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Children's Research Advisory Groups: moving from adult-research agendas to co-creation with children.

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Abstract

This chapter focuses on Children's Research Advisory Groups (CRAG's) against the backdrop of participatory research with children and the increasing requirements to evidence research involvement by users of services for funding bodies. The authors will discuss capacity building as essential in working with CRAGs. Furthermore, they examine the potential role and contribution of CRAGs in co-constructing research methods, data analysis and research sharing drawing on two of their research projects (one Irish and one European) supported by CRAGs. The chapter concludes that while Children's Research Advisory Groups have the potential to contribute to deeper participation, they are not without their difficulties and limitations. They are costly and time consuming, may not always be appropriate and in some cases are tokenistic. A case is made for a pragmatic, flexible approach to help promote ethical practice.

Introduction

Societal changes and political support for children's rights have coupled with theories on childhood to establish a new understanding of children as competent social actors (Broström, 2012). The importance of the child's perspective or 'voice' and the child as participant have been incorporated to a large extent into children's research (Horgan et al, 2017; Mercieca and Jones, 2018).Their inclusion in research can better influence practices and policies which are child-centred and appropriate to children's contemporary circumstances.

Christensen and Prout in 2002 argued that, while research with children addressed the formal requirements of research, it has paid much less attention to the 'broader aspects of the research process' (pp. 490–491) such as, participation in the research process and its design, the interpretation of the data and the later dissemination of results. Much has changed since then, with a trend towards involving children and young people in other aspects of the research process, from advising research studies as expert consultants, to analysing data as part of the research team, to child and youth-led research (Ergler, 2017). Yet, the tendency is still to concentrate on the middle stages of projects. This may be because research in schools and universities, mainly aims to add knowledge rather than disseminating the results (Pinter and Zandian, 2015). Furthermore, strict ethical regulations surrounding research with children creates a significant challenge in genuine co-production with children especially in the conceptualization stage (Collins et al., 2020). Additionally, the funding structure for research often frustrates such deep and wide engagement with children. Paradoxically, then, while funding bodies increasingly require evidence of research involvement by users of services (Bird et al., 2012) the complex and

demanding funding mechanisms and time constraints in research may exacerbate the tendency for parachuting in and out of children's worlds in order to quickly collect data and analyse data (Spyrou, 2011: 157).

Children's Research Advisory Groups (CRAGs) can respond to and mitigate some of the problems related to such adult-only research agendas and can be seen as promoting children's active role in research concerning them (Mercieca & Hill, 2018). While, there is now a significant body of work on participatory research with children, there is little focus in the academic literature on children's research advisory groups and limited systematic evidence on the methods and impacts associated with such groups although these are increasingly used (Sellars et al., 2020). CRAGs are mechanisms with their own specific attributes and challenges which need to be explored. We argue, in this chapter, that the CRAG is an aspect of participatory research with children that has the potential to contribute to deeper and more meaningful participation. As such, children's involvement in the design, implementation, analysis and dissemination of research through CRAGs merits further exploration and research.

Childrens Research Advisory Groups

> When adults know what a young person's view can be, it's actually, 'Wow! Like a young person knows what they're talking about'. When you understand that, then you would always take it into account…. But a lot of adults just forget, and they forget what it was like to be a young person and they really need to know that (youth participant in Martin et al, 2015).

In Children's Research Advisory Groups, children are both informants and researchers (Bradbury-Jones and Taylor, 2015), they are not the research subjects (Bird et al, 2012). As Mercieca and Jones (2018: 256) point out, CRAG members need to make sense of a space for *thinking about research* as a different space from *participating in research*. They are not being asked to speak directly about their experiences but rather, as an expert group, to reflect on the experiences of children in general (Lundy and McEvoy, 2012). Critiques call for a much-needed effort to specify and to evaluate the outcomes, benefits and limitations of CRAGs, rather than merely assuming them as inherently beneficial (McCarry, 2012).

