



A systematic review of the principles of co-production in relation to the mental health and wellbeing of care leavers

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This paper reviews prior applications of co-production principles and their potential impact on the mental health and wellbeing of care leavers. There is minimal research available on care leaver narratives of their experiences and consequent mental health and wellbeing needs. This paper explores the relevance of different, sometimes opposed, approaches to co-production, the knowledge which can be gained about the mental health and wellbeing needs of care leavers, and finally the potential for lifelong learning through co-production with care leavers. A systematic review was selected to draw conclusions about how the method of co-production could improve awareness of and provisions for care leaver mental health and wellbeing. This review included 14 sources with a total of 541 participants. Following a rigorous systematic review on these themes, conclusions were drawn suggesting that co-production involving care experienced individuals, whilst faced with a range of considerations to ensure success, can have largely positive impacts on care leaver mental health and wellbeing and is therefore a recommended methodology.

Keywords: co-production, mental health, wellbeing, care leavers, education

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Introduction

Although the World Health Organisation (2018) states that mental health is vital to general health, the social, emotional and mental health needs of looked after children are significantly higher than the general population (Department for Education, 2020; Luke et al., 2014). This implies that when they become care leavers, between 16 and 25 years, these difficulties will likely continue, often with delayed symptoms (Sims-Schouten &

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Hayden, 2017; Faller, 2020). The move to adulthood is therefore likely to be more difficult for care leavers than their peers, facing increased social exclusion, lowered attainment, financial difficulties and poorly supported transitions (Children and Families Act, 2014; Lancashire Children's Social Care, 2019). If the health of younger generations directly impacts the health of society (Shaw & Bailey, 2018), unresolved mental health difficulties could cause lifelong adversities (Midgley et al., 2017).

Despite considerable quantifiable data about the circumstances of care leavers in the UK, there is little data about how these circumstances are experienced (Sims-Schouten, 2020, Sims-Schouten & Hayden, 2017). Co-production could play a central role here, grounded in three key purposes, being involved in decision making, improving the value of a project, and enhancing knowledge (Filipe et al., 2017; Involve, 2018; Paylor & McKeivitt, 2019). This paper aims to provide insight into applications of co-production in research around the mental health and wellbeing of young care leavers. Whilst co-production is increasingly implemented (McConnell et al., 2019; NIHR, 2020; Scottish co-production network, 2015), those who undertake this methodology do face challenges, such as cost (in time and finances), prioritising needs, power balancing roles and responsibilities, engagement of participants and essential training, which is seemingly irrespective of research location (including Switzerland, UK, USA, Peru, Japan, Tanzania and Nigeria) (Beran et al., 2021; Farr et al., 2021, Khine et al., 2021; Turk et al., 2021; Tait & Lester, 2005). Yet this research also suggests that regardless of these potential barriers, co-production can still prove to be a valid and worthwhile methodology, to support lifelong learning and development, for individuals and the wider society.

Co-production works to facilitate collaboration between 'experts by experience' and 'experts by qualification', achieving culminated knowledge (McConnell et al., 2019). Through freedom of expression, participants can achieve empowerment, reversal of negative outcomes and mental safety (Gal, 2011; Hughes, 2016), though there is minimal evidence of care leaver involvement in mental health and wellbeing based co-production. Moreover, while co-production represents a useful start to making sense of lived experiences through informal learning, the working principles of its implementation remain disputed, surrounding rationale and techniques (Involve, 2018). On one hand, approaches resonating with social sciences treat co-production as an immersive, user-led process (Beresford, 2019), ensuring involvement is for necessity and relevance (Social Care Institute for Excellence (SCIE), 2013). Whereas approaches resonating with medical sciences, whilst similarly aiming for the best outcomes, appear less flexible towards factors such as time and cost, instead focusing on set goals, encouraging transparency and clarity surrounding terminology (NIHR, 2015). This idea was similarly reflected by Weare and Nind (2011) in reference to different approaches to mental health and related problem solving in schools, dependent on geographical location; they explore the idea of 'bottom up' approaches promoting empowerment, ownership and autonomy in opposition to more prescriptive approaches where there is less room for flexibility and user-involvement but more scope for achieving measurable outcomes.

