



# **An introduction to independent advocacy**

This document is based on Section 1 of Key Ideas on Independent Advocacy, Advocacy 2000, February 2002

### **A word of caution**

One of the very valuable aspects of the advocacy movement is that the projects that are associated with it have an individual identity and are independent. This gives them and the movement strength and allows new ideas to develop. Advocacy is carried out in a wide range of different ways, by a wide range of people, in a wide range of projects, which have a wide range of structures. All of these will have their advantages and disadvantages.

The language used in this document is not intended to be universal or proscriptive. Local projects may use different terms and describe themselves in different ways.

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# What is advocacy?

Advocacy is about standing up for and sticking with a person or group and taking their side.

Advocacy is about standing alongside people who are in danger of being pushed to the margins of society.

Advocacy is a process of working towards natural justice.

We all come across advocacy every day. Parents stand up for their children, children stick up for their friends. Someone who has to go to a difficult meeting or into a new situation might ask a friend to go along with them. The friend is being an advocate.

Sometimes people don't have family or friends or anyone else who can help. Sometimes they might not understand information being given to them, or options open to them. Sometimes people may not have had enough experience or may not be confident enough to have developed their own aspirations.

For whatever reason, people may need someone on their side, someone to help them stand up for themselves or who can stand up for them. When someone has no-one available to do this, and doesn't know how to go about finding anyone, an independent advocate might be able to help.

## What is "independent advocacy?"

'Independent' advocacy means the advocate is not connected with carers or services that have a strong influence on the life of the person being supported.



**NOTE: The examples and quotes used are included to illustrate the points made - the characters, events, and places are fictitious.**

## Anthony O'Brien and John Stewart

I'm an independent advocate employed by Falburn Independent Advocacy. I met Anthony O'Brien two years ago when he came into conflict with the manager and some staff of the home where he lives. Anthony had told the manager that he didn't like one of the care assistants and that he didn't want this care assistant to help him. The manager had told Anthony that the care assistant was a good member of staff and that Anthony would get used to him. A few days later Anthony broke three windows and the television set.

We knew about Anthony because of our contact with another resident. Anthony shared a room with someone he didn't really like, he had few personal possessions, he was apparently wearing someone else's clothes, but his only complaint was about having support from this particular staff member. He has no close family and I worked with him for about three months until the issue was resolved.

I attended several meetings with Anthony and spoke up for him in the way he and I agreed before hand. We put a lot of pressure on the social work department and eventually they put pressure on the home to try to ensure that he was supported by other people. We were worried about Anthony in the long term so we suggested to Falburn Citizen Advocacy that they might be able to help him and I believe he now has a friendship with a citizen advocate they introduced him to.

## Jane Johnstone and Karen Edwards

I've known Jane since we were teenagers. I moved into her street and Jane and her sister Anne were the first people to talk to me. I think Jane knows what it felt like to be outside of things. Even though she didn't talk, I thought she was trying to make me feel welcome.

I didn't see Jane and Anne for a while when I was away from home at college. When I returned Anne told me that their mother had died and she and Jane were on their own. Their father left years ago and hasn't been in contact. Anne is also ill herself and her health is likely to deteriorate.

Anne gets really worried about Jane, especially now her own health is in question. The future is a bit frightening for both of them. Anne can look out for Jane, but sometimes I think she forgets that what suits her isn't always what Jane wants for herself. She wants Jane to be safe but I have a feeling that Jane would like to live a little.

I did try to say these things at the last meeting at Falburn Resource Centre but I felt frustrated because no-one was willing to give anything new a go. Jane's key-worker at the centre told me about Falburn Citizen Advocacy and I contacted them to find out more.

## Sheila Donald and Emma Saran

My name is Sheila Donald, and I know about advocacy because I used Falburn Independent Advocacy a couple of years ago when I had a few problems in my life, and again recently.

In 1995 I had a breakdown and went into Falburn Hospital. I was in and out for a couple of years and my life changed completely. After a while everything started to sort itself out, but when I got pregnant I stopped taking some of the drugs I'm prescribed in case they damaged the baby - the doctors gave me alternatives but the change made me ill. While I was in hospital that time the Social Work Department decided the baby wouldn't be safe with me - I wasn't sure exactly what was going on, but I knew she was going to be taken away.

I wanted to explain about how happy my other child is, even though she has had to live with her gran occasionally, but I couldn't make anyone listen, or if they did they said that it wasn't their job to tell the doctors and social workers what to do. Emma from the Advocacy Project was great - she isn't a lawyer or anything but she knew about what was going on. She spent ages with me, and came back even though I wasn't easy to get on with. She really listened to me and then she spent a long time working out how to help me to get the right people to listen. She didn't tell me or the social worker what she thought - she was just on my side. In the end the social workers found a way to give me support with the baby in the hospital which wasn't ideal, but it kept us together for long enough for me to get better.

