

REAL LIVING OPTIONS ASSOCIATION INC.

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SUBMISSION TO THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT INQUIRY

EXECUTIVE SUMMARY

1. About our Organisation

Real Living Options Association Inc is a small Far North Queensland community-based, family-governed Disability Lifestyle Support Service. The Service has been operating since 1996, is funded under CSTDA 1.06 & 3.01 and supports fourteen (15) people with a disability to live as participating citizens of the community in a home of their choice.

2. Our Beliefs

The comments presented in this submission are made as a result of our experiences in working with people with an intellectual disability (some of whom also have a physical disability) and their families/advocates, in a way which values:

- A right to **choose a place of residence**, whether it be within the family home or a home of their own, in the community of their choice;
- A right to **be supported at a level which respects and meets their disability needs**, in a culturally appropriate and non-discriminatory way;
- A right to **lead an ordinary life** through participation in community social, recreational, employment and learning opportunities and activities.

We strongly support the establishment of a Disability Care and Support Scheme that would fund the support needs (physical, intellectual, social, emotional and spiritual) of people with a disability throughout their lives. This support must be provided within an **entitlement framework** which includes access to generic services such as housing, education, transport and health care.

Funding for support must be **portable**, enabling people with a disability to live anywhere in Australia and move according to their life choices and/or circumstances. There must be flexibility around how support is used, with a focus on the needs and aspirations of the person with a disability

In summary

A Disability Care and Support Scheme should facilitate people with a disability, in close consultation with their family/advocate where necessary and desirable, to design and direct their own service/s so that they receive the right amount and type of service, by the right people in the right way and at the right time.

THE SUBMISSION

INTRODUCTION

Real Living Options Association Inc (RLO) presents this submission which is soundly and solidly based on fourteen (14) years of continuous operation as a community-based and family managed Disability Lifestyle Support Service to up to fifteen people with an intellectual disability, some of whom also have a physical disability.

In this submission ‘the person or persons with a disability’ will be referred to as ‘the person/s’.

The principles on which RLO operates include:

- All support is provided with a focus on ‘an ordinary life’ for the person
- The person is a participating and contributing member of their community
- The person lives in a home and community of their choice
- Support to the person is individualised and is in response to their specific needs
- The person is central to, and engaged in all decision-making around all aspects of their life
- There is recognition of the importance of family/advocates in assisting the person make lifestyle choices
- The concepts of Human Rights, Social Justice, Equity, Equality, Non-discrimination, Valued, Respected, Empowerment and Dignity are ones which underpin all actions of RLO

RLO appreciates the opportunity to contribute to, and influence, this Inquiry into Disability Care and Support. We trust that our considerable experience and expertise, built up over our fourteen (14) years of commitment and service delivery to people with a disability, will be beneficial in assisting to shape a new and fairer system which values people as participating and respected citizens of their community.

RESPONSES TO KEY QUESTIONS RAISED IN THE INQUIRY

1. What should a new system aspire to achieve?

- Support as **entitlement**
- **Equitable** response to all people
- Recognition of **geographical and cultural differences**, including regional, rural and remote
- Focus on **people’s abilities** – support provided with the ‘least restrictive alternative’
- Recognition of the **role of families/advocates** in people’s lives – either formally or informally
- Recognition of the **decreasing capacity of families/advocates** to continue to provide a consistent level of support in their **advancing years**
- **Social inclusion/** participation in, and contribution to the person’s community
- **Opportunities** for education, work, leisure, recreation, spiritual aspirations, personal development as well as for meeting people and developing friendships

- **Collaboratively work with generic services** in the community to provide access to and benefit of these services to the person and their family/advocate – eg medical and dental care, transport, housing, education
- **Coherence** with a National Disability Strategy

These principles are ones which, over the fourteen years of its operation, **RLO has found to be essential** to provide a meaningful and dignified service to people who need support to live their lives as respected citizens of their community.