Nevertheless, effective co-production is generally centred around knowledge acquisition based upon inclusivity, diversity, respect and strengthened relationships built from mutual accountability (Batalden et al.,

2016; Involve, 2018; Lushey & Munro, 2015). However, where care leavers often struggle with attachment and emotional safety, this reliance on relationship building may prove problematic (Nicholson et al., 2019; Turakhia & Combs, 2017). This idea is similarly portrayed in work undertaken around the Adverse Childhood Experiences scale (ACEs) describing children who have experienced childhood maltreatment and the resulting negative outcomes they might experience, both academically and emotionally, with trauma informed care being deemed essential for ‘whole child’ support (Chafouleas et al., 2021). This review contributes to the emerging body of research around co-production, specifically in relation to mental health and wellbeing.

Mental Health and Wellbeing of Care Leavers

Despite decades of research, the concept of mental health and wellbeing remains disputed, highlighting that individual mental health needs cannot be easily categorised, as biological treatments suggest (British Psychological Society, 2018; Faith, 2020; Mental Health Foundation, 2020). Care leavers tend to have lower mental health and wellbeing, compared to the average population, due to recurring, traumatic experiences causing a chain of disadvantage (Cloitre et al., 2009; Stein & Dumaret, 2011; Wymer & Carlson, 2019). Their often traumatic childhoods increase the likelihood of long lasting negative effects, including difficulty problem solving (Kottenstette et al., 2020), poor self-image (Osofsky et al., 2017), trauma triggers in unknown or similar situations (Bartlett et al., 2016), delayed recall of events (Faller, 2020), feelings of guilt (Norman et al., 2019), dysregulated emotions, a sense of grief for lost relationships (Cohen et al., 2016) and disrupted attachments (Bentovim et al., 2009; Mucci, 2013). All of these can have lasting impacts on an individual’s learning and development.

Noting the internal and external effects of trauma (Hughes, 2016; Larkin et al., 2013), makes it easy to assume that care leavers will indefinitely retain poor mental health (Golightley & Goemans, 2020). However, even if a care leaver is not impacted to this extent, it still seems appropriate for practitioners to, at minimum, be aware of potential adversities (Thrive, 2019) and the cumulative, cyclical barriers which may result from care experience (Stein & Dumaret, 2011; Wymer & Carlson, 2019). Similarly, an EU Commission report (2013) collates the range of ways that educational settings across the globe target Early School Leavers, many of which note the importance of holistic approaches, recognising the individual needs of the students, involving individuals in decision making and reflection. This further evidences the importance of recognising ongoing, individual needs, both socially and academically. Yet, although ‘The ACEs survey toolkit’ (National Crittenton Foundation, 2015) highlights trauma symptoms and their lasting impacts, there are few methods to monitor longer-term wellbeing.

Research highlights that decisions around support and mental health provision are primarily coordinated by practitioners (e.g. educators, psychologists and social workers), rather than centralising the voices of those affected (Baker, 2017). It is suggested that active participation, with children and adults, can promote education and awareness-raising experiences, beneficial to all involved; by building understanding of abstract concepts such as freedom of speech, human rights and self-knowledge, individuals can become ‘social

actors' (Day et al., 2015). Similarly, through actively listening to care leaver voices this can highlight personal growth, positive attitudes and behaviours ((Sims-Schouten & Hayden, 2017; Osofsky et al., 2017; Rivera & Sullivan, 2015). Thus, there is a need for centralising the voices of young care leavers, and co-producing practice and support systems that work, particularly as trauma symptoms are highly individualised; with some care leavers finding unfamiliar situations unexpectedly stressful (Bartlett et al., 2016; Charlier et al., 2018; Hughes, 2016). Trauma awareness recognises the ethical and practical requirements for clear expectations, safe environments and patient involvement (King & Gillard, 2019; Menschner & Maul, 2016).

It should also be acknowledged that individual narratives may become less reliable where recall changes over time (Simpson & Sheldon, 2019; Shaw, 2016; Engelhard & McNally, 2015; Elliott, 2011; Rose & Philpot, 2005). This includes the notion that altered perceptions can demonstrate involuntary coping mechanisms, aiming to avoid mental or physical danger (Vaillant, 2011). Through co-production and trauma awareness, practitioners can recognise that whilst care leaver experiences are often a combination of external and internal 'realities', they remain valid and should play a central role in support decisions (Larkin et al., 2013) regardless of setting (e.g. schools, universities, foster homes). Additionally, there is a need for this collaborative, integrated approach to extend beyond individual cases and support larger initiatives, aimed at targeting potential needs rather than solely resolving escalated ones, which could also inform a global approach to giving voices to marginalised groups (Donlevy et al., 2019).

