

Taking advocacy back to basics



A discussion paper from the Ideas Collective

<http://www.theideascollective.org.uk/>

Introduction

This is a discussion paper produced by the **Ideas Collective**.
(For more about who we are - please see the end of this paper)

This paper on advocacy for or led by people with learning disabilities is the first time we are sharing our thinking & questions around an issue. We are writing about this because we want to be part of a debate about what could or should happen next in helping people live their lives as full citizens with choice & control over what happens to them individually.

The paper is in 2 main parts

- 2 stories or vignettes that we think tell some of the story for the last 15 years or so
- Our questions, ideas or concerns – we hope these will start people thinking and sharing their views

When the Valuing People White Paper came out back in those heady days of 2001, most of us really did believe in the possibility of the world becoming a radically different and better place. The mantra was the four key principles of civil rights, independence, choice and inclusion. People across England plotted about what they were all going to do to enable people with learning disabilities to have radically different lives.

The chapter in Valuing People on Choice and Control (Chapter 4) included the thinking we had at the time about advocacy, and outlined how people could tackle the fact that services and supports had not recognised the rights of people with learning disabilities as the same as those of other citizens. There were commitments around the development of self and citizen advocacy, with the recognition that both were underdeveloped around the country. There was also a facing up to the fact that the voice of people with learning disabilities in thinking and planning strategically was missing and the development of Learning Disability Partnership Boards (LDPB) set out to tackle this. The Learning Disability Development Fund (LDDF) was to provide some financial support on a national, regional and local level to help ensure that people really did get the advocacy support they needed. The aim was that people became involved in genuine partnerships with service commissioners and providers, in particular through Partnership Boards, to ensure that services really did work and individuals were getting support to speak up or have their voice heard through an advocate. This one cornerstone ensured that people really did get the lives they chose.

A story of Anytown and Othertown

Now it's 2013 and in Anytown, things are different. The big out of town day centre has closed and we know some people who have jobs - real paid jobs. Those that don't are definitely better connected to their communities and local mainstream services, for the most part, do a pretty good job of making sure people with learning disabilities are welcomed. The leisure centre won an award for its work to coordinate a pool of Personal Assistants to enable people to come and swim or take part in other sports, the cinema has weekly autism friendly screenings, there are changing places in a cafe, a department store and in the local bowling alley, and every Council department actively recruits people with learning disabilities, carving jobs where it makes sense to do so.

Josef and Emily are members of Speak-out Anytown, the local self-advocacy group. The group was set up in 2002 with a small pot of money from the LDDF and they now have 36 regular members. Emily was only 20 when she first joined the group in 2003 and, if she's honest, she only did it because her Care Manager thought it would be a good idea. Back then she really didn't know what advocacy was all about, but the group really has helped her to change her life. Some of the early work the group did with their funding was to plan a program of work with the Council as part of the commissioning strategy - they worked with the Council to understand the decision-making cycle and then agreed how they could make sure the ideas of people with learning disabilities and their families contributed at every stage. They hold four '*come and tell us*' events a year, where commissioners, providers, people who use services and family carers come together to think and plan.

Emily now has a part-time paid job at the Anytown Weekly News, putting together a 'what's on' page where local (genuinely inclusive) events are listed and reported on. She also got the support and encouragement she needed from other members of the group to get her own flat - in fact, this was because of the work the group did with the Council housing department, planning affordable and accessible housing for all of Anytown's residents. The group run a peer support programme for young people with learning disabilities who are thinking about their choices as they leave school and also hold weekly open sessions where people can come to get help, advice and inspiration to write their support plan.

The Anytown LDPB has survived what people talked about as, 'the end of Valuing People'. Bob, the senior commissioner recognises how useful it is and he's working with the Health and Wellbeing Board as it gets going to make sure they learn the lessons of really effective partnership working with people who use services and family carers. All the self-advocate representatives on the Partnership Board were set up as paid roles and these

have grown and developed as things have changed. The Health and Wellbeing Board are using the same model because it has been so successful.

In Othertown, things are a bit different.

