

MAKING SENSE OF SELF ADVOCACY TODAY

Report to RTR June 2019

ABSTRACT

THIS REPORT WAS WRITTEN BY ALAN ARMSTRONG AND JAN WALMSLEY WITH HELP FROM MEMBERS OF BAROD.IT EXPLAINS WHAT WE DID, AND WHAT LESSONS WE LEARNED ABOUT SELF ADVOCACY IN ENGLAND TODAY

Jan Walmsley

Making Sense of Self Advocacy Today

Our Aim

To gain a picture of the state of self advocacy for people with learning disabilities in England in 2018-19 with a view to strengthening it.

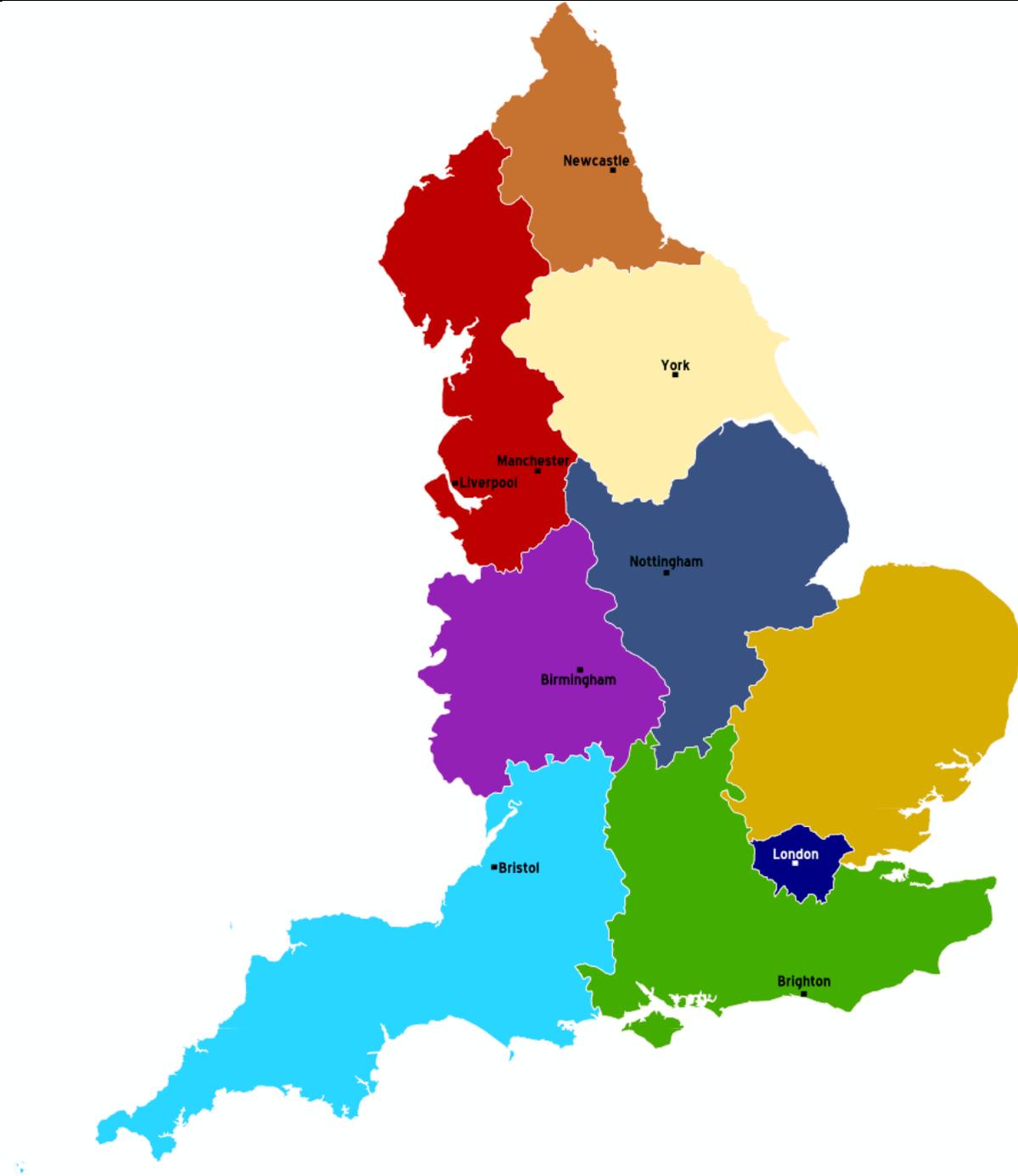


This is our report to our funders.

It was written by Jan Walmsley and Alan Armstrong, with help from the BAROD team.