## **Why is independent advocacy needed?**

Health or social care workers will often act as advocates for their clients or patients within the system, and family members will often act as advocates for those they care for. Sometimes however, support is needed from somebody who doesn't have to worry about other interests such as their own, their employer's, or their colleagues' - someone who can be on one side only. People who are socially isolated or who have been relying on care services often have no such support and no knowledge of how to find it. Independent advocacy is organised to minimise conflicting interests.

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People need to be able to stand up for themselves. Not everyone can do that without support. Perhaps they don't have much confidence, or have become used to doing what is expected of them. Maybe they don't understand the information given to them, or have difficulty communicating. The role of an independent advocate can be to help them get their point across.

Many of those who most need support to get their point across are also those who have least confidence in their own opinions and aspirations and who may therefore be easily influenced. Independent advocacy is a good way to support people to develop their own opinions, aspirations and their confidence in these.

While legislation or inspection services are in place which are designed to prevent serious abuse in care services, this sets only very basic standards. In some services few people visit who are independent from those providing the service. Advocacy projects can



ensure that ordinary community members are involved with, or know about, these services, thus making the standard of their service public knowledge and safeguarding those people who use it.

Some people have no real friendships and relationships in their life. Some people spend all their time alone, or with people who are paid to be there, or with those who use the same services but with whom they have no other connection. Some advocacy projects are set up to change this directly by linking people with ordinary citizens who can make a long term personal commitment to supporting or getting to know them and to connecting them to other friends or contacts.

Often people have an expectation that those needing support in their everyday lives will have this provided by local authorities, health services, charities, or governments. Ordinary people may not offer support until the need for this is demonstrated to them, or until they are asked. Advocacy projects can be set up to develop the ability of the community to provide such support and help.

## Anthony O'Brien and John Stewart

When Anthony had the problem in his home there was nobody there who could be on his side. There were obviously staff who were sympathetic, but they weren't free to act. He needed support to think through his arguments, and he wasn't confident enough to say them himself when in a formal meeting.

The other problem is that there has been nobody in Anthony's life who has had the time to develop a genuine personal relationship with him. While he sees the staff as friends this certainly isn't reciprocated - none of them would ever consider inviting him for a meal for instance. We thought about working with him over a longer period and trying to introduce him to some things outside Falburn Residential Home but in the end we thought that in this case Falburn Citizen Advocacy might do that better.

In the long term I think that Anthony needs support to pursue some of his dreams. I'm sure he won't become a fighter pilot, which he says is his main desire, but he has very few aspirations and I think the only way to bring him to develop those he has is to treat them seriously. With time he might start to recognise the poverty of his surroundings - the manager of the home certainly isn't going to encourage this, "registration and inspection" are unhappy with some of the aspects of the home but don't see it as any worse than most others and there has been nobody else to care.

At least our involvement with Anthony has meant that all involved can see there are independent people who are concerned about him - our presence and now the relationship with the citizen advocate must safeguard the others in the home too.

## Sheila Donald and Emma Saran

One of the best things about having an advocate was that she wasn't part of the hospital. She could support me without worrying if she was stepping on any toes - and in fact she helped me step on as many toes as I needed to in order to get someone to listen to me. I couldn't have done this without her - I was finding it difficult to get my thoughts in order and I was so angry with everyone for not being able to help. Before Emma was involved I'd just about given up - I'd started to believe that the best thing for my child would be to be separated from me - everyone seemed to think this and it was difficult to keep faith with my own beliefs.

I often wonder if the social worker that was behind the plan to take my child was just against me because of how angry I was when they called at my home - I pretty much threw her out, but I wasn't well at the time. I don't think she likes me personally - and I don't much care for her. I don't think I could ever have persuaded her my child would be safe if there hadn't been someone to be on my side.



## Jane Johnstone and Karen Edwards

Jane and I went ahead and contacted the project co-ordinator of Falburn Citizen Advocacy. The co-ordinator and I had a long discussion about what might be involved. She asked how I might feel about supporting Jane against Anne's wishes.

She has said that she will help me to think clearly about the issues and try to equip me with the skills I will need.

I think I'm in a good position to support Jane. I don't have the kind of conflicts the staff at the resource centre could have in voicing concerns about her care. I'm not employed by any of the agencies that care for Jane and I'm not in the same position as Anne. I hope Anne will be able to consider what she wants for herself, without feeling guilty about disadvantaging Jane, if she knows I am around to stand alongside Jane.

I thought it would be a good idea to spend a whole day with Jane and share her experiences of the day centre. Jane seemed happy and used her sign for yes when I joined her on the bus, so I think she was OK with this.