Kate runs Othertown advocacy. There used to be a small speaking-up group in Othertown, but Kate had the chance to bid as part of a consortium across the region to offer an Independent Mental Capacity Advocate (IMCA) and Independent Mental Health Advocate (IMHA) along with some issue-based advocacy support and, apart from the Thursday group (people with learning disabilities who meet down the pub to play pool every week) they mainly just take referrals. Kate works as an advocate along with Tim and Farid, both of whom used to work at Anytown day centre until it closed. To meet their funding agreement (and make the money work), they've developed tight referral criteria and are able to report 300 advocacy interventions a year with outcomes graded on a 43 point measure. They're currently working on a bid to offer case advocacy in the two neighbouring regions.

Julie is the senior commissioner in Othertown and she thinks that Othertown advocacy must be doing a good job because they always get their outcomes measures in every quarter and they seem to be supporting 300 people a year (at least that's what she assumes it means when they report 300 advocacy interventions...?). She hasn't met Kate, Tim or Farid but all the Local Authorities in the region commission advocacy from their consortium so they must be ok?

George used to be part of the speaking up group in Othertown and now goes to the Thursday group that meets in the pub. He finds it a bit frustrating because he doesn't like pool and his real passion is politics. He remembers leading the campaign for paid roles on the Partnership Board back in 2002, and then working with Rosie, the Valuing People lead to write the job descriptions (their process was even used as a good practice example on the Valuing People Support Team website). Back then, the group had a programme of campaigning and of working with Othertown Council and people got support to learn to use public transport so they could get to meetings and take part in campaigns. Unfortunately, the Valuing People lead role was only temporary and Rosie moved on. The Partnership Board ended last year and there were some difficult newspaper headlines after someone missed the last bus home after a particularly successful campaign led to an evening in the pub. George doesn't know anyone who really wants to be part of a political movement any more, and most of the Thursday group get picked up and dropped home by taxi.

Anya and Sophie both have the label of complex needs and live in the 'PMLD' supported accommodation in Othertown, along with 2 other people who don't use words to speak. Anya used to have a support worker who understood her facilitated communication but she left and now no one takes the time to hear what she has to say and she gets really angry and screams. Staff have made a referral to Othertown advocacy but they say she doesn't meet their criteria at the moment. Sophie's Mum is anxious about how Anya's screaming is affecting Sophie and commissioners are now looking at a more specialist placement for Anya - unfortunately that will need to be out of area.

So what?

The challenge of these vignettes is in knowing whether we are living in Anytown or Othertown. The truth is probably that we live somewhere between the two, in that sometimes exciting, sometimes frustrating borough of Averageville. We know some people whose lives have changed for the better, some who get an OK deal and a few people whose experiences really should mean that we are shouting from the rooftops, 'what's going on?' But where are those commitments from Chapter Four of Valuing People in all this?

The Ideas Collective is concerned that elements of the advocacy support that we all hoped and planned for in 2001 have got lost in 2013. There are too many Othertowns and too few Anytowns. There is a real risk that the whole concept of advocacy has become little more than a mantra that many people speak about – without really understanding what advocacy is or could be.

Perhaps more importantly, across much of the country we have difficulty in seeing the impact upon people's lives that we had hoped effective advocacy would contribute to. Significant amounts of money have been invested in advocacy development, but if we cannot see widespread benefits, then we have to question whether that money is being (and has been) wisely invested.

It is particularly important to ask this question given that a recent survey by the Improving Health and Lives Public Health Observatory (IHaL) has indicated that investment patterns in learning disability advocacy are changing – moving away from self-advocacy to professional advocacy and from learning disability specific organisations to multi 'client group' services. Is this an informed change in investment that is designed to improve advocacy and/or is it a response to a perception that advocacy is failing to deliver? If the money that is available in difficult economic times is not being used to best effect, that is unforgivable.

A Debate about Advocacy

This paper has been written to encourage an open debate about how advocacy might develop in the future. We suggest there are six key questions that should be considered in this debate:

Question One: Has the concept of advocacy been confused by policy makers and commissioners?

