



ACT
Government
Community Services



Exploring the Feasibility of a Citizen Advocacy Program in the ACT Community

A Scoping Research Study

December 2013

About ACTCOSS

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples. We celebrate Aboriginal and Torres Strait Islander cultures and ongoing contributions to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for not-for-profit community organisations, people living with disadvantage and low-income citizens of the Territory.

ACTCOSS is a member of the nationwide COSS network, made up of each of the state and territory Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS' vision is to live in a fair and equitable community that respects and values diversity and actively encourages collaborations that promote justice, equity and social inclusion.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

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ACTCOSS acknowledges the contributions of the many people who gave their knowledge, time and experience to this project.

ACTCOSS advises that this document may be publicly distributed, including by placing a copy on our website.

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Acronyms

ACT	Australian Capital Territory
ACTCOSS	ACT Council of Social Service Inc.
ADACAS	ACT Disability, Aged and Carer Advocacy Service
AFI	Advocacy for Inclusion
CA	Citizen Advocacy
CAPE	Citizen Advocacy Program Evaluation
DACT	Disability ACT
DANA	Disability Advocacy Network of Australia
DISH	Disability Information and Support Hub
NDIS	National Disability Insurance Scheme
USA	United States of America

“ Disability is not purely individual. Human rights are not purely about individual entitlements. Disability is not simply a matter of individual impairment which can be summed up or addressed in purely medical terms.

Rather, disability involves interaction between a person's impairment and social environments, systems, structures and attitudes which are too often disabling and excluding in their effect, instead of being enabling and inclusive. ”

Graeme Innes, Disability Discrimination Commissioner, Australia – National Disability Summit Keynote Address, 30 April 2010, Melbourne.

Executive Summary

The research conducted for *Exploring the Feasibility of a Citizen Advocacy Program in the ACT Community* has found that a Citizen Advocacy program would make a significant contribution to increasing the range and capacity of disability advocacy programs available in the ACT to support people with disabilities. We also found that it is feasible to set up a Citizen Advocacy program in the ACT.

Citizen Advocacy would complement existing Individual and Systemic Advocacy activities that are currently provided in the ACT for people living with a disability. The provisions of DisabilityCare, and the expectation of more consumer choice and control, will increase the need for advocacy. Citizen Advocacy programs cannot and should not replace existing advocacy programs, activities and services, nor on its own can provide a sufficient advocacy resource to meet the community's needs.

The establishment of a Citizen Advocacy program in the ACT will contribute to building a platform on which people living with disabilities in our community can have rights as a citizen respected, exercised and upheld.

Background

The Australian Capital Territory (ACT) will be one of the launch sites of DisabilityCare¹, commencing fully in July 2014. The introduction of DisabilityCare and direct funding of individual people with disability was welcomed by the disability sector, and especially by people living with a disability, their families and carers. However, DisabilityCare does not come without its challenges and will require institutional, community and grassroots support to be effective and successful.

The ACT Government, through the Community Services Directorate, supported ongoing community consultations to facilitate the roll-out of DisabilityCare. This included support for consumer groups to exercise more choice and control in the support and services they access through DisabilityCare and for community organisations to be ready to offer services that respond to consumer expectations in the new funding and administrative environment. The ongoing and growing need for advocacy support was affirmed by all participants in these consultations.

A variety of ACT community organisations conducted separate research projects exploring the different ways to extend disability advocacy models in the ACT. The focus of research activities has been to assess the efficacy of different disability advocacy models in improving the capacity of consumers to

¹ Originally known as the National Disability Insurance Scheme, 'DisabilityCare' is now the commonly used term to describe the insurance initiative.

exercise choice and control, and to enhance inclusion in their community. *Exploring the Feasibility of a Citizen Advocacy Program in the ACT Community* complements findings from other research projects.

The research team consulted with key stakeholders in the ACT. It also met with representatives from currently operating Australian Citizen Advocacy programs. Information cited in the Report was obtained through individual and group interviews. Lessons learned from the previous Citizen Advocacy program operating in the ACT were also investigated and incorporated into this report.

The Citizen Advocacy Model

Citizen Advocacy happens when a valued and competent citizen who is unpaid and independent (Citizen Advocate), with the support of an independent Citizen Advocacy office, represents the interests of a person who has a disability (protégé) as if those interests were her or his own. Its aim is to identify people with disabilities to become protégés, to identify people from local community to become citizen advocates and to support each protégé and citizen advocates in their relationship².

Citizen Advocacy programs are established using a fairly simple formula. A Coordinator and a small team of paid staff in the Citizen Advocacy office, with the help of a Board of Management, identify potential protégés (people with disability), and then carefully match them with a citizen advocate (a valued member of the community). A relationship between the protégé and advocate is established and supported to be sustained for the long term. The purpose of this relationship is that the protégé is supported to achieve their full potential, is able to exercise their human rights and pursue optimum wellbeing.

The Citizen Advocacy model originated in the United States (USA) in the late 1960s³ as a response to parents of people with a disability expressing deep concern for the care for their children, once they were no longer able to provide support. From American beginnings, citizen advocacy programs were quickly replicated in other countries, with a number of programs established in Australia in the early 1980's. At one stage, there were over 20 Australian initiatives in

2 H Hindle, 'Citizen Advocacy', *Australian Disability Review*, vol. 2, 1993, pp. 29-34; J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.

3 It was designed as 'a means to promote, protect and defend the welfare and represent the interests of people who are impaired in competence, diminished in status or seriously physically or seriously isolated through one-to-one unpaid voluntary commitments offered by people with relevant competencies'. See B Page-Hanify, 'Citizen Advocacy: Hopelessly Idealistic, Successful, or Poorly Implemented?', *Australian Disability Review*, vol. 92, no. 2, 1992, pp. 87-99. See also J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.

operation, but their number has slowly decreased. Currently, eight Australian agencies apply a pure Citizen Advocacy model in their work (to the exclusion of other advocacy models), while other programs offer citizen advocacy in conjunction with other forms of advocacy within their service offering to clients. In the ACT, a Citizen Advocacy program functioned until 2005, when it ceased operations.

The ACTCOSS Citizen Advocacy Feasibility Project

In February 2012, the Disability Information and Support Hub (DISH) facilitated several forums with government representatives and community sector agencies, as well as inviting members of the community, to discuss establishing a Citizen Advocacy program in the ACT. The idea for this research project was generated in one of these community consultations, with forum participants highlighting the need for a more thorough analysis of the benefits and impact that such an advocacy tool could have on improving the lives of people living with a disability. Disability ACT then approached the ACT Council of Social Services (ACTCOSS) to undertake a scoping study to explore the capacity and willingness of the ACT community to engage in such a program. Its results and findings are contained in this Report.

The Citizen Advocacy Research Project was implemented from May-July 2013 under the auspices of ACTCOSS. Its focus was to:

- Explore the essential ingredients that would provide for the functioning of a Citizen Advocacy program. This was done through examining existing experience from other similar initiatives in Australia, through a review of relevant literature and a thorough investigation of the Citizen Advocacy model;
- Articulate potential benefits to people with a disability through supports offered by the Citizen Advocacy model. The project took into consideration the emergence of greater consumer control in service priorities, design and operation, as well as the potential of Citizen Advocacy as an ongoing non-paid safeguard measure that could complement formal regulation and quality improvement processes.
- Identify of the resources required for the program to start and continue – including funding, logistics and other infrastructure. Suggestions for funding options take into consideration non-government sources, Government funding and volunteer capacity in the ACT.
- Discuss whether the kind of support offered by the Citizen Advocacy model is lacking in the ACT and the role of this particular model in the wider context of disability advocacy work;
- Provide recommendations which identify the actions that might need to be undertaken to facilitate the set up and further support of a Citizen Advocacy program in the ACT.

The project investigated several structural and operational models for this program. A summary of three options for the model most likely to work well in the ACT is provided in the last section of the report.

Core Ingredients and Key Challenges

The necessary ingredients and specific challenges that would need to be addressed prior to starting a Citizen Advocacy program are:

- **Having clarity around the purpose and functioning of such a model** - this will be a crucial determinant of the program's success in the ACT. The potential for support (i.e. helping those most isolated, vulnerable and at the edge of the service system) as well as its limitations (small number of relationships facilitated by the office) must be fully understood by all stakeholders.
- **Ensuring long-term commitment** - The relationships supported by the Citizen Advocacy program require a long-term commitment, supplemented by staff and Board Members becoming fully familiar and cognisant with citizen advocacy concepts and principles. Sufficient time needs to be given after program commencement, to observe initial results.
- **The ACT citizen advocacy program will need support through government funding** - The proponents of the model in the USA called for financial independence from government institutions, preferring the use of multiple funding resources. However, experience in Australia shows that citizen advocacy programs have primarily been sustained with Federal or State Government grants. All currently operating Australian Citizen Advocacy programs are funded through the National Disability Advocacy Program (NDAP).
- **Citizen Advocacy is generated and maintained in the community** - It focuses on the identification and use of community linkages and capacities to support those more vulnerable and in need. Citizen Advocacy needs to be understood as a social and/or community tool able to be used to increase the visibility and social role of people living with disability, support community engagement and enhance public awareness around issues of disability.

Commencing an Initiative

The Canberra community offers great opportunities for recruitment of Citizen Advocates. Experience from the previous Citizen Advocacy program in the ACT combined with that from other Australian counterparts and research findings, indicate there would be valued members of the community who will help support the development of interest in the initiative and volunteer to be citizen advocates. The ACT could also quickly source effective, experienced and

professional office staff to establish the program in a relatively short space of time.

The three possible operational models for the program outlined in this report are:

- A completely independent office that operates separately from any other agency. While it is closest to the genuine model in principle, it may require adequate funding to support paid office staff.
- A Citizen Advocacy program to be attached to an existing agency that provides disability advocacy support. This model has been used before, and would allow the initiative to operate with fewer costs.
- A hybrid model, with a program that is attached to an agency that manages volunteering services or volunteering work.

Further consultation with interested organisations and community members currently involved in the area of disability advocacy work would be required prior to implementation of any citizen advocacy model in the ACT.

Key Findings and Recommendations

Feasibility of Setting Up a Citizen Advocacy Program in the ACT

The views expressed by key stakeholder during this research indicate it is both desirable and feasible to set up a Citizen Advocacy program in the ACT.

A Citizen Advocacy program would:

- Provide advocacy support for those individuals most in need, who are isolated and vulnerable through identifying, matching and supporting one-to-one relationships between protégés (people living with a disability) and Citizen Advocates;
- Complement the spectrum of advocacy support in the ACT along with other Individual and Systemic Advocacy models currently implemented by ADACAS and Advocacy for Inclusion, as well as other agencies in the ACT;
- Utilise the existing experience from the previous program Citizen Advocacy in the ACT combined with that of other similar programs currently operating in Australia, to fulfil its role, mission and operate according to the principles of the Citizen Advocacy model.

Individuals and Key Leaders in the Community who could be Approached and Invited to Become Members of the Board of Management or be Involved in the Citizen Advocacy Program.

Overall the report recommends that more time and further close consultations are needed in order to identify members of the community who may be involved in the governing structures of a Citizen Advocacy program. However, the ACT is well served by valued members of the community who are willing to support a citizen advocacy initiative and generate volunteers to be citizen advocates. Some activities that would assist with progressing establishment of a CA program are:

- Ongoing engagement and consultations with members of the Citizen Advocacy forum facilitated by the Disability Information and Support Hub, Disability ACT;
- Awareness raising campaigns in the community focusing on the role of the Citizen Advocacy and benefits that this model brings for people living with a disability – showcasing experiences from other programs would assist in the process;

- Promotion of the Citizen Advocacy program in local community and social hubs, such as service clubs, church groups, volunteer organisations and other agencies;
- Registering with ACT Community Sector Boards and Committees list and delivering presentations to them on Citizen Advocacy;
- Participating in broader community education about the importance of disability advocacy services in the ACT and the benefits they bring.

Advice on the Commitment Levels Required in Order to Adequately Support the Citizen Advocacy Program in the ACT

General Commitment

- A Citizen Advocacy program requires a long term commitment, both financially and structurally, from all the interested stakeholders in order to allow the initiative to be fully set-up and to reflect initial results;
- A Citizen Advocacy program should be considered as an advocacy tool that will increase the range of choice for people with disability who need different kinds of advocacy support, therefore should be supported adequately in the long term.
- The existence of a mid-long term funding commitment will assist the program to build its credibility and efficacy in the community.

Commitment from the Board of Management

- Members of the Board of Management would need to commit into acquiring knowledge and understanding of the principles of citizen advocacy as well as a strong dedication to effective governance.
- Members of the Board of Management should play an active and effective role in promoting the program, recruiting citizen advocates and organising and facilitating fundraising events;
- Members of the Board of Management, as well as paid staff, should participate in networks of Citizen Advocacy programs currently operating in Australia, to share information and increase their understanding of managing a program;
- The Board of Management holds primary responsibility in assisting and ensuring that the work of paid staff remains within the principles and mission of Citizen Advocacy model, managing risks and building the capacity and capability of the program.

- Effective representation of people living with disability on the Board of Management membership would facilitate a more robust approach in taking decisions about how to ensure the program operates in the best interest of protégés;
- The Board of Management should not include representatives of formal disability services, as this is perceived as presenting a conflict of interest in operating a Citizen Advocacy program.

