



# **Rethinking Advocacy**

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#### Introduction and Context

In 2011 Inclusion North and NHS North East began a project to better understand the provision of advocacy for people who were accessing assessment and treatment services across the North East. The project was an initial response to the many horrifying issues raised by the abuse at Winterbourne View. As the project developed the focus and scope moved to understand advocacy provision in our communities in general. Inclusion North supported the following initiatives

- Who Cares the production of a report that outlined the need for better developed professional advocacy and the inclusion of other forms of advocacy including self advocacy and peer advocacy.
- The development of the Advocacy Hub an innovative approach to commissioning advocacy in a local region offering a range of advocacy supports coordinated locally
- A project supporting Self Advocacy groups across 6 local authority areas supporting self advocacy initiatives in restrictive environments such as assessment and treatment services
- The development of the Top Ten tips for delivering advocacy in specialist services for people with learning disabilities.

You can find all of this work at -

http://inclusionnorth.org/projects/what-we-are-doing-now/advocacy-project/

http://inclusionnorth.org/resources/information-packs/self-advocacy-project-funded-by-the-department-of-health/

This report is based on the 4 years work as described above and a further series of consultative workshops held in both the North East region and the Yorkshire and Humber region in May 2015.

The model outlined here is coproduced with key stakeholders across both regions. The paper proposes a change in the way that advocacy is delivered and commissioned.

Kate Fulton Inclusion North 2015

#### Why a rethink?

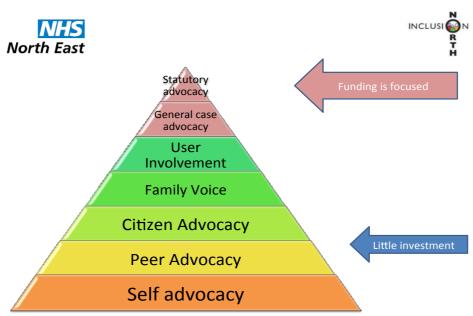
**Figure 1 Investment in Advocacy** 

'Advocacy promotes social inclusion, equality and social justice. It takes action to help people say what they want, secure their rights, represent their interests and obtain services they need'.

(Advocacy Charter 2002, Action for Advocacy)

The learning over the last 4 years has helped national and specifically the two regions build up a picture of the current advocacy arrangements, the delivery and commissioning of advocacy.

One way of understanding this is depicted in the following graphic Figure 1 Investment in Advocacy. There are a range of models of advocacy, however most of the funding currently spent is largely invested in professional advocacy (some of which has statutory duties). Regional discussions would suggest that this picture is mirrored nationally.



Another way of exploring the current advocacy provision is in line with the recent classifications of support and intervention as described in the Care Act 14<sup>1</sup>

**Primary** - **Prevention** / **Promoting Wellbeing** – universal services that aim to maintain independence, good health and promote wellbeing.

**Reduce** - **Secondary prevention** – targeted services at people who have an increased risk or developing need.

**Delay – Tertiary prevention** – services and supports aimed at minimizing the effect of disability for people to manage or reduce needs.

<sup>&</sup>lt;sup>1</sup> Care and Support Statutory Guidance, Department of Health 2014

#### **Tertiary prevention / Professional Advocacy**

This above picture depicts the most popular forms of advocacy currently being commissioned. They are primarily 1-1 short-term interventions, with a 'professional advocate'. Typically they are issue based and focused on protecting people's rights and voices in their relationship with systems such as IMHA – Mental Health system, IMCA – the social care and legal system.

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. A typical professional advocate in 1 year can work with approximately 100 people with individual people cycling through referral and re-referral as and when they face another issue in their interaction with the system or state<sup>2</sup>.

In both the North East and Yorkshire and Humber regions professional advocacy is funded, however all Advocacy Providers involved in this project reported it is still not enough to adequately support all people. Many Advocacy Providers argued they are insufficiently funded and are always operating at maximum or over capacity.

Professional advocacy is clearly needed, there is much evidence to support this, however rethinking how this operates is important if we want advocacy for all.

