



For people with disabilities

Victorian Disability Advocacy Futures Plan 2018-2020 - Discussion Paper

A submission from:

Community Lifestyle Accommodation LTD

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Victorian Disability Advocacy Futures Plan 2018-2020 Discussion Paper

A Response from Community Lifestyle Accommodation Ltd.

Community Lifestyle Accommodation Ltd. (CLA) welcomes the opportunity to submit this paper to the Victorian Government for discussion on Victorian Disability Advocacy Futures Plan 2018-2020.

CLA is a grass roots, community-based organisation on the Mornington Peninsula that has risen to respond to the needs of carers and their sons and daughters with a disability. We are a not for profit entity, a company Ltd by guarantee with Deductible Gift Recipient (DGR) status. A dedicated group of parents and skilled volunteers that joined together to address the critical need to provide suitable supported accommodation options for our middle-aged sons and daughters before their carers died. Now with the roll out of the National Disability Insurance Scheme (NDIS) on the Mornington Peninsula we are also responding to the urgent needs of younger families who also need assistance to navigate the complex NDIS system and disability service sector.

Many carers have cared for their dependents impacted with anywhere from a mild to profound intellectual disability since that person was born, often giving up careers and income opportunities to provide essential support for their son or daughter. Our nation's carers are in urgent need now of pro-active advocacy and flexible support that will enable them to continue in their caring role knowing they have a strong voice in Government.

CLA feel very strongly that local areas need government funded independent regional carer support and advocacy networks. These local networks are in the best position to deliver individual advocacy/local support to the person with a disability and their parent/carer and implement local solutions.

To date, CLA has been successful in meeting its objective of supporting the person with a disability and their family carer to enjoy a life of quality in the community by achieving the best outcomes in terms of support, advocacy, empowerment and lobbying for housing options.

The CLA experience has provided the principals with real life experiences that have significance for local advocacy and its inclusion in the Futures Plan. The complexity of the planning system of the NDIS (and the confusion caused to the participant and their carers in the interpretation of the guidelines) has highlighted the need for local person-centred advocacy. Vulnerable people need to be protected and empowered to have the right of choice and control.

1. A Word About this Submission

The submission writers have elected not to follow the script as presented in the Discussion Paper. Their rationale for the approach they have adopted is because they consider that the Discussion Paper tends to focus on broader based issues as associated with advocacy.

By contrast, CLA contends that as a family-based entity, what they have experienced over the past nine years provides them with a unique experience to make critical comments on advocacy.

Specifically, CLA submits that it has relevant experience and therefore legitimacy in commenting on the following:

- i. Lobbying – fund raising – advocacy
- ii. The nexus between families, people with a disability and advocacy
- iii. The NDIS and supported accommodation – Implications for CLA families
- iv. Gaps in family advocacy

Given the above, the sections below therefore address these key areas. It should be noted however, that as considered appropriate the submission has incorporated particular aspects of the issues raised in the Discussion Paper.

2. The CLA Experience: Self-help Not Funded Advocacy

As an organisation with membership of over 70 individual families, CLA has a limited set of experiences associated with advocacy. Indeed, over the nine years of its existence, CLA's successes have been achieved not as a result of being supported through funded advocacy but instead as a result of their own actions. Until recently, CLA has largely existed as a purely voluntary self-help entity.

Certainly, CLA acknowledges the receipt of Transition Support Package (TSP) funding in 2017 from the Department of Health and Human Services (DHHS) and also that further TSP funds have been provided in the current financial year. The Victorian Government provided an additional \$10 million for the Transition Support Package to help Victorians with disability, their families and carers, the disability workforce and service providers to transition to the National Disability Insurance Scheme.