Our experience is that if you talk to people in influential positions nationally or locally and ask them to define advocacy – a range of different definitions will emerge. Some of those definitions will cover things that, in our opinion, are not really advocacy. A problem when you win a policy or political argument about the need to do something – and the case for advocacy was won a few years ago – it does not mean that everyone will understand and embrace the idea. People who either don't really get it or even do not agree will start to 'bend' the concept. So, we have begun to speak about 'information, advice and advocacy' in the same breath. As a result, local commissioners have been developing much needed information resources, and setting up advice facilities and (sometimes genuinely) believing they are providing advocacy.

Advocacy should not be seen as a service but as someone's right to have a voice and be heard. Society should see this as a priority and the powers at be should funded appropriately. Our end goal would be that advocacy becomes redundant, because society are listening to people and their lives are improving, but until that point in time

We need to think about:

How we can start a national debate about advocacy that includes a shared understanding of its purpose. Is it separate & different from information & advice services?

Question Two: Do commissioners understand the difference between various types of advocacy?

Linked to this is the fact that there is a range of different types of advocacy for people with learning disabilities¹. Reaching a definitive definition of those could be a paper in itself, but for argument's sake we will describe those as:

- Self-advocacy – where people (with support) come together to speak up for themselves.

¹ We are not in this paper considering issues of family advocacy – either in terms of when families are advocating for their family member or families being supported to advocate for themselves. We know that this is closely linked with all the above forms of advocacy, but it is also an issue in its own right to which the Ideas Collective will turn its attention in the near future.

We are also excluding non-instructed advocacy from our definitions – where someone is taking a judgment on what, in their opinion, is in the best interests of the person.

- Peer advocacy – often inextricably inter-linked with self-advocacy, where people with learning disabilities (with support) speak up with and on behalf of other people with learning disabilities. Increasingly this is being extended to encompass people with other forms of disability advocating with their learning disabled peers.
- Citizen advocacy – where, often on a volunteer basis, non disabled citizens develop a long-term relationship with a person with a learning disability and, through knowing them and listening to them, speak up on their behalf.
- Professional advocacy - where people are paid to speak on behalf of a learning disabled person, usually on a short-term basis by getting to know the person as far as possible and then representing what the person wants.

These four types of advocacy are not the same thing. They all have important roles to play – in different situations. They have different ‘control’ aspects in terms of the place of people with learning disabilities in the advocacy process. Effective advocacy in a local area will require all four to be present. What we are seeing (and the [IHaL](#) survey evidenced this) is a move of public spending away from self-advocacy to professional advocacy without, in our view, the thinking and decision making taking place to determine why that should happen.

We need to think about:

How can key people and policy makers be helped to understand the different types of advocacy and what different contributions they might make?

Are there examples of decision makers who have worked with people to develop different kinds of advocacy that work?

Is there a need for a policy or legal requirement for the development of, and listening to, a comprehensive range of advocacy supports in a locality?

Question Three: What is the purpose of advocacy – in particular self-advocacy?

Has advocacy become little more than a service? If we revisit the roots of advocacy, its prime focus used to be around ensuring that the voice of people was listened to. The welcome growth in public sector funding for advocacy has resulted in it becoming a commissioned service. As a result its ‘success’ is being defined and measured by inputs and outputs – how many people attend events, how many ‘contacts’ for the money provided? We think that the core purpose of advocacy should be about making sure that people have a strong voice and get to live the life they choose, and that services and support operate in ways that enable this. In other words, the key measurement and objective of advocacy funding should be about the difference it makes in helping people achieve what they want from life

All types of advocacy should have this at the core of their purpose – including Professional advocacy which, whilst sometimes being brought in to help resolve a particular crisis or situation in a person's life, should still have that whole life, empowerment mind-set to its operation. However, this 'purpose of advocacy' question is particularly important for self-advocacy, which we think is losing its way in many places.

Advocacy is a political concept that is about power and people gaining control over their lives. There are some great things going on when advocacy support sees itself as part of the bigger solution to people getting the life they want, rather than a service or activity that exists for its own sake. Why would people be part of an advocacy group just because that is what happens on a Thursday, or it means a trip to the pub, rather than because they are passionate about making things better or because they know that the group will give them the support they need to get what they want in their life?

