what they want. How can we help you have a good life?'

Alternative planning and case management experiences were described as organisationally and process driven, 'top down' and achieving little. Planning was a paper process controlled by planners.

'All planners have those recording sheets but nothing happens. The action plan didn't/ couldn't happen. Each review meeting things haven't happened, we haven't got staff to do it, ...it all fell in a heap.'

'The planner said to us: 'We have seven sessions, we need to wrap up, we have achieved (description)... you can come back to me or other people.'

Planners were described as having conflicting roles within their organisation. Most often the conflicting role was gate keeping for resources or access versus planning possibilities with individuals and families (See also Case Study 3, above). As PLA is independent and does not allocate resources it is constrained by competing organisational requirements.

Families and individuals noted that other than PLA staff, other planning staff had a limited vision and knowledge of what could happen. There was frequent comment that planners and case managers weren't sufficiently knowledgeable about possibilities and simply 'slotted' people into available service responses.

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'Families feel they have to use traditional services – and DHS planners are reinforcing this.'

'It's not personalised, everyone has to do the same thing.'

'We'd say, 'what about?' and they (planners) would say, 'no'.

Individuals and families said that their other experiences with planners were reduced to responses to events, issues or crises, rather than a cumulative building 'towards a life.'

'They (case managers) think that a weekend away will fix everything.'

'The case manager had a set of ideas, not what to do in life; for example, here's where you get aids.'

Family members felt the frequent message from planners and case managers was, 'it's all about the funds' rather than an exploration of possibilities for formal, informal and natural supports. That is, planners and case managers did not present possibilities beyond what any organisation alone could provide.

'DHS can only see it as a funding issue, that is, an institutional (pre-determined) response.'

With other approaches to planning, there was no relationship described with the individual, family and the planner, possible or expected.

It was argued that PLA is not case managing or planning as currently conceptualised – and this may be the issue. Through information and training, *'PLA is a change facilitator. Thinking of PLA now – that's where the DHS planning model is headed – we (DHS) can really learn from them'.*

4.4 Who is PLA suited to?

The principles of PLA define options and definitions of acceptable life in the community. Not everyone would concur with these principles for example, not sharing housing with another person with a disability, or a combination of traditional services and more flexible arrangements. PLA is suited to individuals

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and families who agree with PLA's principles and vision and want to control the support responses enabling each individual lifestyle. This takes effort from individuals and families not required in traditional services. All respondents said PLA, *'is not for everyone'*, and that PLA is one way to achieve individualised responses. However, *'it (PLA) should be available for those who want to use it'*. As PLA enables and supports, rather than provides, this means the family or the individual (and less often so far, organisations), are often very involved in order to make projects and the vision happen for example, a parent being the back-up if support workers are not available.

'Individuals have to be prepared and decide to do the work'.

'Standard services are OK for some, but not for everyone'.

There was a pattern of individuals and families coming to PLA when dissatisfied with the traditional service system and:

- Not being happy with what is offered which they perceived as standardised, not individualised and restricting what they wanted to do.
- Being prepared to query, challenge and independently seek out information.
- Believing in the importance of the person with a disability having their own life separate from parents and not solely defined through their disability.
- Being prepared and able to, *'put in the hard work'*.

It was noted that it helps to have a strong family and strong connections, although potentially PLA could take on this role, especially for people in services. Other families suggested that not all families can cope with PLA. PLA says: *'If you want someone to have a good life, you have to react, take responsibility.'* PLA better suits individuals and families with more personal resources and energy. This hasn't restricted PLA working with some families and individuals experiencing very complex circumstances if families and individual were committed to the PLA approach.

Most of PLA's work is with younger adults. It was felt that perhaps older individuals and families are settled, satisfied, acculturated into the limits of what to expect, or exhausted. So opportunities for a different life pattern, at least for some individuals and families, may have been lost.