Paid Staff

- If the Citizen Advocacy program operates independently and it is *not* attached to an existing agency, the paid staff composition should be comprised of at least 2 to 2.5 full time employees.
- If the Citizen Advocacy program operates attached to an existing agency, a Citizen Advocacy Coordinator would be responsible for all the relevant activities. A part-time assistant may also be needed to work with the Coordinator;
 - The Program Coordinator would need to be fully committed to the principles of Citizen Advocacy model and is responsible for sustaining the integrity of the scope, mission and role of the Citizen Advocacy program;
 - The program Coordinator (and other paid staff) need to be properly, adequately and continuously supported by the Board of Management;
 - The Program Coordinator (and other paid staff) does not explicitly provide advocacy support – their role is to facilitate matching, initiation and continuation of relationships by assisting the Citizen Advocates to best fulfil their role.

Advice on Funding Resources that could Support the Set-up and Continuation of a Citizen Advocacy Program in the ACT

The research project identified two approaches to funding a Citizen Advocacy program:

1. The program accesses funding prior to the program operating, building on the successful experiences of programs in other jurisdictions;
2. The program starts to operate without funding through the commitment of Board of Management and a Coordinator that works voluntarily and applies for funding as the program demonstrates community interest and capacity.

While both approaches may bring to a similar result, the second depends on the commitment of the Board of Management and Coordinator to ensure continuation of the program. It is a higher risk approach, and could compromise the establishment of a program at all.

Set Up and Operation Costs

- A Citizen Advocacy office in the ACT would require approximately \$120-150,000 per year in order to operate effectively. This estimate is based on information collected from other Citizen Advocacy programs currently operating in Australia.
- A Citizen Advocacy program in the ACT will require full or partial financial support from federal or territory government funding in order to be sustainable. More specifically:
 - The National Disability Advocacy Program of FAHCSIA needs to be considered as a primary source of funding for the initiative;
 - Partial funding from the ACT Government through its disability advocacy or social inclusion pool may be allocated for the program;
 - The ACT Government could consider provision of premises free of costs for rent and/or utility bills;
 - The Citizen Advocacy program in the ACT could seek participation and support from private organisations and/or Corporate Social Responsibility Programs to assist with financial costs (i.e. financial support to offset costs of operations through payment of utility bills; stationery and computing equipment, reduction of business overheads; assisting with recruitment processes, covering advertising costs, etc.).

Additional Funding Opportunities

- Members of the Board of Management need to be involved in fundraising activities as part of their overall role in the program;
- The Citizen Advocacy Trust of Australia may provide limited financial support for the program;
 - Opportunities for additional funding of the Citizen Advocacy program through the roll out of DisabilityCare need to be explored;
 - The program could also explore other small funding opportunities for specific activities through periodical (or one-off) grants offered for community sector organisations.

Further Considerations for Setting up a Citizen Advocacy Program in the ACT

- The office of the Citizen Advocacy program may be located in a community hub or co-located with other community sector organisations. It should not be co-located with a disability support service provider as this may affect the independence, the role and mission of the program and may lead to actual or perceived conflicts of interest.
- The Citizen Advocacy program would need to be clear in expressing the strengths of their work and its limitations. This would avoid unrealistic expectations from potential protégés, Citizen Advocates, funding bodies, community members and other relevant stakeholders.
- The Citizen Advocacy program should periodically undertake a Citizen Advocacy Program Evaluation (CAPE) in order to ensure that it is maintaining the theoretical and practical principles of Citizen Advocacy model. This will need to be undertaken after two years of operation but not later than three. For other fully established programs operating in Australia the frequency of a CAPE is every 4-5 years.
- Manuals and other supporting documents that will guide the work of the program and assist with training/ orientation of protégés and advocates can be borrowed or purchased from existing programs currently operating in Australia.

1. Background and Methodology

Project Background

Australia introduced DisabilityCare (formerly known as the National Disability Insurance Scheme - NDIS) in 2013 to offer greater control and choice to people living with disabilities in accessing financial and additional supports, and enacting primary decision making control over the process. The overarching principle is to provide a fairer approach to funding disability support for people who are eligible to access the DisabilityCare scheme. According to the NDIS Rules Consultation Paper⁴, 'people with disability [will] have the right make their own decisions about the type of support and service they use, who provides them, how they are designed and provided, and how supports are able to be managed and how their funding is managed'. As part of its planning process, people living with disabilities, their families and carers are required to identify the best ways to administer supports required by the person with a disability⁵.

Advocacy is one of the most important mechanisms that will facilitate this engagement. The role of disability advocacy has been strongly stated in several recent documents. The National Disability Strategy 2010-2020 describes disability advocacy as a supporting mechanism that 'enables and supports people with disability to safeguard their rights and overcome barriers that impact on their ability to participate in the community'⁶. The National Disability Advocacy Framework has articulated as its main objective: 'People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation'⁷. The need for increasing and improving access to advocacy services for people with disability had been previously highlighted by the Coalition of Australian Governments in the National Disability Agreement, 2008⁸ and the Consultation Report on the National Disability Strategy⁹.

4 Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *National Disability Insurance Scheme: Rules Consultation Paper*, 2012, viewed 4 June 2013, <<http://www.fahcsia.gov.au/disability-and-carers/news/2013/national-disability-insurance-scheme-rules-consultation-paper-released>>.

5 *ibid.*, p. 17.

6 Australian Government, *National Disability Strategy 2010-2020: An Initiative of the Council of Australian Governments*, 2011, viewed 17 June 2013, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy>>.

7 Council of Australian Governments (COAG), 'National Disability Advocacy Framework', 2008, Viewed June 15, 2013 from <http://www.dprwg.gov.au/research-development/publications/national-disability-advocacy-framework>

8 Council of Australian Governments (COAG) (2008). 'National Disability Agreement'. viewed 15 June 2013, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement>>.

9 Commonwealth of Australia, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*, National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council, 2009, viewed 8 June 2013, <<http://www.fahcsia.gov.au/our>

The Australian Capital Territory is one of the several launch sites for the first stage of DisabilityCare, commencing it in July 2014. As part of the preparation process, the ACT Government through Disability ACT has supported a number of community information sessions. In these forums, the need for advocacy has been affirmed and relevant models and their funding have been explored.

From May - July 2013, a scoping study exploring the feasibility of a Citizen Advocacy program in the ACT was undertaken under the auspices of the ACT Council of Social Services (ACTCOSS). It looked at the history of Citizen Advocacy model while at the same time considered information and collated experiences from other Citizen Advocacy programs in Australia. Furthermore, it analysed the current state and need for advocacy support in the ACT.

The Citizen Advocacy research project complements the work conducted by other similar projects. More specifically, agencies involved in the area of disability advocacy and support have conducted focused research activities. They have attempted to explore the efficacy of different advocacy models in improving the supported decision making¹⁰, and analysing the effects of better choice and control on behalf of people living with a disability.

Purpose of the Study

The primary objective of this project was to identify the level of capacity and willingness in the ACT community to engage in a Citizen Advocacy program. The main areas of research included:

1. An exploration of the essential ingredients that would provide for the functioning of a CITIZEN ADVOCACY program.

This was done through a focused review of relevant literature and a thorough investigation of the Citizen Advocacy model while also examining existing experience from other similar initiatives in Australia and previous program in the ACT.

2. Articulation of potential benefits to people with a disability through supports offered by the CITIZEN ADVOCACY model.

For this objective, the project took into consideration the somehow impeding consumer controlled environment of the ACT and the potential impact of Citizen Advocacy as an ongoing non-paid safeguard measure different to issue based advocacy;

[responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia](https://www.adacas.org.au/responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia)>.

¹⁰ ACT Disability, Aged and Carer Advocacy Service (ADACAS), *Spectrum of Support: A Report on a project Exploring Supported Decision Making for People with Disability in the ACT*, 2013, <<http://www.adacas.org.au/decision-support>>.

3. Identification of the resources required for the program to start and continue – funding, logistics and other infrastructure.

In particular, the project sought and collected specific suggestions for different funding options, in order to avoid complete reliance on Government support. In addition, it looked into the volunteer capacity in the ACT, due to the fact that governance arrangements in this model are volunteer based.

4. A discussion whether the kind of support offered by Citizen Advocacy work is lacking in the ACT.

Although Citizen Advocacy is a specific advocacy tool, the research analysed the role of this particular model in the wider context of disability advocacy work in the ACT;

5. Provide recommendations which identify the actions that might need to be undertaken to facilitate the set up and further support of a Citizen Advocacy program in the ACT.

Methodology

The project team engaged in consultation process with key stakeholders from the disability advocacy sector in the ACT. They included representatives from government institutions, disability advocacy agencies and consumer organisations representing people with disabilities in the ACT.

In addition, participants in a discussion forum for Citizen Advocacy that was facilitated by Disability Information and Support Hub (DISH) of Disability ACT in 2012 were invited to provide their views around the feasibility of such a model in the ACT. A list of questions was circulated to this forum and information was discerned from their individual responses.

Finally, representatives of other Citizen Advocacy programs currently operating in Australia, the Citizen Advocacy Trust of Australia as well as other leading advocates of such a model, and Social Role Valorisation Theory provided valuable information for the research outcomes¹¹.

Data Collection

Information was collected by using semi-structured interviews with individual participants. Most of the interviews were conducted face to face, with a limited number done over the phone. The research team took detailed notes during these sessions and reflected them in this report.

¹¹ See Appendix A for a list of organisations and individuals engaged in the consultation process.

Report Structure

There are four main sections in the report.

- **An overview of the current context of disability advocacy in which this project was undertaken.**

This section articulates changes initiated through recent undertaken reforms concerning disability support in Australia and the ACT.

- **A description of the Citizen Advocacy model, its principles and program structure.**

Information from a range of publications and other documents has been reviewed in order to provide a clear view and understanding of the principles of this social tool for disability advocacy and support. It also includes an explanation of its theoretical advocacy framework, important definitions, as well as the common operational structure of a Citizen Advocacy program.

- **An analysis of the information collected from the consultation process.**

This is the largest section and is designed to address the main objectives of the research project. It draws on contextual information on disability advocacy work in the ACT as well as suggestions from other Citizen Advocacy initiatives operating in Australia.

- **Possible models of a Citizen Advocacy program in the ACT.**

Considering the needs for disability advocacy support in the ACT, the report outlines three possible blueprints. While one of them is based on the 'traditional' model of an independent initiative, the other two suggest templates that would allow a joint coordination of resources and efforts of a Citizen Advocacy program with other existing community organisations.

Recommendations on the feasibility of a Citizen Advocacy program in the ACT

This section advises on the levels of commitments needed in terms of funding, governance and other infrastructure and support, which would facilitate the implementation of such an initiative. It provides suggestions for safeguarding the program based on lessons collated from previous experiences of Citizen Advocacy in the ACT, experience from similar programs in Australia and comments from local stakeholders. They conclude the Executive Summary of the report.

2. Context of Disability Advocacy Support in the ACT

The Wider Sectoral Reforms

The Australian social sector is currently undergoing considerable transformation and change with the introduction of DisabilityCare (the National Disability Insurance Scheme), the Living Longer, Living Better reforms (2012), together with amendments to the Charities Bill (2013), the ongoing *Mental Health (Treatment and Care) Act 1994* (ACT) review, and development of other advocacy-focused initiatives. These are all factors that must be taken into account when weighing up how citizen advocacy would enter the market, how best it would appeal to its core constituency, and how it would continue its operations into the future.

DisabilityCare and Living Longer, Living Better

DisabilityCare and the Living Longer, Living Better reforms are two key sectorial changes. By relaxing eligibility criteria for access to support, they will increase the capacity to generate new knowledge and recognition of a vulnerable demographic that previously has been invisible. The coming societal shift in the treatment and inclusion of people with disabilities and purchasing power combined means that the ACT Government's duty of care towards vulnerable individuals has changed. The transition processes throughout 2013-2014 will be crucial in determining the impact of these reforms in the future. However, by supporting a broad offering of advocacy services, the ACT government has a much stronger chance in being better prepared for adequately facilitating the implementation of these schemes.

ACT Mental Health Act Review

The Review of the ACT Mental Health Act specifically looks at definitions and expectations around decision making capacity, conflict of interest, principles of decision making and supporting, by any practical means possible. In addition, what support individuals need and how this can be offered is currently under consideration. Further, 'Guardians' consent for some decisions to be made by an individual are being investigated, particularly in conjunction with a conflict of interest between their responsibilities as guardians, and the right of the individual to make a decision that others do not necessarily agree with¹².

12 For more information see *Review of the Mental Health (Treatment and Care) Act 1994 – Second Exposure Draft: Proposed Changes and Explanation*, <<http://timetotalk.act.gov.au/consultations/?engagement=review-of-the-mental-health-treatment-and-care-act-1994-second-exposure-draft>>

Types of Advocacy Subsets

Supported Decision Making, Circles of Support and Citizen Advocacy are all individualised advocacy approaches that seek to expand the informal network of support available to a person living with a disability. They may be focused on different aspects of the vulnerability spectrum, and they necessarily have different tasks. Nevertheless, they work towards the same goal - allowing the isolated and vulnerable amongst us to have better access to respect, dignity, and a good life.