Provider Advocacy is another form of professional advocacy. This is the person's Support Provider taking an active role in advocating on behalf of the person they are paid to support. Historically this approach been seen to be inappropriate, on the basis that Providers are seen to have a conflict of interest. Nonetheless most Providers will say advocacy skills and 'looking out for people' is inherent in their role and function. Northumberland County Council recently included advocacy requirements in all new contracts for service provision.

#### Secondary Prevention / Self and Peer Advocacy

There are a range of approaches that we have grouped as secondary advocacy – these are typically less formal and are focused on investing in the person and or their family / allies to learn their rights and advocacy skills. Self Advocacy is focused on investing in people to speak up for themselves. Peer advocacy is where an individual with similar or shared experience advocates alongside or on behalf of a person. Family Advocacy is where family members advocate alongside or on behalf of their finally member.

<sup>&</sup>lt;sup>2</sup> Figures based on a Durham CAB an Advocacy Provider.

The more informal forms of advocacy such as self advocacy, family advocacy and peer advocacy can reach many people, have a longer term connection and cost less to resource, as evidenced by the Personalisation Forum Group (PFG) and Duffy.<sup>3</sup>

Furthermore, for people whose communication systems can be difficult to fully understand i.e. no verbal communication, it is often only their family members or those very close to them who know them sufficiently well to be able to accurately interpret their indications and understand their likes, dislikes, wishes and aspirations. In these situations secondary advocacy becomes an essential component in the support of their wellbeing.

Importantly VODG 2012<sup>4</sup> argued that all advocacy approaches have an essential role to play in preventing, detecting and responding to abuse, enabling people to understand their rights and have the confidence to promote them.

Speaking up Rotherham a self advocacy organisation reaches a significant amount of people annually and is focused on building the skills, capacity of individuals to self advocate. Their focus is developing the person to advocate for themselves on a daily basis in all aspects of their lives. In discussion with regional advocacy partners it was argued that Self Advocacy groups can also offer a level of safeguarding for its members given their long term connection. This approach is also likely to increase people's friendships and the opportunity for meaningful connection in communities<sup>5</sup>.

Equally peer networks designed to support carers or family members reach and connect with a significant amount of people offering a further layer of informal advocacy support and assistance as demonstrated by Newcastle based Pass it on Parents.

#### **Pass it on Parents**

Pass it on Parents<sup>6</sup> is a peer advocacy network of families of disabled children in Newcastle, whose aim is to equip parents with information and when needed a buddy (peer advocate) to enable their disabled child to achieve the best outcomes in their life. This is a form of family advocacy and peer advocacy the purpose of which is to educate and share families lived experience. The experience includes interactions with the state and its' systems as well as in life in general. After operating for 3 years there are over 800 parents connected to the network – the cost of such an initiative we believe is significantly lower if compared to a Professional advocacy approach attempting to reach this amount of people.

Citizen advocacy is based on recruiting and supporting volunteers to partner with a disabled person (or a person considered to be vulnerable) to develop an ongoing advocacy relationship. Citizen advocacy support often includes recruitment support,

<sup>&</sup>lt;sup>3</sup> Peer Power, Duffy, The Centre for Welfare Reform, 2012

<sup>&</sup>lt;sup>4</sup> VODG, Voice Ability Advocacy: A voice for the future. 2012

<sup>&</sup>lt;sup>5</sup> Peer Support, Fulton and Winfield, The Centre for Welfare Reform, 2011

<sup>&</sup>lt;sup>6</sup> www.centreforwelfarereform.org/library/by-az/pass-it-on-parents.html

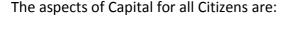
training and support for the volunteer, matching facilitation and ongoing low level problem solving. There is little citizen advocacy available across the regions.

However again this is a model that costs significantly less than professional advocacy and has long term investment.

#### **Primary Prevention / Community Advocacy**

In a context where austerity measures are significant the need to build citizens knowledge and understanding about their rights is important. Having access to support to promote their rights and have connections to others at times of difficulty is crucial, particularly in relation to our most vulnerable citizens. To have connections beyond that of the state or welfare services is essential, not only on an economic basis but for some people who have no access to formal services, informal connections in local communities may be the only approach that can support their safety and wellbeing – local people looking out for neighbours.