2. Who should be the key focus of a new scheme and how may they be practically and reliably identified?

- The scheme should deliver an entitlement that is available to **all people who genuinely require support**. The basis of this is fairness and equity. Currently the access to funding is inequitable, resulting in people being inadequately funded or not in receipt of funding at all.
- It needs to be noted that people with an **intellectual disability** are perhaps the most vulnerable group of people in our communities. People with an intellectual disability are commonly excluded by society's lack of understanding. Those whose disability is not readily apparent face additional social barriers and exclusion, based on ignorance, fear and prejudice
- People can be both practically and reliably identified **within their local community** by local services (both generic and specific to disability) as well as families, friends and other individuals within the community.
- **Local systems** need to be set up to identify the local need
- There must be recognition of the fact that **need is related to more than a personal disability** – need is also influenced by the **person's environment**, which may include availability of services (eg regional, rural, remote areas as opposed to metropolitan), family/support network, financial status

3. What are the kinds of services that particularly need to be increased or created?

- Services which **offer flexibility**. People need to be able to **choose** a service model or combination of services that truly meets their needs.
- The opportunity to easily transfer from one service to another – **portability** – is essential
- Funding and accountability processes need to be **assigned to the person** and their vision for a good/ordinary life
- Services need to **value people**, focus on the **ability and strengths** of the person and be **individually tailored** to the person's needs. The experience of RLO is that this is not achieved when people are congregated in their living, recreational and work environments
- **Generic services** need to be encouraged and assisted to include people as ordinary members of the community – eg transport, health, employment, sport and recreation
- **There is no place** for the segregation, congregation or sequestering of people **for the convenience of the service provider**

Community capacity building encourages and supports the inclusion of all people. This enables the skills and qualities of members of the community to be valued and positively regarded as beneficial to all, as well as increasing the self esteem and self worth of individuals.

If given a choice, whom amongst us would choose exclusion over acceptance in the place where we live?

4. What are ways of achieving Early Intervention?

- It is a well-known fact that the sooner people and their families/advocates begin envisioning and planning their present and future, **it is more likely that they will take charge of their lives**, and less likely that they will become increasingly dependent on external assistance
- Provide resources and assistance, earlier rather than later, to people and their families/advocates **to develop creative thinking** around the person's dreams, goals and aspirations
- **Timeliness is vital** – the right support at the right time by the right people is a relevant form of early intervention

5. How could a new scheme encourage the full participation by people with disability and their carers - in the community and work?

- In a nut-shell, this can be achieved by **strategies which promote inclusion of the person, capacity within the community and a spirit which embraces the equality of all people, regardless of their circumstances**
- These strategies can include:
 - a person living in a **home of their choice** in the community
 - **planning and decision-making** by the person and their family/advocate which utilises the opportunities available in the community
 - **education and promotion** - where opportunities do not exist pro-active representation to the power-brokers in the community such as local council, established training and employment services, recreational and social clubs and organisations, with an emphasis on inclusion
 - a recognition that the opening-up of opportunities often requires **financial injection**. Assistance by the scheme to community organisations/agencies/services may be an essential component of achieving this desirable goal of inclusion
 - **individual support** to the person to assist them to participate. This can be achieved through the provision of adequate funds in their individual packages as well as developing unpaid friendships and relationships

6. How can people with disabilities or their carers be given more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)?

- Provide **flexible, portable, transferable and individualised** funding to the person
- Ensure the person and their family/advocate is involved and has **control at every level of decision making**, including **hiring and firing** of staff
- Where a **Service** is managing the person's funds ensure that it is **transparent** in the management of the funds and **flexible** in responding to the needs of the person and **has values which are consistent with those of the person**
- **The scheme should include the cost of management within the total cost of support** so that people can transparently negotiate the level of assistance with their service provider
- **Appropriate and accessible appeal** and safety-net mechanisms need to be included in the scheme to protect the person and to investigate complaints, such as a **disability specific Ombudsman**