June 2019

**We listed all
the self
advocacy
groups in
England**



**The list is on
Learning
Disability
England's
website**



**We visited 6
brilliant self
advocacy
groups to find
out what they
do well**



**We
recommend
that self
advocacy
groups think
about *earning*
money, not
*getting funding***



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If groups want lots of people to come, they need to find a nice place to meet



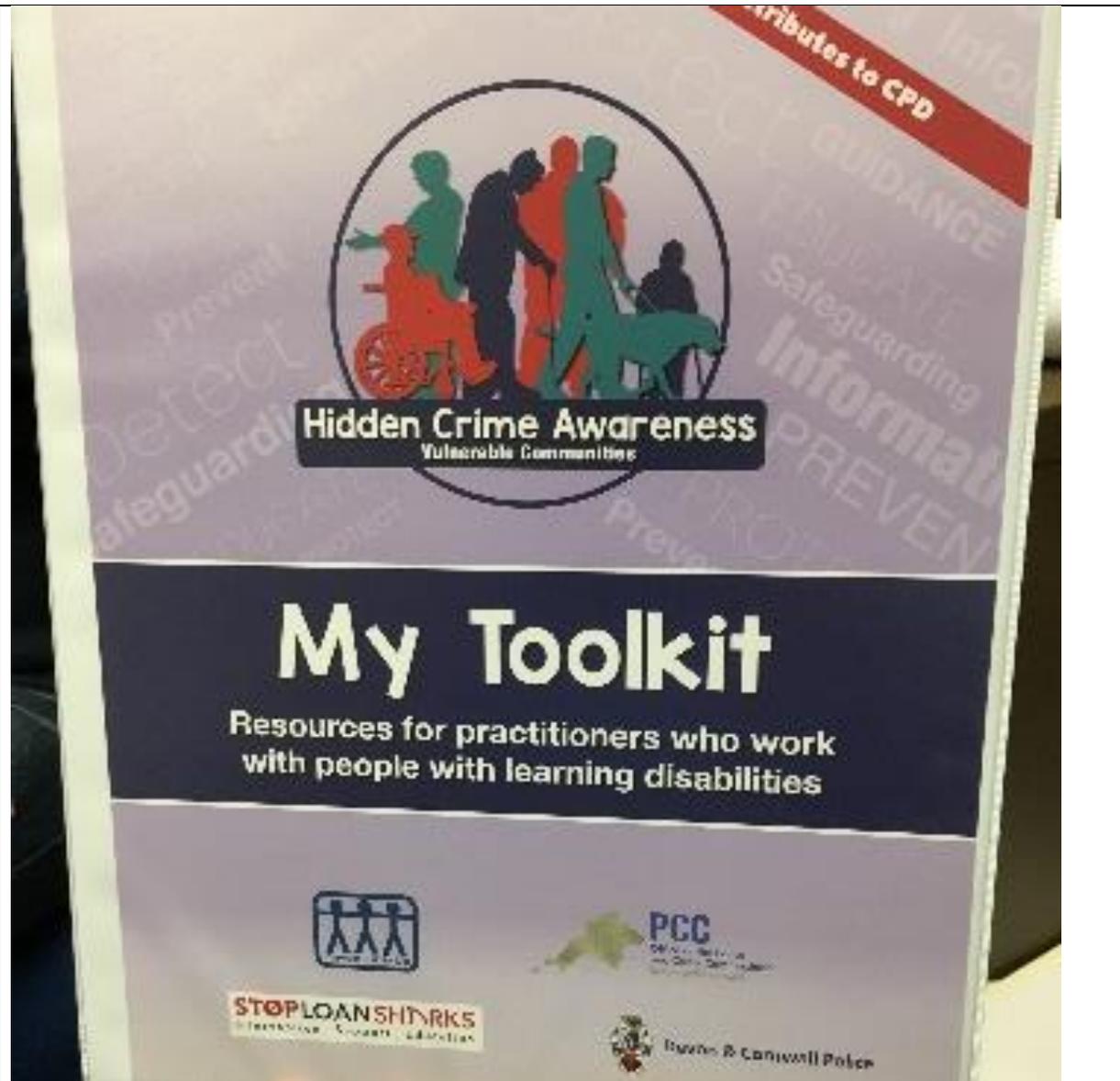
Self advocacy groups can run with very little money if they can find good volunteers