Benefits of CRAGs

The limited literature identifies the potential of CRAGs as a participative and co-reflexive activity which can inform research design and where both researcher and CRAG participants can reflect on their assumptions and on the research methodology (Moore et al., 2018; Mercieca and Jones, 2018). They can minimise social difference and distance between researcher and child, which facilitates children's contribution and makes ethics central to the project's design and implementation (Atkinson, 2019). Thus, CRAGs can help to ensure the quality and credibility of the research (Mercieca & Jones 2018).

Some recent reflections on CRAGs in the literature include Moore et al.'s Australian study on children's experiences of safety from abuse in institutional contexts. Here

the CRAG confirmed many of the research team's views and plans regarding informed consent and their feedback provided some confidence in the tools to ensure quality in research conducted with children (Moore et al. 2018: 104). Mercieca and Jones (2018), in their study of looked after children's engagement with mental health services in Malta, outline how the CRAG contributed to the design of data collection methods, identified key ethical issues from the point of view of young psychotherapy service users and reviewed and appraised research information material. They contributed significantly to the researcher's reflexive process especially in terms of acknowledging the researcher's power and positioning as an adult practitioner/ researcher.

Children's research advisory groups allow us to build research relationships with children, tapping into the qualities that young people bring including empathy, innovation and creativity (Caldwell and Jarret, 2018). They provide us with 'insider' perspectives (Fleming, 2012; Jones et al., 2020). Data collection tools are improved as a result of collaboration with children which contributes to good response rates (Lightfoot and Sloper, 2003). Moreover, the insights derived result in better quality research outcomes (Lundy and McEvoy, 2012; Bradbury-Jones and Taylor, 2015) by ensuring that findings are grounded in the perspectives and experiences of children themselves (Turtle et al., 2010; Bradbury-Jones and Taylor, 2015). The benefits of CRAGs from young people's perspectives are to push research forward, make it more applicable, more relatable to children and to help kids (Caldwell and Jarret, 2018). Benefits of CRAGs for the child participants, as reported by researchers and children themselves, include affective benefits such as children's increased confidence, enhanced critical thinking and other research skills (Kellett, 2010; Turtle et al., 2010). It promotes their sense of empowerment and that they have contributed to something important (Lundy & McEvoy, 2012).

Limitations of CRAGS

Researchers need to be objective and honest about the complexity of achieving benefits from CRAGs both for the young people and for the research. There are tensions between the models prioritising children's voices in social research and the realities relating to negotiating with gatekeepers, pragmatic boundaries such as restricted time frames and researchers and children's differing work schedules, research questions about knowledge and scientific rigour, and ethical considerations such as equitable partnerships and methodologies (Bradbury-Jones and Taylor, 2015; Collins et al 2020).

The uncritical ways in which participatory approaches are sometimes deployed (Gallacher and Gallagher, 2008) is especially true of Childrens Research Advisory Groups. Choosing to work with a CRAG is complex and challenging. CRAGs may not always be appropriate and in some cases are tokenistic, particularly where the conditions of funding and ethical approval limit their potential involvement. Children and young people are not typically consulted about their role before submission of tender documents and so a model of inclusion is imposed upon them rather than negotiated with them. Another challenge presented by CRAGs and inherent to all research with children is power imbalances both among young people in the group process (Kellett, 2010; Horgan, 2017a; Gillett-Swan, 2018) and between them and the researcher (Mercieca and Jones, 2018; Moore et al., 2018), which can make genuine

partnership unobtainable. However, a fixed positioning of 'adult as powerful' and the assumption that power is almost wholly negative needs to be challenged (Atkinson, 2019). Instead, recognising research with children as a relational process with power operating at multiple levels and with the potential for participants to engage in ways to lessen or neutralise the power relations inherent within group settings is appropriate (Horgan et al, 2017; Moore et al., 2018).

