



Am I Invisible? Using co-production to advocate change in social care

Learning from the COVID-19 pandemic: A co-production project with people with learning disabilities and autism.

Summary of the project



A group of experienced London-based self-advocates met online to discuss their own stories from the COVID-19 pandemic.



The group agreed to meet again in person to create a video which captured their discussions. In this video, they put forward their suggestions for how staff at all levels could better support and be more accountable to the people that they work with in the future.



“Listening to the individual”



“You have to get to know the individual”



“Look at ways they can communicate to work together” and find a new “rhythm of working”.



Knowing what we know about what has worked well recently and where there are still gaps, it is time to explore doing things differently.

Watch the video here

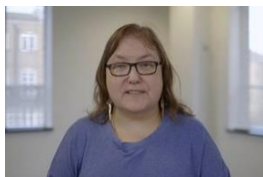
View the video online at <https://www.scie.org.uk/co-production/examples/am-i-invisible>

AM I INVISIBLE?

Lessons for health & social care from the pandemic



‘The SCIE Fliers’: Our co-production group



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Am I Invisible? A poem by Sedley Wilson

I am invisible

We walk down the same street together but you still cannot see me

Is it because I am different

We live in the same community but you refuse to acknowledge me

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What needs to change: Learning from our experiences

Our ideas for organisations



- Look at different ways of hearing back directly from the people you work with, so that you can provide the kinds of services that will carry out their views and wishes.

“The problem is if we don’t get listened to you don’t get the stuff needed for those people who need it.”



- As we move towards more ‘hybrid working’, using a mixture of communication methods try to find a good balance between meeting with people face-to-face (which they usually prefer) as well as making contact by phone and online.



- Disability Awareness Training can and should be delivered by people with learning disabilities and autism.

Why co-production matters

Why is it good to have co-production groups as sounding boards?

“Hearing it from people that have got lived experience.”

- The process of talking together builds up people's abilities and confidence.
- Bringing together service providers and the people that they work for.
- Over time everyone learns to talk straight to one another.
- We all share in the benefits.



Involving people in making decisions



- Person-centred care still matters. For example, knowing the individual's likes and dislikes and creating a care system designed around the person.
- Involve people directly in making decisions about their care, benefits and rights.
- Recognise the roles of an individual's informal carers and advocates, especially regarding capacity issues.

- Work towards collaboration.



- Find more information here:

<https://www.scie.org.uk/dignity/care/freedom>

Our ideas for care agencies and providers

- Being able to choose your own carer.



- Better communication. Find more information here:

<https://www.scie.org.uk/dignity/care/communication>

- Building of trusting relationships through the continuity of carers.



- Protecting the safety and mental health of individuals who need close personal support.

- Importance of employing vaccinated workers, and using effective PPE. Find more information here:

<https://www.scie.org.uk/care-providers/coronavirus-covid-19/blogs/vaccinations-home-care>



Our ideas for health and social care services



- Access to care – people with learning disabilities prefer face-to-face to virtual connections, although many have learned to use Zoom effectively. Find more information here:

<https://www.scie.org.uk/care-providers/coronavirus-covid-19/social-workers/building-rapport-with-technology>



- Consent issues – don't make assumptions about capacity.



- The talk of 'Do Not Resuscitate' (DNR) during COVID-19 alarmed people.

“Worried this will happen to me.”



- Recognise that people’s health and care needs change over time. These needs should be monitored and reviewed with regular updates.

Our ideas for local authorities

People 1st



- Re-invest in community support services especially self-advocacy groups.

- Involve people with lived experiences in co-designing support. Find more information here:
<https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/during-covid>



- Be clear about what can be paid for through self-directed care and personal budgets.
- Hiring personal carers may not work for everybody. The Local Authority needs to offer the right support to make this possible if it’s what is asked for.

“People are equal, not an afterthought.”

Acknowledgments

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If you are interested in supporting future SCIE work, **find out about how you can support us** (<https://www.scie.org.uk/contact/resourcefeedback>).



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