4.5 Strengths

PLA is valued because of its independence from government and service providers. There is no conflict of interest with services or DHS. There is very high satisfaction with PLA from individuals, family members and service providers involved. This is reflected in the involvement and contribution of so many family members. The willingness of individuals and families to be involved in the evaluation was exceptional. The strengths of PLA are:

- A small organisation where relationships are personal and not organisationally driven.
- PLA's independence from the service system means the principles can be pursued.
- Consistency of staff (ie the one worker) and ready availability. The staff role is flexible and there is involvement over years, but not in a pre-determined fashion. It is not that the PLA approach necessarily takes more time than other formal processes (this remains to be tested) but rather it is an open and interactive process over years.
- Always being respectful of the person with a disability.
- Extensive knowledge of issues and possibilities, network and systems.
- Individuals and families feel in control of their lives again after PLA's involvement.
- Participation from the start by individuals and families which is unlike traditional services and responses where, *'families are not closely involved, except at a problem.'*
- The strong sense of the individual variation possible for example, there are lots of ways to have circles or an individualised life.
- The emphasis on learning and development of individuals and parents: *'Other programs take the person away and then drop them back and parents learn nothing.'*

4.6 Difficulties, challenges and obstacles

a. PLA the organisation

The difficulties facing PLA relate to the size of the organisation, lack of resources, organisational capacity and infrastructure and the isolation of and workload on one person (and arguably the other coordinators of the self governed groups). Individuals and families are relying on the PLA-style of support, a little at a time and in various individual, group and networked ways as they want it, over time.

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PLA in its current form has no mechanisms in place which guarantee its existence in five years.

It is convenient for PLA to be administratively hosted by Melba. However, as a hosted group PLA lacks a separate identity from the host agency and could have activities in conflict with the host. This has already occurred with submissions for funding which both PLA and Melba are seeking. Lobbying activities appropriate for PLA may not align with the interests of Melba. Such competing interests are less likely with the self governed groups whose role is more discretely defined.

There is a desire – and demand – to expand PLA’s role with more individuals, families and services. There are individuals and families now wanting PLA’s individual assistance that can’t be responded to with the current workload. Currently PLA is largely inseparable from the one part-time staff member.

There are two aspects to PLA – the personal qualities of the PLA staff member and the underpinning principles which are shared with other organisations and individuals here and overseas. While PLA is not exactly the same as organisations in other places, the same components are done elsewhere, guided by the same principles. That is, these activities and directions are able to be replicated in the other states and countries and in slightly bigger projects and organisations. Experience from other places suggests it is possible for PLA’s activities to be replicated. There is a need to mentor and train more staff, as well as support existing staff.

Questions therefore arise about the optimal size for PLA given the disadvantages of organisations which are too large (and therefore rigid) or too small (and therefore vulnerable to collapse and staff overload.) It is also noted that many services have started as ‘consumer driven’ and have been changed as organisational imperatives have become dominant. It will be important to have ways to preserve what are seen as the essence and strengths of PLA initiatives.

If PLA is to expand, decisions are needed about priorities for the future. That is, the relative priority to be given to work with individual and families and the promotion of informal support and service development arising from that, versus reform within existing services based on a ‘one person at a time’ approach.

b. Lack of systemic recognition of PLA

The PLA approach is supported from respondents nationally and internationally. For example, DCS WA in its recent publication (2008) quotes PLA as a resource regarding supported living. PLA is regarded as, '*unique in Australia*' and outsiders to Victoria are perplexed at its rocky funding path. Equally there is a misunderstanding from these perspectives about the pilot origins of the program and the extent of individual positive endorsement from DHS staff regionally and centrally.

Nonetheless, within Victoria there is a lack of recognition of PLA and where it fits in the service system and therefore for government funding. This was attributed to PLA not adopting government terminology to describe its activities and not articulating differences with other funded options. There were several comments from members of PLA about how the individualised support arrangements are misunderstood as if this was the same as regular planning and case management.

Allocation of government funds is dependent upon a tightly prescribed accounting system which is not calibrated for 'bottom-up support'. Such 'bottom-up support' is often slow to develop, activated by individuals and families (not staff initiated), and requires subtle, at times intangible, encouragement for families and individuals to keep going. While it is possible to nominate some outcomes or activities, the time frames involved in the PLA 'bottom-up' approach are longer than annual government performance targets often allow.

