

The Role of Advocacy Services in the Tasmanian Disability Sector

An Information Booklet
Compiled by Advocacy Services

In Partnership with Gateway
Services and Disability and
Community Services

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I. Introduction

The provision of independent advocacy services is an important safeguard for protecting the rights of people with disability. These rights are enshrined in the *United Nations Convention on the Rights of People with Disabilities (May 2008)* and also provide the basis of the principles and standards contained in the *Tasmanian Disability Services Act 2011*.

The *Disability Services Act 2011* states that people with disability have the same right as other members of society to make and actively participate in, direct and implement the decisions which affect their lives.¹ Advocacy is one of the keys to ensuring that people with disability are able to participate in decisions about the services they receive, and the Disability Services Standards require that services be designed and administered to ensure that access to advocacy support is available where necessary.²

The National Disability Strategy, an initiative of the Council of Australian Government (COAG), sets out a 10 year national plan for improving the lives of Australians with disability, their families and carers. The Strategy outlines the importance of advocacy services in enabling and supporting people with disability to safeguard their rights and overcome barriers that impact on their ability to participate in the community.³

Ensuring that people with disability have access to an advocate provides an important driver for continuous improvement in the quality of disability services.

Service providers have an obligation to remind people with disability that advocacy supports are available when they are making decisions about the services they receive or other significant life matters. This will help to guarantee that consultation – with the option of support from an advocate – is the foundation for all decisions related to service provision and development.

The Tasmanian Government provides funding to Tasmanian advocacy services through Disability, Housing and Community Services within the Department of Health and Human Services. The Australian Government also funds advocacy services for people with disability.

This booklet was initially developed in May 2007 to ensure that the role of advocates and the practice framework under which they operate was understood by the Tasmanian community, including the disability sector. In late 2007/early 2008, an external review was conducted of Disability Services in Tasmania resulting in publication of the *Operational Framework for Disability Services* in 2009, which underpins the disability reform process and provides a clear direction for service provision into the future. The Framework focuses on building partnerships with people with disability, their families and carers, and the community sector with an emphasis on human rights and improving outcomes for people with disability. The Framework highlights the significant role that advocacy services play in protecting the rights and interests of people with disability. The emphasis is on enabling people with disability to make their own decisions, speak on their behalf, understand their rights, and acquire new skills.³

As a result of this, there have been extensive reforms across the Tasmanian disability sector as the recommendations from the Review have been implemented. This has resulted in a new service system, and therefore there is a requirement to update this handbook so that it aligns the new service system, particularly in relation to the role of the Gateway Services.

To illustrate some of the common situations faced by advocates, and some of the myths about advocacy, hypothetical case studies have been included throughout the booklet. These case studies appear next to the relevant topics. The case studies are hypothetical, and are not intended to be followed prescriptively. They may be used as a guide, and should help to clarify the role of advocates in real life situations.

¹*Disability Services Act 2011*, Principle 2.

²*Disability Services Act 1992*, Standard 12.

³National Disability Strategy 2010-2020, page 17.

⁴Operational Framework for Disability Services 2009.

2. What is Advocacy?

Advocacy is speaking, acting, and/or writing to promote and defend the rights, needs, and interests of people. The primary aim is to promote advocacy by assisting people to speak for themselves, but if they are unable to do so, an advocate speaks on their behalf. Advocates present things from the person's perspective.

Advocacy is about giving a voice to people who are marginalised and powerless.

Kevin Stone (2002) suggests that being an advocate can involve three separate functions, namely:

1. standing beside people with disability by assisting them to advocate their own interests
2. standing behind people with disability by supporting them to represent their own interests
3. standing before people with disability by representing their interests.

Assistance

Strategies involved with standing beside people can involve:

- accompanying a person or group to meetings
- prompting and reinforcing the expressed views and interests of a person or group
- assisting in clarifying goals, developing strategies and advocating the views and interests of a person or group.

Support

Strategies involved with standing behind people can involve:

- providing the individual with effective training in self advocacy and advocacy skills
- supporting the individual to speak up
- providing advise to people with disability and their families on issues and strategies
- providing information which might enhance the advocacy of people with disability and their supporters.

Representation

Strategies involved with standing before people can involve:

- speaking or acting on behalf of people who are unable to assert or express their own views and interests
- speaking or acting as the nominated representative of an organisation or group
- speaking or acting as the appointed representative of an individual or group.

3. Types of Advocacy

Individual and Systemic Advocacy

Assistance, support and representation are all forms of individual advocacy. Individual advocacy focuses on the specific needs and rights of individuals and provides an environment in which individuals with disability can assert their rights, to challenge the decisions and actions which restrict their opportunities and to obtain justice and equality in their daily lives.

Systemic advocacy focuses on influencing and changing the systems – including government laws and policies, departmental procedures, generic community and disability service practices – which may be adversely affecting people with disability and their families.

4. The Principles of Advocacy

The principles of advocacy for people with disability in Tasmania are:

4.1 Person Directed

Advocates work at the direction of the person utilising their service.