Another dilemma of CRAGs relates to achieving reflexive ethical practice and an attentive focus on informed and ongoing consent (Collier, 2019). Our experience is that children often do not fully appreciate what is involved in CRAG membership until they begin to experience it. So, we must consider consent as an ongoing process with children's right to withdraw central (Dockett et al, 2012; Moore et al., 2018). Finally, CRAGs incur time and financial costs. They require additional time commitments by personnel, training for the child-collaborators and provision of child-friendly resources and locations to allow the children's ongoing engagement. They also place time and financial burdens on the children, families and researchers in terms of missed opportunities and travel costs (Bradbury-Jones and Taylor, 2015) over a potentially long period of time.

Research Projects guided by CRAGs

In this chapter, the authors are drawing on two research projects which involved children's research advisory groups, to offer insight into some key issues around structure and process. The research projects we present here do not meet all of the criteria for 'deep' participation (Ansell et al., 2012; Horgan, 2017). because the reason being, they were commissioned by funding bodies to meet specific objectives, they have a limited timeframe linked to the funding and were constrained by our reliance on schools in recruiting some of our participants. However, we attempted to mitigate these limitations through our establishment of CRAGs in the very early stages after the research was commissioned and working with them through various phases using co-creation methods.

Project 1: Children and young people's experiences of participation in decisions affecting them at home, in schools and in their communities

The first project is an Irish Research Council/Department of Children and Youth Affairs funded study on children and young people's experiences of participation in decisions affecting them in their everyday lives (Horgan, D. et al., 2015). Central to the project's design was the absolute importance of children and young people having a real opportunity to assist in producing the best possible research. Two Children's Advisory Groups recruited through schools were set up, one comprising eight children aged 7-12 years attending a primary school and the other comprising five young people aged 12-17 attending a secondary school. Their involvement ensured that the project maintained its focus on decision-making issues that were important or of concern to children of their age.

Verbal and written informed consent was obtained from all members of the CRAGs, in addition to written parental consent. Through detailed discussions within these groups, the research protocol and methods were agreed. The proposed child-centred

ice-breakers and visual and verbal data collection methods to capture children and young people's lived experiences of participation were tested and refined with these groups. The CRAGs also contributed, as detailed further below, to the analysis process by working with the raw data generated from the focus group interviews with children and young people.

Project 2: IMMERSE

The second project is a Horizon 2020 (2018-2022) European Research Project to measure the socio-educational integration of migrant and refugee children in Europe of which the authors are the Irish research partner with Spain, Italy, Greece, Belgium and Germany. Outputs include: the development of a dashboard of 30 integration indicators; results from a survey of thousands of children across Europe; an online data and resource hub for educators and policymakers; and policy recommendations. In ensuring children's voices are incorporated throughout IMMERSE's activities a Children and Young People's Advisory Group was set up in Ireland, given the partners experience in this area. It comprises eighteen children of migrant and refugee backgrounds resident in Ireland, aged 9 – 16 years at the formation of the group. There are seven girls and eleven boys. Parental and child consent was obtained through a process involving the provision of information sessions and written material on the project and the CRAG role within it.

The CRAG meetings take place twice yearly and will do so for the duration of IMMERSE. In addition, members are invited to attend other associated activities related to the project, to inform them of its progress, direction and any other relevant project outcomes. The CRAGs role involves engaging with the research objectives of IMMERSE in assisting researchers to ensure that we go about the research in ways that young people will understand and are important to them. They do so through:

- providing input into themes for qualitative data collection;
- validating survey instruments;
- piloting and providing feedback on quantitative data collection methods and instruments.

In future phases of the project the CRAG will contribute to data analysis and dissemination.