While all complementary to one another, in practice they carry dissimilarities in how they are applied to an individual's life. For instance, Supported Decision Making focuses on enabling people to access the information and tools in order to express their expectations and preferences and make their own decisions. Citizen Advocacy works to increase the social interaction or diminish isolation a person experiences in their local community.

Circles of Support are not formalised, and they have this in common with Citizen Advocacy, but they work to the individual's existing natural friendships. These structures bring together family members, friends, and acquaintances, as well as their associates, such as GP's, social workers and advocates working at the institutional or systemic level.

The Spectrum of Capacity and Spectrum of Support

The spectrum of need for advocacy in Canberra is determined by, and depends upon, the capacity that individuals living in Canberra have to independently and actively seek out such support when needed. The spectrum of support an individual has or needs to execute his/her own decisions varies according to social and economic factors. So if the person is very socially isolated, even if they have the capacity to seek out such advocacy, they may have no supports available to maintain any decisions they make through such advocacy.

If citizen advocacy is not made available as an advocacy choice in Canberra, the community is not necessarily going to know if there is adequate support for the program, or what the quantum of such need is for citizen advocacy itself, within the wider advocacy demographic. The following remark offers a better view on this issue:

The support that a Citizen Advocacy program provides for people living with a disability is unique. Since this model targets those more in need and who are the most isolated individuals existing at the edge of the service system; there will always be people who will benefit from the presence of a Citizen Advocate in their life. (Citizen Advocacy Program Coordinator)

To conclude, all types of advocacy clearly have their natural or designated community where they will work best or optimally; so as a suite of services providing a full range of advocacy options will allow the Canberra community sector to address the needs of an entire community in a holistic manner.

The Previous Canberra Citizen Advocacy Program

Experience from previous experience in the ACT demonstrates that not only is there a need for Citizen Advocacy support, but that the original program was successful for a long time, including after its demise. In fact, most of the relationships established during the life of the program are still going, although the initiative ceased operating in 2005.

This project could not find any documents that would shed some light on the reasons that led to the program's termination. However, information collected during research activities suggested that the initiative had somehow diverted its role and focus from that of Citizen Advocacy. This in return, contributed to the role and purposefulness of the program being questioned, ultimately resulting in the closure of the initiative.

In a way, the program's cessation effectively reiterates the vital need for a Citizen Advocacy program Board of Management to be properly trained, exercise correct and thorough oversight of the coordinator, and engage in regular monitoring of relationships. It is important to highlight this point, as the capacity of the Canberra community to actually find advocates is not especially taxing given the high public servant demographic base.

Further, maintaining a program over the long term relies upon continuing to have potential advocates interested in a project like this. The study suggests that provided the Board were guaranteed to be properly resourced and trained, their investment could quite feasibly be considered to be long-term.

Disability Advocacy Trends

One of the main objectives of Citizen Advocacy programs is to recruit people with disability that have no family support at all, or who have family members that are unable to offer adequate support. As one participant noted:

Citizen Advocacy can deliver support and protection to people beyond the life of their parents. (Citizen Advocacy Program Coordinator)

Through this comment, it is quite clear that the Citizen Advocacy model was designed as a response to concerns that parents had about future support for their children who had a disability. Indeed, the history of many citizen advocacy programs in Australia and overseas shows that it was a group of parents who founded and drove efforts towards establishing Citizen Advocacy programs. They saw those programs as the strongest safeguard against the hardships their son or daughter would potentially face without them.

Anecdotal evidence from the consultation process noted that in the ACT, there is an evident increase in the number of elderly carers struggling to properly support their children who have a disability. In most of these particular households, parents are reaching their later years of life, while their children are predominantly over 35 years of age. It was suggested by representatives of

disability advocacy organisations in the ACT that there may be a dramatic rise in the numbers of people with disability not having any kind of family support in the future. Currently, a lack of specific data makes it difficult to predict any trend in the short term future. However, with the need for more individual support likely to increase in the coming years (also due to changes brought by DisabilityCare provisions), the work of a Citizen Advocacy program would help to relatively alleviate the isolation and sudden service dependence of their children.

3. An Overview of the Citizen Advocacy Model

Brief History

Citizen Advocacy originated in the United States (USA) in 1966. It was designed more as social engagement tool rather than a disability advocacy model. The United Cerebral Palsy Association of the United States ran a conference in response to parental concerns and issues surrounding the care of their children who had disabilities, once they were no longer able to provide support.

Dr Wolf Wolfensberger, a social theorist, attended the conference and wrote about the limitations of then-current protective measures, while suggesting also new ways of transforming existing service systems. His aim was to develop a disability advocacy scheme that attempted to avoid conflicts of interest encountered in the service provision. The lack of individualised attention to the person living with disability in the contemporary service system was another issue he identified.

The Citizen Advocacy Model

In 1968, Dr Wolfensberger presented the Citizen Advocacy model for the first time. Although it evolved in the years to follow, its main principle remained the same – ‘it was [is] premised on the idea that community members or other interested individuals with no human service connections, would respond to the needs and protect the interest of people with disability when asked’¹³. A number of safeguards were also suggested for use in order to guide and protect the functioning of the model. They included that:

- Citizen Advocacy offers the potential for long-term continuity of personal relationships between individuals with a disability and other community members;
- Citizen Advocates are separate from service provision;
- Citizen Advocates are as free as possible from conflict of interest;
- Citizen Advocates provide a flexible and wide range of options to meet each individual’s needs and wishes;
- Citizen Advocates remain committed to the protection of each individual’s interests¹⁴.

The first Citizen Advocacy program was established in Nebraska, USA in 1970. Wolfensberger’s recommendations were adopted into USA federal legislation,

13 W Wolfensberger & H Zauha, *Citizen Advocacy and Protective Services for the Impaired and Handicapped*, National Institute on Mental Retardation, Toronto, 1973.

14 B Page-Hanify, ‘Citizen Advocacy: Hopelessly Idealistic, Successful, or Poorly Implemented?’, *Australian Disability Review*, vol. 92, no. 2, 1992, pp. 87-99.

which started at the time to fund systems designed to protect and advocate for the rights of people with developmental disabilities. The success of early Citizen Advocacy initiatives resulted in a proliferation of programs due to generous government financial support across the 1970s.

However, of the approximately 600 Citizen Advocacy programs started in the 1970s, only 200 survived¹⁵. A key problem which developed in the broader sector was a poor understanding of how citizen advocacy was intended and funded to work, leading to weak outcomes¹⁶. As a result many programs failed and the Citizen Advocacy concept came under severe threat. In order to address this, a program evaluation document was developed that would provide clear guidelines and standards for the work of Citizen Advocacy programs.

Standards for Citizen Advocacy Program Evaluation (CAPE)

The main principles of Citizen Advocacy work were finalised by Dr Wolfensberger and John O'Brien in the *Standards for Citizen Advocacy Program Evaluation (CAPE)*¹⁷. Although revised several times, this document has now been adopted as worldwide best practice. CAPE is effectively considered as the foundation for the operation, monitoring and evaluation of Citizen Advocacy programs around the world.

The value of CAPE is that it provides practitioners with clear guidelines and evaluation standards for Citizen Advocacy programs to measure their work. The initial version of CAPE document first distributed in 1978 'was a reflection of the results collected from an extensive research and consultation work with initiatives operating at the time, as well as a response to the misinterpretation and inappropriate implementation observed in some programs'¹⁸. Its main objective was to guide Citizen Advocacy practice and ensure that the concept of Citizen Advocacy remained within its initial formulation.

The CAPE manual is divided into three main sections:

1. **Adherence to Citizen Advocacy Principles** – relates to identity of the program;
2. **Citizen Advocacy office effectiveness** – relates to quality of the functions of the Citizen advocacy office, namely the key activities of arranging and supporting protégé/advocate matches;

15 J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, p. 8, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.

16 Citizen Advocacy New South Wales Association Inc. (CANSWAI), *Citizen Advocacy Board Member Manual*, 1999, viewed 15 June 2013, <<http://www.bmartin.cc/CAN/boardmanual/index.html>>.

17 J O'Brien & W Wolfensberger, *CAPE: Standards for Citizen Advocacy Program Evaluation*, NIMR/CAMR Publications, Toronto, 1979.

18 W Eliuk & C Wheeler, 'The Evaluation Instrument: CAPE', *Citizen Advocacy Forum*, 1993, pp. 13-15.

3. **Program Continuity and Stability** – relates to the viability of the program^{19 20}.

‘Learning from Citizen Advocacy’, developed by O’Brien– is a shorter version of CAPE that aimed to help programs to maintain the principles of citizen advocacy work. It also attempted to expand the description of citizen advocacy objectives and principles. These include that:

- The focus of energies devoted to the program is on creating and supporting a variety of responsible personal relationships that encourage identification with and active representation of the person with a disability, bring the person with a disability into social and community life, and usually involve long term commitments;
- The citizen advocacy program purposely seeks diversity among the people it invites into relationships;
- Over time, people will be involved in relationships that can be described in a variety of different ways;
- Citizen advocates freely choose to enter a relationship which is independent of the human service system and not controlled by the Citizen Advocacy program. Citizen Advocacy relationships are voluntary, but Citizen Advocates are not ‘volunteers’ to an agency. They find direction in their relationship - it is not suggested and monitored from a supervisor;
- Citizen Advocates are supported by the Citizen Advocacy program but not supervised, evaluated, or fired by the office;
- Citizen Advocates are not paid or compensated in any way by or because of their involvement in the program;
- The Citizen Advocacy program itself is a model of positive interactions and interpretations of people living with [disability];
- The program defines its identity and develops its support in the community, is able to act independently of the human service system, and is not identified with the human service system²¹.

Defining Citizen Advocacy

The literature review undertaken for this research project identified different approaches in articulating the concept of Citizen Advocacy. In a recent analysis of Disability Advocacy Models in Australia, Pearson et al²² used Hindle’s

19 T Doddy, A Barton, J Rowley, A Simmons, J Smith & M Peters, *Report on the Independent Evaluation of Citizen Advocacy South Australia Inc.*, 2011, viewed 24 June 2013, <<http://citizenadvocacysa.com.au/pages/cape-report-2011-2>>.

20 A detailed table of the content of CAPE sections can be found in Appendix B.

21 J O’Brien, *Learning from Citizen Advocacy Programmes – Including a Revised Short Form of CAPE: Citizen Advocacy Programme Evaluation Standards*, printed & distributed in Australia by AMR Inc., National Association on Intellectual Disability, Canberra, 1987.

22 J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability->

definition, commonly cited and referred to by most current Citizen Advocacy programs operating in Australia:

Citizen Advocacy happens when a valued and competent citizen who is unpaid and independent, with the support of an independent Citizen Advocacy office, represents the interests of a person who has a disability as if those interests were her or his own. Its aim is to identify people with disabilities to become protégés, to identify people from local community to become citizen advocates and to support each protégé and citizen advocates in their relationship²³.

Martin further noted that: 'in a sense, citizen advocacy tries to create the linkages that should exist in a community²⁴'.

The Essential Conceptual Components

Page-Hanify (1992), Pearson et al, (2009), Doddy et al, (2011), the Citizen Advocacy Trust of Australia, and International Citizen Advocacy Safeguard Group (October, 1990) have all referred to three essential components which must be incorporated into running a successful Citizen Advocacy program. These are:

- Citizen Advocacy is a **means** to promote, protect and defend the welfare and interests of, and justice for, persons who are impaired in competence, or diminished in status, or seriously physically or socially isolated, through one-to one (or near one-to-one) unpaid voluntary commitments made to them by people of relevant competencies;
- Citizen Advocates strive to **represent** the interests of a person as if they were the advocate's own; therefore, the advocates are supported, and usually recruited, by a Citizen Advocacy office with paid staff that is so funded and governed as to be essentially free of conflicts of interest;
- Citizen Advocates are **supported**, and usually recruited, by a Citizen Advocacy Office [Program], and choose for a wide range of functions and roles. Some of these commitments may last for life²⁵.

[and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program](http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program)>.

23 H Hindle, 'Citizen Advocacy', *Australian Disability Review*, vol. 2, 1993, pp. 29-34.

24 B Martin, 'Citizen Advocacy', *Doing Good Things Better*, Irene Publishing, Sweden, 2011, p.103.

25 See B Page-Hanify, 'Citizen Advocacy: Hopelessly Idealistic, Successful, or Poorly Implemented?', *Australian Disability Review*, vol. 92, no. 2, 1992, pp. 87-99.; J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.; T Doddy, A Barton, J Rowley, A Simmons, J Smith & M Peters, *Report on the Independent Evaluation of Citizen Advocacy South Australia Inc.*, 2011, viewed 24 June 2013, <<http://citizenadvocacysa.com.au/pages/cape-report-2011-2>>.

Citizen Advocacy in Australia

Based on the USA experience, many countries including the United Kingdom and Ireland replicated the model by establishing similar initiatives. Australia's first Citizen Advocacy programs were founded in Perth South Australia (1980), followed by Melbourne Victoria (1981) and Canberra Australian Capital Territory (1982). Up to 21 different programs existed in 1992 when the *Page-Hanify Review* (1992), was published.