4.2 Conflict Management

Advocacy is often involved in situations of conflict. Advocates endeavour to avoid confrontational approaches as much as possible.

4.3 Confidential

Confidentiality builds trust between the person and their advocate. Persons have the right to expect that their issue will be dealt with confidentially.

4.4 Culturally Sensitive

Advocates must take into consideration the cultural and linguistic and communication requirements of the person(s).

4.5 Duty of Care

Advocates have a duty of care to not advocate in ways that are illegal or that will significantly harm or disadvantage the person or other people associated with the person.

4.6 Empowerment

Advocacy works to increase the power and control the person have over their lives.

4.7 Independent

Advocacy must be independent, with no conflicts of interest. It must focus solely on the rights and interests of the person whether this is a person with disability, their family or carer.

4.8 Needs Based

Service is provided to individual need. The service is free and operates state-wide.

4.9 Partisan

Advocacy is on the side of the disadvantaged party. It exists to assist people who are unable to represent themselves independently. Advocates are not 'neutral umpires' or mediators.

5. Advocacy Services in Tasmania

The Tasmanian Government, through Disability Housing and Community Services, currently funds three advocacy services: Advocacy Tasmania, Speak Out Association of Tasmania and the Association for Children with Disability (ACD).

The Commonwealth Disability Program of the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) provides additional advocacy services to people with disability. Under this program funding is provided to Advocacy Tasmania, Speak Out Association and Citizen Advocacy.

Advocacy Tasmania and Speak Out Association of Tasmania have similar models of advocacy, though each organisation has a unique emphasis, or mix of functions, as described in Section 6 below.

Individual Advocacy

The advocacy services provide advocates to assist individual people who have a disability as defined by the Tasmanian *Disability Services Act 2011*. This includes assisting people to raise complaints or concerns, speaking on behalf of people when asked and support with self advocacy.

Systemic Advocacy

Each advocacy service provides systemic advocacy on issues impacting on the person or a group of people. This work stems from the case work carried out by advocates on behalf of individuals, and by any other means which identify issues that can adversely affect the person or group. Advocacy services funded by Disability and Community Services have membership on each of the Area Advisory Groups so that they can be involved in planning for services for people with disability by area, and at a state-wide level.

Education, Information and Promotion

All the advocacy services except Citizen Advocacy provide rights and advocacy education, information and service promotion activities to people with disability, families, service managers, support staff and other stakeholders.

Person Participation

All advocacy organisations are involved in supporting people to develop self-advocacy skills and active participation in the decision-making and consultative structures of the services they use.

6. More About the Four Tasmanian Advocacy Services

Advocacy Tasmania Inc.

Advocacy Tasmania Inc. (ATI) is an independent, community based advocacy service that has been operating since 1991.

ATI has five Advocacy Programs:

1. Disability – for people with disability
2. Mental Health – for people with a mental health disorder
3. Home and Community Care (HACC) – for people in receipt of, or eligible to receive, HACC services
4. Aged Care – for older people living in aged care facilities or receiving Community Aged Care Packages, Extended Aged Care in the Home (EACH) packages, or who are eligible to do so
5. Alcohol, Tobacco and other Drugs (ATOD) for those receiving services from, or seeking to access services in funded ATOD services.

ATI also has two special projects:

- The Mental Health Tribunal Representation Scheme – for people appearing before Mental Health Tribunal Hearings. The Scheme provides free, competent, trained volunteers to represent people at hearings where their mental health orders are being reviewed
- The Dementia Rights Advocacy Project – for people with dementia, with priority given to people in the early stages of dementia who have no family or friends to support them and advocate on their behalf.

ATI's primary role is to provide advocacy to individuals in the various target groups. In 2009/2010 ATI assisted over 1 250 people with individual advocacy, with the Disability Program assisting 480 people. In 2009/10 ATI and Speak Out each received funding for an additional advocate under the Sector Reform Project to help safeguard the rights and interests of the persons of the State Government run day support and respite services through the transition to non-government service provision.

ATI is involved extensively in systemic advocacy. In 2009/2010 this included:

- work on unmet need for services, particularly individual support packages and supported accommodation
- prevention and responses to abuse of people with disability
- representation at Area Advisory Groups in each region, providing comment to the disability working groups and supporting persons and family members to have a say via their website and BLOG at www.yoursayaag.org.au

ATI also conducts education and group work. In 2009/2010, ATI facilitated education and group work sessions involving 5 523 participants. Of these, the Disability Program worked with 1 023 participants.

In group work, ATI was involved in running residents' groups in both government and non-government run residential facilities and workers' groups in business services and day options services.

Association for Children with Disability (Tas.) Inc.

The Association for Children with Disability (ACD) is a state-wide organisation providing advocacy, case management, information, training and support for families with a child or children with disability. ACD was established in 1997, it began as a support group for parents with children with disability. Since then the organisation has become incorporated, employed staff to support and empower families/carers and grown in stature as a service provider organisation. ACD's direction is dictated by the needs of children with disability and their families/carers.