While there may be funding solutions which can support the individual planning and support aspect of PLA, it is the networking, collective, ripple effect qualities which can (and are) creating service system reforms consistent with the State Disability Plan. There was concern that if PLA is to be funded solely via people's individual support packages, then any requirements for formal support would often not be able to be funded. Further to this the potential for the ripple effects from PLA activities leading to wider system reforms would be lost.

There is an irony with this highly individualised 'bottom up' PLA process which generates expanding effects of informed and educated networks and collective effort. It seems that this knowledgeable and collective effort may restructure relationships between providers and individuals more dramatically than individual

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services agreements. However this effect is not recognised within the service system.

c. Difficulties for some individuals and families

PLA needs to reflect on the involvement of some individuals and families. Some families and individuals described how progress has been slower than hoped for,

'It can be very challenging for families if they have aimed or things and if after five to six years it hasn't happened.'

'Can I fail? What if I don't achieve the vision?'

It was not obvious how these families are assisted by PLA. There was recognition of the possible tension for some families, *'telling their stories as a point of advertisement versus getting on with life'*. Some other comments suggested concerns about PLA creating dependence with some families.

5. OUTCOMES AND ACHIEVEMENTS

The first achievement to note is how much work has been done by a very small organisation. This work includes the individual activities with families and the restructuring of the power and control relationships between individuals and families and the service system. While this work centres on a part-time staff member, there is a network of individuals and families who can take credit for the achievements of PLA. The volume and variety of activities undertaken is impressive. The outcomes from these activities (described in the following sections) are divided into outcomes for individuals and families and system-level outcomes. These two sets of outcomes are not unrelated. The discussion below outlines how the 'bottom up' activity with individuals and families can gradually re-shape power and control relationships within the formal service system consistent with the State Disability Plan.

5.1 For individuals and families

a. Individuals and families as drivers

PLA is harnessing the enthusiasm of families and individuals to consider long term typical lifestyles for people with disabilities. The goal of long term typical lifestyles is not reliably achieved – or necessarily aimed for - through other more traditional service-based approaches. The enthusiasm and involvement of family members is not retained so consistently within the formal service system, except perhaps with families with younger children. Maintaining this level of involvement from family members is an achievement of PLA and an asset for the person with a disability. This enthusiasm provides the energy to consider a life time of possibilities for partnership between formal and informal support.

b. Knowledge and informed choice as the foundation

Information, training and education are the foundation to planning and implementing the vision for each person. This is described as encouraging people to, 'think differently,' with an emphasis on practical examples shared between individuals and families.

c. Significant lifestyle changes for individuals and families

Through PLA some significant outcomes for individuals and families have been described. Many of these families indicated that they had a long history of wanting inclusion and normalisation. Some of the descriptions suggest improved

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lives for people who were experiencing isolation, restriction and punishment including some people defined as needing very high support.

Included here are some brief stories provided by PLA:

- A young man with autism who was attending the ATSS, and living at home with his family. Now he is supported through an individual/family-governed collective which is hosted through a support provider, and has a circle of support. He has local art exhibitions as a solo artist, a mud brick making job, he volunteers at a State nursery, and is a volunteer at an artist Community. He commutes independently, is a local community member and shopper, with a friendship with person from his local pub. He wants to move into his own place.
- A man with an intellectual disability, mental illness, and cerebral palsy who was living unsuccessfully in a unit on his parents' property, attending the local ATSS. He was lonely and socially isolated. He is now supported through an individual/family-governed arrangement, which is hosted through a support provider. He lives in his own place closer to work opportunities, shares with a housemate, is employed as a receptionist, and has joined a gym. He has become a local identity and public speaker. He recently had a weekend interstate attending a special event with his employer.
- A man with cerebral palsy, intellectual disability and obsessive compulsive disorder who requires support most of the time. He was living in a group home a long distance from his familiar community and attending an ATSS. He is now supported through an individual/family-governed collective which is hosted through a support provider, and has a circle of support. He is living in his own home back in his local community and with housemates. He is a Victoria Police volunteer, artist, police museum volunteer, Salvation Army band member, and café volunteer.
- A young woman with cerebral palsy, high physical support needs, and reliant on electronic communication. She is living at home with her family. She individually manages her funds through a hosted arrangement with a support provider. She is an on-line music blogger, writer and poet.
- A woman with an intellectual disability, mental illness, anxiety, significant health issues, and a history of violence. She had been living at home with her family and attending the ATSS. She is now supported through an individual/family-governed collective which is hosted through a support provider, and has a circle of support. She is a local identity, member of two community choirs, YMCA gym member, Daffodil Day fundraising volunteer