Issues for consideration in working with Children's Research Advisory Groups

Group Formation

The recruitment and formation of a CRAG are critical to ensure a balance of young people who can speak to the experiences of the research topic. Sometimes this will be a very targeted group (children with migrant backgrounds in the case of project 2) and in other cases it will mean recruiting children and young people in a particular age bracket (children of school-going age for project 1). McCarry (2012) speaks to the issue of young people genuinely volunteering as opposed to being volunteered for research projects, which is worth considering when working in schools. Schools wanting to project a positive image to external audiences often select their 'best' students to the exclusion of the less academic students. In many ways this limits the chance of achieving the attributes of CRAGs – passion, solidarity and diversity

(Caldwell and Jarret, 2018). In project 1, the criteria for involvement in the CRAGs was simply expertise in issues based on their status as children and young people. The researchers were reliant on schools to recruit and, although we emphasised the need for diversity in the group, we were sceptical that this was sought by the schools. In Project 2, in order to reflect the target survey sample, a range of pupils with migrant backgrounds were required for the CRAG and these were recruited from the research team's established and wide network of associations with refugee and migrant communities. There are many criteria that can be used to select children to participate in CRAGS and there are many ways to select (and therefore also to reject) potential participants. It is important that the criteria being used, whatever they are, are made clear and transparent, so that all involved know what they are.

As with any group, the initial stages of group formation are fundamental to its operation. Key to this is a recognition that, while they have a shared social experience related to their age, members of a CRAG may have 'diverse intersectional identities' Collins et al., (2020: 5). Tusla, the Child and Family Agency in Ireland, in their Child and Youth Participation Toolkit recommend investing time in getting the panel[1] to know each other, establish ways of working and developing solid relationships with staff and with each other (Tusla, 2016). This process can involve all team members – researchers and children – sharing their different contexts and realities (Collins et al., 2020). In particular, Project 2 facilitated this through longer unhurried sessions with our CRAG involving icebreakers, games and an opportunity to get to know each other over pizza and informal chats with research team members. However, the chosen activities must be adaptable to take into account differences of age, gender, ethnicity and otherwise.

Venue

The importance of a neutral venue is emphasised in the literature, especially in light of restrictions imposed by conducting research in schools (Christensen and Prout, 2002; Moore et al 2018). Previous studies have suggested that school-based research participants find it difficult to slip out of their usual student role where they are required to do everything that adults (i.e. teachers) ask of them (Horgan et al., 2017). So, CRAGs are often in conflict with other models of participation used in the school where there is already a set hierarchy and agenda (McCarry, 2012). In recognising the importance of a space where students feel able to engage in a different type of relationship with the adult researchers, in Project 1 we, like Moore et al., (2018), used non-classroom locations in the schools, for example, the boardroom to differentiate the researchers from school staff. In Project 2 we used university buildings which are aesthetically nice and adaptable for group activities. Ultimately, of most importance is providing a safe, private physical location in which the research can take place and ensuring participants' anonymity and confidentiality. Increasingly in international research projects, there is a reliance on virtual communication with CRAGs. Collins et al., (2020) highlight some general limitations of virtual communication including, accessing children in remote/rural parts of the world because of lack of internet or reaching children in certain countries or age groups because of their exclusion from Google or Facebook. However, young people themselves have highlighted technology and social media as an adjunct to more traditional ways of reaching out to young

[1] Tusla speaks of "panels" while this chapter speaks of CRAGs. However, the terms, as used here, are roughly equivalent.

people (Caldwell and Jarret 2018). Such approaches not only make CRAGs possible across time zones and for groups traditionally at risk of exclusion, but can also be valuable, as experienced during the COVID -19 global pandemic, when it is difficult to physically meet with participants.

Capacity building

McCarry (2012: 65) asks why we expect children and young people to participate in research without some level of capacity building when, 'as social scientists we undergo substantial research training which is deemed necessary to conduct ethical research?' The Tusla *Child and Youth Participation Toolkit* stresses the need to develop a programme of training and support with appropriate staffing to co-ordinate and support CRAGs. Any such training should be: experiential, drawing on participants existing knowledge and skills; practical, tailored to the needs of the CRAG and be properly resourced (Tusla, 2016). Every research project has to take into account children's level of information on the topic and skills required for their engagement (Lundy and McEvoy, 2012) and plan accordingly the level of input or training required by the CRAG. As such, 'bespoke' capacity building strategies developed for the two projects were informed by the wealth of literature in participatory research with children and were designed to be consistent with children's rights standards: safe, inclusive, engaging, flexible and responsive to children's needs and optional (Lundy and McEvoy, 2012).