Currently, there are no Citizen Advocacy-specific programs operating in the ACT, although Citizen Advocacy ACT Inc. provided support until 31 March 2005²⁶. The number of Citizen Advocacy programs in Australia has decreased dramatically during the last two decades. The Citizen Advocacy Trust of Australia (CATA) offers a list of currently operating programs in Australia, with 8 initiatives fully dedicated to citizen advocacy. An additional 7 'claim[ed] to provide a 'Citizen Advocacy' function within a general advocacy service' (See Table 1 below for a list of these programs).

Table 1: List of Citizen Advocacy Programs currently operating in Australia.

States & Territories	Citizen Advocacy Programs	Services that Claim to Provide a Citizen Advocacy Function Within their Advocacy Support
Queensland	Capricorn Citizen Advocacy Inc. Citizen Advocacy Sunshine Coast.	
South Australia	Citizen Advocacy South Australia Inc.	
Tasmania	Citizen Advocacy Launceston	
Victoria	Citizen Advocacy Sunbury & Districts. North East Citizen Advocacy	Gippsland Disability Advocacy Melbourne East Disability Advocacy
Western Australia	Citizen Advocacy Eastern Suburbs Citizen Advocacy Perth West	Advocacy South West Inc. Citizen Advocacy South Metropolitan.
New South Wales		Citizen Advocacy Western Sydney Illawarra Advocacy Inc Side by Side Advocacy

Source: Adapted from Citizen Advocacy Trust of Australia (CATA)²⁷

26 Based on the information collected during research activities, the office may have ceased to operate earlier, however this is the date when its Australian Business Number was cancelled. See <http://abr.business.gov.au/SearchByAbn.aspx?abn=90772317280>.

27 See 'Citizen Advocacy Programs', Citizens Advocacy Trust of Australia, <http://www.citizenadvocacytrust.com.au/citizen-advocacy-programs/> for a detailed list of Citizen Advocacy programs in Australia, their contact details and websites.

The age of current programs varies with some being established in early 1980's while others starting a decade later. As a key feature, their primary support largely derives from members of local communities. Citizen Advocacy programs usually work and focus within a limited geographical area although they may cover a population of up to half a million inhabitants, especially in the large urban areas.

Structure of Citizen Advocacy Programs

Operational Structure

1. Funding

Core funding for most of Citizen Advocacy programs in Australia is provided by the Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) through the National Disability Advocacy Program (NDAP)²⁸. An exception is Capricorn Citizen Advocacy, which is supported by the Queensland Government through its Department of Disability Services. Some programs have also established partnerships with other government, not-for-profit and private organisations in order to acquire more resources, expand the range of activities and increase collaboration. In Australia, such arrangements vary between programs and additional funding usually is very modest and does not contribute to a significant level of financial independence for citizen advocacy programs.

2. Management Bodies

Utilise a common governing structure of Boards of Management comprised of 6 to 9 members who themselves have typically been or currently are active advocates for people living with disabilities. Board members' knowledge and experience in Citizen Advocacy, together with professional expertise in other areas, assist the program's office to forge links with communities and individual members. As one Program Coordinator noted during research activities:

Citizen Advocacy work requires a Board of Management that goes beyond the normal Boards that we see across the sector. Their role is no limited in governance responsibilities. It extends to engaging with community members, providing advocacy themselves and secure the sustainability of the initiative.

3. Staffing

Members of staff usually involve a Program Coordinator (or Executive Director), one administrative assistant who helps running the financial and other daily

²⁸ For detailed information on state and territories agencies funded under NDAP please see 'National Disability Advocacy Agencies funded by the Australian Government (by state or territory)', Australian Government Department of Social Services, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory>>.

activities and one Assistant Coordinator who helps in outreach activities and the process of matching protégés and citizen advocates. Volunteers are drafted to assist with specific gap-filling in operating the program such as attending the office when paid staff is not present. For those general advocacy services that include a function of Citizen Advocacy in their work, a coordinator and/or an Individual advocate are assigned to facilitate the Citizen Advocacy component activities.

Governance and Practice Documents

Citizen Advocacy programs have constitutions which clearly define the role of each member of staff, the Board of Management and the standards of their work. They also have strategic plans which are aligned with the principles of Citizen Advocacy model and have incorporated requirements of their funding bodies. Overall, Citizen Advocacy offices in Australia maintain all the key features of a small size organisation, including the governing arrangements largely and commonly applied in the community sector.

Specific manuals for paid staff, Board of Management, protégés and Citizen Advocates guide the practice work of the program. Information contained in them ensures that everyone who participates in the matching process is aware and clear about the expectations, capacities for support and responsibilities they have to the Citizen Advocacy office and with regard to participation in a relationship. They also reflect the indicators and evaluation standards used in the 'CAPE' and 'Learning from Citizen Advocacy Programs' documents.

Key Activities of a Citizen Advocacy Program

The following is a description of key activities that randomly are performed by a Citizen Advocacy program. Information collected from other Citizen Advocacy program in Australia, noted that generally their programs follow the same pattern sequentially. These activities are required to allow for the back-up and support of volunteer Citizen Advocates and maximises the probability that relationships will last over time, despite the changing needs of their protégés²⁹.

1. Identifying and Recruiting Protégés

Programs undertake several activities to ensure people who are unaware of, and who could benefit from, the work of Citizen Advocacy are identified through outreach. This includes visits to facilities like prisons, nursing homes and boarding houses as well as the promotion of the Citizen Advocacy office within existing community clubs and organisations. Primarily, the program seeks those that are not represented; the most vulnerable and most isolated and as one coordinator noted 'those people with disability that are at the edge of the service system'.

²⁹ Information on the key activities of Citizen Advocacy program, unless cited, was largely collected through research activities and interviews with stakeholders.

Other additional avenues may bring protégés to the attention of the program. Sometimes a person with a disability approaches a Citizen Advocacy program for assistance. In other instances a parent, service worker or concerned member of the community will contact the service on the person's behalf. Joint collaboration with other government and non-government organisations that provide services for people living with disabilities also bring potential protégés to the attention of the Citizen Advocacy program. However, while the office considers all referrals, usually it does not accept passive or external referrals immediately.

Underpinning this point is the fact that Citizen Advocacy enshrines the principle of the protégé's consent being engaged before they have even interacted with the program and/or engaged in a match. Further, the protégé must continue providing their consent for their advocate to act on their behalf. Consequently, potential protégés are not admitted into a Citizen Advocacy program in a manner similar to service support for various needs, because the whole premise of the protégé-citizen advocate relationships is that they are developed slowly, last for the long term and are based on reciprocal consent.³⁰

Once the protégé is part of the program, the Coordinator (paid advocate) spends a considerable amount of time getting to know the protégé well. This includes consulting very carefully with the person to ascertain their own views and aspirations, carefully observing the circumstances of the person's life. With their permission, relevant information is sought from other people who may know the person (such as family, neighbours and service workers). Through this process, the coordinator is able to collect sufficient information which will be crucial in identifying the most suitable match with an advocate.

2. Recruiting People to be Citizen Advocates

Based on the information collected from recruited protégés, the Coordinator starts the process of identifying potential advocates on the basis of situation, interests and desires of the potential protégé. This process is very specific and it usually begins with the coordinator using his/her own resources and then extends to the networks of the Board. The most important aspect is that 'the coordinator must be able to articulate the needs of the potential protégés and to approach the potential advocate with a specific rationale for his or her involvement'³¹.

No specific criteria are applied to recruitment and selection processes. However, potential Citizen Advocates usually are caring and responsible members of the community, who have considerable skills and life experiences and are willing to support protégés on a voluntary basis. Recruitment approaches vary, including personal networking, 'word of mouth' and public promotion of the service in existing community groups and forums such as church and service clubs, to mention a few. Some advocates are proactive in

30 See Appendix C for a description of the effects that acceptance of passive or external referrals may have on the overall performance of the program.

31 Z Lutfiyya, 'An Overview of the Key Activities of Citizen Advocacy', The Citizen Advocacy Forum, October-December 1999.

making themselves known, but commonly, citizen advocates become involved in the program through direct approach from the Coordinator. Members of the Board of Management actively work to identify members of their communities who potentially can become citizen advocates.

Character of the Citizen Advocate: O'Brien provides a description of the role and skill set of the Citizen Advocate:

a valued citizen who is unpaid and independent of human services [and] creates a relationship with a person who is at risk of social exclusion and chooses one or several ways to understand respond to, and represent that person's interests as if they were the advocate's own, thus bringing their partner's gifts and concerns into the circles of ordinary community life³²

Role/s of the Citizen Advocate

Some of the roles played by a citizen advocate in assisting a protégé include:

- **Emotional support** – Break the cycle of negativity by offering emotional support and friendship to the protégé, as well as facilitating a more active social and life experience often by using different resources and networks in the community. Companionship and friendship are an integral part of this role;
- **Guide** – Assist the protégé in practical problem solving, such as bus travel, doing the laundry, grocery shopping, budgeting, or accessing appropriate housing;
- **Monitor** – Review service provision and hold the service provider responsible for the quality and availability of required services. For example, visiting a nursing home periodically to see if an individual is properly fed, dressed and is receiving adequate medical care;
- **Spokesperson** – Representing the interest of the protégé in situations where his/her rights are at risk of being compromised;
- **Guardian** – Officially and legally appointed to assume responsibility for making, and assisting in making important decisions for the protégé.
- **Representative Payee** – handles the finances of the protégé, who receives payments from Social Security services (or more contextually, through DisabilityCare).
- **Adoptive Parent** – Assumes legal responsibility for a protégé who is a child. This is regulated according to the legal provisions of each state.

32 J O'Brien, *Learning from Citizen Advocacy Programmes – Including a Revised Short Form of CAPE: Citizen Advocacy Programme Evaluation Standards*, printed & distributed in Australia by AMR Inc., National Association on Intellectual Disability, Canberra, 1987.

Other additional roles may be 'a nominee, a companion, co-advocate, mentor, financial sponsor, crisis and/or short term advocate'³³.

Citizen advocates are not expected to fulfil each and every one of these roles. Rather, they are encouraged to provide support based on their skills and life experience. For a group of advocates working as a team in a Citizen advocacy office, they will often work together to increase the range of areas of assistance required by any protégé through adopting different roles as it is appropriate or necessary.

Formal Roles

Several formal roles can be undertaken by Citizen Advocates such as becoming a guardian, becoming a representative payee and/or an adoptive parent. Consultations with other Citizen Advocacy programs in Australia revealed that they do not encourage Citizen Advocates to become guardians or to provide consent for the person with disability, or to undertake any of these formal/legal roles. However, they agree that if the person with disability asks the Advocate to undertake any of these positions, it is their choice to make the final decision.

In addition, programs' staff members are very clear in suggesting to advocates not to assist with an issue if they do not have the appropriate training or qualification to do so. As mentioned below in the report, for most of the issues that require a professional approach, Citizen Advocates are assisted by associate or crisis advocates who come from a range of professional backgrounds and can offer specific assistance and knowledge on a particular matter.

Associate and Crisis Advocates

When a long term commitment as a Citizen Advocate is not possible, individuals who desire to contribute in a similar way may be recruited as Associate or Crisis Advocate. These are usually professionals, agency personnel (not in disability service provision) and other individuals, often in influential positions, who have been involved in advocacy activities without directly or willingly playing an individual Citizen Advocacy role.

They assist long term Advocates by offering advice and expertise in areas such as legal, financial, health, counselling and government agency processes. Crisis Advocates share the same beliefs as long term Citizen Advocates, but their role is more task-oriented and usually lasts for the period needed to resolve specific issues in protégé's life.

Finally, additional opportunities are offered for people willing to contribute in the scheme. They may:

- a. become active players in their communities in order to identify potential advocates;

³³ Citizen Advocacy New South Wales Association Inc. (CANSWAI), *Citizen Advocacy Board Member Manual*, 1999, viewed 15 June 2013, <<http://www.bmartin.cc/CAN/boardmanual/index.html>>.

- b. become a trusted professional and/or community leader who voluntarily provides expert advice to Citizen Advocates;
- c. become a member of the Board of Management;
- d. facilitate fundraising and program promotion activities; and
- e. contribute financially to the Citizen Advocacy program.

3. *Orienting / Training for Citizen Advocates*

It is compulsory for all advocates to participate in an orientation program. This is provided by paid staff at the Citizen Advocacy office on an individual basis. Other people with experience in Citizen Advocacy work, such as former advocates or Board Members may assist. Through this process potential advocates gain an understanding of the model's concept, its overall framework and functioning of the program.

As one representative of a Citizen Advocacy office noted, 'orientations are never the same for any two people'. Each advocate is encouraged and supported to develop an understanding of their role and the protégé's needs throughout their relationship by clarifying mutual expectations. Peer support is also encouraged, allowing advocates to share experiences and get answers for any of their questions. Resources, opportunities for training and other learning activities are regularly distributed for advocates through the program's newsletter or other means of information dissemination.

During the orientation process, the coordinator uses different ways to address a number of topics with the new advocate such as written articles, handouts, summaries or verbal communication such as chats, informal conversation and informal presentations.

4. *Bringing Advocates and Protégés Together: The Matching Process*

The ranges of roles for staff members include conceptualising and planning the matching process for individual protégés and advocates. Individual plans for people with disabilities according to their needs and priorities are designed prior to the start of the relationship and discussed during the introduction phase. The coordinator has a crucial part into shaping, guiding and developing the advocate/protégé relationship at its early stages. The coordinator seeks the help and endorsement of the Board in the process to ensure that the match is suitable for the protégé. Their support for the advocate during the first steps of the relationship is vital.