Creating opportunities for people with learning disabilities to meet other people with learning disabilities is important (provided this is part of opportunities to also engage with and live their lives within their wider community). However, we have to be really clear about the difference between a social club and an advocacy organisation. Advocacy organisations can and should have a social dimension but the core purpose of an advocacy enterprise should surely be about how people speak up to improve their lives.

We need to think about:

Has self advocacy changed? Do people really understand what self advocacy is? Should we re-ignite the spark of political self-advocacy?

Question Four: Is advocacy money being spent effectively?

We are concerned that the process of commissioning advocacy support has become more of a transaction than a relationship; that advocacy groups/organisations are not always clear what they are offering and that commissioners are not always clear about what they want and/or should be looking for. Put another way, there is very little evidence sought or offered about the impact of advocacy and no real focus on outcomes by either those paying for advocacy or those providing/using it.

Too often, advocacy is commissioned simply because the commissioners think or know they should be doing it, rather than because they understand what impact advocacy should be having. As a result, the wrong things are asked in terms of any contract content or monitoring information. Equally, advocacy organisations have often not thought through what the definition and evidence of success would be and/or are more concerned with getting the money than helping commissioners to understand what effective

advocacy could look like. We wonder how many advocacy organisations feel confident that they can demonstrate the difference their support makes individually or to local service provision or culture?

As this paper said earlier, we believe the focus of effective advocacy is about changing and improving people's lives. The definition of success should thus be around this – not the number of social activities organised by a group or the number of people an independent advocate has on their 'caseload'.

Advocacy is also fundamentally about shifting power – from services and professionals to people and communities. Commissioners and others funding advocacy thus need to accept that effective advocacy will be a challenge and possibly a threat to them, and welcome and accept this as evidence that they are using their money wisely.

We need to think about:

How advocacy organisations can develop ways of evidencing their impact that are around how people's lives are changing.

What would be good ways of showing that advocacy is being used well?

How this knowledge can be shared so it helps commissioners move to commissioning for the impact on people's lives – even if the results will often challenge their power?

Question Five: Why has so much self-advocacy apparently had so little impact?

Where we have seen self-advocacy have a significant impact of the types we describe above, such as shifting how local authorities commission services or changing the behaviour of service providers, we have seen one consistent element – skilled support. Similarly, on the many occasions that we have witnessed ineffective self-advocacy, there has usually been one consistent element – poor quality support. We believe that the failure to recognise that self-advocacy support is a skilled and complex role which should be properly valued and rewarded has been a major failing over the last ten years.

Being able to provide that effective support to an individual or an organisation is not easy. It requires an ability to stay in the background, whilst helping people to understand often complex issues and order and articulate their own thoughts. It requires supporting people to work with (possibly) new concepts such as being a representative of other people. It will mean being engaged in emotive or political issues whilst helping to put forward other people's views rather than your own. When supporting self-advocates to influence policy or services either locally or nationally, it requires knowledge of policy, practice and the dynamics of organisational behaviour.

However, the majority of self-advocacy supporters are poorly paid, receive no training for the job and often have limited life-experience in relation to the issues and situations that self-advocates are dealing with. At its most extreme, is it any wonder that national representatives of the learning disability movement have limited impact when face to face with policy makers if their paid supporters have no experience or knowledge of such situations themselves?

We need to think about:

Is the self-advocacy supporter role well understood & supported? If not what can be done so that it becomes recognised as a valued role or even profession?

Will training, support and career development and pay rates to match the role be helpful?

Question Six: Why have the majority of learning disability partnership boards turned out to be ineffective?

As we noted at the start, Valuing People put a lot of faith in the idea that Partnership Boards would provide a vehicle for people with learning disabilities (and families) to influence and shape how local services developed. In some places (like Anytown) this has worked and there is little doubt that things have changed for the better since 2001. But the reality is that most representation on Partnership Boards has limited impact on what subsequently happens. Often the presence of people with a learning disability in meetings affects how other people behave there – but whether there is substantive change beyond that is questionable.

