Valuing participation and involvement in a Community Psychology Service

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We explain the process and findings of a participation project involving children and young people, and parents/carers from a community psychology service.

Background

WENT Community Psychology (GCP) believes it's important that we share 'power' and control over service decisions with those we hope to benefit from them (Orford, 2008). Not having a say or a choice in life situations or in our relationships with others can leave people feeling unheard or even abused - something we know impacts mental health and wellbeing (Johnston & Boyle, 2018). In this way, done well, participation has the potential to both prevent distress and support those affected by not having a say. We want to ensure that the voices, concerns and solutions of children & young people (CYP), their families and communities are expressed throughout the service in its design and delivery. This is also in line with

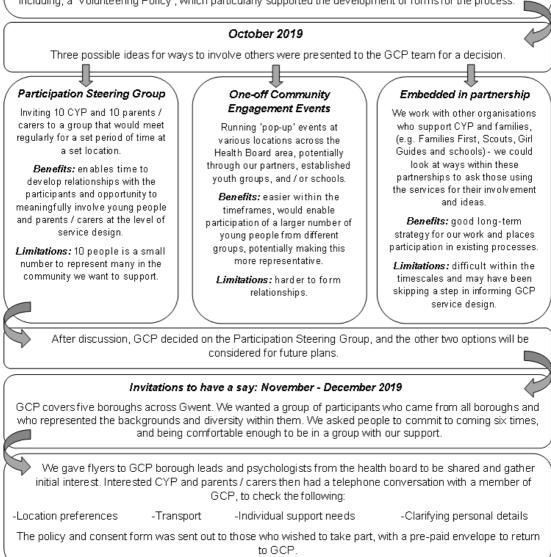
a children's rights-based approach, providing 'meaningful opportunities to influence decisions about their lives' (Holland, 2017, p.3).

There are many levels of participation depending on the amount of 'power sharing' involved between services and those community members involved (Tresedar, 1997). There are also different types of benefits from participation in health care services, for both the organisation and those people taking part (Haldane et al., 2019). The aims of this project included what's known as both 'process' and 'project' outcomes (ibid, p.8). The process outcome was to influence the organisational way of working to show commitment to the importance of GCP 'doing with' rather than 'doing to' others in line with our values. The Figure 1: Flowchart of the process to establish paid participation

Bid submitted June 2019: Payments secured for one financial year (until April 2020) for two participation groups, one for CYP and one for parents / carers.

June - October 2019

Paying for participation of children, young people, and parents & carers was selected as a method for improving equal participation in the project (Health and Care Research Wales 2019). We had thought that the health board would already have methods to pay people for participation but this was not the case; and so we first had to write a policy and agree ways for payments to be made. This was done through meetings with the Finance team and Senior Leadership. Other relevant Health Board policies were also taken into account including, a "Volunteering Policy", which particularly supported the development of forms for the process.





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project outcomes were to develop relationships with our communities, have their feedback to 'reality check' our service development, raise awareness of GCP and, potentially develop further community led projects.

We want to share our experience of setting up paid participation within the NHS. The diagram (Figure 1) shows how we went about setting up the project. We will then share our learning points from the groups and some thoughts we have as reflections.

Running of groups

The CYP and parent/carer groups were run separately but at the same times and dates. There were five sessions run every other week. The parent group was facilitated by two GCP team members and the CYP group was facilitated by three team members. Based on feedback from the participants, the sessions were run at a central location in the evenings (5pm - 7pm) to make sure they didn't get in the way of school and work commitments.

Nine people came to the parent group (all female); attendance varied, with an average of six parents attending every week (min = 4, max = 9). Ten CYP (N = 3 males, 7 females; between 11-18 years old) came to every week (except one). There were two sibling pairs, a friend pair, and four had parents attending the parent/carer group.