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and has bike riding and skating lessons. She wants to live in her own place with housemates and staff support.

d. Supporting personal development of individuals and family members

People are actively involved with PLA, not passive recipients of services. Individuals and families are in partnership with PLA. Involvement with PLA leads to the personal development and increasing confidence of individuals and family members. Examples of leadership roles were described within the individual and family-governed groups as part of organising PLA education activities, as contributors to evaluations and presentations in other organisations including interstate.

e. Building informal and natural supports

PLA works with individuals and families to expand the numbers of people in their lives through informal and natural support networks, as a platform for achieving the individual's vision. Families and individuals recognised that they are increasingly part of a larger network and therefore are less likely to feel alone or isolated. The support systems for parents are the family-governed collectives where families with common goals explore ways to achieve individual approaches for their sons and daughters, including the use of individual support packages and employment of support staff.

For individuals with disabilities, circles of support aim to reduce isolation, build more people into every day life and preserve arrangements for the future because more people are interested in each individual and understand their life aspirations. Circle members may have a direct support role through spending more time with someone; they may also have a 'looking out for role' in relation to safety, problem solving and ongoing monitoring. Circles may meet often or rarely and some people may not have a circle. Circles of support always introduced more people into an individual's life than simply a case manager and support worker/s.

'There was more support for S while in hospital – more familiar people were involved. There is no need now to organise (formal) emergency accommodation during a family crisis.'

'Amongst the various circle members: one provides respite, while another family member is now more involved.'

At the individual level, there has been considerable learning described about forming, supporting and maintaining circles of support including the different timing, facilitation requirements and purposes for different people and families.

5.2 System level outcomes

a. Reducing demand on government

The work of PLA is shifting the locus of control and responsibility in funding relationships to individuals and families and away from services and DHS. PLA involves working with individuals and families to re-negotiate their relationship with, and expectations of, the service system. Simply put, individuals and families feel that they are (more) in charge of their own lives, that is, they are empowered.

'Individuals funds are only part of the contribution to a good life – more is needed such as to build relationships, natural supports etc.'

'We had first thought government would get us through this but now we know families have to do this.'

'PLA has saved DHS money by 'cutting out the middle person' rather than having funds through DHS, TAFE, ATSS etc.'

These processes lead to cost effective responses and changes within individuals' and families' capacity and resourcefulness, without the assumptions of changes to funding. There was never an assumption that the directions generated through a PLA approach would cost government more, and most respondents thought that the PLA approach cost less (See also Case Study 2 above).

PLA helped 'us to a direction to head towards, not a series of handouts'

'We used to have an \$80,000 package – now X has one third of that for a real lif.'

However, the individual has more resources for support from informal, natural and community sources or requires less because of living a preferred individualised lifestyle. Comments suggested there is reduced reliance on government funds as the only possibility for support in people's lives. PLA aims to

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reduce dependency on the formal service system so that individuals' support arrangements are able to continue.

'There are ways to do things that don't take funds.'