**Self advocacy
groups can
learn a lot from
each other**



Self advocacy groups want to share resources and ideas



**Self advocacy
helps people
get paid work**



Introduction

This is our Report into the state of self advocacy in England in 2018/19. It is in 3 parts.

1. A list of self advocacy groups in England with a social media presence
2. Reports on visits to 6 self advocacy organisations across England
3. Lessons for self advocacy

The project was co-produced by Alan Armstrong, self-advocate researcher from BAROD and Jan Walmsley, professional researcher, with input from the rest of the BAROD team.

We wanted to do this research because self advocacy has been struggling. Many groups have closed after losing funding. Those that remain are often isolated from one another. Groups are vital for people's social lives and social inclusion.

We have sent the list of self advocacy groups and reports on all the groups we visited with this Report.

List of Self Advocacy Groups in England

How we did it

The survey of English self advocacy groups was a desk based activity, noting those groups which had presence on social media.

We included organisations if:

- based in England **and**
- the organisation describes itself as a People First or self-advocacy organisation

or

- the organisation lists a self-advocacy group as a project/activity.

We did **not** include:

- service provider or statutory organisations running self-advocacy/participation groups for people using their services
- organisations where the self-advocacy group is clearly stated to have no autonomy, to be time-limited or to be run solely by people without learning disabilities for the benefit of self-advocates.

After we had made a list we checked it against other lists

1. a list compiled for the Government in 2015.
2. a list Learning Disability England sent us
3. a list put together by Skills for People in the North East.

We also asked the Regional Forums if they knew of other groups in their areas. We had replies from Yorkshire and the Humber and London.

What we learned from making the list

Making the list was less straightforward than it sounds as it was often hard to know whether a group met our definition of self advocacy.

People have argued about what makes a proper self advocacy group ever since self advocacy arrived in the 1980s.

The argument often pivots round whether a group is independent of services. If a self advocacy group is inside a service, however good it was, people say it isn't a proper self advocacy group. We found a few groups like this, though not often because very few services claim to run self advocacy.

In 2019, it is more likely that self advocacy is a project within a bigger advocacy organisation, one of many different advocacy type things they do. This begged the question – how much say do self advocates have in running that organisation? Given we did not have much resource to do this work, we were relying on websites, Charity Commission information, Facebook and sometimes Twitter so it was difficult to know how much power self advocates really have.

We know some would argue that proper self advocacy demands that all Trustees have learning difficulties. Again, it was quite hard to answer this question from a distance. Many organisations which 'do' self advocacy do lots of other things too, so the self advocacy part may not even have its own board of Trustees. Where groups met our criteria for inclusion, we included them even if they did not have Trustees, or Trustees did not all have learning difficulties.