Underpinning all work with CRAGs is 'informing' children which can have a transformative effect on their understanding of their role, their ability to express their views, and the degree to which children's voices ultimately exert influence (Mayne et al., 2018). Central to this is use of child/youth friendly language and 'jargon busters' (Collins et al., 2020). Examples of capacity-building the authors have used include child-friendly versions of information on children's rights, in particular Article 12 UNCRC (see Figure 1), as well as the Lundy (2007) model of participation.

Insert Figure 1: Why include children and young people in research?

Since exploring children and young people's opportunity to participate in decision-making was at the heart of Project 1, it was crucial for the CRAG to build an understanding of what decision-making involved. The 'Decision-making chart' (see Figure 2) supported children in understanding decision-making by asking them to evaluate a pair of options and to make a choice and then extended their learning to the concept of 'majority rule'.

Insert Figure 2: Decision-making chart for 7-12-year olds

Another aspect of capacity building relates to providing CRAG members with information on the project itself - explaining the research funding, research partners, who the research is for the key research questions, building on the information previously given to them as part of the consent process, providing more detailed information on proposed research methods and opportunities for questions and updates as the project progresses. A critical aspect of capacity building is an understanding of ethical research including consent, child protection, anonymity and confidentiality. For example, in the first meeting with the CRAG in both projects, having completed informed consent forms, the children were welcomed and engaged in some ice-breaker activities, followed by a short presentation on social research, research ethics and the fundamental children's rights principles underpinning the child participatory approach of the project. Capacity building in later aspects of the projects are discussed next.

CRAG Role in Designing and validating methods

Perhaps the most important role of Children's Research Advisory Groups is their contribution to the design and testing of research methods (Jones et al, 2020). Here we have children of a similar age to those ultimately participating in the research, informing and shaping the research tools suitable for their peers, testing that they are age appropriate and user-friendly. In project 2, the CRAG engaged in data collection activities proposed for qualitative research in order to test and further develop these methods, identify their appropriateness for workshops with children of different age groups and begin the process of identifying issues of concern to them. They were divided into groups based on age: comprising younger children, aged 9 –12 and older children, aged 12 –16 facilitated by members of the research team. The younger children engaged in 'Talk and Draw' methods of engagement (comprising placemat and lifeline work) while the older children engaged in focus group discussion, post-it, lifeline and voting activities. All activities focused on what facilitates migrant children's sense of belonging in school and what barriers they encounter. Immediately, it became evident from observations of their engagement in the activity and feedback from the children afterwards that the use of lifelines as a group activity with the younger children was problematic. The research instruments were subsequently finalised for the project based on the children and young people's feedback and the facilitators evaluations.

In a subsequent meeting the CRAG validated an inventory of 30 indicators of socio-educational integration of migrant children developed initially through a literature review. They responded as part of an engagement with groups of experts including academics, public servants and professionals involved in immigrant integration and refugee services and management in education settings. The CRAG was heavily involved to ensure that migrant children's voices were central in the co-creation of the integration indicators for use in a survey. Three key questions were asked of the CRAG for each question on the draft survey:

1. **Clarity:** Do you understand the questions?
2. **Adequacy**: Do you think the question is important for understanding if children are integrated into school?
3. **Suggestions for improvements?**

Some thoughtful suggestions were offered including extending a question on learning

supports available at school. The Advisors also made suggestions about informing children as to why the questions are being asked. Overall, they confirmed that the survey was clear and asked appropriate questions. Subsequently, the CRAG tested the online survey through an app and provided feedback on its user-friendliness, clarity of questions and use of visuals.

CRAG role in Data Analysis

Few 'participatory' studies include children at the data analysis and dissemination stages. However, ethical guidelines refer to these stages explicitly (Pinter & Zandian, 2015) and we know of the ability to increase the richness of data obtained by including children's perspectives and contributions in data analysis processes (Gillett-Swan, 2018).