Methodology

Search Strategy

The review adopts an inductive approach to the systematic review process, drawing on the PRISMA (Moher et al., 2009) structure and using strict criteria to select sources (2015-2020), with 14 sources in the final review. The basic PRISMA principles (2015) are also reflected in other systematic reviews, suggesting validity to these general steps (Aromataris & Pearson, 2014; Centre for Reviews and Dissemination, 2009; Møller & Myles, 2016; Lockwood et al., 2015). Two databases were used: PsycInfo (<https://www.apa.org/pubs/databases/psycinfo>) and Google Scholar (<https://scholar.google.com/>).

Inclusion and Exclusion Criteria

The PRISMA flowchart (Moher et al., 2009) (Figure 1) was adopted to maintain organisation of sources, as well as to double check for duplicates or edits of the same study, whilst avoiding researcher bias (Methley et al. 2014). Alongside the two databases named above, we also reviewed grey literature key to this discussion, held externally from these databases, regarding it met the eligibility criteria. The following criteria were adopted:

Inclusion criteria:

- Participants above 16 years (care leaver age)
- Co-production methodology

- Studies referring to mental health benefits

Exclusion criteria:

- Participants under 16 years
- Papers more than 10 years old
- Studies using co-production without mention of mental health benefits
- Papers not fully retrievable online (Covid-19 limitations for access)
- Studies not written in English

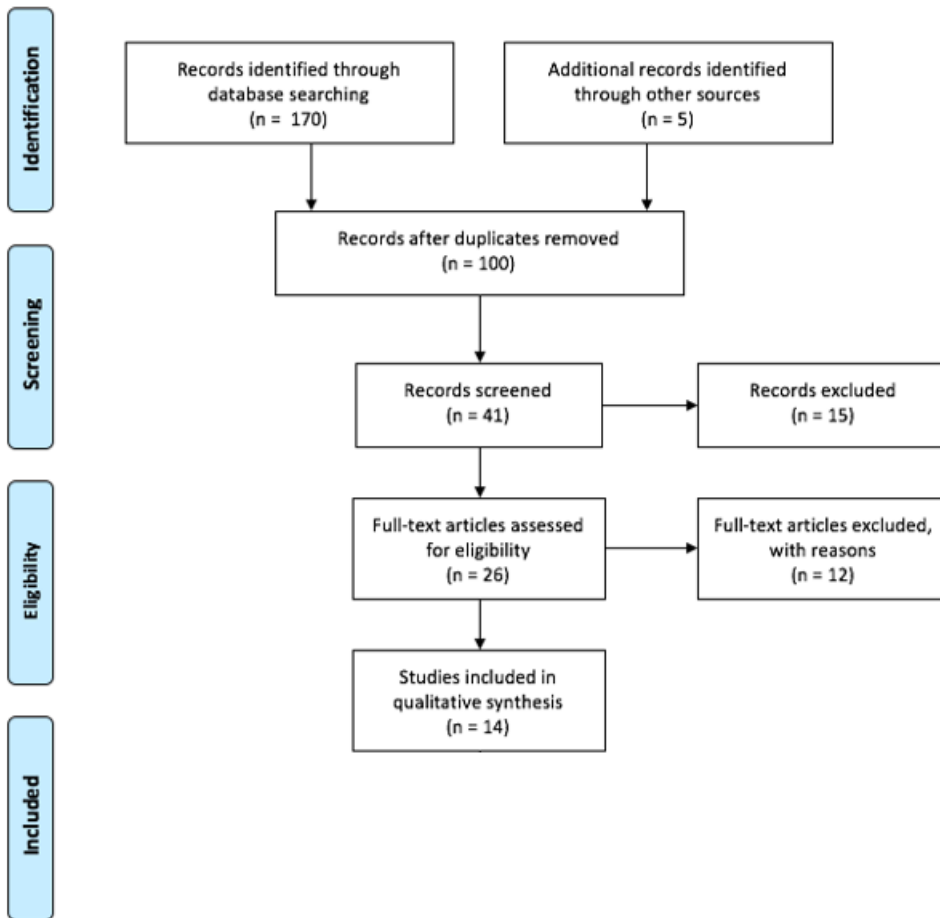


Figure 1 Prisma Flow Chart (adapted from Moher et al, 2009)

Selection Process and Data Analysis

Data was aggregated into sub-themes, allowing for concise analysis with relevant themes discussed and analysed using narrative description. Whilst qualitative data analysis can be challenging (Evans, 2002; Methley et al. 2014; Shaw et al., 2004), the strict screening process allowed for better selection and synthesis of data. Here the PRISMA flowchart (Moher et al., 2009) was applied, to reduce the number of search results (See Figure 1) removing irrelevant and duplicated sources. ‘Meta-aggregation’ was used by considering studies

with ranging methodologies (Florczak, 2019) to synthesize a larger number of studies implementing different approaches and reach more conclusive results.

