

ARC WM APPROACHES TO CO-PRODUCTION CASE STUDY

Name of Researcher	Hayley Crawford
ARC WM Theme	Integrated Care in Youth Mental Health
Project Name	Annual Health Check Project
Case Study Details	Authors: Hayley Crawford/Magdalena Skrybant
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Further information	Hayley.Crawford@warwick.ac.uk m.t.skrybant@bham.ac.uk 0121 414 6026

WHAT DOES THIS CASE STUDY SHOWCASE?

This ARC WM Approaches to Co-Production Case Study highlights how researchers in ARC WM’s [Integrated Care in Youth Mental Health](#) Theme are working with families and young people to shape ideas about a future research project to explore Annual Health Checks for young people (age 14-17) with moderate to profound learning disabilities.

Incorporating the principles and features of co-production in this important stage of the project helps ensure that from the outset, young people and their families have a strong voice in shaping our work. Young people and families will work with in partnership with members of the ARC WM team: from co-designing the intervention to then co-designing evaluation of the proof of concept pilot study.

WHAT IS THE PROJECT ABOUT?

Annual Health Checks are available to most people aged 14 and older on GP learning disability registers. Annual Health Checks provide opportunities for young people and their families to talk with their GP about anything that is concerning them relating to their health and wellbeing. Annual Health Checks also help spot early signs of some conditions that young people with learning disabilities are at a higher risk of getting. The checks are also designed to help young people with learning disabilities get more used to appointments with the GP. Although Annual Health Checks for young people over 14 on learning disability registers is recommended by the NHS and GPs are offered a financial incentive to offer them, over half of people aged 14-17 years on GP learning disability registers did not have an annual health check between 2018 and 2019.

Our research team have existing links with young people with learning disabilities and their families. They shone a light on the challenges with Annual Health Checks and some of the reasons why they hadn’t had an Annual Health Check. They told us that they had not been offered one and that they already had multiple appointments with different specialists and so didn’t feel that they needed one. They also told us about things that are difficult about going to the GP such as issues such as rigid appointment times, lack of continuity of care, waiting rooms that are not suitable for people with behaviours that challenge, all of which make Annual Health Checks stressful. They wanted Annual Health Checks to be more flexible and more suited to individual needs of young people. One idea our research team have been exploring with people with learning disabilities and their families is the possibility of holding Annual Health Checks in settings that young people were familiar with (e.g. schools).

This project originated from a drive to increase the low uptake of Annual Health Checks for young people with learning disability. In 2018-2019, 37% of people aged 14-17 on GP learning disability registers had an annual health check (gov.uk). Our research team wanted to work with people with learning disabilities and their families to identify reasons why the uptake is low and what can be done to improve the uptake. Our research team is particularly interested in exploring whether integrated care between Primary Care services and health care professionals working with Severe Learning Disability Special Schools would be beneficial to people with learning disabilities and their families.

We are working with young people, their families and people that administer the Health Checks to understand the Annual Health Check process for young people. We are finding out what works well and what's not working so well, and exploring ways the Annual Health Checks can be improved.

At the end of the project, we hope to have evidence that will shape Annual Health Checks in the future. We want to provide options that enable young people and their families to choose Annual Health Check options that are right for them.

WHAT IS YOUR APPROACH TO CO-PRODUCTION?

We cannot do this work without involvement of young people and their families that use Annual Health Checks. Right from the start, we wanted to work with them to shape the project: we wanted their steer on directing the project and shaping our research methods.

To help develop partnership working and facilitate co-production, we had discussions with parents and young people in two local schools. Getting the setting right for meetings was really important to us: the schools were a familiar setting for parents and young people and it's important that everyone was in a setting that was comfortable to help them feel confident to make contributions.

HOW DO THE PRINCIPLES OF CO-PRODUCTION FIND EXPRESSION IN THIS PROJECT?

Sharing of power – We are working in partnership with young people and their families and we want them to have ownership of decisions we make about the project. We're always listening to what they feel is important and what they want us to explore through the project. We are constantly listening to and incorporating their perspectives and adapting our project in response to their perspectives. Some parents, for example, expressed that choice is important – we're now looking at how Annual Health Checks can be flexible to offer a range of options for young people and their families.