During the first meeting that the protégé has with the advocate, the coordinator aims to clarify the expectations of this initial meeting and give a chance to each person to get to know more about the other. Some considerations are needed regarding the place of meeting. This will depend on the circumstances of both individuals and what location would best allow a comfortable participation for them.

Once these details are clarified, the coordinator facilitates the initial meeting by focusing on the scope of the relationship in the early stages and responsibilities

that both will have to each other. The coordinator reaffirms the agreement and the expectations after protégé and advocate have spent some time together, which usually occurs after the second or third visits.

5. Keeping in Touch

The coordinator regularly contacts the Citizen Advocate to find out how the relationship is proceeding. While this may be quite frequent in the early stages (weekly, then monthly and slowly decreasing the frequency) once the relationship is fully established citizen advocates are contacted rarely (usually once a year to describe the progress or any other issue that may arise). The office usually has a system in place which keeps track of the number, timeframe and frequency of contacts with advocates, allowing staff to periodically contact all of them.

6. Supporting the Relationship

Whenever requested to do so, the coordinator or other paid staff offer support, assistance and information, suggest other individuals who may help with an issue or additional information and offer encouragement for advocates. They also advise continuously advocates to seek assistance and support from other people directly or indirectly involved in the program. Again, peer support is facilitated between different advocates where they can share similar concerns and clarify their specific situations. Possible options for dealing with a particular issue are discussed as well as courses of action.

Balance of Key Activities

Lutfiyya suggests a final step which is important in ensuring that all the key activities are performed with appropriate time and energy dedicated to each of them – the balance of key activities. Otherwise, she notes:

A Coordinator may spend too much time in initiating relationships and not enough time in actually supporting the advocates. Thus many relationships may end in the first few months after the initial introduction. Achieving a positive balance is quite a challenge for any Citizen Advocacy program and is usually only achieved (although never perfect) over time³⁴.

Outcomes of Citizen Advocacy in Australia

A review of the of models of advocacy funded under the National Disability Advocacy Program found that 'during financial year 2008-09, around 8 per cent of service users' advocacy issues were supported through Citizen Advocacy programs³⁵. It may be argued that this is a substantial volume judging from the

34 Z Lutfiyya, 'An Overview of the Key Activities of Citizen Advocacy', *Citizen Advocacy Forum*, October-December 1999.

35 J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability->

relatively small number of such initiatives and amount of funding that FAHCSIA allocates to Citizen Advocacy programs. Nonetheless, the overall contribution of their support to aspects of disability advocacy often is not fully recognised.

Representatives of Citizen Advocacy programs in Australia noted that due to their specific focus, the impact of their work often is perceived as 'limited' when compared to that of other disability advocacy agencies. The reason may be that other agencies are able to better quantify the number of hours spent in advocacy support. That would be difficult to articulate in the context of Citizen Advocacy model and this project was not able to identify independent research undertaken to measure and analyse quantitative impacts.

Risk/Benefit Analysis

Number of Relationships and Advocacy Work

Experience from other Citizen Advocacy programs in Australia suggests that a successful initiative usually manages 50-60 established relationships at any given time. Current targets of their work require on average 8-10 new matches every year although this number can be higher. For example, Martin (2003) in an analysis of the work undertaken by (then) Illawarra Citizen Advocacy, found that 'around 185 new matches had been made between 1990 and 2002, an average of more than 14 per year'³⁶.

However, more attention needs to be given to the amount of preliminary work undertaken when identifying the best match for a protégé. This is vital in ensuring the longevity of relationships. As one participant in research activities highlighted:

It takes usually two months for the coordinator to complete the assessment of a single protégé and start to identify a potential advocate for him or her. People have to be clear that the Citizen Advocacy model is not a service based one. I guess that is why our numbers may appear to be insignificant to other models. We make matches for life; we do not provide a one-off service.

On the other hand, by inquiring and exploring what are the best options for a protégé's needs, citizen advocates conduct considerable preventative work. For example, if the program is able to facilitate long-term and well-functioning relationships, advocates through their engagement often do not allow an escalation of protégé's situation, which on the other hand would require additional costs to be addressed through service provision. However, a rapid review of relevant literature could not find an accurate assessment of return for money or the financial impact that Citizen Advocacy model could produce overall.

[and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>](#).

36 B Martin, 'Citizen Advocacy and Paid Advocacy: A Comparison', *Interaction*, vol. 17, no. 1, 2003, pp.15-20, viewed 25 June 2013, <<http://www.bmartin.cc/pubs/03interaction.html>>.

Another important component when attempting to quantify the cost/benefits of Citizen Advocacy programs is the volume of work conducted by advocates. Since their role is voluntary and they do not report to the office, programs are not able to assess and demonstrate the number of hours they spend with the protégé. In another service model, this would be acknowledged as advocacy support. The following box provides an example of what this contribution would look like if quantified.

Brian Martin attempted to provide a modest estimation of the work conducted by Citizen Advocates. In a joint effort with the Program Coordinator of Illawarra Citizen Advocacy in March 2002, all advocates were invited to tell how much contact they have had with their protégé in the previous month. They were told to be as accurate as possible, although there was no easy way to verify that.

The response showed a total of 650 hours per month, which was more than four times what a paid advocate could provide if doing advocacy 35 hours a week. The author is aware of the limitations of this research and that additional information is required to provide a more accurate comparison of paid and Citizen Advocacy. In spite of this, based on these results, he suggests that advocacy hours should not be the sole criterion. The quality can be as significant as quantity and that can be true of paid advocacy as well.³⁷

Advantages and Limitations

The review by Pearson et al (2009), found some advantages and limitations in relation to the work of Citizen Advocacy programs operating at the time:

Advantages

- The disability advocacy model has strong principles which are clearly understood by coordinators and advocates;
- Citizen advocacy is capable of finding people missed by service systems and agencies - it proactively seeks and finds vulnerable people;
- Citizen advocates have principal loyalty to the person with disability and are not constrained by conflicts of interest associated with human service affiliations, income or funding;
- The Citizen advocacy process has a highly individualised focus with a one-to-one relationship;
- There is good governance and regular review and evaluation using CAPE standards in many agencies;
- The long-term duration of the relationships between citizen advocates and protégés has powerful benefits for the protégés;

37 Adapted from B Martin, 'Citizen Advocacy and Paid Advocacy: A Comparison', *Interaction*, vol. 17, no. 1, 2003, pp.15-20, viewed 25 June 2013, <<http://www.bmartin.cc/pubs/03interaction.html>>.

- These long-lasting relationships may go beyond advocacy and provide people with disability with friendship and a sense of belonging;
- Citizen advocates provide an unpaid person in the life of the protégé when people with disability increasingly have only paid people in their lives;
- Citizen advocacy provides advocacy support outside normal business hours;
- This model has a holistic and flexible approach and Citizen Advocacy responds to an individual's fluctuating needs over time with varied support strategies.

Limitations

- The role that citizen advocacy has in fulfilling a significant advocacy role is sometimes questionable;
- Citizen advocacy should be considered more as support for people with disability rather than a component of advocacy;
- It may encourage a perception that people with intellectual disability cannot speak up or decide for themselves;
- Reliance of protégés on the support from advocates lessens the individual's independence and capacity ;
- It is a high risk model since it places considerable pressure on one person – the citizen advocate – meaning that if the advocate leaves, there will be a big void left for the protégé and supporting services;
- Since the model depends in finding a good match for the protégé, there are no clear timeframes when this will happen, resulting in a non-responsive approach that may affect the situation of the protégé;
- There is a risk of inappropriate relationships since the advocates are not bound by the same obligations as the paid professional staff and the training they receive may not fully prepare for the fulfilment of their responsibilities³⁸.

The Future of Citizen Advocacy Programs in Australia

The Citizen Advocacy programs in Australia have dealt with a number of challenges in order to continue their operation. Experience from disability advocacy services that claim to include a Citizen Advocacy component in their programs, indicates that Citizen Advocacy models are less often functioning as individual entities and their structures have been modified in order to accommodate additional Individual Advocacy services.

38 J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, pp. 24-25, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.

For example, the 2010 Annual Report of Advocacy South West in South Australia noted that the organisation '[was] no longer actively recruiting volunteer advocates under the Citizen Advocacy program due to the changes in the individual and advocacy service provided by the agency'³⁹ and that 'this shift in focus ha[d] resulted in 95% of resources allocated to Individual Advocacy and 5% in maintaining the existing 35 one to one volunteer advocate matches'⁴⁰. Illawarra Advocacy Inc., an agency that started as a pure Citizen advocacy program 'underwent major transformation [since] expectations of both the funding body and the Illawarra community had over time changed'⁴¹. The Citizen Advocacy program now sits alongside an Individual Advocacy Program.

Such changes to Citizen Advocacy programs are not exceptional only to Australia. In a study of such initiatives in the UK, Monaghan found that:

Virtually no citizen advocacy schemes remained which adhered to the original model. Organisations which still provided Citizen Advocacy tended to contain other forms of disability advocacy (i.e. issues based or crisis advocacy, statutory advocacy)⁴².

In addition, Chapman and Mitchell use the work of Monaghan (2007, 2009) to suggest that 'the diversity in how schemes operate is a response to a number of factors:

- People often need short-term support with a single issue or crisis in addition to wanting a long-term advocate;
- Issues around finding long term advocates;
- Funders' demands and a lack of recognition of the need for long term support and time needed to recruit and match long term advocates;
- Some advocacy providers use short term advocacy to get long term partnerships going;
- Some feel that there is more than one way of supporting people and citizen advocacy should be one of a range of responses.⁴³

These examples illustrate the responses of Citizen Advocacy programs to changes in community capacity and expectations from funding bodies, leading some of them to change their structure and model of work. The Citizen Advocacy Trust of Australia (CATA) lists a number of threats that have or may affect feasibility and continuation of citizen advocacy programs in the future:

39 Advocacy South West Inc. (ASWI), *Annual Report 2010*, 2010, viewed 23 June 2013, <http://www.advocacysouthwest.com/asw/annual_reports/Annual-Report-2010.pdf>.

40 *ibid.*

41 See 'About Us', Illawarra Advocacy, <<http://www.illawarraadvocacy.org.au/about-us/>>, for more information.

42 J Monaghan, *Informal Volunteer Citizen Advocacy in England*, National Coalition of Citizen Advocacy Schemes, Liverpool, 2007.

43 *ibid.*; J Monaghan, *Citizens and Advocacy: Advocacy Plus - A Community-based Approach to Protecting and Promoting Human Rights*, 2009; M Chapman & D Mitchel, *Citizen Advocacy and Circles of Support*, report for Wigan Learning and Disability Partnership Advocacy Subgroup, 2011, viewed 22 June 2013, <<http://www.peteandwendycrane.co.uk/images/reports/MMU%20academic%20report%20into%20advocacy%20including%20Lancashire%20model.pdf>>.

External Threats

- The dependence on being fully funded by either federal or state government provides relative security for programs exposes this kind of disability advocacy to a relative financial security;
- The recent focus of governments' policies has been into seeking a professionalised' form of advocacy and a short –term one, which is not compatible with the long term-relationship and commitment advocated by the Citizen advocacy model;
- Citizen Advocacy is frequently viewed by bureaucrats as merely a 'relationship' or 'friendship' program (and therefore not very crucial);
- The fact that advocates and protégés determine the nature of their relationship has been considered alarming although the Citizen Advocacy model in its core is an informal and independent process. The match is not answerable to any external party –even to the Citizen Advocacy program, let alone government.

Internal Threats

- The possibility that Boards of Citizen Advocacy offices can select unsuitable professionals to conduct the role of Program Coordinator which may lead to diversion of the position's role into one that suits better to the person. This may affect the process of making matches that would benefit more to the protégé and the Citizen advocate;
- Programs may slowly depart from the Citizen Advocacy model without realising it, leading to a distorted mission and values of the program. Not seeking or receiving regular and up-to-date training may contribute to this;
- The lack of regular and external evaluations and reviews using CAPE does not allow programs to identify issues and take appropriate measures to deal with them;
- Failing to develop a plan for protégé and advocate recruitment and internal reviews of one's work and results could hamper the efficiency of the program.⁴⁴

Lack of steady funding has always been a critical factor for the continuation of Citizen Advocacy work. A review of such programs by Page-Hanify more than two decades ago advised that 'funding agencies should provide sufficient resources to State Citizen Advocacy offices to enable essential support, training and evaluation to be carried out'⁴⁵ while warning that 'there is a great risk that funding agencies might say the return on public money is not sufficient.'⁴⁶ Sector reforms undertaken during the 1990's resulted in more pressure for Citizen Advocacy programs. As Hunter and Tyne noted:

44 See 'Threats to Citizen Advocacy', Citizen Advocacy Trust of Australia, <<http://www.citizenadvocacytrust.com.au/what-is-citizen-advocacy/threats-to-citizen-advocacy/>> for a detailed description of threats to Citizen Advocacy.

45 B Page-Hanify, 'Citizen Advocacy: Hopelessly Idealistic, Successful, or Poorly Implemented?', *Australian Disability Review*, vol. 92, no. 2, 1992, pp. 87-99.