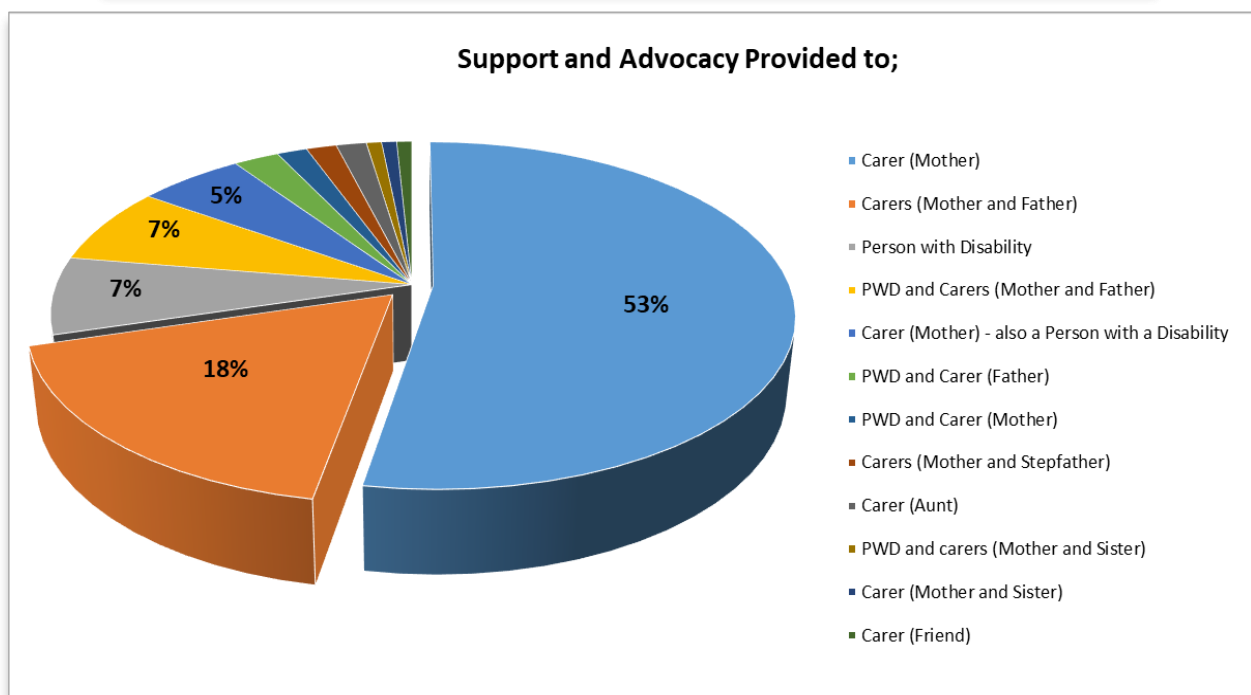
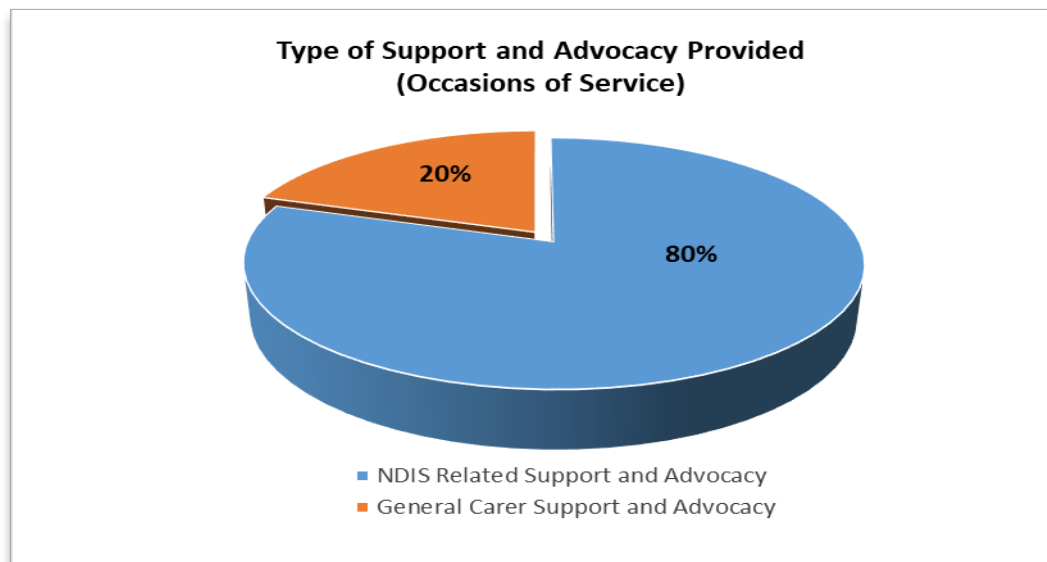
As a result of their lobbying and fund-raising efforts, CLA has been instrumental in raising funds and establishing collaborations to establish disability accommodation and advocacy services to families on the Mornington Peninsula surrounding areas.

