



Reflections Stories of Change



Preface

Over the past few months and in preparation for our AGM we felt it was really important for the organisation to celebrate the significant milestone of 20 years delivering independent advocacy services.

It would have been easy to produce a blow by blow account of the background, history and development of The Advocacy Project written by the people who have been involved in the organisation over the years. However we felt that, in order to reflect the values and ethos of our work, the stories, views and comments should come from the people who benefit from the

services we deliver on a daily basis. Describing the advocacy process and how it can help can often frustrate those who work in this field, so we felt that our clients and the variety of people we support were the best people to do this.

We hope you enjoy the positive contributions and are inspired by our work to spread the advocacy message.

Our thanks to all who contributed; particularly the people who shared their very personal stories, it has been a privilege to work with them.

Moira Nicholson

Director



“We set up The Advocacy Project because lots of people at that time felt that “we can’t ask for that because we’re not allowed it” - advocacy is about changing that belief” Ina Rennie, a founding member of The Advocacy Project

Foreword

Colin McKay is the Deputy Director of the Legal Division within the Scottish Government. He was Chair of The Advocacy Project from 1993 – 1996. At the time he was legal policy advisor to Enable.



“When I first got involved with The Advocacy Project, advocacy was being talked about in the learning disability field; it was felt that people needed help to be listened to.

It was the philosophy of the Project that anyone who considered themselves to be disabled would be offered a service; this felt like a departure from the usual ‘compartmentalising’ of people. As a lawyer, I was used to giving information and telling people what they should do. Advocacy was a different thing, it was dealing with people’s right to have a choice in all aspects of their lives; it was about empowerment. There wasn’t really much comparable to paid advocacy at the time and The Advocacy Project was one of the first.

In the beginning the approach to advocacy was that support would be given for as long as it was needed, ‘it would take as long as it takes’. Over the years, advocacy has developed more of a professional rigidity, in many ways similar to the path the social work profession has tread.

One of the key parts of our mental health legislation is that support be accessible to prevent issues arising rather than at crisis point. It would be beneficial if advocacy provision was of this model - in today’s world of welfare reform and a changing labour market, where people are being expected to be able to manage and articulate themselves, advocacy needs to be available.

My biggest disappointment for advocacy is that it’s not as embedded now as people thought it would be. In regards to independence, the most important aspect is that the advocacy is there first and foremost for the individual. It is important that advocacy is talked about in the language of outcomes, even if the line between the two is sometimes difficult to trace.

It is encouraging that The Advocacy Project is still going strong from such small beginnings, and I wish the organisation all the best for the future.”

Timeline

The Beginning...



Steering Group
(Fernan Street.)
Urban Aid
Funding to
provide advocacy
in South East
Glasgow



Lottery Funding
allows expansion
of group work and
training



1992



1993



1996



1999

London Road –
New premises,
now providing
independent
professional
advocacy

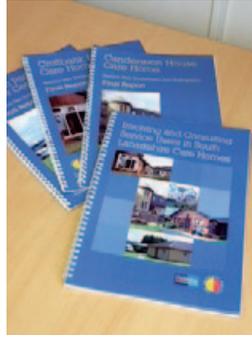


Having been
working in
Rutherglen and
Cambuslang,
the project now
begins to provide
advocacy across
South Lanarkshire
for people with
mental health
issues





Start to provide advocacy in North Lanarkshire for people with learning and communication difficulties



Win re-tendered contract in East Renfrewshire
Beginning of Engagement & Involvement Service



2006

NOV 2006

2010

2012

Move to Cumbrae House – Centralised premises brings staff together to work more efficiently



20 years of providing Advocacy

Our service increases in North Lanarkshire



The Future...

A day in the life of an advocate...

8:50am

I set off to meet my first client. During the bus journey I read over the new tribunal guidelines for advocates. I have a tribunal later and want to be prepared.

9:30am

My client welcomes me into his house and I show him letters I have received from his housing association about repairs he has requested. My client had been getting nowhere on his own and now his house repairs are almost finished

11:00am

I arrive at the office and have messages left for me regarding other clients. I return the calls after I have updated my notes from this morning. I send emails and compose a short letter to a client confirming our next meeting. I read over my next client's file to ensure I remember all important details.