46 *ibid.*

The move to regularise, accredit, train, approve and legitimise advocacy for selected eligible service clients is a bureaucratic response to the ungovernable nature of community [and citizen advocacy principles].⁴⁷

They also predicted that:

as Citizen Advocacy schemes have moved towards adopting procedures of the world of professional services,[...] they become less capable of delivering what Citizen Advocacy is set out to do: long term, freely-give, independent relationships which offer the possibility of belonging in a network of community connections.⁴⁸

To conclude, it is not easy to predict what the future holds for Citizen Advocacy programs in Australia. Though their number has diminished, they have managed to continue their work and maintain the initial principles of the model. The relatively stable funding they currently receive from government, being federal or state/territory and the recognition of Citizen Advocacy as a complementary form of disability advocacy in the National Disability Strategy⁴⁹ are positive indicators for their future continuation.

It is also important to note that this kind of support for people living with a disability is a complementary component of the overall advocacy system. Citizen Advocacy, 'while it falls within the larger category of Individual Advocacy, it provides strong support for Self-advocacy and Legal Advocacy'.⁵⁰ 'The success of a Citizen Advocacy program usually may depend on whether other forms of advocacy exist in a community'.⁵¹ For Ward, 'while Citizen Advocacy as a model cannot fulfil its role if constantly responding to demands to engage in wider and more complex issues around disability advocacy, it should be considered a part of the suite of advocacy programs including group advocacy work, self-advocacy, ombudsmen offices at state and federal levels, human rights commission, lawyers and other specialised services'.⁵²

47 S Hunter & A Tyne, 'Advocacy in a Cold Climate: A Review of Some Citizen Advocacy Schemes in the Context of Long-stay Hospital Closures', *Disability & Society*, vol. 16, no. 4, 2001, p.555.

48 *ibid.*

49 See Australian Government, *National Disability Strategy 2010-2020: An Initiative of the Council of Australian Governments*, 2011, viewed 17 June 2013, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy>>.

50 J Hadlow, 'Citizen Advocacy Observed: Tool or Tokenism?', *Journal of Community & Applied Social Psychology*, vol. 6, 1996, pp. 403-408.

51 J O'Brien, *Learning from Citizen Advocacy Programmes – Including a Revised Short Form of CAPE: Citizen Advocacy Programme Evaluation Standards*, printed & distributed in Australia by AMR Inc., National Association on Intellectual Disability, Canberra, 1987.

52 J Ward, 1986, 'Citizen Advocacy: Its Legal Context', *Australia & New Zealand Journal of Developmental Disabilities*, vol.12, no. 2, June 1986, pp.95.

4. Exploring the Feasibility of a Citizen Advocacy Program in the ACT – Reflections from Consultations

Citizen Advocacy has proven to work and it provides a kind of support that other advocacy and service support model are not able to fulfil. (Citizen Advocacy Program Coordinator)

The content of this chapter is predominantly based on the information that the research team collected during the consultation process. It is more descriptive than analytic. It is important to note that our primary goal was to discuss the capacity and willingness of the ACT community to engage in a Citizen Advocacy program. The project team is aware that a final decision on the process of setting up such a program cannot be made based solely on the information offered in the following sections. We believe that there would be value in consulting further with interested stakeholders who could reflect on and respond to the findings from this research.

Based on the review of a number of documents and information collected from consultations, it is clear that Citizen Advocacy as a program model offers an additional resource for enhancing opportunities and supporting people with disabilities to exercise their rights and fulfil their expectations. It also offers intercultural understanding for the advocates, who does not necessarily face the same life challenges or degree of social isolation. A number of important components would need to be in place to enable a successful and well-functioning Citizen Advocacy program in the ACT.

The strength of a Citizen Advocacy program lies in ensuring each component is given adequate attention, for if one is missing, the program is less likely to survive and make a positive impact. The core features of a successful citizen advocacy program are: having **clarity around the purpose** of the citizen advocacy model, understanding that Citizen Advocacy is **not a service**, recognising **independence is a key to success**, that the Citizen Advocacy programs are **generated and maintained in the community** by tapping into its strengths and capacities, that Citizen Advocacy requires a **long term commitment**, and that Citizen Advocacy programs in Australia require **Government support**.

Program Features

Clarity around the Purpose of the Citizen Advocacy Model is Crucial

A Citizen Advocacy office needs to fully understand the nature of the model and possibilities that such a program has in supporting people living with disabilities.

Members of staff communicate this understanding by 'supporting, *not supplanting*, advocate protégé relationships and by directing their energies toward building and maintaining the Citizen Advocacy program as a whole'.⁵³ Part of this process include clear and effective staff functioning in terms of well-defined staff roles as distinct from the role of a citizen advocate, the position and responsibilities of the Citizen Advocacy Board members, procedures in recruiting protégés and advocates and ensuring that there is no competition around other advocacy roles. Failing to have this clarity and understanding may fatally undermine the role and the purpose of the initiative as well as its existence.

Lack of clarity about the role of coordinator is detrimental in the overall functioning of the program. Information collected from research activities suggests that in the past some programs have failed in fulfilling their role due to a **shift in the principles of Citizen Advocacy by the Coordinator**. For representatives of Citizen Advocacy programs:

It is also the responsibility of the Board to ensure that the program and the work of staff members are conducted towards achieving the principles of Citizen Advocacy. When Boards become complacent with the 'new ideas' that some Coordinator/s suggest, this has resulted in the major flaws in the program and closure of initiatives.

Citizen Advocacy is Not a Service – It is a Social and/or Community Tool

In current Australian social structures and models of support services for people living with a disability, paid professionals are often assumed as the main medium by which people's needs may be addressed.⁵⁴

However, Citizen Advocacy is not a service. Citizen Advocacy programs do not maintain features of one or several service support systems. Potential funding and interested stakeholders would need to fully understand this aspect from the beginning, in order to comprehend the role of the program in the area of disability advocacy and support. John Armstrong, a strong and active supporter of Citizen Advocacy initiatives and an expert in Social Role Valorisation Theory suggested by way of explanation, that:

The unpaid relationships (of Citizen Advocacy) are not limited in their scope or action to the rules, regulations, policies and professional limitation places on paid roles. As such, they have the capacity to be the strongest safeguards available for protecting the wellbeing of vulnerable people and the bridge from devalued world to the valued world. No other form of paid advocacy or service can achieve those outcomes.

The experience from existing Citizen Advocacy programs has shown that relationships work better when there is minimal or no monitoring of them –

⁵³ Citizen Advocacy New South Wales Association Inc. (CANSWAI), *Citizen Advocacy Board Member Manual*, 1999, viewed 15 June 2013, <<http://www.bmartin.cc/CAN/boardmanual/index.html>>.

⁵⁴ *ibid*.

which is not compatible with current individual paid advocacy models. This is not to suggest that once the matching is finalised and relationship is established, the programs would have no further involvement in the process.

There are many ways in which the program can retrieve information on the progress that protégés have achieved, including through the support a Coordinator gives to Citizen Advocates on different issues, general progress reports given by the Coordinator to the Board of Management and through individual and compulsory yearly meetings held with advocates by the office's staff.

The real safeguard for the success of the relationship is the work done prior to a match to ensure its suitability, followed by frequent contact with advocates during which the coordinator provides questions that stimulate the advocate's attention to various matters, though not to control the advocates actions. It is up to the advocate to respond to the protégé's needs. (Participant in the Research Activities)

The coordinator continuously works to manage expectations in a relationship, especially in the early stages and carefully monitors its development in order to avoid any unwanted consequence in the protégé's life. Yet, no specific mechanisms are used to monitor and identify safety and risk processes

This approach may seem to run counter to the move towards increased professionalisation of support programs for people living with disabilities in Australia. However, the unique and valued opportunities and benefits they can get through the support offered by Citizen Advocacy need to be balanced against the expectations for close monitoring and professionalisation of the service provision.

Independence is a Key to Success

The work of Citizen Advocacy programs is completely independent of the human services system. Independence thus 'implies the greatest possible freedom from conflict of interest in the administrative structures and funding'⁵⁵ of a Citizen Advocacy program.

From a practice point of view, independence means that the Citizen Advocacy office must be administratively and physically separated from agencies which operate direct service programs involving (potential) protégés. This would allow the program to undertake its own protégé recruitment activities and not be subjected to any "pressure" to accept referrals from service providers. Furthermore, one of the roles that Citizen Advocates is to hold service providers accountable for the quality of their support for people living with disabilities.

From a funding point of view, it means that the program must not depend on a single source of funding from the human service system/s but should seek different funding options.

⁵⁵ See Citizen Advocacy New South Wales Association Inc. (CANSWAI), *Citizen Advocacy Board Member Manual*, 1999, viewed 15 June 2013, <<http://www.bmartin.cc/CAN/boardmanual/index.html>>.

More importantly, the notion of independence extends to the Citizen Advocates, who commit to enter into a relationship to support an individual living with a disability in a completely independent manner from the Citizen Advocacy program as well as any other service systems the protégé may access. As one participant in the consultation process suggested:

Although frequently Citizen Advocacy is considered as a component of the individual advocacy, Citizen Advocates are different from Individual Advocates in terms of their appropriateness for this kind of involvement because:

- The commitment a Citizen Advocate makes is to the person, not the program so they are not 'volunteers' of the agency and hence not subject to its direction, only its influence;
- The commitment a Citizen Advocate makes is to be alongside the person for the long term and to seek to develop a personal (natural), not professional (bound by rules and process) relationship with the person with disability;
- Part of what the Citizen Advocacy Program was developed to address was the issue of marginalised and disadvantaged people with disabilities having most or all of their contact with people paid to be there for a particular professional purpose only – Coordinator of Citizen Advocacy Program.

To conclude, the support provided in matching is perhaps one of the most powerful determinants of success that a program can achieve through the exploration of a highly individualised range of advocacy options, to meet both practical and emotional needs of the person living with a disability.

Citizen Advocacy is Generated and Maintained in the Community

Since its conception, Citizen Advocacy has acted as a 'social tool' solely focused on the identification, engagement and use of community linkages and social responsibility to help those more vulnerable and in need.

Citizen Advocacy programs work far better where there is a capacity in the existing communities to properly support the initiative - pure Citizen Advocacy programs always stay local.

Further, it is common practice that members of Citizen Advocacy Boards come from different areas of the geographic territory within which the program operates. This allows for the program to have a strong and active presence in different communities by maintaining a level of active engagement and awareness about the initiative.

Citizen Advocacy Requires a Long Term Commitment

Each new Citizen Advocacy program requires sufficient time in order to observe initial results and long-term relationships need to be properly supported.

Consultation feedback for this project suggested it may take between two and three years for a Citizen Advocacy project to be fully established and start to have some impact through the supported relationships.

First and foremost, enough time is required for all the staff and Board Members to become familiar with the concept and principles of the Citizen Advocacy model and to build their capacity to generate and support relationships. Although some knowledge may exist in the ACT, it was strongly suggested that the new program would benefit from:

- a. retrieving information from other Citizen Advocacy programs in Australia; and
- b. organising exchange visits to other locations across Australia and participate in networks and forums of Citizen Advocacy.

Secondly, the ultimate goal of a program is to support the continuation of long lasting relationships. Therefore, securing and attaining a long term commitment both financially and at the community level would be imperative for the initiative.

Citizen Advocacy Programs in Australia Require Government Support

Early USA models of Citizen Advocacy required programs to be financially independent from government or other major funding institutions in order to maintain the principles of the model. However, this requirement has not been replicated in the Australian context.

Anecdotal evidence from research participants who have contributed in CAPE evaluations in the USA, demonstrated that Citizen Advocacy programs there usually attain only 20 per cent of their funding from government institutions. The remainder is secured through fundraising activities, contributions from the community and other philanthropic donations. However, Citizen Advocacy programs in Australia have a history of mainly being funded through government resources, with a combination of federal and state grants. A new initiative should not be an exemption from this pattern otherwise its future would be uncertain.

Currently, around ten Australian initiatives receive core funding from FAHCSIA under the National Disability Advocacy Program (NDAP)⁵⁶. Members of staff consulted for this report noted that very recently their programs underwent an external audit initiated by FAHCSIA. This is part of an overall assessment of the compliance of disability advocacy services against the *Disability Advocacy*

56 For a list of disability advocacy organisations, including Citizen Advocacy programs funded under NDAP, please see 'National Disability Advocacy Agencies funded by the Australian Government (by state or territory)', Australian Government Department of Social Services, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory>>.

*Standards*⁵⁷ which govern how disability advocacy in Australia is conducted and maintained.

In addition, the implementation of the new Quality Assurance⁵⁸ system commenced on 1 July 2012, with every NDAP funded agency being required to achieve a certificate of compliance against the Disability Advocacy Standards by 7 November 2013. This process ensures Australian Citizen Advocacy programs can be registered as recognised disability advocacy organisations under the requirements of DisabilityCare. The attainment of such accreditation will allow Citizen Advocacy program in Australia to be better positioned when seeking government funding.

57 See Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Disability Services Standards (Advocacy Standards) Determination*, 2012, viewed 12 July 2013, <http://www.fahcsia.gov.au/sites/default/files/documents/08_2012/advocacy_standards_determination_2012_-_signed_by_the_ps_2.pdf>.