ACD employs staff with knowledge, experience and expertise in working with families/carers and disability and is governed by a Board of Management who bring a relevant range of professional backgrounds and expertise, also including a number of parents/carer's of a child or young adult with disability.

ACD staff work to a Family Empowerment Model, a social model that focuses on strategies by which families use assistance to identify and achieve self-defined goals. ACD believes that the most important needs of the family and individual members of the family are those identified by the family/carer, not the professionals.

The guiding principles of ACD are choice of, access to, and equity of all services for all Tasmanian children, irrespective of their disability and regardless of where they live.

ACD's Family Advocates provide services in the South, North and North West of Tasmania. ACD is primarily funded through the Department of Health and Human Services.

The organisation provides:

Information

- via the telephone on a FREECALL 1800 number (see Contacts, pages 27-28)
- through its magazine PEPTalk
- by conducting or facilitating information forums on issues concerning family and their child/children
- through a family service directory titled 'Finding Your Way' – a comprehensive guide to benefits and services for families of children with disability
- through their resource library with books, toys and games.

Advocacy

- ACD's Family Advocates assist parents/carers of children with disability to develop skills and knowledge so they can make informed decisions; exercise their rights and advocate on their own behalf in order to gain positive outcomes for their children with disability
- Family Advocates assess each individual situation; assist families/carers in determining the issues present appropriate response options to them for consideration
- Families/carers require different levels of advocacy support options dependent on their need at the time. Where appropriate and in direct consultation Family Advocates can advocate or act on behalf of families/carers of children with disability. ACD provides systemic advocacy for families/carers where there is policy or systemic barriers affecting or likely to affect service provision to families.

Support by

- listening
- attending meetings with parents/carers
- facilitating support groups
- assisting families/carers to determine needs
- ensuring that families/carers are supported to access the services that they require
- developing informal networks amongst parents/carers
- talking with service providers and government about issues of concern.

Training

ACD provides a fee for service, "Working with Families" training and information package to anyone who works with families/carers who have children with disability, ensuring parent perspective input into professional development and training sessions.

ACD also provides training in the use of the 'Participation Model' Beukelman and Mirenda (1992, 2005) as a tool for identifying how a child or young person is participating in any environment on the following four levels:

- integration
- social
- academic (education based)
- independence.

Citizen Advocacy

Citizen Advocacy is a federally funded community group which provides support services for individuals within the Launceston area which are provided by suitably skilled advocates.

Citizen Advocacy employs a small team of staff who seek out suitable individuals who may form meaningful, pro-active and supportive relationships with people with disability, who are homeless, institutionalised or have a reduced capacity to represent themselves and therefore require assistance to have their needs met.

Whilst Citizen Advocacy does not maintain a Wait List, it actively pursues suitable advocates for all who request the service.

The types of support provided are diverse and may include, but is not limited to assistance with:

- emotional and material support
- individual advocacy
- companionship
- budgeting
- accommodation
- housing
- transport.

Citizen advocates may also take on formal roles/relationships such as Guardian or nominee for Centrelink payments.

Speak Out Association of Tasmania

Speak Out provides advocacy support to people with disability.

Speak Out aims to support people with disability to:

- advocate for their own interests and to become more active and instrumental in claiming their rights
- create an awareness of the individual and specific needs of people with disability
- educate the community on issues relating to people with disability.

This is achieved through one-to-one support, self advocacy skills development and community education.

Speak Out offers support for:

- employment committees
- residents' committees
- Day Service committees
- individuals on Boards of Management
- training and education for people with disability (e.g. assertiveness training)
- training for support workers
- interest groups that meet monthly in Hobart, Launceston and Burnie
- an annual conference
- information and referral to other services
- an information and resource centre (videos, books, posters, pamphlets, training manuals etc)
- Networking with other services.

Individual advocacy is provided when a person with disability feels that their needs are not being met, that they have been treated unfairly or when the person's supports have broken down and the individual is at risk.

Due to its extensive membership throughout Tasmania, Speak Out is able to provide opportunities to facilitate effective community consultation with people with disability/and or their family on the issues that affect them.

7. An Advocate's Mandate to Act

Ideally advocacy involves a conscious choice on the part of a person. It usually happens because a person feels their rights are being violated and decides to act for themselves (self advocacy) or have someone, such as an advocate, act for them. In the usual course of events the advocate takes their instructions from the person they represent and therefore the advocate works at the direction of that person. The advocate's authority to act (legitimacy) comes directly from the person with disability asking the advocate to take certain actions on their behalf.

As a rule of thumb, an advocate has a mandate if the person or their guardian can:

1. Understand the concept of rights
2. believe that their rights of the person with disability have been violated
3. communicate a wish to have assistance to have the situation remedied.

The exception to this is where the person, whose rights are being violated, cannot direct the advocate. Due to age, intellectual or cognitive disability, dementia or mental illness, the person may not understand that their rights are being violated or be able to easily communicate their concerns. In this instance, someone else may see the violation and take it upon themselves to act. They might advocate directly for the person or they might contact someone else such as an advocacy service to do so.