1:00pm

I have some lunch and catch up with colleagues before I have to leave for my next appointment.

2:00pm

I arrive at a local hospital for a Mental Health Tribunal. I speak with my client. She is nervous as this is her first tribunal. I assure her I will be there to support her, and if need to we can ask for a short-break. We talk about how she is feeling and I check that she still feels the same as she did when I spoke to her previously.

4:00pm

After the tribunal, my client feels she has been listened to, when she got a bit upset I reminded her of what she told me she had wanted to say. The outcome was not what she was hoping, but she had her views heard.

4:30pm

I call my office again and tell them that I am finished for the day and head home.



Ian

Ian lives in South Lanarkshire and has had a physical disability since childhood, as Ian has got older, his condition has degenerated and now Ian is reliant on services to help him remain at home.

Ian had always worked for a living despite his disability, but eventually he had to give up work and retire on medical grounds. A fall at home further affected Ian's mobility and without support he was restricted to his bedroom. Despite repeated calls to social work, the support Ian got was never increased and when advocacy became involved he had not had a shower for over a month.

“I had no quality of life. I asked time and time again for more support, but I struggled to get my views across. I felt my freedom was limited. I wanted to go into the living room and paint, but no one listened to what I wanted.”

A friend told Ian about advocacy and made a referral on his behalf. Ian is clear about the difference advocacy made to his situation:

“When Antoinette became involved, I felt I finally had

“When you're on your own, you're fighting a battle and it's difficult.”

some moral support and practical support too. She contacted a councillor, attended meetings with me and told me what my legal rights were. I was so glad she was there to help me do this. When you're on your own, you're fighting a battle and it's difficult.”

Ian's care package was increased; two staff members visited at regular intervals and a special chair was ordered so that Ian could paint in his living room and sometimes in a different room.

Ian says: **“I absolutely got the outcome I wanted, without Antoinette I would not have this freedom to enjoy my own home.”**

What Is Advocacy...?

Advocacy is.....

- » Standing up for and sticking with a person or group, and taking their side
- » Listening to someone and trying to understand their point of view
- » Helping someone to know what choices they have and what the consequences of these might be
- » Enabling a person to have control over their life but taking up issues on their behalf if they want you to.
- » Offering the person support to tell other people what they want or introducing them to someone who may be able to help.
- » A process of working towards natural justice.

Advocacy is not...

- » Making decisions for someone
- » Befriending
- » Telling or advising someone what you think they should do
- » Filling all the gaps in someone's life
- » Acting in a way which benefits other people more than the person you are advocating for.
- » Agreeing with everything a person says and doing anything a person asks you to do.

Taken from Scottish Independent Advocacy Alliance's 'Cope of Practice for Independent Advocacy'.



Debbie

Debbie's story illustrates how people can make assumptions about a person's ability to make decisions because of their communication difficulties.

Debbie lives at home assisted by support staff. She has a rare genetic disorder which affects her physically and impacts on her speech, making communication difficult.

When her advocacy worker Leanne became involved, she quickly noticed that staff were assuming that Debbie lacked capacity due to her difficulties with verbal communication.

Leanne says: **“I felt that the client was not being treated fairly and that some support staff were disrespectful towards her and did not take into account her wishes.”**

Leanne had already spoken to Debbie about her support and Debbie had indicated that she was unhappy with many aspects of her care.

Leanne called for a social work review which was also attended by support staff. At the review Leanne advocated on Debbie's behalf: **“I highlighted that communication was a barrier but that all attempts should be made to overcome this barrier.”** The review also addressed the question of capacity and an assessment was arranged.

The assessment has since confirmed that Debbie does indeed have capacity and is able to make her own decisions about her care. A referral has also been made to a speech and language therapist to look at non-verbal means of communication for Debbie. Debbie has since changed her support team and is more positive about her day to day living.

“The most important thing in communication is to hear what isn't being said.”
Peter Drucker

“What does The Advocacy Project Mean to you?”

At the 2011 AGM we had a Talking Wall attendees were encouraged to write something on it when they arrived at the AGM. This is what they told us...