'PLA has different ways of involving people in his life.'

b. Changing risks

As expectations and relationships change, the PLA approach is reducing demands and risks on government and risks to the person with a disability for example, changing the inevitability of older parents still caring for middle aged people with disabilities. Families recognised that government funds alone won't contribute to 'a good life' and that families in isolation can be restrictive upon the person with a disability. Individuals can be at risk and isolated within services. There is a history of catastrophic failures of disability systems and of distress and lost potential when individuals with their families remain unsupported over decades. PLA has an emphasis on sustaining benefits and relationships into the long term which government cannot assure. Through the development of each person's individual vision, *'families do have an answer to 'what happens when I die?'* There is little or reduced risk to the individual through circles of support as there are numbers of people working over time to achieve and monitor an individual's vision and safety. The parents' needs are distinct from the individuals. The person centred approach also *'brings the family along'*.

c. Re-orient disability services to new roles

PLA supports the formation and maintenance of individual and family-governed collectives either involving individual support packages or an individualised support service, like Nightlife.

'M. does love drumming at a public venue. His life is based around his passion - dance and music. Workers love what they are doing by going to live bands. Quality of life has increased for M. (and behaviour too) and for his parents.'

Disability support agencies are assisted to have new roles in these arrangements. These new roles include being host agencies, training support staff to work with individual and family-governed collectives and assisting with the identification and assistance to natural and informal supports.

6. DISCUSSION

All contributors to the evaluation were highly supportive of the work of PLA. This, of itself, is a significant aspect of the evaluation.

6.1 Understanding PLA

PLA aims to enable people with disabilities to live better lives in the community, and have valued roles within it. There is unambiguous rejection of segregated and congregate solutions to support, or compromises which suit organisations at the cost of possibilities for individuals and families. In PLA the emphasis is always on the interests of each individual. PLA is working with resources and capacity which government can't mandate but can stifle – individual, family and community resources. PLA encourages (but doesn't 'do') lifelong and reflective individual planning and promotes service development and service reform. In contrast other planning processes do not have a role to develop services based on a collective of individual activities and planning processes.

The components of PLA are typically described as: support to individuals and families; building networks and collaboration between families; the establishment and support to self-governed groups; and the training events and courses including the biennial conference. Work with individuals and families include activities ranging from information dissemination, problem solving, advocacy, representation, mediation, counselling and support and re-assurance. This can produce a vision, a plan, a circle of support, a family network, a parent or individual speaking at a conference or evaluating another service, or an idea and can be over any time span. PLA resolves some of the tensions between the needs of parents versus people with disabilities by pursuit of a better life for the person with a disability. Inherent in the PLA processes is support (information, emotional, collective effort) to parents along the way. What, how and the form of these activities varies person by person. These types of activities are termed 'products' in government reporting systems. The variability of the PLA 'products' and the long time frames may create difficulties for traditional accountability processes often needed as part of annual and short term bureaucratic reporting.

All of the PLA components and activities are part of planning and implementing where the foundation for each individual or family's planning is a common set of principles, values and supporting information. From an individual and family

perspective this is better termed 'living'. Individuals and families develop their own plans based on a vision for how the individual could live. Families and individuals have the opportunity over years to learn, reflect, trial, and compare possibilities. Individuals and families are linked in various ways to share information, support each other, problem solve, monitor safety and so on. The process is 'bottom up' and follows the time sequence of each individual or family, interspersed with a stream of ideas, materials courses and conferences via PLA and opportunities to develop supportive networks, including enabling personalised support.

The PLA approach is in contrast to 'top down' approaches to planning and service delivery, where staff are the planners or initiators (who develop the plan and nominate when to start and how long it must take), and typically lack a collective aspect where families and individuals might share ideas and learn from each other. These 'top down' processes also tend to cease with the production of the plan.

The learning from PLA is that when the individual and family develop a vision for the future and undertake planning, the ongoing facilitation role of PLA with implementation is essential. Families get important information and support from each other and wider resources. When these activities have a collective approach, or are undertaken with services, the results are system reforms achieved person by person.