In such situations an advocate may act without formal authority 'in the best interests' of the person but the person providing the advocacy if they strongly believe that the rights issues are unequivocal. This might be in cases of abuse, or where documented policies, practices or standards are not being followed (e.g. a person's right to receive correct medication or to participate in meaningful activities during the day). In these situations advocates must be able to justify why they are acting without a clear mandate from the person.

From the human rights approach, older people and people with disability who are in need of high levels of support have the greatest need for an advocate. The right to an advocate is not a wavering one. It is not dependent on the vulnerable person's ability, or inability, to access, engage, instruct or direct an advocate. Advocacy is a safeguard for vulnerable people to ensure that they are safe respected and have their needs met.

If the person has a limited ability to understand or communicate, the advocate should seek guidance from someone close to them. Sometimes this may be an informal arrangement where an unpaid carer or a close relative can approve the actions of an advocate where those actions do not require a legally binding decision on behalf of the person. If there is no one who can provide the necessary authority and/or the rights issues are not clear, a substitute decision maker, with the legal authority to make decisions on the person's behalf, should be sought (Disability Action Inc, 1997) (1). In Tasmania this is through the Guardianship and Administration Board (GAB) who can appoint a guardian to make personal decisions or an administrator to make financial decisions on behalf of the person. Where the person has no suitable relative or friend to act as a guardian or administrator, the GAB may appoint the Public Guardian or the Public Trustee to make decisions on behalf of the person. Appointing a guardian or administrator is seen as a 'last resort'.

8. Advocacy and Complex Situations

Advocates are often involved in situations where, from an outside perspective, their role may not appear to be clear-cut. Two common situations are discussed below. These are:

- working with people with profound disability
- working with families.

Working with people with profound disability who cannot indicate their wishes

Even though advocates work at the direction of the person, it is still possible for them to work on behalf of people with profound disability who cannot indicate their wishes.

Advocacy is issue-based, that is, advocates work for people to resolve a particular issue or group of issues. To do this the advocate must first have a referral from someone relating to an issue or issues. One of the misconceptions of advocacy is that advocates have permanent clients – for all Tasmanian advocacy services except Citizen Advocacy this is not the case. In the case of Citizen Advocacy, the citizen advocate and the person with disability have an ongoing relationship.

However, some people have complex issues which can take a long time to resolve, while others are familiar with using advocates to help them and do so regularly – both of which can give the impression that some people have ongoing advocacy support.

Although some people who have profound disability are not able to verbally express their wishes to their advocate, many are able to indicate whether they are satisfied or dissatisfied with a situation through non-verbal communication. However, people who have profound disability rely more than anyone on other people to identify their issues and make a referral to an advocate. People who can make a referral to an advocate include a family member, friends or support staff.

Advocates will also initiate a referral themselves, on behalf of a person, if they become aware of an issue that requires advocacy. This can occur through chance contact with a person while working on behalf of another person (e.g. a housemate or work colleague). Issues may also be identified through group discussions (e.g. house meetings or workers' rights meetings).

Much work on behalf of people who have a profound disability also occurs through systemic advocacy – where advocacy services are working to improve a situation affecting a group of people with disability (e.g. identification of poor medication practices; development of abuse guidelines; advocating for improved evaluation and monitoring systems).

Scenario 1

An advocate has made a number of visits at different times to a community access service in relation to an older man's dissatisfaction with his program. During these visits the advocate becomes aware of a young woman who has a profound disability sitting in the corner of the room. No matter what time of the day the advocate visits, he sees the woman in the corner engaged in no activity other than gently rocking from side to side.

Advocate's role

The advocate would raise his concerns about the woman's lack of program activity with the manager of the community access service even though the woman has not indicated to the advocate that she has any issues with her situation. If the concerns are not addressed with the community access manager or is not able to be resolved at a service level, the advocate would then contact the person's key worker (if living in supported accommodation) or the person's family member/person responsible. The advocate could also raise this issue as a quality concern of the service to the relevant Community Partnership Team, or the Area Manager, Disability and Community Services.

If it has been identified through discussions with the key worker and/or person responsible that the person needs a funded community access placement, the Gateway Services would be contacted for this process to occur as per the Disability and Community Services Filling of Community Access Vacancies Policy April 2011.

Scenario 2

An advocate was speaking on behalf of a person with disability to a worker regarding the use of behaviour management strategies for that person. The worker mentioned strategies used by the service provider for a resident of another shared home that involved the denial of desserts and outings when the resident 'misbehaved'.

Advocate's role

The advocate initiated a referral on behalf of the second resident and spoke to management about the need for the service to adhere to the Department's policy on Aversive, Restrictive and Intrusive Treatment Practices. In this situation, the advocate acted at an individual level but also at a systemic level in relation to policy and procedure within the organisation. If this matter was not resolved at a service level, the advocate could contact the relevant Community Partnership Team or the Area Manager, Disability and Community Services to make a formal complaint. This would then be resolved following the *Quality and Safety Standards Framework for Tasmania's Agency Funded Community Sector 2009-2012*, as outlined in their Funding Agreement with the Department.