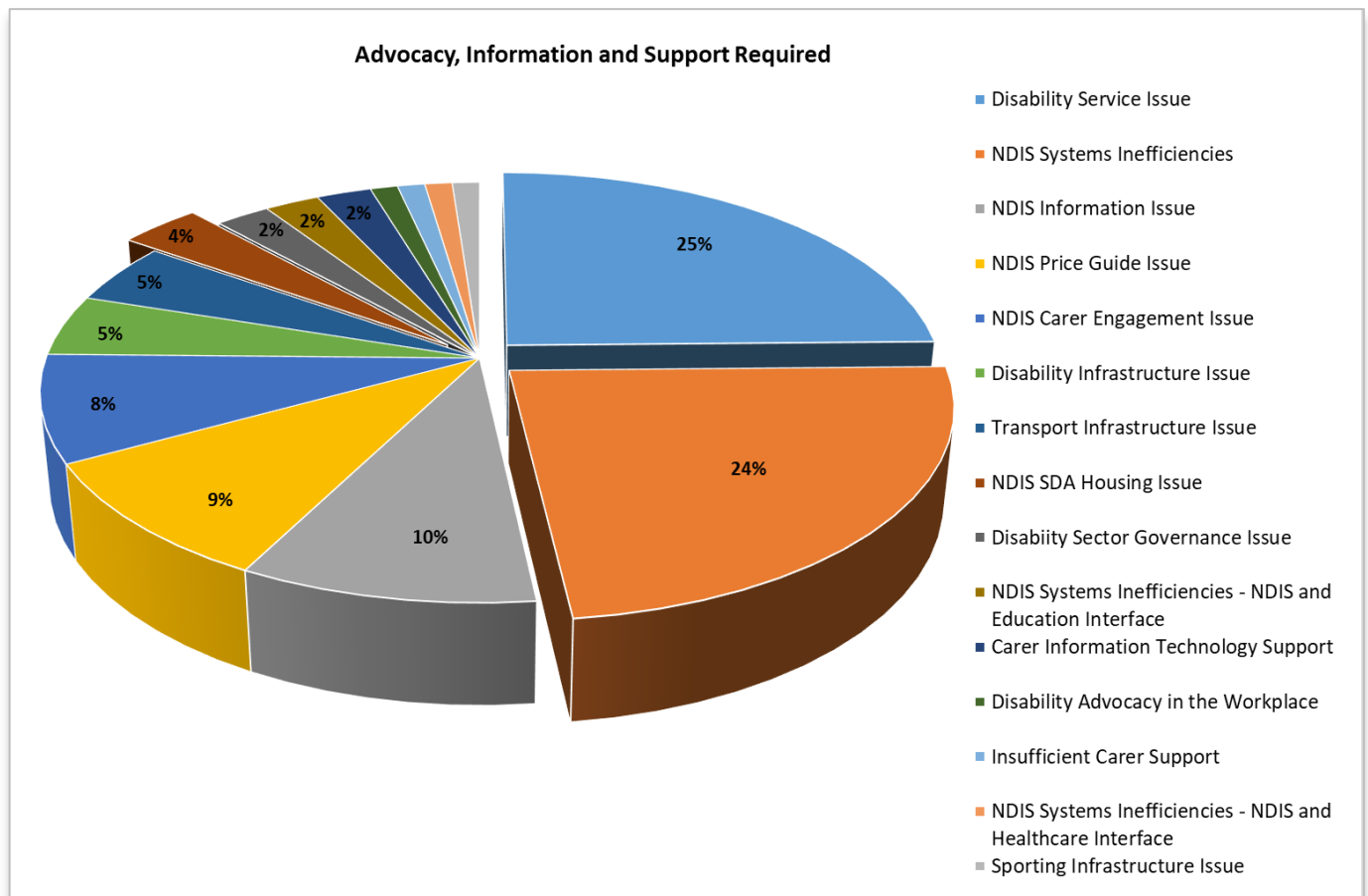
CLA was established as a self-help organisation and has continued largely to exist as a self-help organisation. This has significantly limited our capacity to attract and employ experienced advocates and expand our highly regarded advocacy service on an ongoing basis. The vast majority of families who care for people with disabilities do not have the financial means to employ professional advocates, nor is there any recognition of the value of advocacy in NDIS planning in the current NDIS price guide. Advocacy of families in the NDIS planning phases is essential to ensure successful NDIS plan outcomes and reduce the occurrence of preventable, prolonged, highly stressful and expensive NDIS plan reviews. All

people with a disability and their carers have the right to be supported via quality funded family advocacy.