- » Supporting people to empower themselves
- » Caring for another's rights
- » Making sure people have a voice and are listened to
- » Helping others speak up about their issues but not guaranteeing successful outcomes
- » To hear those who are seldom heard
- » Making a difference to people's lives
- » A chance to make a difference
- » Respect, being listened to
- » Being involved
- » Making a difference



- » Big challenges
- » Being involved in ACE groups
- » Allows people to have a voice and be heard who would otherwise not be heard
- » Despite the injustice you see, sometimes it's a good laugh.
- » A wage at the end of the week and a chance to make a difference to someone's life

Ina & John

Ina is a full time carer for her husband John who has dementia and other physical health problems which affect his mobility.

Ina is 80 years old and has health problems of her own.

A fall at home, resulted in John being hospitalised and it was then that Ina contacted The Advocacy Project. She admitted that she was struggling as a carer and did not know if she could cope with John returning home. Ina said she had contacted social work several times for support, but felt they were ignoring her. Ina felt she had no other option but to put John into a nursing home.

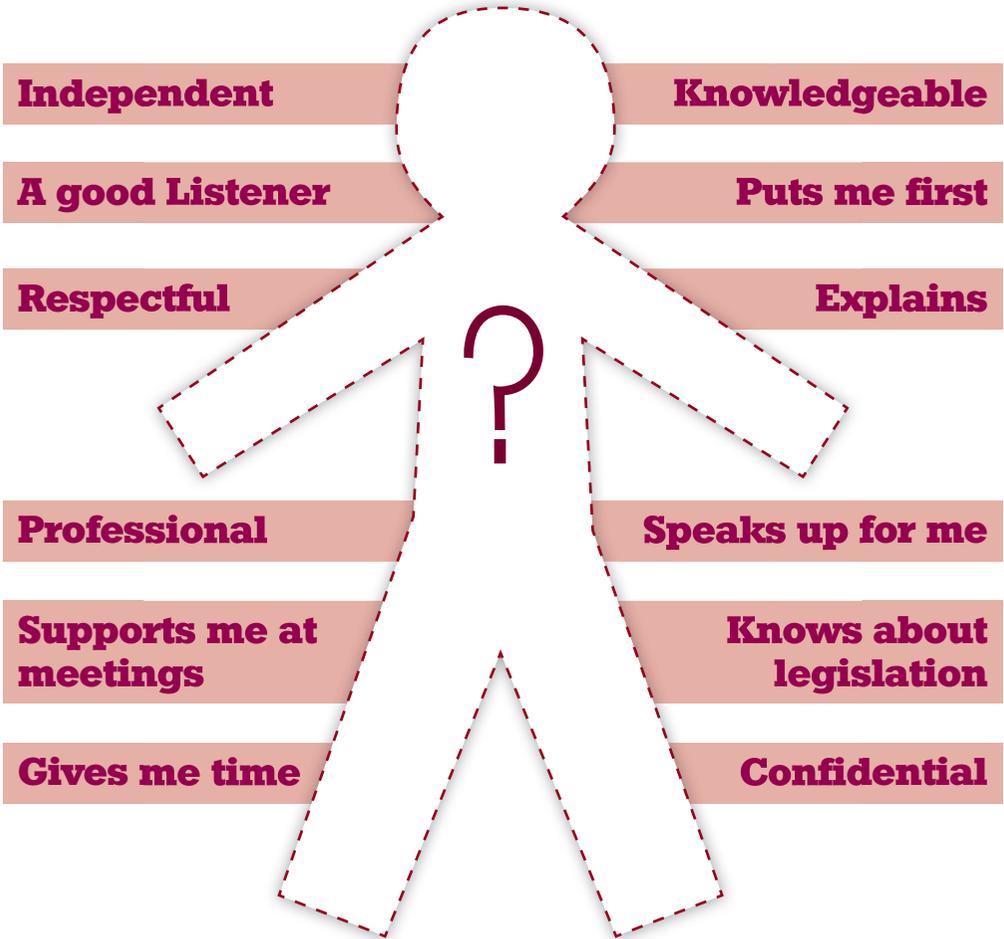
The advocacy worker met with Ina and John at the hospital and informed them of their rights, a community care assessment for John and a carer's assessment for Ina. The advocate referred to social work and ensured the case was allocated and the assessment's carried out.