Finally, we asked ourselves – and our very helpful Reference Group - Do you think we should include organisations which support self advocacy and co-production but are not themselves self advocacy organisations? Such groups were not included on this list, but do need recognition as a development of self advocacy.

The list

We produced the list in December 2018. We have sent this with this Report. We did our best to make it up to date and accurate. The good news is that, despite most people thinking self advocacy is in decline, we found around 100 groups. The bad news is that they are unevenly spread. Lots in the north west of England, very few in the East Midlands or the South West, and, considering its population, relatively few in London.

The List is hosted by Learning Disability England (LDE) and is available on its website <http://www.learningdisabilityengland.org.uk/about/>. LDE is committed to updating the list annually.

We know people are using the List.

LDE used it to recruit new members

The Fellowes Project, led by Katherine Runswick-Cole, Dan Goodley (Sheffield Uni) and Sunderland People First are using it to contact groups for their well-being research.

Jan supplied a copy to the All Party Parliamentary Group on Disability who were seeking to find out what say disabled people have in politics.

The Case Studies

How we did it.

We said we would visit 6 groups with something special to tell us that other groups can learn from.

We decided that we wanted to visit groups with something good to share about one or more of these things:

- Self advocates in charge of the office work
- Groups that get money in a lot of ways, not just grants
- Groups that are good at campaigning for people's rights
- Groups that have changed local policies or how services are run
- Strong Boards and Committees
- Self advocates who get paid to do self advocacy work
- Groups who work with a diverse range of people
- Groups that are run without paid support, or know they could keep running if they couldn't pay for support

We sent this list to everyone on our list and we asked our Reference Group their views. We had seven responses and selected 5 of those as our case studies.

We looked for diversity, using geography, rural versus urban, different emphases (eg campaigning or socialising), local authority versus contract or charitable foundation funded. As we did not have a response from a group in the North West, where self advocacy is strong, we asked to meet with Together All Are Able, based in Birkenhead, because we knew they run without paid support, thus meeting one of our criteria.

We arranged a time to visit, hoping to observe an activity and meet members. This proved quite difficult to arrange given everyone's diaries, but we managed in each place to watch and talk.

The Six Case Study Sites

Name	What is special	Region	Date of Visit
Sheffield Voices	No funding, no office, run by volunteers	Yorks and Humber	6 Feb
Together All Are Able, Birkenhead	No funding, entirely run by disabled people	North West	7 Feb
Dudley Voice for Choices	Funding to rebuild West Midlands Regional Forum Including people with profound and	West Midlands	15 Feb

Name	What is special	Region	Date of Visit
	multiple learning disabilities		
Rotherham Speak Up	<p>Large and long lived group</p> <p>Brilliant easy read resources</p> <p>Parliament</p> <p>Employ 4 people with learning disabilities as core staff</p>	Yorks and Humber	1 April
Ace Anglia, Stowmarket	Coordinate self advocacy across Suffolk – 6 groups	East	17 April

Name	What is special	Region	Date of Visit
	Suffolk PF meet 4 times a year Co-produce Id strategy with Suffolk CC		
Devon Link Up	Coordinate self advocacy across South Devon Strong partnership with Police	South West	25 and 26 April

After the visits Jan wrote a report and sent it to them to check for accuracy. We have sent these reports with this Report.

Lessons for Self Advocacy

Change the way we think and talk about Money

Money was an issue for every group, and lack of money has been widely cited as the cause for a decline in self advocacy. We think it is helpful to change the way we talk and think about money:

From 'getting funding' to 'earning money'

Only one group relies heavily on local authority funding. Four groups generate income from a range of sources.

Alan says The way people go and get their funding in. So people getting out and doing work, and how they get funded instead of getting funded by local authorities. It sort of makes sense to talk about 'earning money' rather than 'getting funding'.

Selling services

Five of the six groups sell services including:

- Easy Read resources
- Inspections
- Consultations
- Education on specific topics like fire safety, Annual Health Checks
- Training – doctors, nurses, social workers, police ...

