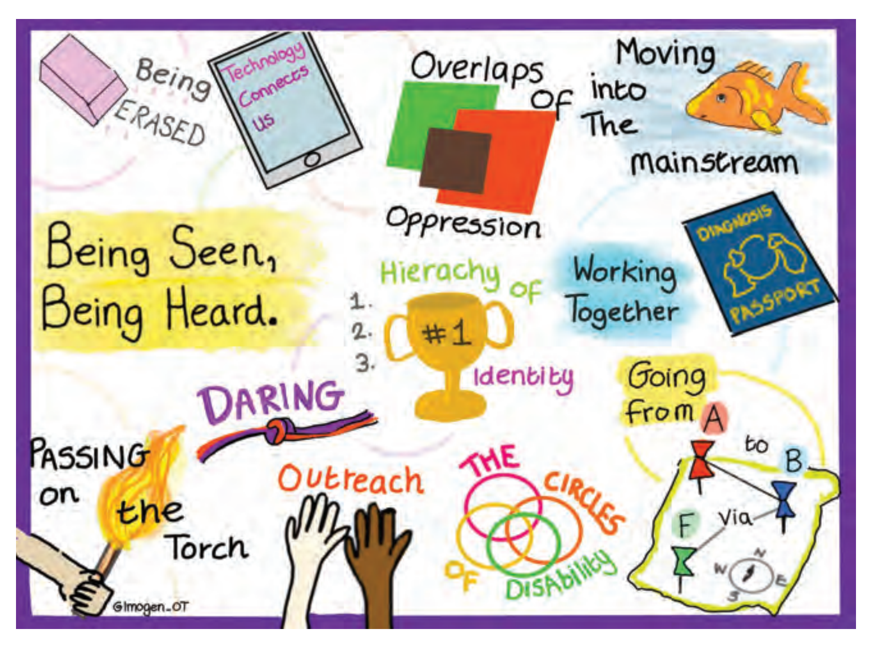
BEING SEEN BEING HEARD



#visual minutes by Imogen Kate @Imogen_OT, 2020.

A Resource for Voice, Rights and Empowerment of Disabled Children and Young People

EDUCATION NOT SEGREGATION

COMMUNITY FUND

RIP STARS

Foreword

Hello we are the RIP:STARS, working in partnership with the Alliance for Inclusive Education.

RIP:STARS stands for Research Into Practice: Skilled Team with Ambition, Rights and Strength. We are all disabled young people aged 18 to 25 and we are from Coventry, in the West Midlands of England. We started our research group in 2017 because we wanted to try and make a difference to young people's lives.

Since then we have tried to change how people view and treat disabled young people through our research, training and activism. You can learn about our work on our website www.ripstars.net

The RIP:STARS work is different because it is research about young disabled people done by young disabled people. We lead everything in our research projects, and we make our own decisions about what we do, and how we do it. We work within the Social Model of Disability and a rights-based approach to challenge any barriers we face as young people, and as disabled young people. We know that we have rights, and that disabled children and young people have to fight for their rights every day.

ALLFIE (Alliance for Inclusive Education) was set up in 1990, and is an organisation led by Disabled people. ALLFIE campaigns and lobbies for inclusive education within mainstream settings. Over the years ALLFIE has led work to help promote and raise awareness to the wider society about the importance of inclusive education in helping to create inclusive communities. For more information about ALLFIEs work visit their website: www.allfie.org.uk

The Being Seen, Being Heard project was funded by the Big Lottery. In this project we partnered with ALLFIE to co-produce this project, it was important to work with a Disabled Peoples organisation because we wanted to learn from Disabled People Led Organisations. We wanted to hear about the history of the Disability Rights Movement. We wanted to learn about how Disabled People have fought for their rights and won rights in some areas but in other areas rights are still denied. We wanted to see if our struggles in education and in life in the year 2020 are the same or different to older generations of disabled people. As disabled young people we are not taught about our history or our rights. We think this is very wrong and believe it should be part of the curriculum.

Being a RIP: STAR has been all about making our voices heard, speaking up, having confidence and becoming empowered as young disabled people. If you are a disabled young person reading this we hope that this resource helps you to see that you are not alone, you are not a 'problem' or something to be 'fixed' or someone to be 'excluded'.
You have rights, you have a voice and you have allies.

