

Collective Action Group

The Collective Action Group has been successful in gaining funds to establish an innovative project which enables the personalised support arrangements for 10 people with disability.

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Who are the people?

Ten people with disability with complex needs will be supported in personalised living arrangements. All people have some funding, with some individuals having more than others. The process of developing the service will happen sequentially, with a new person coming on board when the supports are in place for those already being supported. This first stage of developmental work is seen as a pilot and will be evaluated as such.

The 10 people involved in the project have complex needs, have labels of challenging behaviour and prior experiences of institutionalisation, abuse, assault and neglect. This means they are very vulnerable. A common experience for this group is that traditional services were unable to deliver the type of personalised support each person needed which resulted in further exacerbation of people's negative labels, skills and competencies. Most people have moved from crisis to crisis and have needed emergency funding to assist them at these times. In traditional services, their families and friends have not been welcomed and/or actively pushed out of their lives. As a result, not all people involved with the collective currently have close family or significant others in their lives.

Anchor people

	2 Parents	Sole Parent	Foster Parents	Sibling	Extended Family	Friends	Paid Advocate
Person 1		✓					
Person 2				✓			
Person 3						✓	
Person 4	✓						
Person 5							✓
Person 6			✓				
Person 7				✓			
Person 8						✓	
Person 9	✓						
Person 10						✓	

In the past all the people involved have been supported by other accommodation services. Many of these services have been institutional in their size and practices and have not been able to cater for people's complex needs, in fact exacerbating their problems and adding to the many of the negative labels that the people have acquired. These traditional services did not deliver the type of support that each person needed and did not enable them to live in ways that assured their wellbeing, connections with family and community, or a sustainable future. Their families found that, as well as not receiving good services, their input was not welcomed and they were pushed out of people's lives.

Life Experience—Living Now

	Challenging behaviour	Institution	Group Home	Hostel	Aged Care	Medication	Psych Ward	Gross Abuse	Gross Neglect	Ill Health	Living Now
1	✓	✓				✓		✓	✓	✓	Own Home
2	✓	✓	✓			✓		✓	✓	✓	With Sibling
3	✓	✓		✓		✓	✓	✓	✓	✓	Own Home
4	✓		✓		✓	✓		✓	✓	✓	Own Home
5	✓	✓	✓	✓		✓		✓	✓	✓	Own Home
6	✓					✓		✓	✓	✓	Foster Family
7	✓	✓		✓	✓	✓	✓	✓	✓	✓	Own Home
8		✓	✓					✓	✓		With Friends
9	✓		✓			✓		✓	✓	✓	With Parents
10	✓			✓	✓	✓	✓	✓	✓	✓	Own Home

Advocates became involved when many of the people were found to be living in inhumane situations where their human rights were severely abused. With such untenable situations, advocates and those families who remained in people's lives have had to make do with temporary services. These, incidentally, have worked far better than formal accommodation services because they have allowed family and friends to determine what supports needed to be in place. However they are not designed for this purpose and are not sustainable over time. The only feasible solution, therefore, was to create a personalised service and to find an organisation that was prepared to support people to do what they had to do to assure the well being of the people with disability involved.

A viable alternative was thought to be a hosting arrangement where an organisation holds the legal and financial reporting responsibility, but allows the families, friends and advocates to continue to have the authority to select and direct the level and type of supports that loved ones need, as well as when and how these are best used, without having to be the service provider. Host agency relationships have already been developed in other places, in particular in the *Family Governed Project in Massachusetts* and in *Person by Person in Melbourne*, as well as in many local arrangements with people with physical disabilities.

Our group has been meeting for over three years to develop the concept of a new model of accommodation support service and has become known as the Collective Action Group. The work has created much interest with a request to present a paper at the national ACROD conference in Perth and with several new family based groups forming here in Queensland to consider how similar services might be developed with their loved ones.

How does the Model work?