A draft session plan was shared in the first meeting, which was open to change based on feedback. The outline session plan was:

- 1. Connections & GCP Who are we?
- 2. Wellbeing & GCP Values Why are we doing what we are doing?
- 3. Partners, Project & Gaps Are we doing it 'right'?
- 4. Language & Communication How do we connect with people?
- 5. Parent & Carer Support How can we work together?
- 6. Bringing it all together and celebrating What next? [Didn't run due to COVID-19]

The sessions were designed to share information and gain feedback through different activities. We invited GCP borough leads to

We now share important learnings specific to each group.

Parent & carer group

Language & communication. This covers the way we talk, where we go to talk, and how we talk to parents and carers. Alongside the messages outlined above, we got feedback on our communication tools under development: a leaflet and newsletter. The feedback was that

different sessions over the course of the project to share their work and ask questions. Each session we started by sharing what we had learnt from the previous session to check we were on the right track with the group.

Important learnings from the groups

Although initially groups had the same draft session plan, they differed based on group interests and need, therefore we thought about important learnings for each of the groups separately. However, the process to decide on themes was the same: facilitators collaboratively reviewing session agendas, process notes, and reflecting on significant moments.

There were some similarities in the main take home messages across both groups:

- Directions on who to work with e.g. grandparents and men/boys
- How to share information on mental health and wellbeing (Facebook for parents; Instagram/influencers for young people)
- Relationships are understood as being essential to mental health and wellbeing
- Language is crucial
- Don't use the word 'normal' when talking about mental health, even with GCP messages intended to be supportive e.g. 'children only ever react normally to what is happening in their lives.' This is because people felt the word 'normal', was unnecessary and could imply a judgment.
- People are more likely to engage in projects when they believe that it will impact on a wider level than improving their own mental health and wellbeing (e.g. coming to a group to help others, not just for their own benefit mattered).

these weren't right for parents and carers and we took ideas on how they could be better suited.

Wider professional systems and organisation issues. A central message that was communicated was that 'the system can be part of the solution or part of the problem', acknowledging that a lot of difficulties faced by parents within our group were caused by system difficulties. This also included parents feeling like their voices are not always heard and respected by health professionals. As professionals, this is important for us to hear and bear in mind. It also supports our multi-agency /partnership working to try and address some of these issues, both as a team and wider department. We took some practical feedback that might help improve systems. For example, easier-to-use self-referral forms and increased communication with families throughout the referral processes for a partner service; suggestions which will be followed up with those involved.

Targets and opportunities. We asked who we should be working with and what (information) might be helpful. The people important for us to work with were similar to those the young people talked about (see above). We also talked to parents about information they would find helpful in supporting the mental health and wellbeing of their children. There were 21 topics identified in total at the end of the five sessions. The majority of these came from the session on parent & carer support. These included, supporting children with bereavement, trauma, and family breakdown. Other topics came from conversations in previous weeks, for example, support making visual aids for children with additional needs, helping children make choices and learn independence, and importance of children's rights to wellbeing. These will be used to inform our development of work with parents.

Important beliefs and reflections. As the sessions progressed, we noticed some beliefs that are important for us to know when working with parents. The beliefs were that (1) mental health needs a mental health professional (2) the NHS is trusted as an insti-

tution – having the NHS brand or logo with GCP is important (3) being honest with your own emotions as a parent can be supportive of 'being with' children and their emotions (rather than a pressure to pretend everything is 'OK').

CYP group

Things should change at school. The group felt schools often got messages about mental health 'wrong', and also that the focus on this topic had shifted from 'nothing in primary to excessive and negative in secondary'. The CYP also felt that messages didn't always match the school set up or teacher behaviour. For example, removing points from a point system or being sent to isolation rooms upsets students and affects their relationship with teachers, putting them off following advice to 'go' to them for support. They thought it would be better to be asked 'is everything OK?' to support the CYP with the reasons they may be upset or behaving 'badly'. These considerations have been passed onto the Whole Schools Approach within the Child Psychology and Family Therapies Service and support the work they are undertaking.

