

# **Self advocacy organisations in Cumbria and the North East**

July 2019

Skills for People wrote this report with help from local Self Advocacy groups.

A big thank you to all those who took part!

## Summary

This report addresses the state of the self advocacy organisations for people with learning disabilities and/or autism in Cumbria and the North East.

The following organisations have been surveyed. Details of each organisation is provided at Appendix 1.

Autism in Mind

Better Days

Darlington Association on Disability

Durham County Council, Partnerships & Engagement Team & Durham Parliament

Gateshead People

LD: North East

People First Independent Advocacy

Skills for People

Stockton Helps All (Within Stockton and District Advice and Information Service  
(Citizens Advice)

Sunderland People First

Your Voice Counts

The report draws themes from the feedback given by organisations. Most of these come as no surprise as they reflect the national picture previously provided by a range of research and other reports.

### The main themes address:

There is sometimes a lack of clarity about self advocacy, what it means, and what benefits it brings. This could be a factor which affects the likelihood of organisations working together to promote self advocacy, and the relative lack of funding from commissioners. Definitions are offered and benefits discussed.

The staff in the organisations often promote and enable self advocacy when working with individuals, although there is a lack of evidence about to what extent this is being done by professional advocates. Many organisations invest time and money into supporting self advocacy groups, often at significant cost, in terms of financial and people investment, often unfunded by external sources, or at least severely underfunded. Although current policy (for example Transforming Care) supports self advocacy, self help and peer support, this is not generally reflected in funding, as little public funding attaches to this work, with a couple of notable exceptions.

The organisations provide a wide range of important supports (including self advocacy) which help people to be more well and resilient. These build the health, wellbeing and resilience of those they support, and reduce the need for more formal interventions. Proving the impact of these services in terms of savings to statutory services is notoriously difficult, as the services offered are wide ranging, flexible, and do not always benefit huge numbers of people, and although immediate benefits are felt by beneficiaries, the savings are likely to be felt in the longer term. The benefits of these 'prevention' supports are well understood and promoted in policy.

Like other organisations in the third sector those surveyed spend more and more time in managing limited resources, trying to generate much needed income, and there is frustration about the nature of competitive tenders which can preclude small, local organisations, and make collaboration between organisations less likely.

National and local policy expects co-production, the active involvement of service users in the development and operation of services. Self advocacy groups offer the ideal opportunity to engage with aware, confident service users, who have sufficient understanding through their involvement in self advocacy groups, in order to influence services effectively. It is felt that this is not sufficiently recognised, and sometimes the same few are asked to provide the 'service user voice' when more people could be actively involved were self advocacy groups in a stronger position.

Rethinking Advocacy (Inclusion North 2015) argued for an investment in self advocacy, peer advocacy and community advocacy, and not just professional/statutory advocacy, alongside efforts to ensure that professional advocacy plays its role in building the knowledge, confidence and connections of those supported by a professional advocate. Organisations felt that little has changed in terms of commissioning or funding of self advocacy despite the commitment of the NCNE TCP to fund work to influence current practice.

Some of the organisations employ people with learning disabilities and/or autism. They invest much time in doing this, and it was felt that the cost of this is not recognised by funders.

The main concerns voiced by organisations were lack of funding for self advocacy; the sometimes destructive impact of procurement; the difficulty in proving the impact of self advocacy; a lack of understanding among some health and social care professionals, and commissioners about the nature, importance and impact of self advocacy.

Organisations seek a different relationship with their statutory partners so that self advocacy may be valued and supported. Most recognise the need to work more closely together with each other, and with their partners to create solutions to the challenges faced.

## Self advocacy: its meaning and benefits

It is clear that there is a range of differing views on what self advocacy encompasses.

Action for Advocacy gave the following definition: 'Self advocacy: When a person speaks up about their own interests. A person with learning disabilities may need the support of a self advocacy group to do this.' *From Advocacy by and for adults with learning disabilities in England Roberts et al, IHAL 2012.*

BILD defines self advocacy as 'People coming together to speak up for themselves. It is what most of us do most of the time. It is the best kind of advocacy where people feel able and willing to do so. This should always be worked towards. Many people with learning disabilities are good at speaking up for themselves. Sometimes they find it hard to get others to accept this or to listen to them. Self advocacy groups are a good way of encouraging this. They are run by people with learning disabilities who sometimes have supporters. Self advocacy groups are often groups of people who use services or have the same interests locally. They work together to make sure they have a say in how those services are run. They are a very good way for people to support each other and they can help to build confidence so that people feel more able to speak up for themselves.' <http://www.bild.org.uk/about-bild/advocacy/advocacy-types/>

### Personal and political

As the definitions above make clear self advocacy can be about an individual being empowered (with knowledge and confidence) to represent their own needs, and increase their self determination. They may need support to do this, which may come from their informal networks (family, friends), professional advocates (or others paid to support them) or from being involved in a self advocacy group or peer support network.

There is much evidence that self advocacy groups provide support to individuals to improve their confidence and self esteem, and increase their understanding about their situation and how the world and services impact on their rights and those of their peers.

Importantly, self advocacy groups also provide a collective voice, which when strong enough, can provide a valuable influencing role, whether through campaigning or through working alongside colleagues in a range of settings, through co-production in order to improve services. Co-production is regularly used to describe a range of activities from minimal (perhaps tokenistic) involvement through to active involvement in shaping the world.

Self advocacy is therefore about the power held by an individual within their life, and by a group seeking to speak with a collective voice. It is achieved through a wide range of activities, all of which take time. Its impact depends partly on the understanding and commitment of those who hold power in our communities and services. These are some of the reasons for the confusion surrounding the term 'Self Advocacy'. This confusion may contribute in part to the current state of the self advocacy movement locally, as different organisations have differing understanding.