The model is best described as:

- Being individually based around the needs of each particular person
- Locating people with disability in their rightful place in family, neighbourhood and community
- Recognising the authority of the person and their family to know about, understand and influence what happens in daily life
- Having clarity about what remains the role of service and what remains the business of families and friends
- Maximising the use of formal and informal supports and the use of paid resources
- Using the legalities of an incorporated body in order to administer the funding, but keeping the decisions about individuals close to the people involved
- Considering how life will be played out when parents are no longer able to take the roles that they do now, or for those without family, considering how intentional community can be built around them.

Values and beliefs relating to the model and their effects on practice

- ★ **Each person is entitled to enjoy a lifestyle which is based on what is valued and preferred by other citizens:**

This means that each person can be supported to:

- Pursue their own lifestyles and future
- Contribute their abilities, gifts and talents, some of which may yet be undiscovered
- Have a range of lifestyle activities and friendships that are not prescribed or unnaturally restricted to segregated settings with others who have disabilities
- Have lifestyle arrangements that are highly relevant to what they need the most.

- ★ **Designated members of family or friends have a natural authority and are entitled to influence the vision and direction of the life and supports for their loved one, when they have remained faithful and committed to their development and well being**

This means that each person is:

- Supported by people who know and love them, who are committed to creating an inclusive and respectful life with and for them
- This also means that each person will do well when family and friends are:
 - Heard and listened to
 - Encouraged to be involved in their life and to imagine and create better options
 - Directing how everyday life is played out.

★ **The service, through the project worker, can work with each person's family and friends in a respectful and proper relationship.**

This means that each person, their family and friends and the project worker:

- Work in 'right relationship' with one another involving mutual respect, humanness, individuality, honesty, openness and trust.
- This also means that each person and members of their family and friends:
- Have a high degree of influence on the matters that affect life, but without having to expend an unreasonable amount of time and effort to achieve this
- Can direct resources where and when they are most wanted and most needed
- Have the right to influence, refuse and imagine better, and to counter propose or suggest changes to everyday lifestyle, how supports are arranged and by whom
- Experience processes that are people friendly, without having their lives consumed by bureaucracy, standardised responses, regulations or tedious management or regulatory processes.

★ **Each person's home is a private place where customs, relationships, security and preferences are honoured.**

This means that each person is:

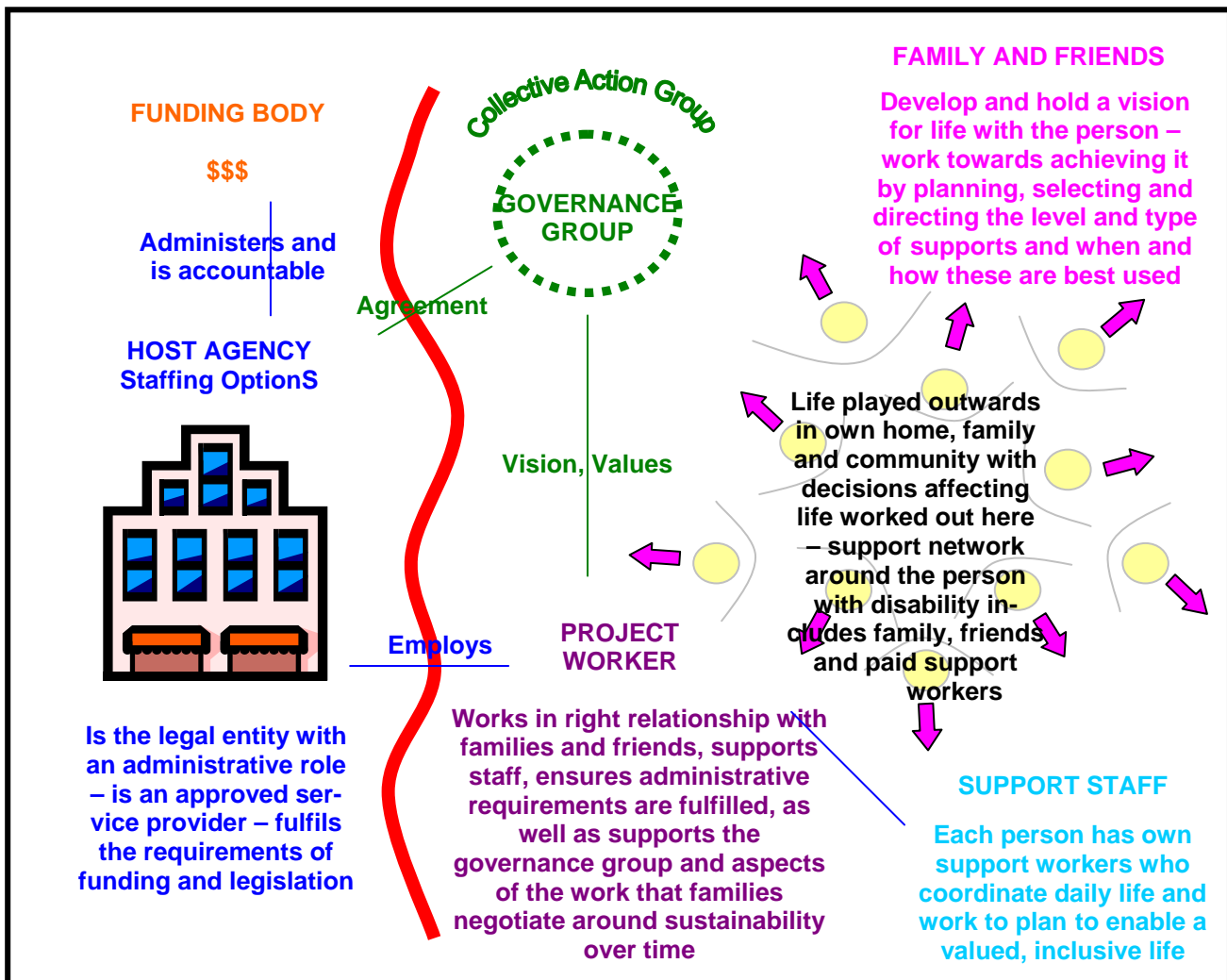
- Treated as unique and supported in a personalised way
- Known well and receives support that is responsive, flexible, creative and informal
- Not 'done to', but rather is treated in a way that generates a sense of working with them and their families and friends in all matters of importance.
- This also means that each person's family and friends:
- Have influence over decisions that affect daily life, including how it is lived, how resources are used and where, when, how and with whom.

★ **Each person's local community is richer because of the participation and contribution of people with disability:**

This means that each person is:

- Supported to be included in the fabric of their neighbourhood and local community and enabled to enjoy real friendships, hospitality, contribution, recreation and living arrangements that are typical and socially inclusive
- Supported to connect with, visit, celebrate with and provide hospitality to family members and friends
- Supported to have committed people involved in their life even when parents no longer have the capacity or are no longer around.

Who does what?



Each person with disability is the starting point and the focus of the model, so that each life and the support to get on with it will look different for each person. Paid supports for each individual are personalised and are not connected or used with other people who are part of the group. Decisions about life and how it is played out are kept close to the people involved and are made by family members and other significant people who know the person best and have a strong commitment to them. How this happens is up to those involved and these arrangements will also look different for each person, based on the situations and capacity of family, friends, advocates and support workers.

The family and/or a support network of committed people play a pivotal role, holding a vision about life for the person and designing and crafting unique support arrangements for and with their loved one, which enable them to lead a fulfilling and valued life in the community, despite the challenges that are ever present. The families and/or networks are acknowledged as having the natural authority to make decisions with and about the person to whom they have a commitment. The family members and networks also remain the safeguards for the person ensuring that services and governments do the right thing by these vulnerable people, who in the past have not been afforded decent lives.

In some sense this model brings about restorative justice for these ten people who have been rejected all their lives by both the community and the traditional disability service system, and for some, even by their families. Because of this, several of the people do not have any significant others in their lives who have a commitment to them. Some do still have committed family members whilst some others have supportive friends in their lives who continue to play a significant and considerable role.

The long term aim is for each person to have committed people in their life so that the model is sustainable over time.