Important Wellbeing Messages. The group agreed everyone has 'mental health' and that there are good days and bad days. Everyday stresses can build-up and lead to feeling upset, low, anxious etc. They said 'what helps' is different for different people and 'there's not always one answer'. The importance of strategies other than talking to a professional were highlighted (e.g. enjoyable activities with others), with the bottom line being 'it's OK not to be OK'. This supports an aim of GCP to help those adults in CYP's lives to feel confident to offer informal, everyday supportive interactions.

Social Media is important. The group expressed frustration at widely held views of social media by adults in particular, that it can be 'harmful'. Social media provides a source of support, a sense of belonging and a source of information for CYP. They stressed the importance of *how* it is used, not simply that risks exist and would welcome space to explore this



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more. Influencers were associated with social media, and again, were seen as really important to CYP. As a role model, it was thought that social media influencers could teach others how to communicate effectively – which was identified by CYP as contributing to mental health difficulties – and due to their large amount of followers, people would be more likely to listen and learn. The group also suggested that, like at school, mental health should be talked about by influencers in their everyday conversations, rather than as a set topic. We have advocated an appreciation of social media in publications and we plan to explore this more as a team.

Advice for involving CYP. Across the group, CYP were clear on what is important for successfully involving them (be it at school or in groups/other life settings). Alongside those stated in the general take home messages, CYP also suggested: (1) making the sessions fun and playful (2) CYP should be welcomed and invited to have a say, with a permission to 'pass' (this includes at times of distress). We aim to build this into future events involving CYP directly.

Final thoughts

Whilst the NHS heath board we work for and the service itself sees the importance of involvement and inclusion, there were practical barriers we'd not expected. An additional outcome of this work is having the policy and processes in place for paid participation, which we hope will make it easier for others in the future. This included introducing bank payments for people's time, rather than only vouchers, which felt more meaningful and provided choice. We recognise that the funding for this project falls outside the normal funding stream and was short term - this means we cannot continue the steering group longer term. To ensure the learning from this project is continued, the two models which weren't used will be used in our work as next steps for longer term involvement. We also plan to raise awareness of the importance of participation and share how helpful we have found this with the health board and to

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encourage/promote (including the existence of the policy for paid participation).

Using a participation group at an early stage of the service development has helped us to put the views of those we hope the service will support at the centre of our work. The purpose of each session, how contributions would be used and the level of 'power sharing' /influence varied across activities and was clear throughout. An example of a high level of power sharing with the CYP group was the development of the GCP logo. Here, an artist joined the group for two sessions and with the group came up with ideas: the top three were shared with GCP and the CYP group to pick. The CYP were united in picking the logo we now use. It will be interesting to get feedback on preferred activities to know whether power-sharing had any impact on enjoyment.

Finally, we recognise the limitations of this work in the numbers we were able to involve and reach, meaning representation of wider community views requires follow up. For example, only females were recruited to the parent/carer group and we would like to involve boys and men more. The involvement of men and boys was explored as part of the group, and plans were made to engage with them in a more targeted way. The attendance of the parent/carer group was inconsistent throughout the project, mostly due to childcare responsibilities. Attendance was most consistent for the parents whose children also attended the CYP group. This provides support for running the two groups simultaneously.

We gave a lot of thought to how to evaluate the project but due to the global pandemic our final session and evaluation plans were put on hold. We had hoped to gather the views of those involved in the groups, GCP team members and those involved in developing the policy (colleagues in finance, administration and senior management). We had also wanted to invite involvement in writing up this project but this has not been possible and so we have written this with thanks to those CYP and parents who we got to know and who we have tried to hold in mind. In

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doing so, we changed some language and the formality of an initial draft to be clearer. This served as a reminder of the importance of our profession working co-productively to reduce barriers. The evaluation and impact of this work will be an ongoing project which we intend to share at a later date.

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