6.2 PLA is applying disability policy and legislation

The key ideas in current Victorian disability policy, which are consistent with world-wide trends, are:

- Formal systems 'enabling' rather than solely 'providing' and controlling.
- Individuals with disabilities pursuing their own individual lifestyle, having maximum control over their own lives and achieving a pattern of life like other citizens.
- Re-orienting disability support services to enable, to provide and to support the involvement of community members in people's lives and opportunities to be part of any aspects of the community.
- Re-orienting disability support services so that formal support doesn't create a pattern of life unlike, and apart from, other citizens.

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In reality these directions are very difficult to achieve for existing organisations and government systems. Reform of existing services is proving challenging. No one disagrees with the directions but it is knowing how to implement these directions which is vexing, particularly when the starting point involves complex industrial and legal arrangements. PLA has operating principles and values consistent with, and aligned to, the principles of the State Disability Plan, Disability legislation and arguably any contemporary disability policy initiatives (such as direct payments, individualised responses, person centred planning, and reform of day and accommodation programs). This of itself is less remarkable than the evidence that PLA is actually assisting individual and families to achieve lifestyle outcomes characterised by inclusion and empowerment. People are living individualised lives in the community as intended from current policy directions.

PLA's particular contribution to implementing the goals of the Disability State Plan and the Disability Services Act (2008) is the emphasis on 'one person at a time' approach. This differentiates PLA from other approaches emphasising a change strategy based around a policy statement, an entire service, large group of people or more diffuse and less targeted community development and education approaches. PLA is one part of the jig saw of services and supports and is a highly effective approach for moving towards independent lives with appropriate support for some people. However, PLA uses an approach which because it is 'bottom up' it will be jeopardised if it is required to be too tightly systematised.

Many initiatives intended to re-orient existing disability support services are not able to match PLA's achievements or at least not to achieve them consistently. PLA, in partnership with individual and families, has achieved much in a short time. It is not uncommon for other approaches to have reasons why great ideas and person centred plans have become impossible arising from rigid program and staff role boundaries. With support from PLA if obstacles have emerged, individuals and families usually indicated they had the control, ideas and a sense of involvement needed to work out what to do.

Often reform of traditional day or accommodation services hinges on involvement of family or friends where someone is living, if the individual is to be able to vary their program and their place-based and time-based boundaries. The PLA approach assists this through working with families. Conversely, when PLA has worked with day services, there are examples of establishing natural supports

and significantly personalising people's lives, away from traditional group-based day services. The mentoring with staff has been an important enabler.

'It is very difficult for government to change service models from the core – without a PLA-type response, institutionalised (pre-determined) service models are likely to persist when that wasn't intended.'

No one with a disability is excluded from PLA, except when PLA resources have reached capacity, and certainly not due to the complexity of someone's disability. This is at a time when some people with high support needs are being excluded from formal services or supported in other arrangements at great cost.

6.3 PLA is much more than individual planning

It is concluded that PLA is contributing to fundamental service system reform - reform which existing service providers alone are struggling to achieve. The system reform aspects of PLA involve: facilitation, enabling and change processes with individuals, networks and groups, and organisations. PLA has flexibility to take time and have multiple roles. PLA side-steps non-performing organisations, and promotes (but doesn't provide) new approaches to formal and informal support truly based on a normal life pattern, not a disability services timetable. In PLA it is individuals and families, alone or in collectives, and not the support providers who are the central point of activity. Hence the service reform aspect can go unrecognised. PLA ignores the difficulties of organisations. This is a total change in the traditional relationship between providers and individuals which gives more control to the individual and family. This change in the relationship between individuals and families with service providers occurs by: enabling individuals and families to set the directions for lifestyle and support; re-negotiating (power) relationships between individuals and families and service and support providers; developing safeguards and succession planning often unavailable in formal service systems; providing ideas for building informal and natural supports, as well as formal supports; and at times with lower or no additional costs to government being reported. This is happening albeit on a small scale compared with the size of the service system and the numbers of people with a disability in Victoria.

Despite significant support, including assistance from DHS staff, *'no one quite knows where PLA should fit.'* At a time when the disability services system is concentrating on redesign and reshaping to be more consistent with Disability

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State Plan goals, it may be it is difficult to recognise when an agency has formed consistent with those directions and without a past in traditional models of service and support delivery.