7. **How can service delivery be improved – including coordination, costs, timeliness and innovation?**
- The service is provided in a **timely fashion** – at the time needed by the person, not for the convenience of the service provider
 - **Funding** is both **adequate and reliable** and takes into account ‘hidden costs’ which may include ones such as coordination, entry fees and charges for generic activities, costs for staff when a person requires assistance to participate in chosen activities and managing changing needs of the person
 - **Staff are right for the person** – that is, they have attitudes, values, working style, skills and personality which align with the person and are also age and culturally appropriate for the person
 - **Good systems** are in place to ensure the smooth, efficient and effective delivery of services for the person
 - The service can respond in a **flexible** and timely way to any changing needs of the person, as identified by the person/family/advocate
8. **What are the factors that affect how much support people get and who decides this?**
- The person should receive sufficient support to enable them **to lead an ordinary life** in their own home (whether in the family home or one of their choosing in the community), in the community of their choice
 - Recognition that **peoples needs change** and therefore the level of support needs to be correspondingly flexible to those changing needs. The person/family/advocate must be the ones who decide when support needs to change
 - **The person/family/advocate must be in charge** of the level and type of support
 - The plight of **ageing parents/advocates** is a huge issue and an ever increasing one. The well-being of the support people is imperative and influences the lifestyle and well-being of the person being supported. **The level of support/funding must take this into account**
 - Decisions about financial support and service entitlements are best made by an **independent community based panel, in close consultation with the person/family/advocate**
 - The assessment process for decision making should be based on a **realistic strengths-based framework** rather than a deficit framework which focuses on diagnosis and limitations.
 - It is imperative that this strengths-based framework focuses on developing the person’s potential and not be used as a means to reduce funding costs. **The decision is person-focused, not funding-focused**

The experience of RLO is that **individual support promotes independence** in the person, whereas those who live in congregated situations develop a much higher level of dependence. This has been particularly noticeable in the way in which **people manage their day-to-day lives** in areas such as: decision-making around choice and preparation of meals; their daily routine; interests and activities; work choices; people they live with and perhaps most importantly, their **level of confidence and belief in themselves as regular citizens of their community**.

Inevitably, this independence is, in the long run, much more **cost effective** from a financial perspective and also enhances the **social health of the community**.

9. **How can we ensure that the good aspects of current approaches are preserved?**
- **The people who know best what is good about an existing service are those who receive it!**
 - **Developing a system** which **captures and documents** this knowledge and information is vital if ‘good practice’, as it relates to current (and past!) approaches, simply makes good sense
 - **Any changes** which are developed for the benefit of people receiving a service need to be implemented in a **sensitive, smooth and efficient way**, ensuring that people **do not suffer** either in the change process or as a result of the changes
 - **Changes need to benefit the person**, not be for the convenience of the system
10. **What should be done in Rural and Remote areas where it is harder to get services?**
- Always look for a **local solution** first
 - Use locally available **generic services** and resources in conjunction with any specialist services which may be available
 - Support, in a practical way, **existing networks** that are part of the lives of people requiring a service – flexibility of funding and the ability to self-direct funds will mean people have a greater opportunity to purchase support from within these networks.
 - Where necessary, people should be supported and funded **to travel** to where they can access services and supports when they are not available in the local community
 - In some circumstances it may be useful for **qualified people** (eg medical specialists, psychologists, therapists, dieticians) to be funded to visit regional, rural and remote areas on a regular or ‘when required’ basis.
 - As in all situations, the **person and their family/advocate should be integral** to any decision-making around their support
 - Perhaps to a lesser extent, but none-the-less worthy of consideration, **regional areas** may need some of the above injections of resources – eg Cairns
11. **How do we reduce unfairness so that people with similar levels of need get similar support?**
- Take **geographical isolation** into account when allocating funds. Services, when available, are generally more costly in regional, rural and remote areas than in the metropolitan areas
 - **Do not means-test** the scheme – people should be funded and supported to live with the same level of dignity and independence as the rest of the Australian population
 - People should not have to personally fund the **additional costs of living with a disability** – eg inability to use public transport, essential aids and equipment, costs involved in needing assistance from others to access entertainment
12. **How do we get rid of wasteful paper burdens, overlapping assessments (the ‘run-around’) and reducing duplication in the system?**
- Ensure there is some sort of a **national system** which captures consensus across states in areas which are likely to **affect people who move interstate** – people need to be able to move anywhere within Australia without being burdened with requirements to “prove” yet again their **eligibility for care and support services**