Support workers would be formally employed by a host agency to work with one individual, but could be chosen and deployed by the family and or support network in ways that best suit the person, their plans and aspirations, and their lifestyle. Such an arrangement gives flexibility and responsiveness enabling the person to have the supports that best suit their needs, within the limitations and capacity of the funding arrangement. Support workers would have direct contact with family and friends and value their role in the person's life.

In all instances the people involved require **coordination of supports in their everyday life** because of the complexity of their needs. This may be in the form of a key worker or other forms of coordination which may be beneficial in keeping things together in the person's life, such as organising diary arrangements and team rostering, maintaining health checks and medication, or in dealing with challenges or crises that might present on a regular basis.

The project worker (the funded position we are seeking) is a crucial role. There are two key components, one being a facilitative role with the governance group, families and significant others, the other being the administrative buffer between the life of people, their family and networks, and the host and funding agencies.

The facilitative role includes supporting family and friends in relation to their vision and plans for each person and future planning and development of sustainable support networks for each individual, as well as supporting the governance and the vision and values in practice, and the activities of the collective. The buffer role includes handling the formal aspects of hiring of staff, overseeing induction, training and support of workers and providing records for the host agency to fulfil legal, administrative and funding requirements.

A governance group oversees the overall vision and values of the provision of service with the ten people. This group is made up of representatives of the people with disability who are supported. The group currently meets on a monthly basis and uses email to connect with one another or to gain agreement about written policy or submissions.

The governance group is different from a traditional management committee, as it does not have formal responsibility for the legalities and expectations of the running of an approved disability service.

However this group does make the major decisions about the overall policy framework about how the service operates, but not about what happens in the lives of individuals. It is the formal body which the project officer refers to for all value based decisions, but not for employer based decisions or for personal decisions affecting specific people. The governance group also has a

stewardship role in considering how sustainability of the group and the service is maintained over time.

The governance group is supported by other members of the broader Collective Action Group.

The Collective Action Group consists not only of the ten people with disability, their families and significant friends, but also includes advocates and other members who have been key supporters of this venture, who want to see good things happening in the lives of people with disability. This broader membership is sought for mentoring, advice, support, strength and courage to take this course of action forward now and into the future.

Members of the Collective Action Group have been meeting for over three years to get this service up and running. The broader members of the group currently include a number of service providers with belief and experience in personalising supports with people with disability and their families, advocates involved in Speaking Up For You who brought people to our collective attention and consultants from the Community Resource Unit who have provided ongoing assistance and a venue for our meetings.

The host agency is the recognised service provider who will take on the responsibilities of employer of the staff, including the project worker and the support staff who work with individuals. They will hold and administer each person's funding in line with their funding agreement and will fulfil the expectations of the Disability Services Act and other requirements of the Disability Service Standards. The agency will provide regular reports of the use of resources to each person's families or friends.

There is implicit understanding about the buffer between the host agency and the operation of the service in people's lives, as well as the natural authority of committed family and significant others to make life influencing decisions with and on behalf of the person. This is outlined in a service agreement between the host agency and the governance group.

The Collective Action Group has approached Staffing Options for Community Services Pty Ltd which is an approved disability service provider, who is philosophically aligned with the group. Staffing Options is already known by some of the families and friends, as it has been prepared to provide services as an interim temporary arrangement until other viable alternatives can be arranged. The agency is keen to be of assistance in developing a new way of operating and has the legal and administrative infrastructure to provide the supports that the new model of service needs. Although the agency is a private company, the director is prepared to consider ways that payroll tax can be minimised by applying for different status for this part of the agency's work.

The funding body provides the funding for direct assistance to people involved in the group. Currently Disability Services Queensland is the funding body for all grants which are individually based. The Collective Action Group is seeking recurrent block funding from Disability Services Queensland for the position of the project worker and the support of their role, as well as non recurrent funds for the establishment of the pilot and its evaluation.

The ongoing relationship with the funding body will be mainly with the host agency as legal service provider who holds and administers the block funds for the service and the individualised funds for the people involved.