We wish to thank the following disabled activists who have supported us, and who gave their time to us freely:

Seán McGovern, Tara Flood, Michelle Daley, Ruth Bashall, Iyiola Olafimihan, Yewande Omoniyi, Rebecca Yoe, Mark Harrison, Zara Todd, Lani Parker, Justine Jones, Saâdia Neilson, Rachel O'Brien, Peadar Odea, Andrew Lee, Bob Williams-Findlay,Miro Griffiths, John Kelly, Armineh Soorenian and Joseph Whittaker.

We would also like to thank Stephen Hodgkins for his fantastic graphics and to Nic Crosby for his digital notetaking during the workshops.

We would like to dedicate this resource to Seán McGovern who sadly passed away in 2020. Seán shared his experiences of activism with us, he inspired and encouraged us. We are thankful to have met him.

The RIP:STARS for this project are: Ben, Eva, Jordan and Tom.

The RIP:STARS are supported by Anita Franklin (University of Portsmouth) and Geraldine Brady (Nottingham Trent University).

The Being Seen, Being Heard Project

You might be reading this and wondering who you are, how you fit in, or what your future life might be. You might sometimes feel angry, lonely or that you have experienced injustice and discrimination but you don't know what to do about it.

This resource has been developed to guide you on your journey and introduce you to a world of possibilities. You know the saying 'hindsight is a wonderful thing?'

Well, we have asked disabled people to look back and think about their life, their journey, and how they became activists and disabled leaders. We wanted to learn from them. We found out that they also wanted to learn from us.

We brought together disabled people from across generations, with different lives and experiences to talk about the barriers disabled people face and what disabled people have done to challenge discrimination. We also wanted to talk about what still needs to be done, and how young disabled people can fight for their rights.

Disabled activists aged from 18 - 70+ years came together in five workshops during 2019/2020 to create change. We worked with ALLFIE to plan, design and deliver the workshops. We talked about how we can:

learn from the past to create future opportunities

challenge negative stereotypes about who we are as disabled people

work together across generations to fight for equality, inclusion and our rights.

In this guide we hope to offer you some brilliant insights that might inspire and encourage YOU to become an activist, or join a disabled young people's group or the Disability Rights Movement. And to realise that you are not alone and you have allies all over the world.

Or, as a starting point, to think differently about disability and discrimination. To support you to speak up for your rights, inclusion and independence, and be part of decisions being made about you.

Discrimination of disabled people – Why activism is important...

Despite there being laws to protect disabled people across the world, many disabled people continue to face discrimination and are treated differently or badly. Below are some examples:

- **Many disabled children and young people do not receive the support they need in school, college or university.**
- **Many disabled children and young people do not get opportunities to be part of their local community.**
- **Many disabled children and young people have to wait a very long time to get help with things like speech and language therapy or physio, many do not have wheelchairs that are the right size for their age.**
- **Disabled children and young people are much more likely to be bullied than non-disabled children.**
- **Disabled children and young people are much more likely to be excluded from school, college or university.**
- **Disabled people are twice as likely to be unemployed as non-disabled people.**

These differences are often due to negative and prejudiced attitudes, and barriers such as inaccessible buildings, inaccessible transport or not being given information, all of which stops disabled people's full inclusion in society.

Many thousands of disabled children and children with Special Education Needs (SEND) are 'awaiting provision' which means a place in school or college. Thousands of disabled children and young people end up being educated at home because schools or colleges do not meet their needs.

During the Covid-19 pandemic, many disabled people had a difficult time getting food or medicine and much of the information published by the Government was not made accessible to disabled people. For example, many people campaigned because there were no British Sign Language (BSL) interpreters at Government briefings about Covid-19, leaving disabled people disadvantaged. Many disabled people have said that they felt abandoned during the pandemic, with many having their care and support cut.

The facts above are difficult to learn about, they made us angry and they are the reasons why we need change.

During the Covid-19 pandemic and first lockdown in England (Spring/Summer 2020), ALLFIE distributed a survey to find out about the impact on Disabled children and young people's education. The findings showed that:

83% of parents were expected to home school their disabled children, yet 54% of parents had not received any support from either the local authority or school to help with home schooling, and a further 34% of parents had received some (but not a sufficient level of) support to help them.

https://www.allfie.org.uk/inclusion-resources/allfie-survey-report-coronavirus-impact-on-disabled-peoples-education/

Although the government announced that they have put money into supporting home-schooling and providing laptops, the support is not accessible for many who are disabled. Many children and young people require assistive technology, adaptive hardware and support in order for them to use technology.

https://www.allfie.org.uk/campaigns/coronavirus-covid-19-and-disabled-peoples-education/

The experience of the pandemic for disabled children and young people has been very difficult, with physical distancing and restrictions impacting on the level of support and services that they receive. This has meant a year of loneliness, isolation, mental health needs, and further exclusion from education, friendships and society which we know will take a long time to recover from.