58 See *Final Report of the Evaluation of the Trial of the National Disability Advocacy Program Quality Assurance System* <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-service-providers/final-report-on-the-evaluation-of-the-trial-of-the-national-disability-advocacy-program-quality-assurance-system>> for more information.

Enhancing Reach and Diversity of Advocacy

It is probably the best advocacy model that provides a long term support for most vulnerable and isolated individuals. (CA Program Coordinator)

The number of people who desperately need the type of support that is only offered through this model is simply overwhelming. (John Armstrong, Chair of Citizen Advocacy Trust of Australia)

The High Need for Advocacy

Throughout research activities, representatives of advocacy organisations emphasised the high demand for advocacy programs for all categories of people with disabilities, as well as the need more adequate funding to support these activities. Conversely, a Citizen Advocacy program could never fully satisfy the overwhelming need for advocates. But the real value and impact of the Citizen Advocacy model lies in its ability and capacity to make appropriate recruitment of protégés and identify those more vulnerable and who are not linked to services, with community individuals (citizen advocates) who possess the right skills and level of commitment to enter a long term relationship.

In the words of John Armstrong, a Citizen advocacy program educator:

Typically, people with a **cognitive or intellectual impairment** who possibly may have other disabilities are those most in need of a citizen advocate. The reason for that is because their (in)capacity to see and resolve problems, be listened to by authorities, be able to articulate their own interests and have others in their life who would otherwise do that, is partly or wholly absent.

Participants in this research agreed that a Citizen Advocacy program in the ACT would be able to assist a cohort of people living with disability that do not have any kind of informal support or those people whose informal support network is not adequate and up to their needs.

Additional comments from the ACT disability sector suggested that citizen advocates may help people living with a disability 'have some kind of rehabilitation from previous negative experiences when other people made all the decisions for them, not necessarily within their best interest'. This kind of support is uniquely placed to provide opportunities to improve confidence in going out more, become more present and create meaningful links in their communities.

Choice and Control

Local stakeholders very firmly noted that the primary focus of a citizen advocacy program in the ACT should be to support choice and control for people living with a disability. This view is aligned with the main principles of DisabilityCare and the National Disability Strategy. Both these documents have placed a great emphasis in 'the importance of people with disability and their carers being

adequately supported in the areas of policy, service support, community, economic, learning and health levels in order to better exercise their rights for choice and control over their lives'.^{59 60}

In practice, the Citizen Advocacy work is underpinned by the loyalty that advocates have to people with disability both in terms of improving their capacity to make their own decisions and support them during the decision-making process. The presence of an advocate in a protégé's life contributes to a significant improvement of choice and control around service support.

On the other hand, the programs are careful to explain to citizen advocates some of the pitfalls that may compromise the impact of their involvement and lead to a shift from the choice and control principles. More specifically, according to the Board Manual of the Citizen Advocacy Network, 'it is essential to Citizen Advocacy that the advocates strive to define situations from the perspective of the protégé and act to influence situations involving the protégé in terms of his/her perspective'.⁶¹ The importance of this detail is highlighted 'in order to avoid situations in which people on whom a protégé depends may develop their own perspectives, which sometimes are as strong as to distort the need of protégé's own interests to conform to the needs of service providers or even families'.⁶²

Social Interaction

Experience collected from other Citizen Advocacy programs in Australia suggest that giving people with disability the opportunity for an open, informal and free relationship is the best option they could be given. This is especially the case for those people who are socially isolated and in need of protection and representation.

It is specifically this category of individuals that Citizen Advocacy actively seeks to identify and provide them with an offer to engage in a long term relationship with advocates.

Some of the experiences I observed from Citizen Advocacy programs include stories in which completely isolated individuals were given for the first time in their life the opportunity to engage in a social interaction with another person. Some of these people had been in an institution for years and workers were the only source of social interaction for them. (Member of CAPE evaluation team)

59 See Australian Government, *National Disability Strategy 2010-2020: An Initiative of the Council of Australian Governments*, 2011, viewed 5 June 2013, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>>.

60 See Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *National Disability Insurance Scheme: Rules Consultation Paper*, 2012, viewed 4 June 2013, <<http://www.fahcsia.gov.au/disability-and-carers/news/2013/national-disability-insurance-scheme-rules-consultation-paper-released>>.

61 Citizen Advocacy New South Wales Association Inc. (CANSWAI), *Citizen Advocacy Board Member Manual*, 1999, viewed 15 June 2013, <<http://www.bmartin.cc/CAN/boardmanual/index.html>>.

62 *ibid.*

Changes resulting from these relationships have been striking in terms of improved quality of life, expression of hopes and expectations and increasing options for enjoying a full and fulfilling life.

Resources Required for the Initiative

The Operational Structure of Citizen Advocacy Programs

Staffing

As mentioned earlier in this report, two or three full-time staff are usually employed to allow for a smooth operation of an independent program. These will include:

- A Program Coordinator (sometimes referred to as Executive Director depending on the size of the program);
- One administrative assistant who helps running the financial and other operational duties on day-to-day basis and;
- One Assistant Coordinator who helps in outreach activities and matching process of protégés and citizen advocates.

It is common for programs to have members of community helping voluntarily and occasionally to assist with different activities of the program.

Previous experience elsewhere but also in the ACT, has shown that the program struggles if all the work is conducted by a single member of staff. However, for agencies that incorporate Citizen Advocacy within a broader advocacy service mode, there is only one full-time employee, with administrative and management support provided as part of the overall financial resources of the agency.

Coordinator and Other Staff Members

The initial phase of the program will require that paid staff undertake an intensive learning process of CA model. This may include visits to other programs and possibly participation in CAPE or Learning Citizen Advocacy evaluations. They were described as very helpful activities by representatives of existing CA programs in Australia.

The program also would need to initiate the establishment of relationships with other counterparts being individual programs, through Citizen Advocacy Trust of Australia or Citizen Advocacy Network.

This learning process, nonetheless, should not pose a delay in the start of protégés and advocates recruitment process. They can and should go hand in hand together with outreach activities to raise the awareness about program's presence.

Board of Management

The structure would benefit from having individuals who come from different areas of professional expertise. Similarly to members of staff, they also need to have a very good understanding of the CA mission, purpose and work. Ultimately, they bear primary responsibility for holding the program within its

role and advice on the recruitment and matching process. They also ensure that the scope of the initiative is not diverted and modified.

Previous experience has shown that if the Board fails to fulfil these responsibilities can be harmful for the initiative, which was to some extent also the case of the previous program in the ACT.

Experience and knowledge in the area of disability advocacy may be an advantage but it is not a precondition. In order to maintain the program's independence, it is recommended that Board members are not involved in the disability service system, since their approaches in fulfilling the needs of people with disability may be a service-based one and quite different from the principles of program. One of the roles of Citizen Advocacy is to hold services accountable for the quality of their support and this may lead to a conflict of interest within the program.

Additionally, comments from other CA programs on the composition of Board suggest that even people with social work or other similar professional background would not be preferred as members.

Area of Coverage

It was almost unanimously agreed that the program should operate ACT wide. Some of the reasons for this are:

- Most of the current initiatives around disability advocacy operate ACT wide;
- People with disabilities are usually very mobile. They move or sometimes are moved in different locations frequently;
- A geographically limited area of coverage may affect the continuation of the relationship and will not allow a person centred approach.
- The ACT has a manageable size with sufficient population density.

However, a small number of participants in the consultation process suggested that the program may start 'as small and lean' in one specific area, and with the experience gained may expand within two years of its existence. This may also be compatible with the prospect of having a pilot program to assess the number of matches that can be generated through a Citizen Advocacy model.

Funding

Overall, costs for administering Citizen Advocacy programs are low especially in comparison to other advocacy approaches. Most of the funds are used to cover the wages of paid staff, rent and utility bills. 'Unlike paid advocates, Citizen

Advocates are not financially compensated in any way by the program or because of their involvement in it'.⁶³

Funding Commitment

The amount of funding each program receives differs from one to the other. The target and the area of coverage are the main factors that determine funding levels.

This report cannot quantify an exact amount that is required to adequately fund the program. However, information collected during the consultation process suggested that an annual funding between \$120-150 thousand would be sufficient to allow the program to run. It is important to note that a variety of other supportive arrangements with local and state governments can be negotiated, such as free rent and free utility bills, especially when funding may be limited.

Secure Funding and Funding Agreements

The Citizen Advocacy model was developed in the USA where there is broader support from charity donations for initiatives such as the Citizen Advocacy model⁶⁴. Programs currently operating in Australia do have some experience in applying for additional funding. However that is often very limited. Usually, these grants are small, are used for a one-off activity and serve a very specific and short term purpose. Some programs have looked at small business models that could provide a continuous and stable funding stream (such as having an Op-Shop), but so far these ideas have not been materialised. Programs cannot raise money by charging for their service since the principles of the Citizen Advocacy model have been interpreted to preclude applying service fees.

Other experiences suggest that with careful fund-raising campaigns, programs can attain considerable in-kind support, such as utility bills, stationery, computing equipment, catering, etc. The development of Corporate Social Responsibility Programs offer opportunities for Citizen Advocacy initiatives to explore additional funding sources, as long as there is not conflict of interest.

Although DisabilityCare may offer funding opportunities for their work, it is unclear at this stage how disability advocacy will be funded under the scheme.

The commitment of government institutions to fund Citizen Advocacy initiatives is considerably affected by its own policies and regulations. Comments from consultation process included that 'paid professionals are usually viewed as superior to unpaid citizens'.⁶⁵ On the other hand, from a bureaucratic point of

63 J O'Brien, *Learning from Citizen Advocacy Programmes – Including a Revised Short Form of CAPE: Citizen Advocacy Programme Evaluation Standards*, printed & distributed in Australia by AMR Inc., National Association on Intellectual Disability, Canberra, 1987.

64 See Appendix D for a description of differences in funding opportunities between Australian and US Citizen Advocacy Initiatives.

65 This was also exemplified in J Pearson & Associates, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, submitted to Department of Families, Housing, Community Services and Indigenous Affairs, 2009, viewed 12 June 2013, <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>>.

view, it is much harder to control unpaid citizen advocates from a departmental or system perspective. As one participant commented,

General public in Australia tend to think that advocacy is a right/entitlement which should be primarily supported by government. This applies to disability advocacy as well, resulting in having very little in the way of truly independent (and therefore powerful) advocacy.

Nevertheless, representatives from other Citizen Advocacy noted that government funding, although contributing to a level of dependence brings benefits for programs. For example, it brings discipline to the way they operate. Negotiating their targets and reporting requirements by using the principles and assessment categories outlined in CAPE helps them to report against the indicators required by service contracts while maintaining the integrity of the Citizen Advocacy model.

The Citizen Advocacy Trust of Australia, a national body, raises and distributes funds for initiatives, but as yet not at a level that would independently sustain one or more offices. The Trust helps programs that are planning to undertake a CAPE evaluation by partially or fully funding the evaluation team.

Citizen Advocacy Program Roll-out Considerations

Lead Up Period

According to the core requirements of Citizen Advocacy, generally speaking, eighteen months is an average time period for program proponents, coordinators, Board members and associated supporters to discuss, formulate and establish a Citizen Advocacy program. With this timeframe in mind, the lead up period to a roll-out of a program will offer ample opportunity for:

- A community, grass-roots driven education campaign to build up the profile of Citizen Advocacy;
- Increasing the knowledge and understanding in the community of what the initiative aims to achieve and what would be the benefits for local community;
- Interested stakeholders to explore and come to an agreement on the organisational model of the program and other infrastructure.

Roll-out Timing

As mentioned earlier in the report, there will always be a need for the unique support offered by a Citizen Advocacy program. Therefore, a discourse on when would be an appropriate timing for setting up such an initiative may be perceived as inapt when considering the high need for advocacy support for people with disability.

Concomitantly, in the ACT and indeed Australian context, broader sectoral development in the community sector such as DisabilityCare and Age Care reforms will bring distinct and significant changes in the area of disability advocacy and support. They will unquestionably play a role on the level of

positive up-take of a Citizen Advocacy initiative by the community. This report suggests that the current landscape offers an opportune time for setting up and rolling out such a program.

Existing Community Support

This research project was not able to identify a core group of individuals that would guide the start-up process of the initiative. This is not to say that this support is lacking. We suggest that further and more intensive consultations with stakeholders who in the past have expressed interest towards facilitating a Citizen Advocacy program in the ACT are needed. They might include:

- Members of the Citizen Advocacy Community Group facilitated by Disability Information and Support Hub (DISH) of Disability ACT.
- Members of the Board of Management and Citizen Advocates involved in the previous program in the ACT may be considered as potential and active adherents who would bring valuable experience into the new initiative. However, it is important to note that a significant amount of time has passed since the cessation of the initiative, therefore is it uncertain to what extent they will make themselves available in the process.
- Other community forums and clubs have proved in the past to be valuable structures from which Board Members and Citizen Advocates can be identified.

To conclude, information collected through research activities points out that there is a great potential for community support for the initiative. This will better identified and utilised once the program is set up and starts to function.

5. Potential Models of a Citizen Advocacy Program in the ACT

The research process undertaken for this project attempted to explore a range of possible models of a Citizen Advocacy program in the ACT. We have tried to incorporate insights and suggestions from a range of different stakeholder in what would work best in the ACT. The models described below are based on the experience gained from other CA programs in Australia, the current trends and demand for disability advocacy services in the ACT and the capacities of the ACT community support to establish and continue a Citizen Advocacy program.