One way of viewing this is to reflect on the range of resources that any citizen needs to enable them to live safely and well, in their local communities. Investing in a person's skills as well as broader connection builds a person's own capital or 'wealth', as defined by Bonyhady, Fulton and Walker 2013<sup>7</sup>. Building people's capital can range from investing in their own resources such as self advocacy skills to building and facilitating people's connections with others, such as peer advocacy networks.





**Personal Capital** - a person's resources in themselves and their ability to assert themselves, inner strength and reliance

**Knowledge Capital** – a person's skills, knowledge and ability to use their knowledge for action

Material Capital – a person's resources and material goods

**Social Capital** – a person's relationships and connections

### **Figure 2 Capital for Citizens**

<sup>&</sup>lt;sup>7</sup> A Personalised Approach to Safeguards in the NDIS. Bonyhady, Fulton and Walker 2013.

Although not exhaustive they may include:

**Personal Capital** including self-esteem, confidence, cognitive and intuitive capacity, ability to self-advocate and be present and their inner strength and resilience

**Knowledge Capital** including skills, and general / specialist knowledge and the ability to access information from people, the internet and the community and to act on this information

**Social Capital** including relationships, family support, friends and community connections.

**Material Capital** including income, material goods, own home and community resources e.g. library, beaches, parks, which vary depending on location.

This definition of capital makes it possible to learn what it takes for all citizens to live well and have safe lives. Considering how each advocacy approach invests in the various aspects of people's capital it is likely that the more informal approaches offer a broader and more substantial investment in people's wealth overall.

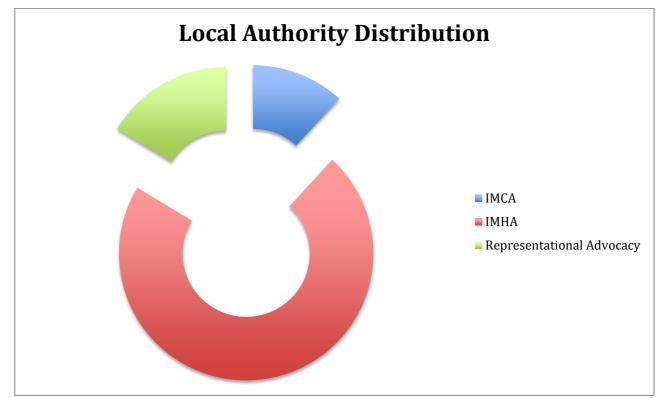
Given this perspective it is vital that we support people's ability to connect with community groups and networks outside of welfare services. Prevention and early intervention proves consistently to offer local communities and its citizens sensible interventions that build their own capacity, skills and knowledge to tackle life as autonomously as possible.

In this context the approaches that we consider to offer Community Advocacy are local groups or networks that build people's connection to each other and community. These are often content based ie a shared interest such as exercise, craft, leisure or faith. There are many examples of these across the region including Knit and Natter groups, Stitch and Bitch, Geordie Mums. These networks offer connection with local people regularly. Empirical evidence is limited across the country on how these approaches support people's capital, however local discussion suggest that community advocacy has supported many vulnerable people for many years with successful outcomes.

#### **Rethinking Advocacy Commissioning**

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 fulfills statutory duties.

An example of how one Local Authority is currently distributing resources is described in the following graphic, depicting 100% of the current funding is targeted at Tertiary prevention or Professional Advocacy. There is no 'advocacy' funding supporting the other layers that are necessary.



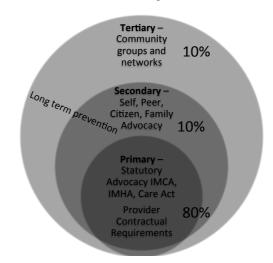
**Figure 3 Local Authority Distribution** 

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. The following model propose one way of distributing the resources in a way that will reach more people and invest in people and communities. This is based on local exploration and figures are estimates to simply suggest an alternative perspective in resource allocation.

Tertiary Advocacy - 80 % of the current resources invested in formal / statutory advocacy for services such as IMCA, IMHA and the recent addition of Care Act Advocacy. Funded by the Department of Health. Secondary Advocacy – 10% of the current resources invested in the more informal advocacy approaches including self advocacy, peer advocacy, family advocacy and citizen advocacy. Funded by the Department of Health.