## Benefits of self advocacy

'For people with learning difficulties to gain real change in their personal lives self-advocacy needs to be developed to ensure they not only have the communication skills, but have an appreciation of the importance of changing rules, policies and laws which institutions, local authorities and Governments make to ensure their rights are protected. If they have an appreciation of laws and policies it will result in real change and self-advocacy won't be a tool for service providers. Also, self-advocacy must include speaking up about alternatives to choices being offered, recognising the importance of supporting one another in common areas of concern and to challenge the political system to legislate to provide relevant changes.' *Self-advocacy for People with Learning Difficulties: Does it have a future? S Apsis 2010*

'Being part of the group is central to the experience of self-esteem, self-development and empowerment'. *What's in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities Clarke et al 2015*

## The state of self advocacy

A report by the National Forum of People with Learning Difficulties (2011) already showed that the funding for self advocacy was already reducing, groups had closed and others were compromised. 'Smaller groups are worried about competition from larger groups who know how to get funding using forms. Smaller groups do not always have the time or the skills to do this. To manage on less money a lot of groups now have less paid workers Some groups have fewer paid workers, working less hours. Groups face less funding at a time when their work is most needed. Self Advocacy is needed to support people with learning disabilities to cope with all the government cuts that affect them. Groups say - "If we had funding, we could support people to be listened to."' (Staying strong but for how long 2011)

## What would self-advocacy groups find helpful?

In 2012, IHAL reported 'It would be helpful to have an extra staff member to support consultations and do some extra training. The more exposure health staff and others have to people with learning disabilities the better. There are still lots of unspoken and possibly unrecognised assumptions about a person's quality of life, which can lead to people being treated differently, or not receiving the treatment they need. If staff can see people contributing to society and enjoying their lives, it challenges those assumptions and makes people think differently.'

And 'It is important to have a bit of money that isn't attached to pieces of work as we need to do things like upgrade the website, produce brochures for marketing and build relationships.'

## How can self-advocacy groups prove their worth?

The report from IHaL said 'Lobbying and campaigning are important, but you also need something to offer. It is no good just being a bunch of moaners. Self-advocacy groups need to be proactive, and provide good services so that they are seen as credible. This is crucial. They need to be able to offer solutions as well as point out the problems, and need to present themselves in a professional manner. It is important to turn up to meetings prepared and able to contribute. A lot of work goes on behind the scenes. This means that support workers need to understand the issues the organisation is expected to contribute on, so they can support the Champions appropriately. It can be difficult to keep up to date with what is happening. Succinct information on easy to access websites etc. is helpful. Health checks information on the IHaL website for example. It may be helpful to provide some one page summaries of health issues for self-advocacy organisations to download. *'Advocacy by and for adults with learning disabilities in England Roberts et al IHaL 2012*

## Rethinking Advocacy

'Rethinking Advocacy', a paper from Inclusion North (2015) has generated much discussion and innovative pilots locally with funding from the North Cumbria and North East Transforming Care Partnership (NCNE TCP). The paper argues that virtually all funding for advocacy goes to professional advocacy, especially statutory advocacy (IMCA, IMHA, Care Act etc.) with none or little being invested in self advocacy, peer advocacy or community advocacy (where the natural supports and social capital of people is strengthened).

'The need for Local Authorities to commission independent advocacy stems from both legal duties and good practice. However as resources are scarce and competition is high, it is little wonder that most of the current commissioning practice is focused on tertiary/professional advocacy that fulfils statutory duties. However smart commissioning might be considered to take into account preventative aspects of supporting local communities and the need to invest in people's capital to invest in a longer term vision of individual autonomy in all aspects of people's lives. Commissioning needs to realign its focus with the need for advocacy for all, across our communities.'

'These forms of advocacy are arguably the most expensive and although they support people to understand and exercise their rights in their particular context, they don't in themselves equip people in the longer term to do this without support. Neither do they build the long term connections of the individual to assist them in their future advocacy. Professional advocacy doesn't necessarily support people to learn about their own rights and practice exercising them. In fact it could be argued that professional forms of advocacy can build reliance.'

Whilst accepting there is much evidence that professional advocacy is needed, the paper argues for an investment in self advocacy, peer advocacy and community advocacy, alongside efforts to ensure that professional advocacy plays its role in connecting those it supports to build their own knowledge connections and thereby resilience.

## Themes

The following themes emerged from discussions with the organisations:

### Funding and finance

Organisations get their funding from a range of sources, differing in proportion:

One smaller organisation gets 70% from one CCG and earns the balance from training, consultation etc. This funding model means the organisation is vulnerable.

One smaller organisation receives 95% of its income from one local authority, making it vulnerable.

A large organisation gets 80% from local authorities, and the balance from the NHS, social care providers and some from charitable trusts.

Only one of the organisations receives legacy income.

All but one reported receiving some charitable funding, but of limited amounts.

Some had received funding from Transforming Care programme but this is almost always a relatively small amount (under £10,000 for engaging with people with learning disabilities and/or learning disabilities) rather than for services which support people, or for self advocacy.

Another theme reported by all organisations is the time spent seeking funding and managing small awards of funding has increased enormously over recent years, leaving little/no time for development. Almost every organisation, starts each year, with an amount which they must raise during that year, through charitable sources, or earned income, which must be identified through the year.

In addition, many rely on small grants often under £5000 each and this requires a disproportion amount of administration, in applying, managing and reporting on the grants.

Several providers reported they used to provide considerable training for service providers (about values, attitudes, communication etc.) but that this has dwindled, particularly in relation to social care providers who often can no longer afford to pay for training or for staff to attend.

In several organisations paid staff also volunteer, providing their time without pay for some of the time. In two of the smaller organisations every member of staff does this. They are prepared to do so because of their passion for the vision and work of their organisation.