Representatives of other Citizen Advocacy programs in Australia advised that a genuine independent model would be the best possible option for such a program in the ACT (Model 1).

Stakeholders from the disability advocacy sector in the ACT noted their current work suggests that overall there is a high need for advocacy support that cannot be fulfilled with the available resources. It was further suggested that in order to have a more robust response and efficient use of resources, a Citizen Advocacy program may be incorporated into an existing disability advocacy organisation (Model 2). This type of structure has been used in the past and present in Australia.

Finally, it was suggested that volunteer capacities in the ACT would need to be considered as potential resources that can be utilised in running the programs activities (Model 3). This is based on the voluntary governance arrangements of Citizen Advocacy.

It is important to note that the research team and ACTCOSS do not favour a certain model at the expense of others. We recommend any final decision to be taken based on a follow-up consultation with government, community sector organisations and other stakeholders who may be interested in being involved in the program.

Model 1 - A Fully Independent CA Program

This model is closest to the pure model of Citizen Advocacy. There are around 8 initiatives in Australia that operate under this structure. Some of its features include:

- The office operates with 2-3 full time workers. The positions include a Program Coordinator, an administrative assistance and potentially an additional worker and/or volunteer who can support the coordinator in recruitment of advocates and protégés, and outreach activities;
- The office may be located in a community hub or in a separate premise but with no service providers co-located. The rent and utility bills may be

subsidised or offered free of charge in order to minimise the costs of the program. This is a practice that other programs in Australia have been able to negotiate with their local authorities, whenever possible;

- The program will have a Board of Management with a minimum of 4 and a maximum of 9 members. They will be responsible for overseeing the work of the program's paid staff, and ensure that the program maintains its role and function within the principles of Citizen Advocacy model and governance arrangements;
- The program will develop and maintain close relationships with other counterparts in Australia as well as agencies that provide disability advocacy services in the same geographical area. However, their work will be independent of other organisations;
- The program would seek financial support from disability advocacy funding grants from the Federal and ACT Government and work towards exploring opportunities for charity and philanthropic donations that would help attain a financial security and a level of independence for the program;
- The program would have an average target of 8-10 new matches per year and provide training opportunities for Citizen Advocates, additional support by suggesting associate and crisis advocates on short-term issues and assist protégés when Citizen Advocates are absent due to travelling or other immediate arrangements of their own.

Strengths

- The program will maintain a high level of independence according to the pure model of Citizen Advocacy;
- With previous experience of Citizen Advocacy work in Canberra, the program's paid staff and Board members will be able to create linkages and utilise community connections to establish support for the initiative. Through these capacities and outreach activities, the program will identify those people living with disability who are most vulnerable, isolated and are not able or have limited capacities to seek advocacy or self-advocate, exercise their rights, express their expectations and fulfil their aspirations and match them with Citizen Advocates.
- Based on the information collected locally during the research activities, the program will benefit from the opportunities that the ACT community offer in terms of potential citizen advocates.

Limitations

- Lack of or limited funding may affect the overall process of setting up the program and hiring the necessary paid members of staff suggested above;
- Difficulties that the program may experience in its very early stages may delay the commencement, and limit the capacity to meet its target.

Model 2 - A CA Program Operating within an Existing Disability Advocacy Organisation

The program will use most of the features described in Model 1, with the following differences in staff arrangements:

- In terms of staffing, there will be only one Coordinator responsible for recruitment and matching process with possibly an assistant to help in sharing the duties;
- The staff member/s who is responsible for the citizen advocacy components will report to the CEO/ General Manager of the agency;
- The program will operate within the premises of the disability advocacy agency, making it more financially efficient in terms of office costs, both for rent fees and administrative work;
- Funding will be channelled through the advocacy organisation with specific allocations for the Citizen Advocacy program.

The initiative will have the same structure of the Board of Management as in Model 1. In addition:

- The Board will maintain a high level of independence from other governing structures of the advocacy organisation. However, it will be considered as a sub-committee that specifically deals with issues that are solely related to the Citizen Advocacy components;
- Its relationship with other governing bodies would be regulated through specific documents that would avoid potential discords in the constitution or interference with governance and organisational structures of the main agency.

Strengths

- The opportunity to target advocacy model to individual needs and align program models across the advocacy system; and
- The program will be able to operate with fewer funds since it will make use of the already existing infrastructure of the advocacy organisation.

Limitations

- It may lead to a level of dependence on the hosting organisation;
- The relationship between the two boards may suffer due to differences in strategic and policy actions thus possibly affecting the functioning of the program;
- The mission and purpose of the Citizen Advocacy program may be compromised or absorbed within the broader advocacy role of the hosting organisation. This risk was firmly highlighted by participants in the consultation process. However, it can be easily resolved through clearly defining and administering the specific role of each advocacy component;

- It will somehow restrict opportunities that the Citizen Advocacy program may consider in terms of other external donations and funding; and
- The continuity of program is dependent on the support from hosting organisation.

Model 3 - A CA Program that Operates within an Agency that Manages Volunteering Services/Work

There is very little difference between this model and the second one. The difference lies with the profile of the hosting organisation. This will be an agency that is involved in representing and managing volunteering capacities and activities in the ACT. Consultations with representatives from such organisations, propose that while it is perfectly possible for them to host the program, specific arrangements would be needed regarding the role and relationship between governing structures. In addition, the decision would have to be approved and accepted by all the interested stakeholders.

Strengths

- The program may benefit from the structures and capacities of the hosting agency to raise awareness about the mission and the role of Citizen Advocacy;
- It may help the program to tap into the volunteer capacity in the ACT community and provide it with a pool of potential advocates that offer to commit to a long term relationship with a person living with a disability;
- The program may benefit from training capacities of the hosting agency, essential for the stability and continuation of the initiative;
- The program may be able to run with less funds compared to the first and second model.

Limitations

- This is a hybrid model. It has not been seen elsewhere in Australia and it is closer to the United States model which largely utilises volunteers to run the program;
- While the work of Citizen Advocates is offered on voluntary basis they are not volunteers. Participants highlighted the risk that the long term commitment required for relationships with protégés may not be fully understood by individuals that enter the relationship via a traditional short-term volunteering approach. They may find it difficult to depart from their previous volunteering role and start a long term engagement that has a different purpose and quality to that of other volunteering roles.

Appendix A. List of Agencies and Individuals Engaged during the Consultation Process

Australian Capital Territory

ACT Disability, Aged and Carer Advocacy Service (ADACAS)

Advocacy for Inclusion (AFI)

Carers ACT

Disability ACT (DACT)

Disability Advocacy Network of Australia (DANA)

Disability Information and Support Hub (DISH)

People with Disabilities ACT (PWDACT)

Red Cross ACT, MATES program

Volunteering ACT

Women with Disabilities ACT (WWDACT)

Citizen Advocacy Programs in Australia

North Eastern Citizen Advocacy, Melbourne, Victoria (NECA)

Citizen Advocacy South Australia (CASA)

Citizen Advocacy Sunbury & Districts Inc. (CASDI)

Gippsland Disability Advocacy Inc. (GDAI)

Side By Side Advocacy

Individuals

John Armstrong, Chair of Citizen Advocacy Trust of Australia

Brian Martin, Former Chair of the Illawarra Citizen Advocacy (1997 -2007)

Fiona Stewart, Former Program Coordinator of the ACT Citizen Advocacy Inc. (1986 – 1988)

Appendix B. Citizen Advocacy Program Evaluation (CAPE) Indicators

Adapted from J O'Brien & W Wolfensberger, *CAPE: Standards for Citizen Advocacy Program Evaluation*, NIMR/CAMR Publications, Toronto, 1979.

Adherence to Citizen Advocacy Principles	Citizen Advocacy Office Effectiveness
<ol style="list-style-type: none"> 1. Advocate Independence <ol style="list-style-type: none"> a. Unpaid Roles b. Loyalty to Protégés Citizen Advocacy Office promotion of advocate loyalty to protégés <ul style="list-style-type: none"> • Internal promotion • External promotion 2. Program Independence <ol style="list-style-type: none"> a. Independent Administration and location <ul style="list-style-type: none"> • CA program separation from direct service • Independent CA office location b. Independence of funding sources 	<ul style="list-style-type: none"> • Vision and creativity of protégé recruitment • Advocate recruitment • Advocate orientation • Advocate-protégé matching • Follow-up and support to relationships • Ongoing training • Advocate associates emphasis • Balance of key CA Office activities • Encouragement of advocate involvement in voluntary associations • Sufficiency of Citizen Advocacy Office Staff
<ol style="list-style-type: none"> 3. Clarity of Staff Functions <ol style="list-style-type: none"> a. Focus on staff role definitions b. Staff independence from other advocacy forms c. Ties to the citizen advocacy movement 4. Balanced Orientation to Protégé Needs <ol style="list-style-type: none"> a. Protégé characteristics <ul style="list-style-type: none"> • Protégé age • Protégé capacity for spokespersonship to defend human and legal rights • Need for long term relationship b. Diversity of advocacy roles <ul style="list-style-type: none"> • Diversity of current roles • Balance of current and planned advocacy relationships • Availability of crisis advocates • Involvement of youth advocates c. Avoiding social overprotection 5. Positive Interpretations and Positive Imagery <ol style="list-style-type: none"> a. Positive interpretations of individuals with disability 	<p style="text-align: center;">Program Continuity and Stability</p> <ul style="list-style-type: none"> • Community leadership involvement • Feasible governance and guidance structures • Composition of governance and guidance bodies • Level of leadership involvement • Fund Related issues • Long term funding participation • Local funding participation • Program legitimisation

Appendix C. Implications from Accepting Passive/External Referrals in the Role of a Citizen Advocacy Program

During the consultation process, North East Citizen Advocacy (NECA) office in Melbourne described the reasons why they do not routinely accept external referrals for people living with disabilities to be matched with an Advocate. There are a number of implications from the passive acceptance of referrals:

1. **Number of people with disabilities (protégés) who can realistically be matched with Citizen Advocates**

Citizen Advocacy is a small –scale response, which cannot be expected to meet the advocacy needs of a vast number of people living with disability. If the policy of our program is to simply accept referrals, it will rapidly yield the outcome of an ever-growing waiting list of people with disability.

2. **Identify the need of people who require Citizen Advocacy**

In order to effectively respond to the real and important advocacy needs of people with disabilities, the Citizen Advocacy office must be absolutely clear in determining:

- a. who it will recruit as a protégé; and
- b. why the person needs an advocate.

Reliance on passive referrals shifts the decision-making away from Citizen Advocacy office to the person making the referral. This may lead the office staff who are unquestioning this approach to end up recruiting an advocate for unnecessary, inappropriate and peripheral reasons. In addition, if protégé recruitment is solely dependent on acceptance of referrals, some of the people most in need of an advocate may not reach the program.

3. **Protégé characteristics and corresponding advocate roles.**

Acceptance of passive referrals may narrow the potential range of protégé needs and advocacy roles in the composition of relationships it arranges, with the likelihood that some types of matches will predominate while others are under-represented or even ignored. For example, the program may end up having too many females, more people with physical disabilities and less with intellectual ones or too many young people.

4. **Perception and practice of program and advocate independence**

A Citizen Advocacy programs itself must be separate from, and independent of, agencies that provide services, whose clients may be matched with advocates. By accepting passive referrals from them, it may help establishing a practice which invites the perception that the advocacy is merely an extension of such services. In addition, the service support staff may feel that they have some 'ownership' or influence over the ensuing match, which has the potential to threaten the independent nature of protégé/advocate relationship.

Appendix D. Differences in Funding Models for Australian and USA Citizen Advocacy Initiatives

The Citizen Advocacy model was developed based on the USA context and community approach to helping those more in need. Their funding model reflects the American tradition of generous corporate philanthropy, compared to other countries at least, and the limited role of welfare state (Martin, 2004). However, the same has not been replicated in Australia due to a number of factors.

Charitable Donation

Most of the funding for Citizen Advocacy programs in the USA is secured through charity donations. Programs frequently organise fundraising activities and are generously supported by members of the community. Usually, only 20 per cent of their funding may come from government grants.

Cost discrepancies

Citizen Advocacy programs in the USA are able to run with much less funding compared to those in Australia. One participant described the average annual funding that a program in the USA requires around AU\$35,000 while a similar initiative in Australia would struggle with a budget less than AU\$100,000 per year.

Staffing Ratio

Usually, USA initiatives have only one Coordinator as paid staff and the Board of Management. Based on their experience, the Australian CA programs noted that it would be very difficult for a single person to manage all the duties required. This statement was reinforced by stakeholders in the ACT, who suggested that having a single person running the previous program in the ACT may have contributed to the difficulties experienced by the initiative.

Use of Volunteers

While citizen advocacy initiatives in the United States extensively use the work of external volunteers for specific tasks, the information collected during the consultation process offered mixed views on the quality of work that volunteers can provide compared to the paid members of staff. However, the contribution of volunteers may directly help programs which do not have sufficient funding to support paid workers.

Note: Information used in this appendix was solely provided by representatives of Citizen Advocacy programs in Australia and their experience from participating in evaluation exercises of similar initiatives in the USA. It does not necessarily represent the views of the research team and it is not supported by literature sources.