The effect of the Covid-19 pandemic on our research project

After piloting our face-to-face workshops with Disabled leaders, we started to plan more workshops and then the country went into lockdown. This impacted on how we planned to deliver the project, so we agreed to deliver the workshops online. At the time everyone was new to working online so we were concerned with how this would work but we were surprised with the number of Disabled activists that engaged in the project. Initially we expected 12 people but we ended up with 19 leaders. Meeting these people for the first time online was not easy for us and we would have preferred to have physically met them – but we are grateful to them and the workshops were very successful. We collected a lot of information.

Learning our History

There are many disabled activists around the world fighting for change. Their struggles, stories and their successes have inspired us to fight – however, small or big we can all make a difference. We think it is important to learn about these struggles and successes.

Here is a timeline of important names, events and laws in the history of disability rights in the UK and it was great hearing the Disability leaders mention some of these defining moments in history which they had been a part of, such as the fight for disability discrimination legislation.

Learn from history; it is still relevant today and relevant to what we are still fighting for.

1913 Mental Deficiency Act required children and adults who were identified as 'defective' to be institutionalised (separated/locked up away from their community)

1939 The Nazi euthanasia programme murdered 240,000 disabled people.

1970 The Chronically Sick and Disabled Persons' Act required local authorities to improve services for disabled people.

1972 The Disability Rights Movement is born - Paul Hunt's letter is published in the Guardian newspaper calling for equality for disabled people and asking others to join him. His letter inspires the start of the struggle against discrimination.

1970s Disabled people created the 12 Pillars of Independent Living.

1976 Union of Physically Impaired Against Segregation (UPIAS) was set up, the first organisation to argue for a **'Social Model of Disability'.**

The social model of disability says that people are disabled by social barriers, not their health issues or impairments. It is the social barriers that disabled people face that restrict them from taking part in society, not their diverse bodies or minds.

1978 The British Council of Disabled People's Organisations was set up to campaign for Disabled people's rights.

1981 International Year of the 'Disabled' - An international conference in this year, which attempted to exclude Disabled people from its discussion. This led to the first global network of Disabled people known as 'Disabled People's International' with a slogan **'Nothing About Us Without Us'.**

1981 The Education Act paved the way for the inclusion of Disabled children with 'special needs' during the United Nations International Year of Disabled People.

1991 The UK Government ratified the UN Convention on the Rights of the Child – disabled children are hardly mentioned but it does give children rights to be involved in decisions being made about them.

1982–95 There were 17 attempts made to introduce legal civil rights for Disabled people.

1995 The Disability Discrimination Act (DDA) made discrimination against disabled people illegal and was an important step forward in the campaign for full civil rights for all disabled people.

2000 The Disability Rights Commission was set up with disabled people forming a majority of its commissioners.

2009 The UK Government ratifies the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

2010 The Equality Act came into force which legally protects people from discrimination in the workplace and in wider society. It sets out the different ways in which it is unlawful to treat someone.

2014 The Children and Families Act came into force, introducing **Education, Health and Care (EHC) plans** for Disabled children & young people 0–25 years. EHCPs outline educational provision to the meet the needs of a child or young person. They are meant to secure the best possible outcomes for children across education, health and social care, and to prepare them for adulthood. Disabled children and young people were given the right to be included in the development and review of their EHCP.

2014 The Care Act states that councils need to assign a personal budget to all people who are eligible for support. The personal budget is the amount of money needed to cover the cost of the support for which a person is eligible.

2017 UNCRPD Committee published its Concluding Observations based on the first monitoring of the UK Government's implementation of the UNCRPD. The Committee's findings were damning and said that the Government's current approach to Disabled people in the UK is causing a **'human catastrophe'.** The Committee also reminded the UK Government that inclusive education is 'not a choice, it is a human right'.

2019 The cross-party Education Select Committee Inquiry on SEND (Special Educational Needs and Disability) was published. It states that a generation of disabled children and young people have been let down by the implementation of the Children and Families Act and that EHCPs and the support they are meant to secure has not been provided to disabled children.

2021 We are still waiting for the full government response to the SEND Inquiry... Another generation of disabled people have to fight for inclusion.

The events above are all regarded as significant steps on the way to aiming for the equal treatment and inclusion in society of disabled young people. The rest of this resource describes what the generations of disabled young and older people who came together in our project learnt from each other during their workshop discussions.

This resource is now divided into four themes which emerged from our workshssions.