The system for obtaining contracts is seen by many as unhelpful as it fosters competition among organisations, hindering constructive collaboration, takes considerable time and does not always produce the best results. The loss of a contract can affect not only the contracted service but also bring about the collapse of other services within an organisation or the organisation itself. It is felt that national, large organisations have an advantage when it comes to bidding for contracts meaning that local organisations often lose out, to

the detriment of the other services they provide and their support of self advocacy and involvement in local strategy etc.

The result is that organisations are overstretched and spending a considerable time trying to raise money to survive and to manage the funding achieved. The organisations do not have dedicated fundraisers, so this process takes staff away from delivery and developing/innovation.

### Funding for self advocacy

It is clear is that most organisations receive little or no public funding to enable self advocacy, although some have funded it through charitable sources. All subsidise self advocacy because of their commitment to it. The self advocacy groups earn tiny fees for projects, sometimes even a few hundred pounds at a time, and the amount of work to manage the funding and deliver the funded projects is disproportionate to the amount they earn. Some organisations are relying on staff working extra unpaid hours (sometimes significant numbers of hours) in order to keep self advocacy going. One group was not interviewed because it has closed and one has reduced the number of times it meets.

Self advocacy groups usually need help from a wider organisation in order to know how to raise funds. It is particularly difficult to obtain funding for 'core' costs, ie the staffing and office functions required, instead often groups are paid for project work, but only for project costs, or only room hire and refreshments.

Several of the organisations have supported self advocates to become leaders, providing in house training and support and supporting them to attend leadership training. Whilst free training has been available (sometimes with travel expenses provided) and is much welcomed, organisations must expend considerable staff time in order to support people to take up these opportunities. There has been no funding to pay for these staff hours, so some organisations have met the cost, or employed volunteers to provide support. Several commented how important it is to recognise the considerable time it takes for any person to grow into a position of leadership.

Some organisations have contracts for statutory advocacy, but the demands of these contracts are challenging and do not lead to income which can be invested in self advocacy.

The nature of self advocacy itself causes challenges when it comes to its funding. Even among these organisations there are different interpretations of what self advocacy means, which makes it difficult to explain to commissioners. Most are agreed that it includes supporting individuals to become more confident, skilled and informed **so that** they can speak with a collective voice, but the mixture of personal and 'political' and the need for a social/peer support element to increase confidence causes confusing in explaining what it is concisely.

Several organisations pointed to the challenges of proving the impact of self advocacy although all have much anecdotal evidence of its positive impact on individuals and on local service provision and raised awareness.

Self advocacy in hospitals and institutional settings provides an opportunity and some organisations have provided this and are set to do so again. They are reliant on intermittent funding from the providers to do so.

### Resources received and expended on providing self advocacy

One smaller organisation reported all staff working voluntarily outside their paid work hours: to an estimated value of £16,000 pa almost a quarter of the income received. In addition the value of only one volunteer's work was estimated at about £16,000 pa.

Another smaller organisation reported that all its self advocacy employees all volunteer in different roles.

'We receive about £5,000 and spend about £25,000 per year on supporting self advocacy.'

A large organisation receives about £10,000 but provides the equivalent of one full time member of staff to support self advocacy groups, to a value of about £50,000.

Organisations spend a significant and disproportionate amount of time spent raising small amounts of funding.

### Sustainability and planning

Organisations were asked how much funding will end in one year. For at least two organisations, none of their funding continues beyond one year.

For almost all organisations, all or almost all of their funding ends within 3 years. Only one reported that much of its funding would be in place in three years time, with about 13% ending after 3 years, if not re-funded.

Income can be in the form of contracts, often for one year only, sometimes for 3 and in one instance only a contract for 5 years has been obtained. Others receive small grants which take an enormous amount of effort for limited return.

Most organisations said, however, that they expect some of their funding to be extended beyond these periods, but the lack of security puts organisations at real risk of not surviving, and makes future planning very challenging.

Contracts for services are so tight in relation to what must be delivered that there is not enough funding to meet core costs for many, let alone allow time to be spent on innovating and future development. The larger organisations have been able to spend time on strategic planning sometimes with the help of external consultants, often funded through charitable sources.

Charitable funders and others will often only fund new project, and not existing even if they are charitable, and not the essential office functions or core costs. Often projects are subsidised as funders will not meet full cost recovery. 'We keep on having to stop the good projects we are doing': one example, several organisations have been supported to train Quality Checkers but cannot get funding to allow the work to continue.

For small speaking up groups, their income is very hand to mouth, with them earning fees sometimes £1000 or less, here and there. One group has recently had to close after many years' existence.

### The issues identified are not new:

'Lawton (2009) describes how 'advocacy services for people with disabilities...have grown and developed over 20 or 30 years, [but are] often largely built on voluntary origins with weak financial foundations' (p. iv). This means that advocacy services often face problems of survival when specific funding streams end (EHRC, 2010). Both Valuing People (2001) and Valuing People Now (2009) helped to strengthen advocacy and highlight its importance in giving people with learning disabilities a voice, and the introduction of statutory advocacy such as Independent Mental Capacity Advocates (IMCAs) should mean help for the most vulnerable people (Lawton, 2009). .....In addition, there are concerns that this focus on statutory advocacy may be at the expense of other types of advocacy (Lawton, 2009; Action for Advocacy, 2011). This is in addition to the 'widespread recognition of inherent difficulties in attempting evaluation' of advocacy services (Lawton, 2009, p.vi), although attempts have been made within the sector to develop measurable and relevant advocacy outcomes (e.g. Action for Advocacy, 2009).' *Advocacy by and for adults with learning disabilities in England Roberts et al IHAL 2012.*

Staying Strong: Taking Advocacy Into The Future (National Forum of People with Learning Difficulties, 2011a) considers how self advocacy groups can continue to make a difference in people's lives with less money available from government. The National Forum of People with Learning Difficulties surveyed 80 self advocacy groups in England, asking about the work groups do now and their plans for the future. Some self advocacy groups in Staying Strong said that commissioners did not always understand what self advocacy is, and some said that large organisations are getting advocacy contracts because they have more time and experience to write the funding bids. Staying Strong suggests that groups need to show commissioners how they change people's lives using numbers and stories, and to find other ways of making money.