Funders

Groups have a variety of funders including Local Authorities, NHS, energy companies, Lottery, and other charitable funders.

Fund raising for specific initiatives – like a step free Stowmarket station.

Funding also comes in kind – the free use of Sheffield Virgin Money Lounge is the outstanding example in our sample.

Alan's view: Planning for a disaster [like all self-advocacy funding in the UK being stopped] will make self advocates stronger and do a better job, and not rely so much on the staff to do the work.

It is important to provide evidence of your value

Ace Anglia is the only group we visited which has substantial Local Authority funding. When we asked why, Andrea explained that they save the Local Authority money because *'co-production gets it right first time'*.

Ace Anglia run the local Partnership Board, coordinate Suffolk People First, ensure that the eight local groups meet regularly and run well, and, most important, co-produce the Suffolk Learning Disability Strategy – see

<https://www.suffolk.gov.uk/adult-social-care-and-health/learning-disabilities/joint-suffolk-learning-disability-strategy/>

Rotherham Speak Up has had a long standing relationship with the Local Authority, which recognises the value of the role it plays. They were able to resist loss of funding

when they explained that without some local authority funding they would be ineligible for some other grants.

At every single group we visited people told us that without it, they'd just be sitting at home, doing nothing.

More needs to be done to help groups provide evidence of their social and economic value.

Venues can make a big difference

Venues – where groups meet – matter if the aim is to attract lots of people. And finding free or low cost high quality venues is another way of getting money.

There were outstanding examples of the difference a venue makes.

Sheffield Voices - Over 50 people came to a social event in the city centre Virgin Money Lounge which offered plush surroundings, ten pin bowling, high quality refreshments, sound system and film showing facilities. Regular weekly meetings only

attracted 6 to 8 people. So well attended was the event that the venue managers had to turn people away.

Alan says There are other Virgin Lounges in the UK – it would be good for self-advocacy groups to know about places like that.

Devon Link Up run its Exmouth Group in a leisure centre owned by the Local Authority at a subsidised rate.

Alan says: Devon stood out because they had it in a place with a theatre and ten pin bowling. It was interesting how they run the group there, rather than the office.

Conversely, one group has a cold, out of the way office.

Alan commented: they didn't have what it needed to be adequate or for people to know about them. The facilities weren't very good, run down. Need to look for support to get set up better. Some one-off support to get established.

Groups can survive on very little money

Groups can run without substantial funding if they can find good volunteers.

Two groups we visited had very little money.

Sheffield Voices is led by a disabled volunteer. A larger Voluntary Organisation allows Sheffield Voices to use its name for room bookings etc., and provides a room for a weekly meeting. The larger organisation helps the volunteer apply for small pots of money.

Together All Are Able is run by four disabled people. No one is paid a salary to provide support. The group earns money through selling services, and this money goes to the four Directors. They have an office which costs £1 a year.

Volunteers are important

In addition to the two groups which rely entirely on volunteers, other groups rely on volunteers for some activities.

Rotherham Speak Up paid staff (including paid staff with learning disabilities) support social events outside their working hours because otherwise these events would not happen.

Devon Link- Up relies on volunteers to run its local groups across South Devon.

Doing things for the group for free is good and bad. Good if it means self advocacy happens in places where it would not otherwise. Good because staff and members want to do things for free. But bad if the group relies on people doing essential activities for free that should be paid work. It makes the group hard to sustain if the volunteers give up.

Partnerships Matter

Strong partnerships with other people and organisations are important.

Ace Anglia's partnership with its local authority and clinical commissioning groups stood out for us. It was a route to funding but also local influence. They influence the Learning Disability Strategy by co-producing it. They have money to peer educate people about Annual Health Checks. They recently campaigned successfully for Stowmarket rail station to be step free.