An OT assessment was also carried out and on John's discharge from hospital he was able to return home to a newly installed wet room, with support in place for his personal care. Ina decided to self fund a chair lift for John as there was little chance of statutory funding for this.

The advocacy worker was there to support Ina through the assessments and changes and inform her of her rights along the way and ensure support was there to allow John to remain at home.

Ina no longer feels a nursing home is necessary. She is awaiting her carer's assessment being carried out, but feels informed and confident enough to deal with this independently.

What makes a good advocacy worker?



Amber and George

Amber and George referred themselves to The Advocacy Project because they needed support to deal with abusive neighbours. The situation was having a massive impact on their health; Amber said it got so bad at times, she had suicidal thoughts.

They had approached other agencies, but had been left feeling frustrated by their systems and didn't feel like anything was making a difference.

Their advocacy worker Michelle met with Amber and George a number of times in the library in their home town, as this was their choice of place to meet. Michelle spent time explaining what their options were, and they chatted through the possibilities of going to speak to the housing department or using mediation services.

“Michelle had a very gentle and understanding manner, she was not judgemental of us; she was very open and fair, but most importantly she believed in us.”

In the end Amber and George decided to move house.

“Michelle enabled us to clear our minds and gave us

choices although the final decision was ours and we made this choice and moved flats”.

The outcome for the couple was more than moving house.

“Our health has improved and is more positive and we can think straight. “You can't see the wood for the trees” but Michelle let us see the trees again and a little bit of sunshine too.”

“She was very open and fair, but most importantly she believed in us.”

Jane

Jane, a client of The Advocacy Project talks to advocacy worker Lynsey Jenkins about her experience of advocacy:



Q: What was your life like before advocacy got involved?

A: Well I referred myself because my social worker wasn't listening to me and I was having quite a bad time with support from different services. I wanted to change my social worker and Stuart was the advocacy worker who assisted me to sort out these problems. Before advocacy you just feel part of the system, 12 years of support not listening to you and finally Stuart sat down and listened to what I had to say. Things are far better.

Q: How did you find out about The Advocacy Project?

A: I'd referred before. The Project had been excellent, any time you want answers or want to ask a question, they'll find out for you. It was getting me down that I was calling people and they weren't listening. Cathie was my advocate then, she came out and explained things fully to me, the Project's been superb.

Q: What did the advocate do for you while supporting you?

A: They both talked me through what was happening and what was going to happen, things about the law, things that I wasn't aware of

before. The law changes all the time, they'll actually go through it with you and take your mind off it. Whenever I had a real problem, the advocacy worker would speak on my behalf. A few times at meetings, things were getting too much for me and my advocacy worker stepped in and said "enough's enough" and asked for a break. The Advocacy Project is a great project, because you know they're always there.

Q: How do you feel your advocate has been different to other people that have been involved in your life?

A: Well I'd had the same support for 12 years and it was a total nightmare, the problems were constant, but when advocacy got involved I felt I could approach people. I trusted Cathie and Stuart to speak on my behalf. I referred myself to advocacy but I think the support agencies and other agencies should have made sure advocacy was in place from the beginning, I think everyone should have an advocate.

Q: How have things changed since you got advocacy involved?

A: What a big difference. I've got a change of social worker and people are listening to me. At meetings if Stuart is there, they seem to listen more, he can explain things better than I can as well. Before I felt like I was being ignored, I didn't see my social worker for four years and I asked her for a home visit, she said 'we don't do that'. I felt like I was getting treated like rubbish. Stuart helped me with the direct payments side of it, and the self-directed support, he told me what my rights were. If it wasn't for The Advocacy Project I wouldn't be anywhere near where I am just now.

Q: Do you feel now that even if Stuart wasn't there, you're more able to have your voice heard?

A: Oh aye, definitely! Oh aye, big time, I never shut up! Since I've been involved with advocacy, it's like being heard and getting your own voice, being able to say what the problem is outright. Now I can phone up and complain, say this, say that!

Q: So now you're on self-directed support..

