

# CHAPTER 5: EFFECTIVE VOICE - SELF ADVOCACY/ADVOCACY

“When the world is silent, even  
one voice becomes powerful”

Malala Yousafzai

Malala Yousafzai is a Pakistani advocate and activist for female education and the youngest Nobel Prize laureate.

# WE ASKED AND YOU SAID

People with learning disabilities and/or autistic people often face barriers making or informing key decisions in their own lives. When we asked people what a good life would look like and what was important to achieve this, self advocacy and access to independent advocacy was a recurring priority. Some of the responses we received were;

Experience is more important than qualifications

Let people take risks

We need to raise awareness of our rights, using the law

We need easy read, accessible information

Be inclusive: if it is about people with a learning disability it should be led by people with learning disabilities

People with learning disabilities should be paid for the work they do and the knowledge they bring

Use respectful language (no service user)

Include people with profound disabilities

We may have different ideas than our families

**“Be my microphone not my voice”**

Dave Hingsburger, campaigner, writer, powerful advocate and public speaker.

## HUMAN RIGHTS FRAMEWORK

The right to freedom of expression is enshrined in Article 10 of the European Convention on Human Rights.

The UNCRPD provides a more detailed account of the rights of disabled people in Articles 5 and 17.

## ARTICLE 5 – EQUALITY AND NON-DISCRIMINATION

- 1 States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
- 2 States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- 3 In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
- 4 Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

## ARTICLE 17 – PROTECTING THE INTEGRITY OF THE PERSON

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

You can find more information about these rights [HERE](#)

# HUMAN RIGHTS FRAMEWORK

# IDEAS WE CAN WORK ON TOGETHER?

We have gathered ideas of things we can work on together to improve the lives of people with learning disabilities in the areas they said are important to them and their families. Some of the initial ideas are:

- Inclusion in decision making – revive ‘nothing about us without us’ ensuring peoples views inform decisions that affect them. Make sure this includes Black Asian Minority Ethnic people as well as those with higher support needs. All means all
- Ensure readily available accessible information so people have the same opportunities and can make informed choices based upon good information.
- Create a national network to work alongside national decision makers. Co-ordinating and amplifying local advocacy work ensuring maximum impact on national policy and practice.
- Collate evidence on the impact of self / peer advocacy. Make this publicly available.
- Highlight the need for investment in training / skills for leadership roles and for learning disabled self-advocates at the same level as non-disabled employees in health and social care.
- Investment in advocacy and self-advocacy by all local and national agencies where decisions are made that impact on people with learning disabilities
- Implement models like Making it Real markers to ensure contribution to quality and accountability in local services
- Increase human rights awareness through increased collaboration with Human Rights based organisations such as the British Institute of Human Rights.

# WHAT GOOD MIGHT LOOK LIKE (HOW WILL WE KNOW WE ARE ON THE RIGHT TRACK)

## GOOD EXAMPLE 1

The Filling in the Gaps report describes research by The Open University on the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the coronavirus pandemic. In July 2020 the researchers spoke to staff and members of 11 self-advocacy groups, representing all regions of England, to find out what they had been doing to support members during lockdown.

The breadth and depth of their work during the pandemic was impressive. Self-advocacy groups responded very quickly, moving much of their work online while also providing essential offline support, and face-to-face practical help where required. The research showed how and where self-advocacy was ‘filling in the gaps’ left by other services.●

“So I’ve had to spend ages looking for the accessible copy, easy read copy, and I’m like thank god for that, because I can truly understand it. Because from the official one you’re like, I was like what does this truly mean? ... This is the thing, it’s like in a pandemic you shouldn’t have to ask for something to be made accessible” Self-advocate ●

## GOOD EXAMPLE 2

The Making Sense of Self Advocacy Today report detailed the state of self-advocacy for people with learning disabilities in England in 2018-19, and provided suggestions for how to strengthen it. One example was Ace Anglia's work with its local authority and clinical commissioning groups which highlighted the benefits of partnership working. This arrangement provided both a route to funding and local influence, including co-producing the Learning Disability Strategy and securing funding to support peer education in relation to Annual Health Checks. They also successfully campaigned for Stowmarket rail station to become step free.

“It sort of makes sense to talk about ‘earning money’ rather than ‘getting funding’”

Self-advocate

### GOOD EXAMPLE 3

The Keeping People Connected project was co-designed and delivered by 12 local community organisations across Cumbria and the North East, in response to the first wave of the Covid 19 pandemic. The North East and Cumbria Learning Disability Network and Inclusion North provided leadership and co-ordinated the project.

Keeping People Connected was designed to help people with a learning disability or autism to understand information from the Government, connect with others to avoid isolation and get the support needed for other things in their lives.

Keeping People Connected was unique in so far as it enabled support at right time preventing issues escalating. There were no eligibility criteria, and while it was aimed at people with learning disability and/or autism there was no formal assessment to gain access. It was delivered entirely by Community Voluntary Sector organisations around North East and North Cumbria.

# WHO DO WE NEED TO ENROL/ENGAGE?

As can be seen by the range of ideas we can work on together some, such the creation of a national network alongside national decision makers may require funding and co-ordination at a government level. Strong advocacy will be required to push this agenda.

Others, such as increasing human rights awareness can be progressed relatively quickly through concerted citizen action. Also, by strengthening alliances with skilled and knowledgeable human rights organisations.

Good practice examples can be used to recruit local authorities and clinical commissioning groups receptive to the positive potential of partnership working.

## NEXT STEPS/FIRST STEP

There are several initial steps that can be taken by just agreeing this is the way we want things to be and standing up and asking.

### FOR SERVICE PROVIDERS

Increase the opportunities for self-advocacy organisations to learn and share to grow capacity.

### FOR GOVERNMENT

Support the development of self advocacy national networks through the disability strategy. Ensure self advocates or user led organisations are a part of all work on policy that affects peoples lives.

### FOR ALL NON DISABLED PEOPLE

We can check when we are invited to speak at events/ activities that are about, or impact on people, with learning disabilities, that people with learning disabilities are contributing to, if not leading the event/discussion. If not, we can ask that this is addressed.

### FOR COMMISSIONERS

Co-ordinate a single place to share the excellent accessible and easy read resources.

Share ideas for 'earning money' to support the development of advocacy and self-advocacy.

### FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Develop a clear brand for self-advocate produced resources, with a quality standard that can be used to show that the service is being delivered by a self-advocate-led organisation.

Look at how voice or advocacy groups are representing all local people including people with high support needs and from Minority Ethnic Communities ●