The experience from FFYA – the first individualised package in Victoria - was that many people continued to choose traditional services. There may be many reasons for this however, without information about what else is possible, assistance and clear goals, it is possible individuals and families will select traditional service arrangements based on the new flexible packages and direct payment initiatives. The 06/07 Disability Divisional Plan mentions new directions in day services – to what arguably is something like PLA. PLA is creating systemic change because of the different ways support is understood and orchestrated by the person with a disability. There has been a gap to date working with individuals and families in a planned, educative and preventative way. As individuals or groups of individuals begin to implement their vision, the employment of support staff happens directly with the individual or collective. Roles are defined in terms of what each individual wants to do, either generally, or within the parameters of the support service (notably NightLife). If support providers are involved, or new organisations formed, they need to demonstrate how staff can be provided – not whether.

7. CONCLUSIONS

The following discussion considers the two main findings from this evaluation. PLA is one example of what services and supports should look like consistent with the goals of the State Disability Plan. PLA is a fledgling organisation which needs to develop internally to ensure it is sustainable.

7.1 PLA implementing the State Disability Plan

PLA is an approach to planning, not divorced from implementing, which empowers individuals and families to create new relationships within communities and with the formal support system. If PLA is only understood as the work with individual families, the extent of possibilities for system reform through the collective actions and work with traditional providers is diminished. It is possible that the role of PLA with system reform is under-recognised because PLA is not starting from a traditional provider base. If funds are only allocated through individual planning and targets are numbers of families, the additional infrastructure needs of PLA which produce the collective and system reform aspects remain unappreciated and unfunded.

Appropriate, flexible and individualised supports are, and will continue to be, an essential aspect of the lives of many people with a disability. The State Disability Plan sets a clear vision involving each person with a disability living in the community. This means transforming the bulk of disability support services and funds so that they can enable people to, 'live a good life in the community.' There has been limited attention to the possibility that an organisation might be an exemplar of the State Disability Plan vision, and not need to make a transition, or might already be beyond the ways organisations are understood. From this evaluation, PLA represents one way that the goals of the State Plan are being achieved, through a facilitative role with individuals and families. In addition, PLA has developed expertise in providing the transition process required by traditional organisations.

7.2 The future of PLA

While PLA has assisted many families to develop their vision, PLA has done little to develop its own vision and mechanism for getting there. There is a need to demonstrate how PLA fits into government priorities in addition to emphasising what PLA can do.

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PLA in its current form and size is not sustainable even if some level of funding is made re-current for the medium term. The PLA workload has no boundaries and is too much for one person both in volume, geographic spread and number of roles. Despite these challenges what has been achieved is significant. However, there is no organisational succession or replication planning. The hosting relationship probably needs re-assessment in terms of the future and whether PLA fits well, with a hosting relationship, rather than, for example, independent incorporation or an independent business. The hosting relationship has been an excellent vehicle for these early stages of PLA. For the future, a hosting relationship may be limiting development of a more strategic board and organisation, or private company.

During the evaluation, the question was asked: 'PLA wants re-current funding, but for what?' Respondents typically answered this in terms of the immediate funding uncertainty. However, the issue is more substantial than recurrent funding for a part-time position. Despite noteworthy achievements reported by individuals, families and organisations, the evaluation finds that PLA is not strong organisationally. There is a need to position PLA as an organisation which can reliably continue into the future.

8. RECOMMENDATIONS

There are two aspects to the suggestions arising from this review, assuming that short term funding has been secured.