A: Aye what a difference from before, a million miles away from the old support. Stuart, together with my worker from the Glasgow Centre for Inclusive Living (GCIL), actually haggled for more hours. My care manager was a new one

and she wouldn't listen to me. So I had to get somebody else, an OT person out to tell her how bad I was. But Stuart helped me do the plan work, that took the worry away. Those self-directed support forms are a nightmare, have you seen them? Worse than the DLA! I said how can I fill this out? It's terrible people without any assistance are told to fill them out. I've got my life back now, I can go out with the workers and do this that and the other, and go wherever I want and whatever it is I need to do.

Q: So I hope I know the answer to this already! But would you use advocacy again?

A: Oh aye definitely, without a doubt. Advocacy is brilliant because you get frustrated when people aren't listening to you, it's a case of they just dismiss you. If you've got an issue or a problem they're going to be there to help you and find out whatever's going on.

Q: And finally, what does advocacy meant to you?

A: I think everybody needs it, because folk with learning disabilities, folk with different conditions, they can't do forms or fill things out. I think advocacy fights on your behalf and does the digging to find out more about your situation. I think it's an absolutely brilliant service. There should be more advocacy everywhere. I think they're super dupe!

Catherine

Catherine is The Advocacy Project's longest serving member of staff, having worked with the organisation since its inception in 1992 until her recent retirement in March 2012.

What is the best thing about being an advocacy worker?

Seeing people get what they want.

What's the worst bit?

It's very frustrating when things don't happen quickly enough for people. The worst thing is when a client, that you've maybe worked with for a long time, passes away without getting the thing that you were helping them with'.

What's been the biggest change in advocacy over the years?

The amount you need to know, especially in terms of legislation. The work is a lot more involved now.



so much more detailed now. I do think that housing is more accessible than it was back then. New houses being built that are all accessible has made a difference, although the issue of public premises being really accessible is still there.

Why do you think The Advocacy Project has survived over the years?

You've got to look ahead at what's coming next – the Project has done this over the years and is still doing it.

Any final thoughts?

Loved it! Wouldn't have missed it for nothing!

Do you think people have more rights now than when The Advocacy Project started?

No. People still have to fight for their care. People need advocacy more than ever, everything is

William

Advocacy worker Evelyn Shields relates her client's story:

I had been working with William for some time when allegations were made against William by a family member. William and his wife had to move to another house for their own safety. I then received a call that William's new address had been discovered and that his home had been broken into and William had been badly beaten by those who had broken in. The result was that William had to go to court as a witness.

As a vulnerable witness with a learning disability, William was able to visit the court prior to the case so that he would know what was expected of him on the day. I supported William with this visit and used an easy read guide on **“Being a witness”** to explain what would happen on the day. I was with him on the day of the court case and afterwards made sure he understood the outcome of the court case.

Eventually, William himself had to go to court as the accused and again I was there to support William through the process. William received probation and I was there to support him at probation meetings.

I think it is essential that someone vulnerable like William has support through the criminal justice system to make sure they understand all the legal jargon and the process as a whole. As an advocacy worker, I had to make sure people were aware of William's learning disability and make sure that adjustments were made with this in mind.

David

My name is David and I was first detained in hospital under the Mental Health Act in 2008. Christine became my advocacy worker and explained her role to me and how advocacy could help me.

Christine supported me to attend meetings with my psychiatrist and also to attend tribunals and seek legal advice. The service worked well for me and gave me something to focus on when I was in hospital. I had talked myself to staff about certain situations but nothing was ever done, when Christine came on board, things started to happen.

A year later I was transferred to a rehab unit and Christine remained involved as my advocacy worker. While I was at the rehab unit Christine referred me to Lanarkshire Association for Mental Health's (LAMH) Recycle project and at the end of the training programme I was given a personal computer, which really made a difference to my life.

I have now been successfully discharged from the rehab unit and now live in the community supported by LAMH. I am still under Mental Health Act legislation, so Christine still attends my meetings with me and this makes a difference.

I am grateful to Christine for the advocacy support she has given me over the years, I think without the help of advocacy, I would probably still be in hospital.



“Advocacy looks out for you and speaks to doctors on your behalf.”

Maria

Maria came to the UK in 2009. English is not her first language and there were significant cultural barriers, and differences in systems and process than she was used to in her home country.

What was life like before advocacy got involved?

It was very difficult. I didn't have any support, I didn't have anyone to go to social work meetings or court with. Advocacy gave me support.