The follow up work to Staying Strong was Staying Strong – but for how long? (National Forum of Learning Disabilities, 2011b). The report found that most self advocacy groups got the same amount of money for 2011/12 compared to 2010/11 but did not know what would happen to funding after April 2012. Self advocacy groups are often competing with other organisations for less funding, and for contracts that join up advocacy activities with other areas such as Advice and Information. To manage on less money a lot of groups have fewer workers or staff working reduced hours.' ' *Advocacy by and for adults with learning disabilities in England Roberts et al IHAL 2012.*

### Employing people with learning disabilities and/or autism, and family carers

The organisations employ many people with learning disabilities and/or learning disabilities, and some also employ family carers (see appendix 2 for a breakdown). This adds

enormously to the offer and expertise of the organisations. These organisations invest a great deal of time and effort to enable them to do this. There are numerous examples of good practice where people with learning disabilities and/or learning disabilities are supported successfully to work and achieve great successes.

Most employees with learning disabilities and/or learning disabilities work part-time with most working a day or less a week. The amount of time spent to enable this work in relation to dealing with issues relating to benefits, support, and the cost of transport is significant, and a hidden cost to the organisations which is not usually recognised in funding.

One organisation said some people feel unable to work due to their fear of negative impact on their benefits: particularly PIP. The fear is that a person will lose their benefits if there is any suspicion they are fit to work, even though they are only able to work within the context of the organisation which provides considerable support.

Others knew of people who could work for the organisations but do not due to the lack of regular funding to enable this. When income is so tight and delivery targets challenging it can be difficult to employ as many people with learning disabilities and/or learning disabilities as we would wish.

This means a huge potential is going untapped.

## Volunteers

The organisations support a large number of volunteers, who are people with learning disabilities and/or carers. Most do not have volunteer co-ordinators and volunteers are supported as an 'add on' to the work of team members. One theme raised by most of the organisations was reflected by one 'it is hard to keep up to date with such limited resources'.

## About supporting leadership

Several of the organisations employ people with learning disabilities and/or autism, and some employ family carers (see appendix for more information). This means they help to develop their confidence, skills, and often leadership. Several support people to develop leadership skills and attend leadership training opportunities but at cost to their organisations. Others support volunteers with learning disabilities and/or autism, and family carers. These team members carry out a range of tasks, from administration to delivering training, consultancy, supporting local strategic development and supporting the governance and planning within the organisation.

One important aspect that is often not recognised is the time it takes for someone to develop their confidence, knowledge, skills and become a leader. For any of us, this process takes years, and is overlooked when people are recruited to take part in a one off project without the possibility of continuing involvement. That said organisations do their best to encourage those who are interested, to continue their involvement and learning.

### About supporting people to stay well in the community

'Recognition that small steps with people can lead to big results in the longer term. Less short sightedness from, e.g. enablement approaches that don't work and often end up with escalating problems as well as costs. Preventative commissioning that doesn't focus purely on a perceived immediate need without looking at longer term issues that are often seen as a 'nice to have'. We know that people need to be connected, they need to have friends, to have some fun, have purpose, feel good and enjoy life if they are to be able to tackle some of the challenges they face in a positive way. Re-defining what is meant by a 'need'.'

### Expertise of self advocacy organisations

Many of the organisations have much expert and technical knowledge in their team which is not being used as much as it could by health and social care partners, examples include support with support planning, direct payments, quality checking, co-production.

### Low level?

Many of the services provided by the organisations could be described as prevention: helping people to avoid the need for more formal services in the future. It is sometimes described as 'low level' support, with the presumption that the issues with which the organisations support people are of a low level, or complexity. Several organisations gave examples of the people whom they regularly support as a matter of course: a person who had not left his house for 13 years, a person with complex mental health needs, vulnerable to abuse, often running out of money; a child whose behaviour risks serious physical harm to himself and his family, risking his institutionalisation in future, people who self harm, people with learning disabilities or autism facing eviction due to their behaviour, a refugee with learning disabilities. It is clear that the issues with which the organisations offer support are by no means 'low level'.

One important point made by several groups is that the pressures on funding have made it more difficult to support people with complex needs (multiple and profound learning disabilities, and challenging behaviour for example) within self advocacy groups, with some limited notable exceptions.

### Flexibility, a safety net

One of the defining aspects of the services provided by the organisations is flexibility. All have an 'open door' attitude, some more formally expressed than others, where they will help each person, with whatever problem they present with. Unlike other services, they are often free to help in ways other services cannot. This is often at a cost to the organisation, unfunded, and difficult to capture when it comes to reporting activities and impact. The organisations know however that this attitude provides a vital safety net, and enables people to get involved with their organisations, and therefore receive the benefits offered by the range of activities provided by each service, connecting people to others in their community, and ensuring people get the right help when they need it being two key elements.

## What are the biggest challenges the organisations face?

‘The lack of funding, and the fact that staff are already doing extra hours just to keep the organisation going, means there is little time to develop our service, either to collect evidence to prove our impact, or to work on generating new ideas, projects, build relationships with organisations or to secure funding.’ This was a recurring theme and is echoed in recent research relating to the VCSE sector.