Results

Summary of included studies

The original search for ‘co-production’ returned 319,600 results, though this was reduced to 170 after adding in ‘mental health’ specifics alongside year, language and access parameters. Only studies that fulfilled the inclusion criteria were included, with the final number of sources being 14. Two sources were theoretical (National Collaborating Centre for Mental Health (NCC), 2019; Rose & Kalathil, 2019) and one did not provide a total number of participants (Tribe, 2019) but the other studies totalled 541 participants. We held no bias towards methodology, gender, socio-economic status, location or ethnicity when reducing sources. The sources selected cover a range of locations, with studies undertaken in Britain, Ireland, Iceland, Norway, Finland, Australia, the Netherlands, Italy and Sri Lanka. The results show benefits and ‘considerations’ (referring to factors for consideration rather than drawbacks) found in the sources (see Figure 2). The studies highlighted practical actions for improving success rates of co-production, its benefits to the mental health and wellbeing of participants as well as the sizeable and long-lasting positive impacts of co-production to the individual and their ongoing development. Though different sources relayed different benefits, it was clear that the majority felt that the benefits outweighed the considerations. Rose and Kalathil (2019) are noticeably absent from the benefits discussion, as their work focuses on the idea that true co-production is not possible due to hierarchical power imbalances.

Roles, responsibilities and relationships

There remains debate surrounding the idea that service users be involved for the entirety of the research process; although many agree with full participation (Casey & Webb, 2019; Dent, 2019; Gheduzzi et al., 2019; Kelly et al., 2020; NCC, 2019), it is disputed that mental capability can impact essential decision making. Yet in terms of learning and development, the positive impacts of even partial involvement present positive outcomes. Whilst increased involvement may demonstrate ‘true’ co-production, some elements of a study may not be appropriate to share. Hence, transparency and mutually agreed objectives, roles and boundaries are deemed necessary, wherever possible (Casey & Webb, 2019; Critchley et al., 2019; Dent, 2019; ; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Pinfold et al., 2015; Rose & Kalathil, 2019).

	Horgan et al., 2020	Kelly et al., 2020	Casey & Webb, 2019	Critchley et al., 2019	Dent, 2019	Gheduzzi et al., 2019	NCC, 2019	NIHR, 2019	Rose & Kalathil, 2019	Tribe, 2019	Lambert & Carr, 2018	Duffy et al., 2017	Mayer & McKenzie, 2017	Pinfold et al., 2015
Roles, responsibilities and relationships														
Users to be involved throughout the research process		✓		✓	✓	✓	✓							
Strengthened working relationships and networks		✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
Role clarity and boundaries put in place	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓
Mutually agreed roles and responsibilities	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓
Ensuring anonymity	✓		✓				✓	✓				✓		✓
Incentives	✓						✓	✓			✓	✓		✓
Ongoing reflection and development of skills														
Requirement of ongoing reflection of barriers		✓	✓	✓			✓	✓		✓	✓	✓		✓
Time to learn basic skills		✓	✓			✓	✓	✓				✓		
Time to adapt services in response to learning	✓	✓	✓			✓	✓	✓			✓	✓		✓
Developing research skills through involvement		✓					✓				✓			
Adaptations for individual needs	✓	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓
Ensuring mental and physical safety							✓	✓				✓		
Improving resilience and coping strategies			✓	✓						✓				
Service provision														
Service quality and satisfaction increased	✓	✓		✓	✓	✓	✓	✓		✓		✓	✓	
Informed decision making via patient contributions	✓		✓				✓					✓	✓	✓
Improved service user mental health and wellbeing	✓	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	
Reduced stigmas and more inclusive mindsets	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓	✓