- **Becoming Aware**
- **Building Your Leadership Skills**
- **Building a Culture and Making Change**
- **Practical steps to bring generations of disabled people together**

We have used our shared experiences and our words in this resource. We have included the words and ideas of the activists - some of these were new for us but we think it is important to learn these and to use these in our own fight for our rights.

Becoming Aware

We started our workshops by asking the leaders:

How did you first become aware that disabled people could be discriminated against (treated unfairly because they are seen to be ‘different’)?

Many of their memories related to starting school. Some went to mainstream schools and some to special, segregated schools (a school just for disabled pupils). They remembered **not being allowed to do** the things that other children could do or being told that it was not possible to adapt things just for them.

People in the workshops described how they had been described in negative language such as a ‘walking disaster’ while many spoke about how they gradually came to realise that they **were treated as ‘less than’, and as ‘different’.** One told us about moving from a special school to a mainstream school and realising that there were suddenly a lot more opportunities available to them.

As RIP:STARS, we also felt that going to school was a defining moment for us too, and often things were really hard. For some of us, the classroom environment just did not work and **teachers often did not listen** to what might have improved things. We felt lost in the system – a square peg in a round hole, when maybe the hole just needed to change shape a bit.

One of us realised that we needed to go from A to F to get to B, whilst other students seemed to just go straight to B. At this early stage discrimination was often a feeling that did not yet have a name - we just knew we were being treated differently and unfairly. **What was being felt was oppression** but this is not a familiar term to most young disabled people. It just felt wrong and made us angry and upset, but we did not know what we could do about it.

We wanted to learn how disabled young people can go from being angry and often feeling alone in being discriminated against to feeling that they can change things and **make a difference.** We were interested to know from the disability leaders:

What or who inspired you to make a difference?

One leader described how they were exposed to the disability rights movement when they became involved in a project for disabled young researchers similar to the RIPSTARS, finding out that it was possible to make change and meeting inspiring disability activists. Another did not consider themselves disabled at the time of being inspired, but they had learnt about **Human Rights** and become involved in other rights movements and only later on became a disability activist.

One leader had a mum who was a feminist and was involved in politics through her community work, from an early age this leader was encouraged to think about her own **discrimination** and also discrimination on a wider perspective. The clear message was that activism in one community overlaps with others. Disablism, racism, sexism, ageism, homophobia are all rights issues.

It doesn't matter who inspires you, or how you become inspired, just get out there and be part of the fight for rights and for change.

Building your leadership skills

We know it is one thing to feel angry and to want to change things but it is not easy to do when you are on your own, or living in the middle of nowhere. So we asked the leaders from the disability movement:

What barriers did you face in becoming a leader/ activist and how did you overcome them?

And very importantly:

What barriers do you think disabled young people face in becoming disability rights defenders?

Many of the barriers spoken about were the same **barriers** that create discrimination against disabled people in society. These included attitudes such as low expectations of what disabled young people can achieve and years of being told, 'you can't do something'.

People spoke of **the medical model of disability** still existing, whereby disabled people are seen just in terms of their impairment, as 'broken' and 'not perfect' and something to be fixed. This can lead to individual, impairment categorisation and divide disabled people who share oppression and who could fight together.

Some participants at the workshops talked about how we need more collective action but this is a challenge because young people are not introduced to **the social model of disability** and do not get taught a political education, they still see disability as an 'individual deficit' – as something that is wrong with them, rather than that society needs to change.

When we talked about how young disabled people could join the **Disability Rights Movement** it was noted that there are a lack of paid opportunities, with few jobs for young people in the disabled people's movement and no clear route in. Young people needed opportunities to develop the necessary skills and have mentoring opportunities.

Some of the younger leaders spoke about their experiences coming into a rights movement which had been mostly led by **'white, older men'** and how it was important to also learn about activism of disabled women, disabled women of colour, activism amongst the disabled LGBTQ+ community for example, and recognise multiple, intersecting discrimination.

As RIP:STARS and **young disabled people** we recognised our and others discrimination, but we did not know where to start, and only became involved in activism because of the RIP:STARS project.

We did not know that **disabled people-led organisations** even existed. We did not know the right language to use, what the culture of an organisation would be, would we be welcome in these spaces? Would we see ourselves fitting into these places? Would we have something to contribute and be listened to? Could we make a difference?

We wanted to see how we could bring the generations together.

Building a culture and making a change

We wanted to find out how, together, we could **build a culture of change** so we asked:

How do you think Disability Leaders and young people can support each other to develop skills and a culture of activism together?