Where organisations provide services funded by public bodies, the nature of commissioning, and tenders for large amounts of money causes difficulties for smaller organisations, also the competition it generates among organisations can be destructive. It can favour larger, perhaps national organisation, thereby reducing the benefit which local groups can bring in their communities. It is recognised that the VCSE can be difficult for a commissioner to engage, given its diverse and dispersed nature. Subcontracting from larger organisations to small ones (prime contractor model), partnership bids and consortia are all possibilities but for many organisations beyond their administrative resources to organise.

One organisation said ‘The role of commissioning is likely to become more emotive from the local organisations in the future, this is across the country. The RSG (Revenue Support Grant) will be pulled from all local authorities by 2020. This means that current commissioning teams are under severe pressure – I can see lots of restructures and possible ‘regional teams’.’

‘Although we continue to grow (steadily), the support for individuals through social care continues to fall, seemingly due to austerity measures, with any opportunity to cut a service taken sometimes without a great deal of thought. Demand for our free to access support is increasing rapidly, often at the direction of those cutting social care budgets. We haven’t yet turned anyone away, but if we can’t maintain e.g. grant income or increase our fundraising then we may find ourselves having to change the way we work. We have broader plans to become more self-sustainable, but this isn’t an overnight fix and doesn’t come without risk.’

All the organisations said the greatest challenge they face by far, is a lack of funding for self advocacy. All said they could do more if they had more funding, and all confirmed there is a demand for all these activities.

For one the understanding of health, social care and other professionals means they have to do more work to protect the rights of those they support.

Several organisations raised the issue of how difficult it is to show the benefits of self advocacy, which is essential in obtaining funding. There are models which would help these organisations to demonstrate the benefits, but even if made available, it is doubtful if most would have time to attend training and do the work necessary to implement the models.

One organisation said ‘People don’t understand what self advocacy is. It is really about citizenship, being a part of a community, belonging, as much as speaking up. It is a vital forum for people to learn to speak up, and understand their rights, and to have a collective voice.’

One organisation said finding accessible affordable venues is a big problem.

People in the third sector who do some good work need to be able to work together. The challenges of competition has impacted on the sector. The impact of the depletion means that organisations are unable to meet the needs.

## Ideas/solutions

- One larger organisation reflected the message from the other larger organisations: 'We are currently looking at what we can do to further extend our reach and offer to people. This includes becoming more enterprising in our approach to community fundraising, corporate interest and other income generation. We have taken steps to support ourselves with this –...business coaching during 2017 which was very positive. We have a positive approach to fundraising (although it's very difficult of course) and are developing our networks with likeminded organisations.'
- 'A different relationship with statutory bodies who have responsibility for people with learning disabilities and/or autism: they could do more to encourage self advocacy, fund it and recognise the need for it and its value.'
- 'Commissioners could build into contracts with local providers an expectation that they seek independent support to collect feedback from their services users.' (One local authority already does this).
- 'The prime contractor model could be a way forward: local health trusts already commission our organisations to an extent, and there seems a willingness from them to do more to encourage and support the development of self advocacy, and service user engagement from independent organisations.'
- Direct Payments offer a way to support the work of self advocates in self advocacy groups. One organisation suggested that we produce a report and submit to Public Health England.
- 'Considering advocacy in silos of different types no longer works. Providing opportunities for people to speak up for themselves in a range of groups is important. We get to know people by helping them with their problems, often these are people not known to services: we need to be more flexible in how we define and provide self advocacy. However there is a risk in this approach as it is more difficult to maintain the principles of self advocacy if the settings are disparate: it is important that self advocacy remains user led and has an influence'
- There is a need for increased understanding among colleagues in health and social care, and among commissioners about the benefits and value of self advocacy.
- Commissioners and colleagues should seriously consider how to enable some funding to support self advocacy, including the amounts groups needs to continue to function and not just small amounts of funding for project costs.
- The organisations need help to know how to demonstrate the benefits of self advocacy. There are models to help with this, but organisations need easy and affordable access to a simple method.
- There may be alternative ways of funding for self advocacy. Some have suggested that direct payments may be used but this solution is not straightforward and not for all. The organisations could do with time and support to consider how funding might be provided in new ways, also an opportunity to work with commissioners on this.
- It would be helpful if groups were encouraged to share good practice more. This is a challenge, because, unless groups are funded to share good practice, they can see this as a threat to their own income generation. There is a tension between the

natural inclination of these organisations to share, and the competition for resources which currently exists between them.

- It would be helpful if organisations were able to 'sell' more of their expertise in order to generate funding.
- Help with volunteers: funding for supporting them, free training for volunteers?
- Opportunities for self advocacy in institutional settings.
- Organisations could work better together by sharing back office costs: finance and HR for example. Organisations could share insurance policies, and share organisational policy which take a great deal of time to write. This could save money and improve quality, without affecting the self governance of each organisation.

## Is there anything else you want to tell us?

'We love what we do.'

'It's not rocket science: our values are at the heart of our work, and what seems obvious to us can seem difficult for others. We have considerable experience of listening to people, supporting them in the way which suits them, encouraging them in their lives and in our organisations.'

'Simple solutions can unlock big problems, we are there at the right time in the right place, for example person struggled for months to complete important forms and did not dare to ask for advice'. For many the self advocacy groups and other groups provide a lifeline, a safety net where staff are able to recognise problems and deal with them early. Examples include tackling abuse and crime against people, getting urgent medical help with significant results, helping people to deal with urgent bills and letters. One effect of the reduction in services, and settings where people come together for support is a risk that people do not seek help and people 'fall through the cracks' without anyone noticing. 'These groups keep an eye out for vulnerable people who have nobody else to speak to, and no services to support them'.

'it boils down to acceptance, we are not trying to fix or change people. Instead we accept they struggle with some things (we all do), and we ask how can we help you

One organisation pointed out that Transforming Care seems to focus on people with learning disabilities and not autistic people who do not have learning disabilities.