Effective advocacy, in all its forms, would be helping to ensure that services, supports and lives really were changing. This works best through co-production, which means not just being involved in all stages and elements of decision-making, but also actively using the skills and valuing the contributions that everyone makes through the design and delivery of services and supports. What we see instead is a tendency for commissioners, advocates and self-advocates to accept that a presence in one place, on one occasion and making one statement, is the definition of representation. In particular, people simply saying something/anything is taken as having a view, without questioning whether it is representative or evidence based. We see this as affecting the process of strategic planning, where there is no mechanism for people who use services and family carers to work in genuine partnership to design and deliver services beyond the Partnership Board meeting.

In other words, there is a danger that Partnership Boards have become a fig leaf to conceal the fact that much advocacy is being ineffective.

The six questions in this paper tell a narrative of what we see as being the current challenge around advocacy – and in particular self-advocacy:

- There is a lack of understanding about what advocacy is. As a result...
- Resources are spent on things that some people think will provide an advocacy voice, but in reality cannot. In particular...
- There is a lack of resources, activities and skills around political advocacy that can provide a voice for people, as a result of which...
- There is little evidence, and no research for evidence that shows that advocacy is having an impact, and...
- The fact that many supporters for self-advocacy do not have the range of skills needed to help ensure advocacy is effective allows these things to continue, whilst...
- Presence at the Partnership Board has become a token The effectiveness of advocacy present at those meetings is hindered by the five previous points which, together with the lack of wider, genuine coproduction, means that the impact of advocacy on people's lives is limited.

We need to think about:

How advocates of all forms can work with those responsible for services and policy to make genuine coproduction the aim – not invest all their energies in a meaningless representation at a meeting with little power.

How we can get the role of support worker to be a more meaningful job and ensure they are fit for purpose

Conclusion

The Ideas Collective believes that effective advocacy in all its forms is an essential component of people being enabled to have rich, happy lives. There are examples across the country of where this is happening for individuals or for groups of people. Some advocacy organisations are doing great things. We have seen everything from front line service workers through to Government Ministers and top civil servants influenced into changing their behaviour and actions by effective advocacy making the case for change. The changes in places like 'Anytown' (obviously a fictional place but everything we described there is something that we know has happened somewhere in England since 2001) are significantly down to effective advocacy and decision makers who were willing to listen and engage. However, we also feel that for the amount of time and money invested over a twelve-year period, the extent of that impact has been disappointing. There is a very real risk now of going backwards, with these examples of impact becoming fewer in number.

Our view is that more of the same will not work. We cannot carry on saying the same things about advocacy as we have for the last ten years and simply

expect the things we hoped for in 2001 to suddenly start happening. We need to all ask ourselves some hard questions about why, despite the undoubted progress, we are still where we are. This paper, which outlines what we see as some of the issues rather than what we think might be solutions, is the first step in our contribution to looking forward.

Our plan is to have this discussion for a couple of months and hear what people have to say. We will then write a second paper that will contain some further ideas about what could or should be done to help ensure that advocacy is a powerful force in the future. A voice that ensures that people with learning disabilities are effectively heard and people's lives improve.

Please let us know what you think

We hope this paper will encourage a debate about advocacy. Please let us know what you think – whether you agree with what we have said, think we are completely missing the mark, or all points in between. You may think there are other questions that we should be considering.

We are interested in hearing solutions, challenges and stories.

Please go to our website and you will be able to send us comments through that.

Our website is <http://www.theideascollective.org.uk/>

About the Ideas Collective

The Ideas Collective is a new group of people who want to make sure that the values and ideas that were behind policies like Valuing People carry on.

We want people with learning disabilities to be able to:

- Live as equal citizens in communities that welcome them;
- Get their human and legal rights;
- Get the same chances in life like education, paid work and decent and safe places to live;
- Have good relationships, including with their families who get good support too.

We work together to share ideas on how these values and good ways of working can happen even though other policies are changing and money is tight given the state that the economy is in.

The Ideas Collective is a network of people and organisations. We have started talking and working together because we want to share our skills and experiences to make a difference.

We want to come up with ways for how policy, society and services can change so that all people with learning disabilities have the same rights and choices as other people

The subscribers to the Ideas Collective are: (in alphabetical order)

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Rob Greig	Charlotte Sweeney
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This Discussion Paper does not represent the particular view of any one individual or any organisation that those individuals may be affiliated to. It is a collective effort, written to promote thinking and debate.