Just getting on the minibus and driving to the centre was enough to show me how differently people can be perceived. Some passers-by stared at the bus and some waved although it was clear they knew no-one personally. It was like being an exhibit picked up for curiosity value.

In the centre itself, staff were very friendly and welcomed everyone in. It was clear by talking to them that most of them wanted Jane and the other centre users to have more individual time to build up their understanding of each other. It was also clear that they had made efforts

to include the neighbours and local organisations in the centre, but with little success. Staff had organised trips to local sports centres, cinemas and pubs, but found that Jane and the others were not included there. They remained alone even in these ordinary places.

The centre was really noisy and I noticed that Jane became upset in the canteen where the level was particularly high. We went outside and as we walked around in the open air it struck me that Jane lacked any free access to personal space and quiet during her time at the centre.

When we went back in I found her key-worker Lorna. We had a chat about what Jane could do to let Lorna know when she needed space. Here I hit my first difficulty. Lorna told me that they had a quiet room, but Jane had become really distressed the last time Lorna took her there. The difficulties were obviously far more complex than I had thought and some creative thinking was in order!

I know Jane likes to walk, so we took a tour around the centre and the neighbouring streets. I began to wonder if it was movement and quiet Jane enjoyed, or just being away from the centre, or being with one person and not 50, none of whom could be called a real friend.

There are so many possibilities to enrich Jane's life. I know I would not like to spend my life on the margins and I don't think Jane should be expected to either.

There are certain key ideas which good Independent Advocacy projects have in common. However an advocacy project is organised some key values are shared by them all:

- Everyone has the right to be listened to and feel respected
- Everyone has the right to be involved in decisions which affect their future
- Everyone has the right to aim for something they aspire to, even if other people don't agree with them
- Everyone has the right to take risks
- Everyone has the right to contribute to and participate in society

## **Independence**

There should be no conflicting interests which limit the action of advocates and project - the advocate will not be connected with carers or services that have a strong influence on the life of the person being supported. This should mean projects not feeling or looking like part of the service system, maintaining appropriate confidentiality about those using the project, striving to avoid conflicts of interest arising, and projects being rooted in the local community. Within citizen advocacy, the advocates are also independent of the advocacy project.



## **Empowerment**

Independent Advocacy is as much about empowering people as it is about solving a short-term problem. It is about working with people in a way that, as much as possible, helps them develop their own aspirations and opinions, and the skills to stand up for themselves in the long term. If possible, advocates work in a way that is directed by the person they support rather than based on what they think is best for an individual. Advocates aim to support the person to act for themselves as a strong preference to acting on their behalf and can give information and support, but avoid providing advice.

## **Loyalty**

It is an advocate's role to be on the side of the person they are supporting - not to be impartial. An advocate is expected to be loyal to the person being supported regardless of whether their position is seen as 'reasonable'. Advocates are also expected to be tenacious in supporting and pursuing the position and interests of the people they support.

## Anthony O'Brien and John Stewart

Anthony kept asking me what I thought would be best - it was quite a challenge not to give in and tell him what I thought he should do and how he should do it. I'm sure he would have gone with whatever I suggested, and I think that would have been fine in the short term, but I think that with the right support he'll start taking his own decisions about lots of things. In the long term this will be of more value.

One of the difficulties I encountered with the work with Anthony was that the staff of the home and the social work department couldn't understand why I kept asking Anthony what he wanted me to do - they couldn't see that I had put Anthony in control of how I was acting and that we sometimes needed to take time to discuss our next move. They wanted Anthony to take decisions there and then in meetings, whereas I thought that it was better if Anthony and I left the meeting to talk through what had been said before he told me what he wanted me to say.

## Sheila Donald and Emma Saran

While I was ill I wasn't happy being told what to do - everyone around me seemed to be doing this. The reason that I was prepared to work with Emma from the project was because she listened to what I wanted. She didn't have any other agendas and she was clearly acting only on my behalf. I felt I could trust her and I was willing to talk to and listen to her even when I was really distressed and angry. One of the things that was really good was that Emma didn't do things for me when she could support me to do them myself, and that increased my confidence.



# Citizen Advocacy

The objective of Citizen Advocacy is to encourage ordinary citizens to become more involved with the welfare of those in their communities who might need this. Citizen Advocacy schemes aim to develop communities whose members are more able, competent and willing to speak on behalf of another person and to protect their interests.

Citizen Advocacy brings an individual together with an advocate on a long term, personal, one-to-one basis. The advocate stands with their partner to defend their rights and the project is structured in such a way to ensure that their main loyalty is to their advocacy partner not to the project.

Although citizen advocacy shares key features with independent professional advocacy, it also has some unique ones:

- People being supported by a citizen advocate can benefit from having a long-term, trusting relationship with an ordinary member of their community - and it can help them feel part of the community again.
- Because the advocate is unpaid, and because the partnership is independent of the project itself, their 'partner' knows they have a true personal commitment to supporting them.