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## Appendix 1 About the organisations

The following organisations were approached by Skills for People and Inclusion North, and asked to be an overview of the current state of self advocacy in Cumbria and the North East. The intention is to identify ways in which the self advocacy movement in the region might be strengthened. Each was asked a range of questions by interview or questionnaire.

Autism in Mind

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Durham County Council, Partnerships & Engagement Team & Durham Parliament

Gateshead People

Independent Advocacy North Tyneside (not available for interview)

LD: North East

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Sunderland People First

Your Voice Counts

Some organisations work with beneficiaries who do not have learning disabilities and/or autism, but the majority of their work is with learning disabilities and/or autism and their family carers, and we have focused only on their work with this group for the purposes of this report, as it has been funded with money from the Transforming Care programme.

This report describes each organisation, its size, the people who work and volunteer there, and its main areas of work. Concerns, themes and ideas are drawn together. The appendix gives more detail about each organisation's legal constitution, services, staffing and activities.

## About the organisations

### Autism in mind

#### Aims:

- to connect with autistic people and their family carers
- to provide individualised support
- to prevent crises

**Income:** £70,000 (2017-2018)

#### Activities:

The organisation provides services for autistic people of all ages and their family members including

- **Self advocacy:** members meet together at the drop in, to support each other, and are involved in delivering training and raising awareness.
- prevention support to help people avoid crisis and stay well
- post diagnosis support as part of the autism pathway
- Information, advice and support to resolve problems, manage crisis
- Drop in: social with support on hand
- Social activities
- All About Me: an autism specific self awareness and understanding course, which promotes good mental health, emotional wellbeing and resilience through presentations, individual exercises and group discussion. Helping people to learn positive coping strategies, to increase confidence, lower anxiety and manage sensory needs. (soon to extend to young people in the workplace in collaboration with Project Choice)
- Training by self advocates for a range of organisations.

**Examples of good practice which could be shared:** The organisation would like to deliver All About Me across the region.

### Better Days

**Aims:** Used led organisations for adults with learning disabilities. Members consider the barriers they face when trying to get out and about in the North East. Members come up with projects and ideas to address the barriers.

**Income:** £36,444 (2017-2018)

**Activities:** Freedom city 2017 – events to celebrate the 50<sup>th</sup> anniversary of Martin Luther King getting an honorary degree from Newcastle University.

We were part of the New Year's Eve parade

We run cycling groups, supporting people to be more independent and support their physical and mental health. We lost access to using bicycles for free. We asked for donations and received over 20 bikes.

Gardening project – We volunteer to tidy up exhibition and Brandling Park. We offer our help to tidy the gardens of older people who are not physically or financially able to do it themselves.

### **Darlington Association of Disability**

#### **Aims:**

Darlington Association on Disability was established in 1986. It is a user led organisation. It promotes independence and choice, and supports disabled people and carers through the provision of services, support and information and by tackling issues locally and nationally. DAD promotes the social model of disability, and as part of that remit is actively involved in promoting disability equality and awareness of anti discrimination legislation.

DAD acts as a focal point for consultation with disabled people and carers. It also manages a range of services / projects to support its aims.

#### **Activities**

DAD provides a wide range of services for disabled people including

- **Self advocacy groups:** DAD supports the Peoples Parliament (funded by charitable trusts) which includes a high proportion of people who have lived in hospital. The parliament raises awareness and aims to influence services.
- **Leadership:** DAD supported young leaders group who have raised awareness about bullying and the SEND Code of Practice.
- Statutory advocacy (IMCA, IMHA, Care Act) to about 1300 people a year
- Support to providers with disability equality training for the police and public authorities, awareness training about IMCA and the Mental Capacity Act, and CIPOLD.
- Support local parent carer forum
- Independent Living Hub: offers practical support to about 50 people regularly, with a range of wellbeing sessions. The Hub helps people to develop personal development plans.
- Mentoring for young people up to the age of 25.
- Easyread
- Regular peer support groups where people help each other to solve problems and take action between meetings

### **Durham County Council, Partnerships & Engagement Team & Durham Parliament**

**Aims:** Lead on partnerships and engagement for the authority. This includes specialist contribution/training. Capacity building and developing networks for all sectors that support people with disabilities.

#### **Activities**

Self advocacy, leadership, information and guidance, raising awareness. Partnerships, training, engagement and Networking. Supporting people to become leaders. Promoting equality and diversity.

#### **Examples of good practice which could be shared**

Co-ordination of region wide events to sustain a connected network to promote good practice of organisations: of disabled people/people with learning disabilities, autism, carers, and health organisations.

## Gateshead People

**Aims:** to support people to gain confidence to speak up for themselves, and provide a collective voice for people with learning disabilities in Gateshead.

**Income:** Approx £10,000 (2018)

### Activities:

Gateshead People, **A speaking up group with a well established membership**, has been in existence for 25 years. It has been supported by two workers to meet weekly but latterly there has been so little funding that they have had to provide just a few hours a week support, and the group meets less often.

The group offers peer support and social time for its members. 4 members work on behalf of the local LDPB as the 'Involvement Now Team' providing consultancy, easyread, etc. They carry out projects, funding permitting, including developing Safe Places, making films with Community Safety and NEXUS about hate and mate crime, involvement in the local Learning Disability Network Cancer project. They have offered training in assertiveness. 14 people attended a recent poetry project, which introduced people to the theatre when group members performed to a sold out house.

## People First Independent Advocacy

### Aims:

People First is an independent organisation. Providing help and support to some of Cumbria's most vulnerable citizens. Helping people stay in control of their own lives.