Together All Are Able have close relationships with Pathways Associates (coordinators of the North West Regional Network of self advocacy organisations) and also Learning Disability England. Through these relationships TAAA Directors can influence local and national policy. Three TAAA Directors chaired the 2019 LDE National Conference.

Self advocacy is stronger when networked with similar organisations

Alan: Getting the regions back on the map by self advocacy groups joining up (Dudley). It makes more impact when groups work together.

The loss of the National Forum of People with Learning Disabilities in 2017 was a blow to the connections between self advocacy groups in much of England. But we were pleased to note that this is not inevitable where there is a commitment to maintaining the Regional Forums.

Together All Are Able are connected to self advocacy groups in the North West Regional Forum, supported by Pathways Associates and North West Training and Development Group. They hold an annual conference in Blackpool. We think this is both cause and effect. Self advocacy is stronger in NW England because of the network, but the network strengthens the groups and gives them a much louder voice.

Ace Anglia maintain relationships with groups from the old Eastern Region, in Hertfordshire and Norfolk. These groups fund their own participation.

Dudley Voice for Choices has raised National Lottery money to revive the West Midlands Forum, and were in touch with 11 groups.

Self Advocacy can be a route to paid employment for people with learning disabilities
Rotherham Speak Up has four long standing employees with learning difficulties who are salaried staff members carrying out a range of duties.

Another self advocate in Rotherham had graduated to paid work as a chef after developing cooking skills in the group.

Dudley Voice for Choices has one self advocate employed in the office and had advertised for 2 more.

Devon Link Up have 2 Safer Places workers

People were paid on zero hours contracts as

- Trainers – of police, health and social care staff, energy companies etc.
- Inspectors – of registered care homes, working for CQC and Local Authorities.
- Care and Treatment Reviews

- Experts by Experience on consultations and enquiries, such as LEDER – investigation of premature deaths.
- Easy Read advisors.

Diversity

We were disappointed that diversity – attracting people from Black and Minority Ethnic Groups, gay, Lesbian and bisexual, people with profound and multiple learning disabilities – was not a high priority.

Two examples suggest that the way to do this is through partnerships with other organisations.

- Rotherham Speak Up work with New Life who represent young Asian women with learning disabilities. They share some activities. They reported that understanding on both sides has improved.
- Dudley Voice for Choices work with local centres who support people with severe and profound learning disabilities. Four times a year they ask the staff at

these Centres to consult their clients about issues for consultation. These are reported to the Partnership Board.

Ideas for the Future

We asked each of the Case Study groups for ideas to improve self advocacy in the future. Everyone's ideas involved more opportunities to share ideas and resources.

Share resources

"We all produce brilliant easy read information. We need somewhere where these can be stored so everyone can benefit."

Alan said It would be good for other groups to know where Safe Places are. They'd know if there was a list of groups doing Safe Places. Also, if someone else wanted to do it, they could contact groups who have done it.

Share ideas for getting money

“We have money from the NHS to raise awareness of Annual Health Checks. We have shown our bid for this work to our neighbours and now they are applying for money to do the same in their area.”

Share what we do

“We are really looking forward to your report so we can learn from other groups and what they do well.”

Quality assurance for self advocate produced resources

“A brand that self-advocacy groups can use to show that the service is being delivered by a self-advocate-led organisation, and promoting that brand nationally to procurement officers.”

Final Thoughts

We are very grateful to everyone who took part in this project. We met some fantastic people and we were reassured that there is plenty of life in self advocacy, and that it really does change lives. In fact we ended by thinking that it is an exciting time for self advocacy – and more people need to shout about it.

We think more work of this kind will help self advocacy grow stronger. There are lots of groups doing amazing things that we did not visit.

We plan to take this Report to Learning Disability England who might be able to take some of the ideas for sharing resources and ideas forward.

Thank you RTR for your generous funding.

Thanks to the Groups who welcomed us.

And thanks to our fantastic Reference Group.

Jan Walmsley

Alan Armstrong

June 2019

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