As disabled young people we want to step into the shoes of the current leaders so we need to know **how to take the steps** for that to happen. Our conversations with the leaders made us think that to keep the disability rights movement alive and feel real for younger generations maybe a different kind of leadership is now needed, leadership for the times we live in now. Learning from the past but embracing the modern challenges we face.

Leadership that recognises and values the intersectionality of identities and is inclusive to all. We all have multiple identities – our ethnicity, gender, sexuality, class, religion, culture or maybe we **do not choose labels** at all. We discussed how all disabled people with all identities should be welcomed within the rights movement and collectively fight for rights.

One recent development that can help us to connect with other people globally and create a mechanism of change has been the internet. The internet has **revolutionised the possibility for young disabled leader**s to become 'influencers' or 'game-changers' with many disabled activists posting and raising awareness of the lives of disabled young people. Through social media, mobilising support and linking with allies, the fight can be a much wider collective action, we can link internationally as well as locally and nationally. As well as raising awareness of oppression and discrimination, we can highlight how society creates barriers, and together we can change attitudes.

To even begin to think about possibilities for leadership **we need role models,** to see someone who has faced challenges or oppression but is powering through, not showing that they are struggling, looking like they are doing well, that gives a disabled young person a boost, we then think 'I can do it'. A number of the leaders said how it important it was for them to see disabled people working within a Disabled People-Led Organisations (DPOs).

Sometimes DPO's involve disabled young people through volunteering or through internships and both of these are important but not the same as seeing a disabled person **valued and rewarded** in the same way as the rest of the other employees. One of the younger disabled leaders told us that the paid roles were often at management level and not entry level and this needs to change.

Rights were mentioned often so we asked:

What advice would you give disabled young people who want to fight for their rights?

We heard the leaders encourage us to have 'constructive rage', to feel rightly angry about the injustices that disabled people are subjected to and to use that anger to do something about it. The message was that **leaders need to be the change**, to be stubborn and to persist in our actions. Most did not just 'wake up and be a leader', it took time, growing confidence and small steps.

Disabled leaders told us that activism takes courage and, at times, it can be quite isolating. This is the reason that **being in it together is important,** so that younger and older disabled people can support each other. Young people can help shape the future by saying this is what we want, this is what our lives should be like, as one of the leaders said:

'We made change for the people that came after us and you will make change for the people that come after you'.

Knowing that we have an important role to play is **inspiring us** to take the steps that we can in our own lives and learn from the inter-generational experience.

As one of our RIP:STARS group said:

'It's time the older disabled leaders passed the torch around, it's time for us to take the reigns'.

To end each workshop everyone wrote messages of encouragement, here are a few of them:

Reach out, connect

Your experience matters and is valuable

Embrace your difference, don't let them define you

Fall over but get back up

Practical steps to bring generations of disabled people together

human rights

These are some of the things we learnt and now want to share with other disabled young people:

Your personal story matters – what you have experienced has shaped who you are.

Get political, learn about disability activism, learn about current fights being led by disabled people.

Learn about your rights as a young person and as a disabled person.

Learn about the social model of disability – it will change your life forever. There are lots of YouTube videos on the social model.

Get in touch with a disabled person led organisation and find out what they are doing and ask to attend one of their meetings to see what it is about.

Finally: Don't let anyone make assumptions about what you can or can't do.

These are things we think DPOs could do to help build partnerships with young disabled people.

Reach out into schools, colleges and universities (mainstream and special) as we don't know where to find you. You will find that many young people want to become activists and feel passionate about oppression.

Allow young people to bring a friend along to one of your meetings, and give us trial sessions.

Show how far disabled people have come – we do want to learn our history as well as shape the future.

Share your shared experiences of oppression – we learnt that we share many of the same experiences.

Be prepared to learn, listen and adapt to empower a young persons' voice. Please ask us to tell you how things could be done better, we have lots of ideas, creativity and enthusiasm.

Be prepared to share your power. Nothing about us, without us should include us all.

Be prepared to consider new ways of inclusion, for example, we may have more social media skills.

Work in a social model of disability way – identify the barriers that young disabled people might face in joining your organisation, these might be lack of awareness, attitudinal or language barriers.

Please offer training and support for young people.

Young people can recognise tokenism in an instance, so only involve them if you genuinely are prepared to hear what they have to say, and are prepared to act on it to make change!

This resource is an example of what can be done when generations of disabled people work together to create change. Together we are stronger. We hope that you have found it useful, inspirational and ask that you please share it far and wide!

Thank you the RIP:STARS – Eva, Tom, Jordan and Ben. January 2021.

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