- **Reduce the “over-kill” in some of the existing systems** – eg the **auditing** system. Currently Services are required to do an internal and an external audit each year. A more efficient and just as effective system would be to **alternate these audits** so that there was only one each year. In a small Service such as RLO this would result in **savings of \$4,500 per annum**

13. How can a new scheme be financed so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

- If the government and the Australian community is **serious about genuine inclusion and equal citizenship** of people who have a disability, and acknowledge that this status is achieved as an entitlement, not a ‘hand-out’, then it is imperative that **a stable and on-going system is in place** to ensure funds are available to enable this to be a reality
- A **no-fault National Disability Insurance Scheme**, funded by tax-payers, would ensure money is available for those who currently have a disability and those who, in the future, are born with a disability or acquire a disability due to illness, genetic condition (eg muscular dystrophy) and accidents
- Develop a strategy to **re-direct existing government funds** for disability care and support into this scheme. This will need to happen in a gradual and systematic way
- **Importantly**, the above strategy must not be a way for **government to “opt-out”** of its responsibility to provide funding for disability services. A National Disability Insurance Scheme should **co-exist with government funding** – the outcome of this is **increased funding** for disability care and support

14. What are the practical aspects of the scheme that will make it work – such as how existing arrangements would fit into a new scheme, how to manage risks and costs and ideas for attracting people to work in disability services?

- The ability of the person and their family/advocate to **choose and tailor services and support** to their individual needs
- The person and their family/advocate are provided the opportunity to **employ staff who are ‘right’ for the person** – this includes values, personality, interests, age, skills and abilities
- Direct support staff need to be supported with **relevant on-the-job training** around the **person’s needs** and the duties they need to undertake to ensure the person receives appropriate support
- Where possible, staff should be offered **sufficient employment** to meet their lifestyle needs, to ensure continuity of service and reduce attrition rates. Constant changes in staff, due to insufficient work, can have a detrimental effect on the person being supported
- A harmonious, well-functioning, respectful and considerate **work environment** will positively influence good work practice. **The scheme can support this** by ensuring **payment and accountability processes** are simple and transparent as well as having **accessible, user friendly and responsive systems** to assist individuals and services when problems and issues arise
- **Auditing processes** which **focus** on the quality of outcomes for people, their families/advocates rather than on the quality of the system

15. What is the role of Services?

- RLO believes there needs to be **flexibility and innovation around service delivery**, to enable the person and their family/advocate to make **real choices** which meet their needs
- **Funding and accountability** processes need to be in the **hands of the person and their family/advocate** – this will enable smooth transition between services if desired
- A network of **flexible and creative community-based services**, structured to manage portable funding
- Services should focus on the **“capacity- building” of the person** – thus assisting people to envision and plan positively
- It is essential that services are supported to **welcome and include people into the community** – building relationships which are nurturing and trusting for all members of the community
- Services which provide **safe-guarding strategies**, including independent advocacy, administrative appeals mechanisms as well as simple, transparent accountability measures for both people, their families/advocates and service providers, are needed
- **Research and development**, based on the experience and expertise of people, their families/advocates, should be on-going

16. How long would be needed to start a new scheme and what should happen in the interim ?

- The short answer would be **‘the sooner the better’!**
- There are obviously **many variables** which have to be taken into account, so it is vital that these are carefully and thoughtfully considered in a systematic, logically and realistic way – this will not be achieved overnight
- **The process so far has requested input from a wide spectrum of the Australian population, and these submissions require an enormous amount of time to write, by people who are already time and emotion ‘strapped’. The manner in which the Productivity Commission deals with this material needs to be respectful of this effort. The Inquiry is being promoted as a collaborative, consultative process – and the outcome needs to clearly indicate this. People must feel and know that this is true consultation**
- Even when engaging in a strategy of the magnitude and complexity of this new scheme, it is possible to **simplify structures and processes**, so that they are understandable to the general population
- The Productivity Commission should be looking at the big picture (what do we want this system to look like?) and at what the system is now – then **develop strategies which will, as smoothly as possible**, move the disability care and support scheme towards that goal
- The **inconvenience** of achieving the above should be felt by the government, **not the people the system is designed to serve.**