8.1 A strategic plan for PLA

Most of the obstacles and difficulties facing PLA are related to inadequate organisational capacity, infrastructure, and an inability to ensure future activities. An organisational reflection and development process is proposed to respond to the issues the evaluation identifies, through the development of a vision for the medium term future for PLA considering:

- Size and geographic spread. How to have more staff involved without the down side of larger organisations?
- Development of appropriate infrastructure for PLA. Consider:
 - Viable office including administrative capacity for: website and materials development, conference preparation etc.
 - Fiscal plan which explores various funding opportunities such as other public sector programs, philanthropic groups, fee for service and corporate.
 - Formation of a Board with governance role rather than a reference group. Is a Board/ governance or a business style best?
- Incorporated or hosted relationship. When does the host relationship become a conflict of interest for host and for PLA? For instance, limiting individuals and families' activist roles. Does PLA have an identity independent of Melba?
- Establishing priorities:
 - What are the priorities for working with families versus individuals without families?
 - How to get to families before their issues are so great and they are dissatisfied with other providers?
 - PLA role with people not with families?
 - PLA role with service providers?
 - Development of a research arm which builds on the tradition of people's stories and systematically records learnings about circles, visions, etc
- PLA at present is not sustainable. Consider:
 - What is the long term commitment to families?
 - There is no ongoing plan for viability.

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- Is there place for strategic alliances with providers, other than a host arrangement?
- Staffing. Consider:
 - How could additional staff be trained/mentored; how many?
 - Staff succession planning.
 - Specialisation within PLA so that roles are spread between staff (and Board).
 - Role and relationship with self governed groups, members and coordinators ie on what rationale?

8.2 PLA: A State Disability Plan organisation

PLA has the potential to be recognised as a leader and an example of what a progressive disability organisation looks like. It is suggested that PLA develop a proposal for funding which highlights the system reform aspects of PLA (linked to working with individuals and agencies, as well as directly with families and groups of families) and requesting funding for a reasonable time period to develop this capacity. That is, demonstrating that PLA has potential for a significant contribution to system reform because the 'product' doesn't readily align with current funding guidelines and categories. The source of this funding may be government and/or philanthropic. Within that time frame, given developing organisational infrastructure, there is the opportunity to develop a more diverse funding base.

This funding proposal could be in two stages:

- A project worker to develop a larger proposal including coordinating some of the organisational processes required to resolve issues outlined in section 8.1. This project may be of interest to a philanthropic group because of the potential of PLA.
- Deciding how this proposal could be implemented and developing an appropriate funding strategy.

APPENDIX

Several people had multiple roles in relation to contributing to the evaluation of PLA, for example, one person may have provided the perspective of committee member, and family member and/or service provider.

Contributors to evaluation

Members of the following groups included people with disabilities, family members and staff:

- PLA committee members and staff
- Nightlife committee members and coordinator
- Equal members
- Living Distinctive Lives members and coordinator
- One by One members and coordinator

Family members

In addition to the people with roles in the groups (above), there were an additional 19 family members, mainly parents, and three individuals with a disability contributed to the evaluation. Contributors lived throughout metropolitan Melbourne, with some people living in rural Victoria.

Service providers

Interstate

Marg Rodgers	Building Informal Networks project Mamre
Jeremy Ward	Parent Leader Mamre QLD professional
Jayne Barrett	Circles Initiative, Community Living Project Adelaide
Jane Sherwin	Was ED of Community Resource Unit in QLD
Ian Ross	Disability ACT

Victorian

Frank Crupi	ED of Milparinka ATSS. Frank away - talk to Claudia
Claudia Veneris	Manager Milparinka ATSS
Carly Visscher	Case Manager Upper Murray Family Care & sibling.
Carmine Laghi	Inclusion Melbourne (Gawith Villa)
Anthony Kolmus	CEO Melba Support Services

EVALUATION OF PLA

DHS

Debra Luttrell	Community & Individual Support Branch Disability Services
Sue Jamieson	DHS Loddon Mallee
Patrice Evans	Manager DPSP SMR
Kim Little	SMR
Jan Arnot (EMR)	EMR (FFYA)
Jenny Dalling	Community & Individual Support Branch Disability Services
Therese Morgante	A/Manager, Access and planning

International

Michael Kendrick	Kendrick Consulting International
Jeff Strully	ED of Jay Nolan Community Services & parent leader
Lorna Sullivan	CEO of Imagine Better NZ