**Income** £1,014,094 (2016-2017)

### Activities:

- **Self advocacy:** The organisation supports five self advocacy groups across the county: each meets fortnightly, involving 100 people. As well as gaining confidence, speaking up, and influencing, the groups work on issues such as hate crime, health and wellbeing, and enjoy a range of activities, including healthy walks, and hearing from a range of speakers.
- The organisation supports the Rethinking Advocacy networks set up with Transforming Care funding which support self advocacy groups and advocates across Cumbria and the North East.
- Advocacy: IMCA, IMHA, NHS complaints, Care Act.
- Accredited advocacy training is being developed: for formal and informal advocates, including self advocacy.
- Delivers Healthwatch Cumbria and Healthwatch Lancashire

- Access All Areas helps up to 200 young people with learning disabilities to carry out access audits in local universal services, including museums, restaurants, public services, sports activities.
- The organisation has over 50 volunteers who have learning disabilities and/or autism. Its new conference centre offers a range of employment/ training opportunities up to 15 people with learning disabilities and/or autism.
- Quality Checkers: the organisation has recently started carrying out health quality checks of NHS services.
- The organisation provides support to 10 experts by experience to take part in Care and Treatment reviews.

### LD: North East

#### Aims:

LD:NorthEast's vision is that people have access to the same opportunities as everyone else. The organisation was set up in 1996 (formerly the Learning Disabilities Federation) by a group of carers who faced similar challenges and wanted to provide a positive future for their loved ones.

**Income** £765,000

#### Activities:

- **Self advocacy:** LD:NorthEast supports people to speak up for themselves through various activities and support methods, including group based activities and workshops, as on a one to one basis. Much of this work is led by our user group, Northern Voices, who support each other and the wider organisation with various themes
- Informal advocacy through our general work
- Trustees and management are guided by our user forum (Northern Voices) who inform the organisation (and others) about important issues that affect them and the people they represent
- Provide a wide range of socially inclusive activities in the community in groups and one to one.
- Wide range of health and wellbeing activities, including health focussed workshops, support at medical appointments, self help support, fitness and wellbeing classes, healthy cooking and shopping, easy read resources, friendship groups, short breaks etc.
- Information, advice or guidance through support and supported signposting with areas such as benefits, money management, correspondence, health and wellbeing signposting, liaison with authorities.
- Influencing service delivery and strategy through involvement locally in various groups, e.g. North Tyneside Sign, VODA Chief Officers Forum, Vonne events.
- Supporting families of pre-school children with complex needs through play (BBC Children in Need funded)
- Supporting people with learning difficulties who are growing older (Big Lottery funded 'Tomorrows' Programme)
- Tackling disability hate crime through delivering a series of workshops and activities via our 'Safer Tomorrows' project, funded by the Northumbria Police & Crime Commissioner Community Fund and Newcastle Building Society.

## Examples of good practice which could be shared

We have had a great response to the work we do to support people who have experienced disability hate crime.

Tackling loneliness and isolation through light touch support for people growing older has seen some life changing / lifesaving results

## Skills for People

### Aims:

Skills for People (established 1983) provides services across the North East and promotes good practice national.

To support disabled people to speak up and take more power and control over their own lives, and to bring about change and improve the lives of disabled people and their families.

**Income:** £500,896 (2016-2017)

### Activities

Aimed at people with learning disabilities and/or learning disabilities and their families:

- **Self advocacy:** SfP supports a range of self advocacy groups, including Geordie Mums, Women's Zone, Men of the North, Geordie Voices. Supports self advocacy and co-production in Redcar and Cleveland, including Independent Voices, Independent Women and Advocacy is not an Avocado (young people raise awareness about advocacy)
- **Leadership:** support and encourage people with learning disabilities and/or learning disabilities to take on leadership roles and attend training etc. to develop their skills
- Information guidance and support for people with learning disabilities and/or learning disabilities of all ages, family carers. (Newcastle, Redcar and Cleveland).
- Peer support through Pass it on parents for parents of disabled children.
- A range of activities aimed at improving wellbeing, co-produced with people with learning disabilities and/or learning disabilities (and often in collaboration with health services) including Mindfulness for Life, Keeping Well, Sense and sexuality.
- Peer support and social groups including drama, film, knit and natter, All Autistics Accepted, dads group, group for young autistic women.
- Support people with learning disabilities and/or learning disabilities to influence service commissioning and delivery through training, awareness raising, service user engagement, consultation and involvement in strategic bodies.
- Raise awareness about the lives of people with learning disabilities and/or learning disabilities and the challenges they face
- Support organisations which support people with learning disabilities and/or learning disabilities, with workforce development, user involvement and user led Quality Checks
- Quality Checkers, established 2004, our team checks a range of services and has been involved in creating Health Quality Checkers and training people with learning disabilities and/or learning disabilities to become Quality Checkers.

## Examples of good practice which could be shared

We continue to share our practice about

- Quality Checkers
- Mindfulness
- Wellbeing

## Sunderland People First

### Aims

Sunderland People First was first established and supported by Sunderland City Council in 1994 as a self - advocacy group for people with a learning disability.

Originally formed 24 years ago within the council's range of day services, they were to provide the Sunderland council with an effective way of ascertaining the views of people with a learning disability and played a fundamental role in supporting Sunderland's Learning Disability Partnership Board.

In 2014 Sunderland People First became a Community Interest Company, when it externalised from council services, and has remained a User led organisation, having three of the seven positions on the board of directors for people with lived experience.

Our aims are to work with people with a learning disability and or autism and their families to improve their status as full independent and contributing citizens of their community.

That people live the life they choose, are able to have communication with organisations which affect their lives and are able to talk to others about the challenges faced by disabled people.