How did you find out about the advocacy project?

I can't remember who referred me, but Michelle rang me and came out to see me.

What did the advocacy worker do for you?

She gave me support writing letters and making phone calls. She also came with me to meetings and I had someone to talk to, to express myself; she listened to me. She would also remind me of appointments and this was important when I was having up to three appointments a week

How is your advocacy worker different to the other professionals involved in your life?

I feel like they are on my side, like I've got a family. She asked what I wanted and so I have someone that is beside me, not opposite me

How have things changed since advocacy became involved?

Things have changed a lot now, in a positive way. I was feeling very lonely but now I feel supported. Everyone that is involved in my case knows I'm not alone. I feel strong now

Would you use advocacy again?

Yes I would, for the support they provide. I would also recommend to anyone!

What does advocacy mean to you?

It means a lot. Before advocacy I was on the road, and with them I find the shelter. I can now express myself and I know my advocacy worker will help me and I will feel ok. Advocacy makes me feel good and gives me hope, and plenty other people need hope.

An example of Collective Advocacy

The Advocacy Project received around ten referrals all from people in the same supported living complex who had a learning disability.

The referrals were concerning a recent social work review in which the majority of people had had their support 'rather than 'there.

As there was a common issue amongst them, the Engagement & Involvement (E & I) team liaised with the service users and took on the case as a collective group.

While some people felt that their support should not have been cut, for others the issue was more around a lack of communication and concerns around the way the review had been carried out.

The group felt that the process had not been explained properly to them and that their learning disability had not been considered when relaying information to them. The group agreed on a common outcome; they all wanted a reassessment and a full explanation on how decisions had been made about the support they received.

The E & I Team wrote to social work informally stating their complaint and a collective meeting was set up in which the clients

were supported by the E & I team. The meeting was not as fruitful as the group had hoped, they felt that their questions were still not really being answered, so they decided to submit a formal complaint to the local authority.

The complaint led to each service user being invited to a reassessment meeting with a senior social worker, supported by an advocacy worker to discuss the change in support and how it was affecting them. The result was that some service users had their hours reinstated, others were signposted to other services which could help them, but ultimately the group had become empowered to speak out against a process they thought was neither fair nor inclusive.

Engagement & Involvement

An Achievement we are proud of
In 2010 The Advocacy Project launched it's Engagement & Involvement Service.

What made us do it

People should be at the heart of every service they receive; advocacy can help to make this happen.

How other people got involved

Service providers and local authorities have been asking us to independently facilitate consultation and involvement - this has meant we get to meet with and talk to people and record their views.

What this achievement says about us

We hope that it says we are helping people to have their voice heard.

How can we have more achievements like this?

We'll continue to support people to be engaged and involved in their services.

How we prepared

Our advocacy workers were involved from the very start in shaping what this service would be for and how we would do it. We created some new jobs to focus specifically on this area.

What has happened so far?

We have facilitated advocacy groups, helped people get more involved in their care planning, told local authorities what people think about services they receive and helped care homes improve on how they involve residents.

What has gone particularly well?

It's great to hear people say that they feel more confident to speak up after being involved in one of the projects.

What are the next steps?

We want to try as many ways as possible to engage with people, and evidence that there are lots of ways to communicate with people and support them to be meaningfully involved.



In Conclusion

With the corporate and legal responsibilities of the organisation at the forefront of our governance role, for board members, it would be easy to lose sight of the very reason why we are involved in advocacy.

This publication epitomises the very principles we stand for and is an example of how beneficial advocacy support can be, reflected by the people who have used it. It's very simple examples of, often very difficult, situations which enables the organisation to raise awareness and promote a better understanding of its work. There is nothing more powerful than people sharing their personal stories – I sincerely thank them all.

Colin's introduction reflects his interest and commitment to the independent advocacy concept over 20 years ago and as present Chair of the organisation, I endorse that commitment on behalf of the current Board of Directors. Safeguarding the rights of individuals will remain the focus of our work in the years to come.

I record our gratitude to all who helped and contributed to this publication. Our appreciation also to our funding partners, partnership agencies and relatives and carers for their continued support.

Tommy McGuigan

Chairperson

20
YEAR
anniversary



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