Including all perspectives and skills – We wanted to ensure that everyone who is involved in Annual Health Checks had a voice in the project. In addition to working with parents and young people in the school setting, we also worked with GPs, school nursing teams and schools. We wanted to make sure that people were enabled to contribute to this discussion. When working with young people with learning disabilities, we made sure that our ways of working were accessible – we made sure that our language and communication was jargon-free and made sure that young people were as comfortable as possible to share experiences and insights with us.

Respecting and valuing the knowledge of all those working together on the research – At the start of discussions, we emphasised that everyone's views and perspectives are important and that there are no right/wrong answers. We wanted people to feel confident expressing their perspectives and we explained that all views are valid and important to helping us decide what we are going to do in our project and the best ways we can do it.

Reciprocity – A big motivator for parents and young people to get something back was the prospect of better Annual Health Checks for young people with learning disabilities. We demonstrated that we appreciated and valued their input to our discussions. We offered parents an honorarium of £75.00 for their contributions and young people a £10.00 voucher, which they could spend in a variety of stores.

Building and maintaining relationships – In this project, we were fortunate to build on existing relationships one of the research team members, Dr Ashley Liew, already had with the schools and young people and families. Ashley is known to the schools, parents and young people and families and young people feel comfortable talking with him. Ashley led the first meeting and introduced other members of the research team to the parents

and families, which helped to build trust and break down any barriers that might have existed between the research team and the families.

HOW DO THE FEATURES OF CO-PRODUCTION FIND EXPRESSION IN THIS PROJECT?

Establishing ground rules – We were clear from the start about why we wanted people to be involved in the project. Prior to any discussions, we sent clear information about the purpose of meeting with the group and how we would work in partnership with them to shape our ideas.

Ongoing dialogue – It is important to us to keep communication channels open with the families and young people we are working with. We are committed to keeping people updated with how our research progresses and invite further comments or feedback. We emphasised that they could contact us at any point if they had any thoughts/reflections they wanted to share.

Joint ownership of key decisions - Throughout the discussions, we listened to the perspectives of parents and young people and took their suggestions on board. Emphasising how their insights make a difference and are shaping the direction of the research helps them feel that they are partners in the project. Importantly, no key decisions about the project are made without their involvement.

A commitment to relationship building – We were fortunate to build on existing relationships with one of the team, Ashley, and parents and young people. When we first contacted parents and young people about the project, we included an introduction from Ashley and we also introduced ourselves, including photos. We also set aside time at the very start of discussions to build relationships with each other. We spent time introducing ourselves and finding out a bit about each other. This helped develop rapport and encourage people to contribute to discussions.

Opportunities for personal growth and development - For researchers, this was a real opportunity to get to know this community and learn different approaches to working with them. It was also an opportunity to gain experience of working with young people.

Flexibility – We held meetings in settings where people feel comfortable. We identified that schools were a good setting as parents knew the venue and it was accessible to them. We were also flexible in our approaches to discussions. We anticipated that discussion groups would be between 1-2 hours, but we were open to extending discussions (if that is what our parents/young people wanted) or having additional meetings. For young people, we worked closely with the school to make sure that we created the right environment for discussions.

WHAT HELPED YOU ON YOUR CO-PRODUCTION JOURNEY?

We were all fortunate that Ashley knew us all and was able to introduce us to each other. This helped us develop trust and build relationships.

We were also fortunate that we could use the schools for meetings. The venues were accessible and it helped that we were in an environment that parents and young people with learning difficulties are comfortable in.

We also had some flexibility in the budget to be flexible about our approach to the research. Whilst we were keen to progress the project, we were not constrained to a tight deadline.

WHAT LEARNINGS ARE YOU TAKING FORWARD?

Hayley: From my perspective, it has been invaluable to work with families that have first-hand experience of GP surgeries and the challenges they present to young people on GP learning disability registers. Their insights have helped us consider things we never would have considered had we not worked in partnership with them to develop this project.