In Project 1, both CRAGs (7-12 and 12-17 year-olds) reflected on the research findings in order to 'member check' the analysis (Cowie and Khoo, 2017). A facilitated discussion game was employed with the children and young people to identify important participation issues and expand researchers' understandings of them utilising the data collected by the research team. The children were then asked to prioritise themes emerging by sorting representative verbatim child participant quotations taken from the raw data transcripts into piles of 'most important', 'important', 'not important' and 'disagree'. CRAG members spent lots of time categorizing and then ranking the issues in order of importance. These informed the final data analysis and write-up of the report. In line with Gillett-Swan (2018), we found that this ensured validity and trustworthiness of the data as well as providing an additional layer of insight and context for the researchers. However, it was quite limited as a once-off exercise given the importance of adequate time for reflection, reviewing and debrief in data analysis emphasised by Fargas-Malet et al. (2010). The CRAG in Project 2 will contribute to data analysis through a range of co-creation methods once fieldwork has been finalised by working with the raw data generated from the surveys and qualitative research and thereby potentially diminishing problems with accurate representation of participants' voice.

CRAG role in research sharing

Children's Research Advisory Group participation often ends abruptly once the project is completed, since the writing-up stages are almost exclusively claimed by adult stakeholders. Furthermore, as Pinter and Zandian (2015) highlight, dissemination of research findings primarily takes place at research conferences and in academic journals, both exclusively targeted at specialist adult audiences. However, as well as being good practice, children's involvement can be used to advantage particularly during dissemination. A limitation of Project 1, which was Irish Government commissioned research, was the CRAG's non-involvement once the report was produced. However, in Project 2 the CRAG will report to the European Commission and produce online blogs, podcasts and videos for dissemination through the IMMERSE website and on social media platforms. Such a participatory dissemination role for children in research is increasingly being advocated as a way of making research dissemination more authentic and ethical (Yang, 2015).

Recognition of children's contribution in CRAGs

In consideration of the reciprocal nature of research engagement, the issue of payment to young people continues to be debated. It is ethical practice to compensate young people for their participation, though McCarry (2012) has found that while token payments were important to the young people, they were not the only motivation for their participation. There are many ways of recognising and recompensing children's contribution in CRAGS. For instance, food, cash, vouchers, research training, certificates of participation that can be cited on a young person's CV. In our projects it is considered important that the children and young people engaging in the Advisory Groups would see specific, personal and immediate outcomes of their engagement through a variety of means. In project 1 this included:

- children and young people received capacity building around child participation, the UNCRC, and social research,
- they were invited to the University at different stages of their involvement where they were given a tour of the campus and provided with lunch,
- they received cinema vouchers and some University merchandise.

Conclusions

Children's research advisory groups can offer us a way in to rights informed research which is meaningful for children and achievable for most research projects. They are well situated and equipped to provide ongoing advice and oversight to research projects. In this chapter we make the case that CRAGs can help to achieve 'deep participation' (Horgan 2017a) with some caveats:

- there are competing tensions between fulfilling ethical requirements and achieving academic research outputs as against facilitating children to have control over the research process.
- CRAGs require more thought, planning and resources, especially time, compared to research that is solely carried out by adult researchers. This is a significant consideration in some longer running projects (four years or more for Project 2).

We highlight the importance of attending to practical issues – such as venue and timings - as well as process issues - facilitation, capacity building and training - as critical way of equalising power between adult researchers and youth research advisors.

We would echo Lundy (2018) and McCarry (2012) who question models of participation which assume that the greater the level of involvement the more inclusive and empowering it is for young people, and the stronger the resulting research. While there are clear benefits to working with a Children's Research Advisory Group, it may often be more practical and respectful of young people's time and other commitments at the different periods in their lives, for example school examinations, extra-curricular commitments or holidays to negotiate 'pockets of participation' (Franks, 2011) or to offer differentiated levels of involvement at the various stages of the research.

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