3. Advocacy and support statistics

The charts below represent a snapshot of local advocacy activities on the Mornington Peninsula undertaken by CLA from the period November 2017 – August 2018;





4. The Hidden Issue

The main driver for CLA's establishment was an immediate need for supported accommodation for those family members with an intellectual disability. The families who became part of CLA generally represented older parents whose sons and daughters with a disability are also older adults. In essence, this can be described as the hidden issue. It cannot be stated too vigorously that the parents have looked after their family member with a disability since the birth of that child. And furthermore, in many instances the person with a disability not only has an intellectual disability, they also have other associated disabilities and very high support needs.

For ageing parents the time is fast approaching, and in some cases has already passed, whereby the parents can no longer adequately look after their son or daughter with a disability in the family home. Whilst they love all of their children, these parents and carers also have the right to retire from their caring role. Parents and carers need to ensure their loved ones are well settled in caring, home-like, supportive environments before the carers themselves pass away or become unable to safely care for their loved ones, and give them the great life they deserve, due to the carer's own illness or ageing. It is for this reason that out-of-home specialised disability accommodation is the one big issue exercising the

minds of the parents who comprise the CLA organisation. However, to achieve this goal requires extensive advocacy and support.

While the world of disability has in some ways changed and there is an increasing focus on areas such as autism, physical disabilities, acquired brain injury, and mental health, the reality for CLA parents is that their sons and daughters have a lifetime intellectual disability. While it is true to note that the establishment of accommodation for people with disabilities has increased in Victoria over recent years, it is also true to say that many of the new places have gone to re-housing those people coming out of institutions.

5. The NDIS and CLA

The establishment of the NDIS, at least initially, created hope in the minds of CLA members. This hope was stimulated by the knowledge that the NDIS intended to allocate around \$700 million annually to accommodation for NDIS participants. Thus, understandably, CLA families reasonably assumed that opportunities would exist for supported accommodation to become available for their sons and daughters with a disability.

Inquiries by some CLA families have revealed that it is most unlikely that they will be able to avail themselves of Specialist Disability Accommodation (SDA) via NDIS funds. The reason for this being because the current definitions of “*specialised disability accommodation*” appear to disqualify their sons and daughters from anything other than current group homes – which are of course in short supply and are not always appropriate for many people with intellectual disabilities. In any event, with the full rollout of the NDIS in 2019 and with the current transfer of government managed disability accommodation to the non-government sector, there is uncertainty as to how vacancies will be managed once the transfers have been made.

CLA contends that it is more likely than not that even if a son or daughter is assessed as eligible for SDA funding, the combination of the limited availability of accommodation in the geographic area where CLA operates, along with the competition for vacancies as they arise, makes it highly unlikely that their sons and daughters will “win the lottery”. As such, the high hopes that CLA parents had for the NDIS as being the saviour in terms of disability accommodation are unlikely to be realised.

6. A Matter of Definition and relationships – Advocacy – Funding – Lobbying

As previously noted, although a significant amount of funds are being provided through the NDIS for SDA accommodation, this SDA allocation will only assist approximately 6% of NDIS participants.

The combination of lobbying, fund raising, collaborating with skilled organisations and advocacy has meant that CLA finds itself in the unique position of seeking to establish systemic awareness as to deficits in disability accommodation as well as seeking funds in order that these collaborative groups

may be able to take the initiative to address this vital housing issue. In effect, CLA are advocating for their sons and daughters with a disability while at the same time advocating for their own needs as ageing parent-carers.

This unique position has placed CLA at a disadvantage created by the fact that there is no funded advocacy organisation that CLA is aware of that has a similar three-pronged set of activities of: One - systemic advocacy promoting the need for additional accommodation for people with intellectual disability, Two - advocacy where accommodation is sought for the individual, and Three - fundraising to support such additional developments.

7. Current gaps and Needs

This submission has highlighted three significant gaps in advocacy from CLA's perspective. As such, CLA urges the Futures Plan to recognise these gaps and direct sufficient future funding to address these needs.

Need 1- Individual advocacy to access appropriate supported accommodation

What is it?

Individual accommodation is the provision of supported accommodation for individual persons with a disability. The objective of advocacy is to represent the person with the disability and work collaboratively with their family and carers to find appropriate accommodation for each individual person's needs.