- The advocate will gain their right to be involved with their partner from being an ordinary community member who has a personal relationship with them rather than by belonging to the advocacy project.
- There is an anticipation that much of the practice of the advocate will come from their natural reactions to observing the situation of their partner rather than through being trained.

Citizen Advocacy projects aim to have a long-term impact on the community, not just on the individuals they support. Because they use 'ordinary' members of the community as advocates and because advocates can work to actively socially include people, they can help to:

- Develop the local community's ability to support and 'include' people.
- Raise local awareness of standards of social care services - perhaps leading to improvements or preventing poor practice.

There are well established guidelines which describe best practice for a citizen advocacy project.

## Jane Johnstone and Karen Edwards

Falburn Citizen Advocacy have been really useful in helping me to think about Jane's fundamental needs. I was a bit upset when I went home after my day with Jane because it all seemed so overwhelming. My mind was racing with ideas and with the problems that could lay ahead.

At the project office I was able to share how awful it had been to hear how Jane curls up in a corner and cries at least twice a month at the resource centre. It also shocked me that the staff were not all aware of the signs she uses. Her communication is limited, so how could one of her basic rights have been so sadly neglected?

Talking all this through helped me focus on the fundamentals and keep Jane firmly at the centre of my outrage. Some decisions I will have to take are on the basis of achieving natural justice for Jane.

Jane and I went back to the resource centre together the following week. We had spent some time together away from the centre and I'm sure Jane knows I am trying to make changes happen. I asked a simple question at the centre - if I can do it why can't the centre staff? Why does it have to get to the stage where Jane has to get so upset before she can go for a walk?

I know I was unpopular that day and may well continue to be, but if the centre is understaffed and Jane gets left to become distressed, that's simply wrong. I will be ensuring, just as a first step, that all the staff know the signs Jane uses, even if I have to write directly to the Social Work director and the appropriate local councillors.

I've also got a couple of friends who go for long walks in the evenings and I'm thinking of introducing Jane to them - I don't know if that's a way forwards for her but its worth a try.

# Independent Professional Advocacy

Independent professional advocacy projects use paid advocates. Advocates working in these projects usually support people in dealing with a specific issue or problem, and work with them until that issue is resolved. If the person needs help with another issue later on, they might be supported by the project again.

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An independent professional advocate:

- Aims to support people to represent their own interests where possible and very much as a preference to acting on their behalf.
- Will not offer advice on how they think an individual should act.
- Will support a number of people, at the same time or one after the other, with different issues.
- May work with someone for a short or long time.

## Sheila Donald and Emma Saran

Some of the psychologists and nurses at the hospital really didn't seem to understand what Emma was there for. She told me that a social worker had complained to the advocacy project that I was manipulating her and that if she had more information she wouldn't be supporting me. They didn't understand that Emma was supporting me because that was her role - and that it was their job to decide whether the arguments were fair.

Another professional complained to Emma that she wasn't following procedures - Emma had to explain that her role was to follow the most effective course of action which may or may not be according to procedure. This person couldn't get the hang of Emma not being part of the service system - he couldn't understand that all Emma was enabling me to do was the things I would have done alone if I'd been well and if I hadn't been completely confused by what was going on.

# Group Advocacy

Group advocacy - sometimes known as collective advocacy - usually refers to a group of people facing a common problem who get together and decide to support each other

This might mean

- Individual members of the group supporting each other over specific issues.
- The group as a whole campaigning over an issue which affects them all.

There are many different ways in which groups organise themselves for advocacy, some formal and some informal. Some of the benefits of people working in a group are:

- An issue might arise which is to do with the overall planning of services, and their impact on a number of people rather than just one. A group can be in a stronger position to tackle this sort of issue.
- Somebody who wants to raise a difficult issue with service providers may gain strength from knowing they have the support of a group, and feel less isolated as a result.
- Groups can be made up of people with personal experience and knowledge of a situation.
- Groups are more difficult to ignore.

# Projects in reality

Every advocacy project is unique, and individual projects are unlikely to fit these descriptions exactly. There are several points worth mentioning.

Some advocacy projects use volunteers who work with more than one person and who concentrate more on providing people with support to put their point across than on building a long term personal relationship. These might be seen as incorporating elements of both citizen advocacy and professional advocacy and could be called volunteer advocacy projects.

Some professional advocates might work with people over an extended period. Others might not only support people around a particular issue, but also actively work to ensure they are socially included.

The effectiveness of any particular combination of features in an advocacy project will depend on their aims. It is also important to remember that it is not always appropriate to compare two or more advocacy projects directly where their aims are different.