Note: Further information can be obtained about the role of the Community Partnership Teams, and the Quality and Safety Framework from the following websites:

www.dhhs.tas.gov.au/disability/publications_and_resources/policies_and_guidelines

http://www.dhhs.tas.gov.au/about_the_department/organisational_structure/groups/human_services/office_for_the_community_sector/quality_and_safety_standards_framework

Scenario 3

An advocate was contacted by a support worker. She was concerned that appropriate procedures were not being followed regarding consent for medical treatment for a resident of a shared home that has a profound disability. The support worker did not feel confident enough to raise the concerns with her manager. The failure to follow appropriate procedures has the potential to affect other residents.

Advocate's role

The advocate made enquiries with the residential service provider and the resident's 'person responsible'. The 'person responsible' took up the issue on behalf of their relative with the advocate's assistance. The advocate worked at a systemic level by advocating for the organisation to develop consent to medication procedures in keeping with Departmental guidelines and current legislation.

Note: Further information about the role of the 'Person Responsible' and consent for medial treatment can be obtained by contacting the **Guardianship and Administration Board** on **6233 3085** or **www.guardianship.tas.gov.au**

Advocacy and families

There are a range of situations where an advocate's work involves family members and carers. The situations described below relate to advocacy services working with families and carers of adults with disability.

Working for families

Some situations involve a person with disability who cannot direct an advocate.

Often, family members are the ones who contact advocacy services to raise their concerns on behalf of the person with disability, and to seek advocacy assistance.

The advocate can proceed in two ways.

- (i) support the family member to advocate for their relative with disability
- (ii) advocate on behalf of the family or guardian – i.e. the family becomes the 'proxy' person.

Scenario – Working for families

A man with a severe acquired brain injury has recently returned to his parent's home as his family are willing to provide the care and support that he needs. They successfully apply for an Individual Support Package through the Gateway Service but feel overwhelmed with the requirements of setting up the support arrangements and contact an advocacy agency for assistance.

Advocate's Role

The advocate would contact Gateway Services with the person's consent to make a referral to Local Area Coordination (LAC). The LAC would work with the person and family to discuss options with regard to choice of service provider and support the family through the process of finalising a contract of service and choosing appropriate support workers.

Working with families

Some situations involve a person with disability who can direct the advocate, at least to some degree and the family is actively involved and seeking the same outcome. In such instances the person with disability and family are in agreement.

The advocate's role is:

- (i) to represent the person, taking directions from them while liaising closely with the family
- (ii) to support the family to self advocate on behalf of the person with disability.

Scenario – Working with families

An uncle of a family has a moderate intellectual disability and lives in a shared home. He has indicated to his family that he is unhappy with where he is living and would like to move because another resident is picking on him all the time. Even though the family have reported their concerns to management nothing seems to have been done to address their concerns. The family and their uncle both want something done about the situation; however the family does not feel confident about tackling the organisation about the issue on their own and contacts an advocacy service.

Advocate's Role

The advocate would work with the uncle and his family. The uncle's wishes would be paramount and the advocate would take directions from him whilst liaising closely with the family and providing support if needed. The advocate would contact Gateway Services with consent for a Targeted Assessment to be completed to identify the most appropriate accommodation option for him. The uncle would then be highlighted with Gateway Services as needing alternative accommodation and be placed as per the Disability and Community Services Filling of Residential Vacancies Policy April 2011.

Working in opposition to families

Some situations involve a person with disability and family members who are not in agreement.

In such instances the advocate's role is to represent the person with disability.

Scenario – Working in opposition to families

A 25 year old woman with a moderate intellectual disability lives at home with her parents. She is unhappy that her parents take care of her money and don't give her enough to spend. She has broached the subject once with them but to no avail. She does not feel able to pursue the matter with them again.

Advocate's Role

The advocate would work at the direction of the woman with disability and support her, or advocate on her behalf, to resolve the issue with her parents. If the matter could not be resolved amicably and there was an issue about the woman's capacity to make reasonable decisions about her money, it would be necessary to apply to the GAB for appointment of a neutral administrator such as the Public Trustee.

Divided families

Another common scenario is where family members are divided on what should happen for a person with disability who typically is unable to express a view. In these cases the advocate endeavours to establish what is in the best interests of the person and advocate for this to occur. If the rights issues are clear (e.g. the person is being abused) this is possible. Where there is a dispute within a family about major issues in the person's life (for example, where they should live) it may be necessary to apply to the GAB for a formal substitute decision-maker to be appointed to resolve that dispute.

Working with children with disability

While Speak Out and Advocacy Tasmania work to some extent with children with disability – usually in relation to the child and their family accessing and using services (eg respite) – it is the Association for Children with Disability (ACD) who work specifically with young people.

ACD advocates seek to assist parents/carer's to meet the needs of their children. In order to do so, ACD needs the consent of the guardian, be that verbal or written. An ACD advocate cannot work with a child without this consent.

In the course of their work ACD advocates will also consider the needs of the family they are involved with, as commonly issues such as respite for the parents or support for siblings can affect the family's capacity to support the child with disability.