#### **Figure 4 Future Advocacy Distribution**



**Primary Advocacy** – 10% of the current resources invested in community networks, community groups that all citizens can access. Funded or subsidised by various sources including councils and health and voluntary sector grants.

An investment in the current resources across the Secondary and Primary areas is an investment in long term prevention.

Other areas of preventative and early intervention teach us that real attention to this area is believed to have an impact on the reduced demand of the primary advocacy. This form of smart commissioning could over time readdress the investment as Figure 4 demonstrates.

In addition this approach could lead to reablement and improved outcomes for individuals with less reliance on an overstretched health and social care system, promoting autonomy, choice and control.

#### **Rethinking the practice of Professional Advocates**

Given the current context that Professional Advocates are operating in, there is a need to rethink how professional advocates practice to ensure they contribute to building people's capital. There are various ways that we could do this including:

- Developing and investing in natural allies
- Standard and routine connection to long term preventative approaches
- Building and investing in people's capital

#### **Developing natural allies**

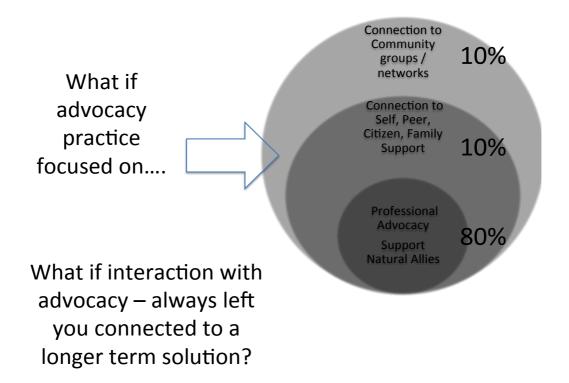
Advocates could support the development of people's natural allies (where appropriate) be it family members, key support staff, key friends, the people connected to the person, who long term with some support, can take an active advocacy approach. The advocate could take on a coaching role to invest and support those natural allies to develop knowledge and advocacy skills to assist the person now and in the long term – using professional advocacy services as more of a support service than the only advocate available to the person. Natural Allies developing may also include family advocacy skills workshops, navigating the system or rights information.

#### **Connection to long term prevention**

Instead of the revolving door model of people accessing formal advocacy as and when issues arise for the rest of their lives. What if access to professional advocacy resulted in not only in people's immediate issues resolved, but a connection to a longer term approach that will invest in building the persons skills and capital such as connection to a local self advocacy group or network.

This model of practice is not in itself a difficult model to introduce but is dependent upon the other options being available in local communities. Advocacy Providers themselves could distribute their internal resources and effort with an investment in secondary and tertiary advocacy. The Advocates practice could focus on connecting with the person's natural allies or the informal advocacy that's available locally. This thinking could also apply to the use of funding for Professional advocacy.

An example may include using funding allocated which would ordinarily fund a Professional Advocate whilst utilizing that money differently i.e. to support 80% of a Professional Advocate model and the other 20 percent to support the development of self or citizen advocacy.



#### **Figure 5 Refocused Advocacy Practice**

#### **Conclusion - Supporting advocacy for all**

This paper is an invitation to explore and push our thinking beyond what we know about existing advocacy models, but to think creatively about how we use scare resources to provide advocacy for all **and** provide investment in citizens themselves over time. The demand for advocacy is significant however we believe there is a need to shift our focus to enable investment into early intervention and prevention. Requiring funding that is ring fenced for advocacy better distributed across the primary, secondary and tertiary approaches.

The paper outlines an early model of advocacy practice and advocacy commissioning that we believe is worth exploring further. Our recommendation is to test the model in practice and further develop its practical application. A local pilot will fully explore the merit and economical viability of this approach. This will require collaborative leadership across the statutory, advocacy and community sector, which has strong foundations in both regions.

The paper is a culmination of discussion, thought and exploration across the two regions North East and Yorkshire and Humber involving disabled people, family members, a variety of advocacy providers and commissioners. It highlights the collective voice for change. Change in our approach to ensure some of the most vulnerable people have access to support that not only protects their rights, but also invest in people, connected to their communities.