Figure 2. ‘Considerations’ and ‘benefits’ for successful co-production

Nonetheless, through transparent communication, it seems likely that ‘working’ relationships can strengthen and develop, allowing for mutual respect of different roles and responsibilities as well as room for increased knowledge and experience of these formal interactions. Unfortunately, relationship building also runs the risk of causing power balance shifts if considerations such as cross-cultural respect, translators, fair incentives, anonymity and truly unbiased participant selection are not recognised (Casey & Webb, 2019; Duffy, 2017; Horgan et al., 2020; Lambert & Carr, 2018; NCC, 2019; NIHR, 2019; Pinfold et al., 2015). Moreover, practitioners must ensure participants are not ‘silenced’ or marginalised due to lower self-esteem (NCC, 2019) caused by non-selection, for example by selecting more confident ‘types’ (Mayer & McKenzie, 2017). These considerations are vital, yet equally relevant to other research methodologies.

Ongoing reflection and development of skills

Co-production requires ongoing reflection, to celebrate successes (personal, social and educational) and address barriers, especially those causing exclusion (Casey & Webb, 2019; Critchley et al., 2019; Duffy et al., 2017; Kelly et al., 2020; Lambert & Carr, 2018; NCC, 2019; NIHR, 2019; Pinfold et al., 2015; Tribe, 2019). Barriers including location, access to transport or mental health difficulties may result in poor diversity of viewpoints (NCC, 2019) as could unconscious privilege or hierarchy (Rose & Kalathil, 2019). Whilst participation should be voluntary, researchers can and should find ethical ways of encouraging diverse

participation e.g. involving the individual's community (Duffy et al., 2017; Mayer & McKenzie, 2017). Also, equally validating those working at different academic levels and with ranging support needs. Participants should be reflective of the target population (Duffy et al., 2017) regardless of the level of adaptation required, to ensure mental and physical safety (Casey & Webb, 2019; Critchley et al., 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Pinfold et al., 2015; Tribe, 2019). This includes consideration of upbringing (e.g. care leavers), attainment, gender, location, cultural background, socio-economic status, age and many other characteristics which fall relevant to the population being researched.

It is suggested that gradual, organic data collection is best (Casey & Webb, 2019) whereas others noted that a timely pace enabled better engagement and avoided unsustainable dependency (Critchley et al., 2019). Time to learn 'basic skills' which would benefit the individual moving forwards, such as time management, form filling or conversational etiquette, was suggested as beneficial to those without this experience but which could prevent full involvement in the process (Casey & Webb, 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Kelly et al., 2020; NCC, 2019; NIHR, 2019). Participants are more able to gain knowledge, research skills, resilience and coping strategies in unfamiliar scenarios simply through their involvement (Casey & Webb, 2019; Critchley et al., 2019; Kelly et al., 2020; Lambert & Carr, 2018; Rose & Kalathill, 2019; Tribe, 2019). Skills which can be learned, practised and further implemented into their future experiences. Participants are individual and thus their approach to the process will likely be different, as will the impacts it has. More inclusive mindsets and enhanced communication channels will likely increase awareness, which will both challenge and educate against negative societal norms and stigmas. Practitioners must be willing to accept where their provisions are not yet effective, remaining respectful, avoiding deception through false expectations and adapting structures or protocols in response (Casey & Webb, 2019; Dent, 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; NCC, 2019; Pinfold et al., 2015). This is relevant to a range of settings, educational, health and social care.

Service provision

There is evidence that co-production can provide mental health benefits, such as increased self-esteem, confidence, sense of identity, sense of purpose, ownership as well as improved physical health (Casey & Webb, 2019; Critchley et al., 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Tribe, 2019). Another equally important factor is enhanced service provision and service satisfaction for current and future service users (Critchley et al., 2019; Dent, 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Tribe, 2019). Participants are able to acquire knowledge on two fronts, about themselves and their personal development but also the provisions they are accessing. Through acknowledging patient contributions, it is also practitioners who can gain a better understanding and consequently better reputation for addressing individual needs through providing a more

sustainable and informed service (Casey & Webb, 2019; Duffy et al., 2017; Horgan et al., 2020; NCC, 2019; Mayer & McKenzie, 2017; Pinfold et al., 2015). Whilst sustainability is perhaps not prioritised over immediate needs, longer term successes can provide better outcomes for their setting, such as reduced stigmas, more inclusive mindsets and cost effectiveness, as co-production promotes a cycle of review and improvement (Casey & Webb, 2019; Critchley et al., 2019; Dent, 2019; Duffy et al., 2017; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Pinfold et al., 2015; Tribe, 2019).