Advocacy support for parents with disability who have children on care and protection orders

Child Protection Services are responsible for the development of the case and care plan for a child with disability on care and protection orders. Advocacy services that are directly involved with a parent who is a client of a funded disability service should be involved in the case and care planning process for their child in care. This could also include transition planning for children leaving care after they turn 18 years of age.

Where possible, a parent/carer with disability should be supported by an advocate or a disability key worker during formal discussions about their child's future. Advocacy support for the parent in that situation could also be to assist the parent to raise complaints or concerns about their child's care, to speak on the parents behalf if requested, or to support the parent with self advocacy.

In the situation where an advocate is involved with a child in the care of a funded service, and is advised that there has been an incident with the child, the advocate is required to work with Child Protection Services as the legal guardian for the child, not work directly with the funded service. The Secretary of the Department is the guardian for children in care until they turn 18 years of age but can delegate this function to Child Protection Services. Formal guardianship is obtained through the Magistrate (Family) Court.

The Advocates' Duty of Care

In all cases advocates have a duty of care to not cause significant harm or disadvantage to people or other people. Whilst, as previously stated, the advocate's role is to carry out the wishes of the person, be that the person with disability, or their family they retain a responsibility to ensure their involvement will not result in harm or disadvantage to/for the individual for whom they are advocating or other persons in their group. However, the duty of care principle means that advocates must always be weighing up whether what they are being asked to advocate will cause significant harm or disadvantage to the person or others in the person's group (i.e. other people with disability).

9. The Myths of Advocacy – What Advocacy Isn't

Advocacy and Adult Guardianship

There are key differences between the role of the advocate and the role of a guardian. A guardian is someone legally appointed by the GAB, or appointed under an instrument of enduring guardianship.

Depending on the situation, a guardian has the power to make decisions/provide consent for a range of issues (e.g. medical treatment, accommodation, lifestyle issues) on behalf of an adult who is unable to do so for themselves.

It is important that disability funded service providers are required to notify the person's guardian if there has been an incident with the person, or to consult with a guardian before making any major changes to accommodation or health care. A guardian must make a decision taking into account the person's wishes wherever possible, their best interests and their freedom of decision and action. A guardian is also expected to advocate on behalf of the person. The Public Guardian is also expected to undertake a systemic advocacy on behalf of people with disability.

As previously mentioned, advocacy is about standing with, and sometimes speaking for, a person to ensure their rights are recognised and respected. An advocate can be a friend, a family member, or someone from an advocacy service. Authority for the advocate to act comes from a request from the person. Decisions to act are therefore made by the person (Disability Action Inc, 1997 (2)).

The primary difference between a guardian and an advocate is that a guardian is a substitute decision-maker whereas an advocate does not make decisions on behalf of the person.

Situations can arise where a person who has a guardian will request the services of an advocate. The person may need assistance in expressing their wishes to the guardian. An advocate also has a role in making sure that the guardian remains accountable for the decisions they make on the represented person's behalf. In many cases guardianship orders are limited to one area of a person's life (e.g. accommodation) and this means an advocate can represent the views of a person in other areas of their life.

Scenario 1

A young man who has a profound intellectual disability has been living in a shared home for six months. He appears to have settled into his new accommodation; however some members of his family want him to return to the family home to live with them. Other family members strongly oppose this idea and believe he should stay living in the shared home.

Roles

Advocate

In this situation the person cannot direct an advocate and the rights issues are unclear. Will he be better off living with his family or in the shared home? The advocate is not in a position to judge. However, having observed how well he has settled in the advocate can at least provide this information to the GAB.

GAB

GAB can investigate the young man's situation and if there is no resolution to the dispute, appoint a guardian under a limited order with respect to his accommodation. Depending on what GAB decides is in the young man's interest, the Board may appoint a member of the family or the Public Guardian as the man's guardian.

Scenario 2

A woman with a moderate intellectual disability has had the Public Guardian appointed to make decisions on her behalf about her accommodation. She has recently become dissatisfied with her community access program and wishes to move to a different service. She has been told that there are no places available in another service.

Roles

Advocate

The advocate would receive a referral from the woman or another interested party. The advocate would gain an understanding of the woman's wishes and assist her to put forward her views – either by supporting her to speak up for herself or by conveying the woman's views to her key worker and the community access service. The Gateway Service would be contacted to undertake an assessment of the woman's support needs, and would be highlighted as needing an alternative community access placement. The advocate would keep the guardian informed about progress in resolving the issue.

Guardian

The Guardianship Order is limited to decision making in relation to accommodation and the guardian has therefore no formal role in this situation. The guardian may however provide the woman with support and/or advice if needed.

Advocacy, Investigation and Grievance Resolution

Advocates work at the direction of the person. Their role is not to conduct an investigation about the circumstances surrounding the person's complaint but to support the person through the process of making a complaint and any subsequent investigation that takes place.