**Income** £132,783 (2016-2017)

**Activities:** SPF supports people with learning disabilities and/or autism with a range of activities including:

- **Self advocacy and leadership:** members of the organisation are involved in all aspects of its work. They have attended training to develop leadership skills.
- Information advice and guidance – all staff have level 2 City and Guilds qualification.
- Quality Checkers: we were involved in creating Health Quality Checkers in CNE.
- Public health and wellbeing: all the team of self advocates are health champions promoting health and wellbeing messages to community organisations. The organisation is involved in the Time for Change project, and self advocates act as mental health champions working to change attitudes about mental health.
- Influencing: the organisation plays a big part in the Confirm and Challenge group of the regional Transforming Care programme. It has helped to develop the new Quality of Life standards. The organisation has worked on the North East Network cancer screening project, aiming to improve screening for people with learning disabilities. Working with NTW to improve their formulation training.

- Members of the North East and Cumbria Learning disability Mortality review programme (LeDER) confirm and challenge group.
- SPF support experts by experience to take part in CTR reviews.
- Training for provider organisations and social workers, and local NHS Trust
- Consultation with local people with learning disabilities and/or autism on issues that affect their daily lives.
- Production of East Read information.
- Hate and Mate Crime training for people with lived experience and professionals.
- Work with Northumbria police to tackle hate and mate crime and value difference.
- Raise awareness in schools and community groups to bring about change in public perception of people with a learning disability and or autism, and value difference.

### **Examples of good practice which could be shared**

Working closely with services providers, universities and statutory organisation locally, regionally and nationally to improve services for people, and change public perception through consultation, advice and guidance, quality checking and training.

### **Your Voice Counts**

#### **Aims:**

We help vulnerable people find a voice and gain control over their lives.

We run advocacy services, support self-advocacy and user-led groups, and run drop-in sessions where people can get personalised help with a range of issues. We help our clients to become better connected to their local communities and raise awareness of the issues that the people we support are facing.

**Income:** £771,641 (17/18)

#### **Activities:**

- **Self advocacy:** YVC supports a range of self advocacy groups including Gateshead People, Talk 2 Us and Equal People. Talk 2 Us have run out of funding, and YVC is currently supporting it for about one hour a week to meet to try and gain funding: it can no longer operate in its work of campaigning, training etc.
- **Advocacy:** IMCA, IMHA, Care Act, RPR, Crisis
- **Help First:** This service supports a huge number of vulnerable people in crisis, often due to being refused benefits, and unable to access services which would once have been available due to cuts. The service offers drop in sessions where people can get information, advice guidance and help from an advocate when needed. Often the service is supporting people in desperate situations and extreme poverty. The service has seen demand increase to more than double (2015/16 84 people to 2017/18 nearly 200 people).
- **Community connecting** – many of the services help people to connect to their community
- **Peer support:** YVC deliver a number of peer led projects including supporting Peer Advocates to volunteer at Help First drop ins, and Mindfulness support sessions in Gateshead and South Tyneside
- **Quality Checkers:** have been trained but have no funding currently to deliver

- **Leadership:** supports people to take part in leadership training
- Making every contact count: members of the team including members of Gateshead People First (self advocates) have been trained with support from Gateshead Council Public Health.

**Examples of good practice which could be shared**

- Help First
- Making every contact count

## Appendix 2 About the organisations

	Status	Employees	FTE employees	Active volunteers	Trustees/Board	People with learning disabilities/autism				Family Carers			
						Employees	FTE employees	Active volunteers	Trustees/Board	Employees	FTE employees	Active volunteers	Trustees/Board
<b>Organisation</b>													
Autism in Mind	CIC Co	8	4	4	3	2	-	4	-	4	-	2	-
Better Days	Charity	1		10 (all trustees)	10			5					
Darlington Association on Disability	Charity Co	45	?	100	7	30 disabled	-	?	6 disabled	9			1
Durham CC, Partnerships & Engagement Team & Durham Parliament	Co	Not disclosed	?	0		27 work for council		0					
Gateshead People	group	2	0 hours										
Independent Advocacy in N. Tyneside	Did not take part												
LD: North East	Charity	53	30	45	6	1				4			
People First Independent Advocacy	Charity&CIO	60		120	10	16		110?					
Skills for People	Charity Co	40	18	20	7	10		10		6			1
Stockton Helps All													
Sunderland People First	CIC Co-op	3	3		6	10		10		1		1	
Your Voice Counts	Charity Co	37	21	15	11	7		7		2		4	

ACTIVITIES PROVIDED	Self advocacy groups	Advocacy	Info, advice	Training consultancy	Social activities	Health and wellbeing	Community connecting	Awareness raising	Influencing services	Supporting leadership	Quality Checkers
ORGANISATION											
Autism in Mind		informal	Y	y	Y	Y		Y	Y		
Better Days			Y	Y	Y	Y		Y			
Darlington Association on Disability	Y	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Durham CC, Partnerships & Engagement Team & Durham Parliament	Y		Y	Y		Y		Y	Y	Y	
Gateshead People	Y	Y		y	Y			Y	Y		
Independent Advocacy North Tyneside	Did not take part										
LD: North East		informal	Y		Y	Y	Y	Y	Y		
People First Independent Advocacy	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y
Skills for People	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Stockton Helps All											
Sunderland People First	Y		Y	Y	Y	Y	Y	Y	Y	Y	Y
Your Voice Counts		Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Organisation	People with learning disabilities	People with autism	People with learning disabilities and autism	Adults	Children	Young people 14-25	Family carers
Autism in Mind		Y	Y	Y		Y	Y
Better Days	Y		Y	Y			
Darlington Association on Disability	Y	Y	Y	Y		Y	Y
Durham CC, Partnerships & Engagement Team & Durham Parliament	Y	Y	Y	Y	Y	Y	Y
Gateshead People	Y		Y	Y			
Independent Advocacy in N. Tyneside	Did not take part						
LD: North East	y		y	y	y	y	y
People First Independent Support	y	y	y	y	y	y	y
Skills for People	y	y	y	y	y	y	y
Stockton Helps All							
Sunderland People First	y	y	y	y	Y	y	y
Your Voice Counts	y	y	y	y		y	y