Current Gaps:

The experience of CLA families is not unique in that there are many families who have a family member with a disability who, although seeking supported accommodation, is unable to access it.

The need:

CLA contends that associated with this gap is the absence of a detailed list of people requiring supported accommodation for whom social housing or open rental is not appropriate for their needs.

In terms of the CLA families and their sons and daughters, this submission notes that the accommodation must cater for people who are intellectually disabled and who have high support needs and who do not qualify for SDA funding from the NDIS.

Need 2 – Systemic advocacy to increase the availability of supported accommodation

What is it?

The idea of systemic advocacy is to seek to effect necessary change whether in legislation, funding, policy or practice. In terms of disability supported accommodation, systemic advocacy aims to increase funding in order to provide the necessary accommodation for those seeking it.

The need:

The need for increased availability of disability-supported accommodation exists across the disability sector. Again however, in terms of the CLA families and their sons and daughters, this submission notes that increased accommodation that might occur as a result of systemic advocacy must cater for people who have high support needs and/or prioritised by the person's social need such as ageing or unwell parents/carers.

Further, consideration must be given to location and geography so as to ensure that areas where there is a deficit of supported accommodation, such as the Mornington Peninsula, do not continue to be ignored.

Need 3 – Funded family Advocacy

What is it?

Comment has already been provided elsewhere in this submission concerning the relative absence of funded family advocacy and the conflict that can occur in relation to advocating for the needs of individual with a disability and those of his or her family. This is particularly necessary during the NDIS application and planning phases to ensure good NDIS funding outcomes that ensure that people with disabilities have the correct supports in place to assist them to achieve their goals and reduce NDIS systems inefficiencies such as preventable, time-consuming, prolonged and costly NDIS plan reviews.

The need:

As such, CLA submits that a current need in terms of funded advocacy is specifically allocated funds for Family Advocacy.

8. How a Futures Plan Could Help CLA - The Relevant Questions for CLA

CLA notes that it is the Victorian Government's intention to develop "*a plan to help disability advocacy grow and get stronger in the future.*" As a group of ageing parents still caring for their adult sons and daughters with intellectual disability in the family home, for the CLA members the future is now.

i. Question 1: How should advocacy agencies use additional funding?

In some ways the question seems to suggest that it should only be current advocacy agencies that should be given additional funds. Thus, as a first comment, CLA submits that it should not automatically be or assumed to be that this should be the case. Either way however, CLA submits that particular additional funds ***must*** be allocated specifically for ***funded family advocacy***, noting that this does not mean broad based ***carer advocacy***.

ii. Question 2: What are some of the ways we can provide better advocacy support for particular groups?

CLA represents a "*particular group*". That is, and as already highlighted, a group of ageing parents still caring for their sons and daughters with a disability in the family home. Families like the CLA families not only need "*better advocacy support*", but also need actual advocacy support because it is virtually non-existent at present. Only one way is needed – that is to dedicate funds specifically

for **funded family advocacy**. There must be no procrastination on this matter. It is required **NOW!**

iii. Question 3: What kind of advocacy activities need more support?

See response to question ii above. Noting however, that currently it is not simply a case of “*more support*” but instead a case of providing actual quality and personalised support on an ongoing basis.

iv. Question 4: How can advocacy agencies be more involved in systemic advocacy?

The disability system has failed to provide sufficient out-of-home supported accommodation options in order to enable ageing parents with a son or adult with a disability still living in the family home, to be offered a home of their own. This failure is indicative of the failure of systemic advocacy. Indeed, other than via its own efforts, CLA is not aware of any concerted effort having been initiated either by individual funded advocacy organisations or the sector as a whole having systemically pushed for supported accommodation in order to enable ageing parents to have their sons and daughters with a disability relocated.

The first step in any campaign must be - **awareness**. Until such time as the advocacy sector is willing to be alert to the plight of ageing family carers their issue will lie dormant. The second step is to **identify the actions** that need to be taken in order to give birth to the campaign. The third step is to actually **activate the tasks** that have been identified. The next step is to keep on keeping on, in the sense of **continue to advocate** and push in order to seek the outcome being sought and ensure that it is embedded robustly in a way that is sustainable over time.