When it comes to following a grievance procedure the advocate will discuss possible options and their likely outcomes with the individual. Although advocacy services encourage the person to use existing grievance processes it is ultimately the person's decision about how they wish to proceed. Where the individual is dissatisfied with the outcome or process or the situation remains unresolved, they may wish to contact a higher authority.

Scenario 1

A person with an acquired brain injury tells an advocate that she has been verbally abused by a member of staff whilst attending a day program. She wishes to complain.

Advocate

The advocate would discuss with the person the circumstances relating to her complaint and the options she has for dealing with it. The person decides she wants the manager of the community access service to receive her complaint and that she wants to put it in writing to him. She asks the advocate to draft a letter on her behalf. The advocate supports the person through the complaints process.

Manager

Investigates the complaint and responds to the person's concerns in accordance with the organisation's internal grievance procedure. The manager works within the *Quality and Safety Standards Framework for Tasmania's Agency Funded Community Sector 2009–2012*, as outlined in their Funding Agreement with the Department.

Scenario 2

A young woman with an intellectual disability who lives in a shared home reports that she has been sexually assaulted by a member of staff.

Advocate

The advocate would provide the woman with information about her rights and discuss with her how she wishes to proceed. The advocate would then support her through whatever process follows, if that is her wish.

Service provider

Follow Disability Services' Guidelines for the Reporting of Abuse and the organisation's own policies and procedures relating to abuse. They would contact the police and fulfil their responsibilities to the alleged victim and alleged perpetrator as outlined in the Guidelines. The provider would then report this incident in accordance with the *Quality and Safety Standards Framework for Tasmania's Agency Funded Community Sector 2009–2012* to the Department as outlined in their Funding Agreement (Consumer Related Incidents).

Police

Investigate the alleged assault.

Advocacy and Gateway Services

As part of the reforms that have been implemented across the disability sector over the past three years, Gateway Services have been established to provide a single access point for information and support for people with disability. The Gateway Service is the intake and access point for people to access specialist disability services.

The role of the Gateway Service is also to provide short term crisis response if required as outlined in the Disability Gateway Brokerage Funding Guidelines and collect data for future planning of services.

1. Information

The Gateway Service provides information and advice to individuals and services about both generic and specialist disability services within their local area. This occurs through a tiered approach.

2. Screening and Assessment

When a person contacts The Gateway Service an initial screening assessment is completed. This helps the Gateway Service to determine what kind of response or service is required to meet their needs. A single session response to someone in immediate need can also be provided at this stage.

The initial screening may show that a person would benefit from specialist disability services. This is when the Targeted Assessment for Disability would be completed to gather more detailed information about the individual, from themselves, family/carers and other previous assessments. The tool also determines eligibility for specialist disability services as outlined in the *Disability Services Act 2011*.

The Targeted Disability Assessment is used to refer the individual to the appropriate services to meet their needs.

3. Active Monitoring

The role of active monitoring is to work with people with a disability and their families in a range of ways. This includes:

- providing help to people who do not need support all the time, and an access point if their needs change
- maintaining a needs register for services. The Gateway Service maintain regular contact with people on the register to monitor their situations and needs, potentially finding interim solutions if the needs increase but a service is still not available. This is anticipated to alleviate crisis responses
- provide support to people at key transition points in their lives, such as school leavers, and people transitioning into accommodation or community access placements
- Providing support to an individual or family member who want to coordinate their own services.

4. Local Area Coordination

Local Area Coordination (LAC) coordinates services for people who access the Gateway Service if needed. This includes:

- ongoing person-centred planning as a result of the targeted assessment prior to referral to other services
- case coordination for people who require ongoing support to access and stay connected with services in their communities and have limited support networks.

LAC focuses on supporting individuals who are living in their community who receive minimal support from the specialist disability service system.

The Gateway Service coordinates services and assists in transitioning for people living in the community through LAC and Active Monitoring.

Gateway and Advocacy Services

Gateway and advocacy services work together in the following situations:

Advocacy

- An advocate may refer the person with disability on their behalf to the Gateway Service for information, or for an assessment for access to specialist disability services. An advocate may also contact the Gateway on the person's behalf if their needs have changed and they require an updated assessment
- An advocate may contact the Gateway Service on behalf of the person if they are requesting a transfer from their current accommodation or community access placement
- An advocate may have an ongoing working relationship with LAC for people who have complex needs, or require ongoing case coordination. This will include being involved in the individual planning process, and case conferences as required – so that the person's needs and wishes are represented if they are not able to advocate for themselves.

Gateway Services

- Gateway Services may make contact with an advocacy service as part of the assessment process to gather more information about the person being referred (with the person's consent)
- If a Targeted Assessment for Disability Services has been completed, the Gateway Services will make contact with the advocate if they are identified as a significant stakeholder (with the person's consent) in the individual planning process
- Gateway Services can refer people they are working with, for advocacy support. This could be for individual advocacy, citizen advocacy, or for family support for parents of a child with disability
- Gateway Services may work with advocacy services in monitoring services for people on their case load
- Gateway Services has an obligation to remind people with disability that advocacy supports are available when they are making decisions about the services they receive or other significant life matters.