Discussion

Practitioners who have effectively prepared to co-produce, should recognise participant needs (Casey & Webb, 2019), particularly in vulnerable minorities where mental health and wellbeing is reduced (e.g. care leavers). They should not be excluded for their barriers but should have the option to opt out, with informed support. This review suggests that co-production can enable health and wellbeing, educational attainment, relationships, employment prospects and financial stability, all characteristics described as adversities for care leavers (Brady & Gilligan, 2018; Duffy et al., 2017; Kelly et al., 2020; NCC, 2019). Furthermore, although co-production relies on interaction, which may be difficult for care leavers, it can be conducted sensitively, in a 'safe' space with informed practitioners. For individuals with significant barriers, there is the possibility that methods such as co-production will not prove effective. Nonetheless, through developing social relationships and awareness, as well as improving the skills required for interactions and coping in unfamiliar social situations (Casey & Webb, 2019; Critchley et al., 2019; Kelly et al., 2020; Tribe, 2019), care leavers are more likely to flourish.

Vulnerable individuals often require sustained support, to allow them to maintain a positive progression through life, regardless of prior experiences. Our research evidenced that stigmatisation and discrimination towards vulnerable minorities, can have detrimental effects on mental health and wellbeing, especially if those in supportive roles hold negative pre-conceptions. Although some care leavers may prefer anonymity, through improving general awareness of their trauma or care experience, empathy could be fostered (Casey & Webb, 2019; Critchley et al., 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Horgan et al., 2020; Kelly et al., 2020; Lambert & Carr, 2018; Mayer & McKenzie, 2017; NCC, 2019; NIHR, 2019; Pinfold et al., 2015; Tribe, 2019). A relatively new process such as co-production could produce more representative and reliable data about minorities, who are otherwise unheard or misunderstood, as is the case with care leaver narratives. Whilst each case is different, allowing care leavers to contribute their thoughts and ideas surrounding services, practitioners and protocols, provides more scope for evidence-based changes.

Care leavers may struggle to engage with services; therefore, co-production relies on trauma awareness and recognition of the higher level of support they will likely require. Overcoming power balance struggles is key for successful co-production (Casey & Webb, 2019; Dent, 2019; Duffy et al., 2017; Gheduzzi et al., 2019; Lambert & Carr, 2018; NCC, 2019; NIHR, 2019; Pinfold et al., 2015), a point of high importance when working with care leavers, who will likely have suffered, in terms of power and control. Nonetheless, power

struggles sit with the practitioners who have a professional and ethical duty to ensure that their participants feel confident and able to speak out, particularly when the purpose of co-production is to give a voice to those without a voice. For care leaver specific services, it is likely that their perspectives refer to a significant time in their lives, requiring respect towards their highly personal and emotive narratives.

Conclusion

Whilst not all care leavers will experience every adversity or to the same degree, mental health and wellbeing is relevant to all individuals and their ongoing needs. Care leaver voices are seldom represented within current literature. It is paramount that this is rectified, using the most effective method possible. This review has highlighted a range of considerations to be made by researchers preparing to implement co-production but overall, there is clear evidence of the beneficial factors which can be achieved, particularly with vulnerable individuals, such as care leavers. Although it is difficult to ascertain whether the benefits are a direct result of co-production or the more specific data collection methods implemented, the frequencies of benefits demonstrate similarities where the key consistency between the sources is co-production.

Whilst this review aimed to explore a range of studies, implementing different approaches and from a range of contexts, there remains a need for further scrutiny into the systems surrounding care leavers and the transitions they experience. An ecological systems review of the support measures put in place to facilitate care leaver needs is required on a country by country basis and in some circumstances broken down further, where regional approaches vary. A further consideration is the use of terminology across international locations, more specifically synonyms for ‘mental health’ which could have drawn a wider range of studies for analysis. However, whilst our search specified ‘mental health’ in the search criteria, many of the search results that did not necessarily use this terminology within their main text, did within their ‘key words’ and therefore were included.

Nonetheless, this review demonstrates that whilst there are a range of definitions and approaches towards co-production, they all promote respectful collaboration. Overall, they aim to improve services and better support service users, whilst facilitating and enhancing informal learning for service users and those supporting them. Moreover, through being given a ‘voice’, care leavers are empowered to share and learn from their experiences, to process the resulting impacts of them, increase awareness and develop better provisions moving forwards.

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