As such, those responsible for funding advocacy must identify those agencies willing to pursue systemic advocacy in addition to any other activities for which they might be funded. However, of equal import is a requirement to identify key issues that must be high on the systemic advocacy list, including supported accommodation, and implement a governance system for quality advocacy reporting to report on the outcomes of advocacy activities and measurement of resulting improvements in the disability sector.

v. Question 5: How can we implement your ideas?

Implementation should not be seen as complex. Indeed, given the right level of motivation and desire of those with the power it is relatively simple:

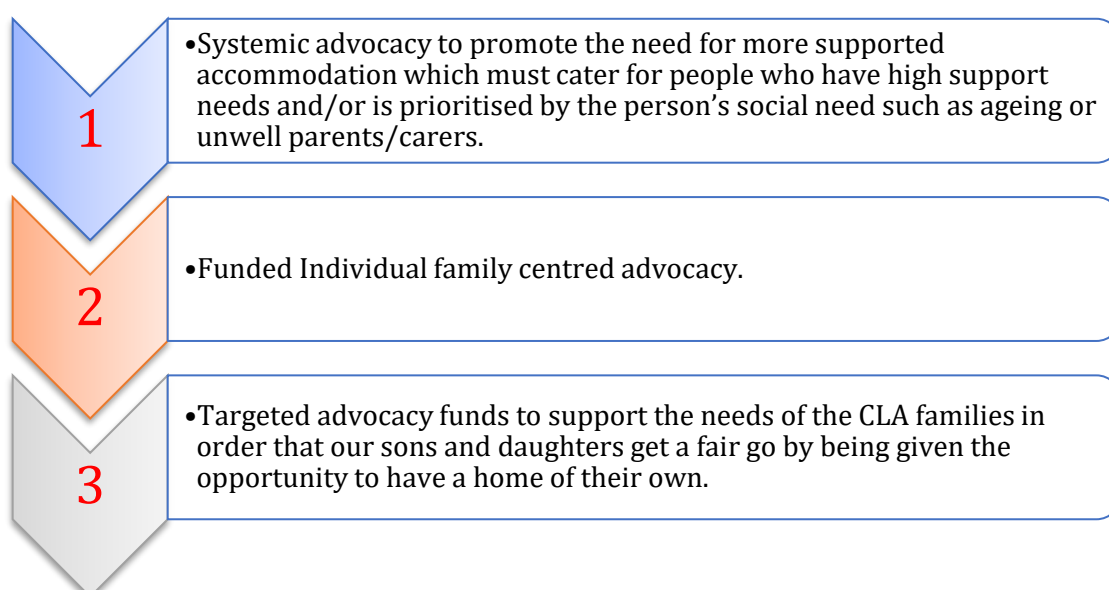
- It firstly requires funds to be allocated to identified and named funded advocacy organisations specifically tagging such funds for family advocacy.
- Secondly, it requires the funder to ensure that systemic advocacy for supported accommodation is written into the funding and service agreement.
- And thirdly, and specifically in terms of CLA, direct advocacy is required for the families seeking supported accommodation for their sons and daughters with a disability.

11. A Final Reflection

This submission has sought to highlight the plight of a particular set of families. Each of these families has a family member with intellectual disability still living in the family home. Each set of parents is ageing and each has always cared for their son or daughter with disability. The objective of each family is to be empowered to obtain a suitable supported accommodation place and the necessary support for their family member with a disability.

The advocacy Futures Fund must address the plight of families such as those that comprise CLA, including the necessary safeguards for protection and the equal rights of choice and control for the participant to have a life equal to that of the general population.

Funded family advocacy must be put on the agenda. It must be funded as a particular and specified form of advocacy. The Futures Fund must not fail ageing family carers. As families, we recommend the following three core actions:



The above advocacy initiatives must be accepted as providing a major platform in giving reality to s.5 (3) (a) of Victoria's Disability Act 2006 (the Act) of helping the sons and daughters with disability of CLA families to achieve *"their individual aspirations."*

They must also be accepted as providing a major platform in giving reality to s. 5 (3) (c) of the Act in terms of maximising *"the choice and independence of persons with a disability."*

And further, from the perspective of the CLA ageing parent carers, and as required by s. 5 (3) (h) of the Act, they must be accepted as a way to *"consider and respect the role of families ..."*

CLA is now in the hands of the Futures Advocacy Plan - we must be supported. After a lifetime of caring, we deserve to be in control to plan positive futures for our families and future generations

End of Submission

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Marie Hell
Secretary

For
Community Lifestyle Accommodation Ltd.