Advocates on the other hand should be concerned with gaining empowerment and justice for individuals. Their role is neither to assess needs nor to plan services. This is the role of the Gateway Service.

In a situation where there is conflict, advocates take a clear position on the side of the individual and are there to assist the person to present their views, either by supporting the person to speak up for themselves or by representing the person's views to the other parties. The role of the advocate in this situation is to assist the person to exercise their right to have their case heard.

Scenario 1

An advocate has been working with a young woman for a number of years, who up until now has been living with her parents. The young woman who has an intellectual disability is in her early 20's and has indicated to her advocate that she would like to move out into a unit by herself, but she would need some support with budgeting, meal preparation and transport training to get to and from her community access placement if she moves out of her current home. The advocate explains the role of the Gateway Service and the person asks her to make a referral on her behalf.

Advocate

Contacts the Gateway Service and makes a referral on behalf of the client and provides an overview of the situation. The advocate explains that she is happy to be involved in the assessment and planning process for the client as required.

Gateway

The Gateway contacts the person involved, does an Initial Screening and determines that a Targeted Assessment is required. This assessment identifies that this person is eligible for access to specialist disability services. The Gateway highlights the person for accommodation (semi-independent options) and she is placed on the ISP wait list for personal support (budgeting and meal preparation 10 hours a week). The Gateway also contacts Housing Tasmania and places her on their accommodation wait list. The young woman is put on active monitoring and the Gateway contacts her as agreed every second month to touch base with her about her about the status of her ISP application and any semi-independent living options that may present. The person discusses with her community access provider that she would like some cooking and budgeting programs to begin to prepare her for independent living.

Scenario 2

A local area coordinator has made extensive efforts to progress a Housing Tasmania application for a person on their case load, in urgent need of accommodation without success. The local area coordinator believes that the consumer has not been treated in an equitable way.

Local Area Coordinator

Make a referral to an advocacy service and monitor the situation by liaising with the advocate.

Advocate

Gain information from the consumer and seek the consumer views, explain options and likely outcomes of those options assist the consumer to follow up with Housing Tasmania.

10. End Note

This booklet has been produced to help clarify the ways that advocates perform their role in supporting and protecting the rights of people with disability. Advocates often work in situations that are complex and where there are a number of interested parties involved. No two situations are exactly the same. The hypothetical scenarios which have been used in this booklet are therefore not intended to be followed prescriptively, and should only be used as a guide when seeking to clarify the role of advocates in real life situations.

Review date

This booklet will be reviewed in August 2014.

11. References

- Disability Action Inc. (1997), Introduction to Advocacy Volume 1, Mile End, South Australia (note – cited as Disability Action Inc., 1997 (1))
- Disability Action Inc. (1997), Advocacy and People with a Disability – A Learning Package – Volume 2, Mile End, South Australia (note – cited as Disability Action Inc., 1997 (2))
- Parsons, I. (1994), *Oliver Twist has asked for more*, Villamanta Publishing Service, NSW
- Stone, K. (2002), *To Stand Beside – The Advocacy for Inclusive Training Manual*, Stone and Associates, Abbotsford, Victoria
- National Disability Strategy 2010–2020 – The Human Rights Imperative
- Operational Framework for Disability Services 2009
- Disability Services Act 1992*
- Disability Services Act 2011*

12. Contact Details

Advocacy Tasmania

Advocacy Tasmania (South)

Address: Suite 6, Mayfair Shopping Plaza,
236-244 Sandy Bay Road, Sandy Bay 7005

Telephone: 03 6224 2240
1800 005 131 (person free call only)

Facsimile: 03 6224 2411

Email: advocacy@advocacytasmania.org.au

Website: www.advocacytasmania.org.au

Advocacy Tasmania (North)

Address: 107/287 Charles Street, Launceston 7250

Telephone: 03 6331 0740

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Advocacy Tasmania (North West)

Address: 77 Best Street, Devonport 7310

Telephone: 03 6441 0201

Facsimile: 03 6423 1900

Email: advocacynw@advocacytasmania.org.au

Association for Children with Disability

Hobart Office

Address: 121 Bathurst Street, Hobart 7000

Telephone: 03 6231 2466

Facsimile: 03 6231 0833

**For Family Advocacy inquiries and/or assistance
state-wide please call:**

FREECALL 1800 244 742

Association for Children with Disability (Tas.) Inc.

Post to: GPO Box 730, Hobart 7001

Email: admin@acdtas.com.au

Website: www.acdtas.com.au

Citizen Advocacy (Launceston only)

**Citizen Advocacy Launceston Region Inc.
(Launceston only)**

Comprises the 63 telephone code area

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Telephone: 03 6331 2177

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Speak Out Association of Tasmania

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North West

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Facsimile: 6431 8333

Email: burnie@speakoutadvocacy.org

Guardianship and Administration Board

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Facsimile: 6233 4509

Email: guardianship@justice.tas.gov.au

Website: www.guardianship.tas.gov.au

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Level 1, 8 Boland Street, Launceston

Gateway Services South West

Baptcare Services

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