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Developing our understanding of the difference co-production makes in social care

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About SCIE

The Social Care Institute for Excellence improves the lives of people of all ages by co-producing, sharing and supporting the use of the best available knowledge and evidence about what works in practice. We are a leading improvement support agency and an independent charity working with organisations that support adults, families and children across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

Written by Patrick Wood, Sharon Stevens, Deanne Mitchell, Tasnim Rahman and Abiodun Arikawe

Contact info@scie.org.uk

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Social Care Institute for Excellence

83 Baker Street, London W1U 6AG

www.scie.org.uk

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Executive summary

Co-production sets out a way of working where professionals and those who draw on services or those who are impacted by a decision work in equal partnership to develop services or make decisions to meet people's needs. Increasingly, the values of co-production are being viewed as a way of developing services or agreeing decisions jointly that are innovative in meeting people's needs.

As social care policy increasingly recognises the importance of co-production in implementing policy ambitions, there is an opportunity to deepen our understanding and knowledge about the difference co-production makes.

SCIE believes that co-production is the right approach and should be taken as a matter of principle. However, we wanted to take stock and hear from people who have been involved in co-production, as well as considering the evidence about what is understood about co-production in social care, and to see what more should be done to better evidence the difference that co-production makes.

During our research we heard about the benefits of co-production for people with lived experiences and professionals. These include an increase in self-confidence, self-esteem and sense of empowerment, better health and wellbeing, increased engagement and trust, and higher levels of satisfaction with and awareness of services. We also found benefits for professionals, including improved job satisfaction, motivation and practice, and increased trust, engagement and dialogue with people who draw on care and support and carers.

We found that the health sector had more research available about the impact and outcomes of co-production than the social care sector, which the social care sector can learn from. While there is an increasing knowledge base about co-production in adult social care, more needs to be done to realise the full potential of co-production in social care. Given the policy intentions, the opportunity to deepen our understanding and knowledge of the difference co-production makes must be taken and therefore the Social Care Institute for Excellence (SCIE) recommends the following:

1. Evaluation of the impact of co-production in adult social care should be undertaken as standard for relevant projects and programmes of work, including focusing on people who are underrepresented in the current evidence base, for example people from Black, Asian and minority ethnic communities and unpaid carers.
2. Evaluations of co-production in social care should be refocused onto assessing outcomes and impact and move away from the co-production process and output.
3. A more universal understanding of co-production should be developed.
4. There should be greater consistency in co-production in social care.
5. There should be greater investment in resources for the evaluation of co-production, including resources for staffing, staff time, remuneration for people with lived experience and the provision of training.
6. People with lived experience should be involved in identifying the outcome measures

to be considered in co-production evaluations.

7. Skilled facilitators should be used to lead the co-production process (including evaluation) and build relationships and support communication between different groups of stakeholders.
8. Managers and leadership should be involved and provide support to enable the impact of co-production to be measured.

To co-produce evaluations fully, SCIE also recommends the following when undertaking evaluations with people with lived experience:

9. There should be greater flexibility in the evaluation process, recognising that at times, things can change at the last minute, and it is important to make changes to accommodate people.
10. Access needs should be properly addressed and managed to ensure evaluations are accessible.
11. Evaluations should be conducted in a safe space that protects and provides training to everyone involved and provides appropriate training for people involved in co-production evaluation.

Although effective co-production can require resources at the beginning of the process, co-production can provide solutions to problems that you didn't even know were there in the first place.

If the impact of co-production is to have meaning and power, it is important not to give up, so we must remain persistent.

> 'The more we do good co-production, the more others will follow. It encourages further co-production.' (Online participant)

1. Introduction

SCIE believes that co-production is the right approach and should be taken as a matter of principle. However, we wanted to take stock and hear from people who have been involved in co-production, as well as considering the evidence to see what more should be done to show the difference co-production makes.

Co-production in social care has strong links with the disability movement, with the belief that disabled people are the best people to make decisions about their own lives and that when disabled people work together, they can make changes in a society that currently disables them.[1]

The term 'co-production' was used 50 years ago by economists describing how communities need police, but also recognising that police need communities.[2] Over the last 20 years, there has been an increase in interest in co-production in social care, recognising that it is right that people should be involved in developing or providing support, and not just have

things done 'to' or 'for' them, and that this is the right approach to support the delivery of key health and social care policies. This thinking led to the Care Act 2014 being the first piece of legislation to include the concept of co-production in its guidance. The legislation acknowledges the range of activities that can include co-production. The guidance defines co-production and suggests that it should be a key part of implementing the Care Act. In particular, co-production should be used to develop preventative, strength-based services, support assessment, shape the local care market, and plan information and advice services.[3]

More recent policies continue to build on the concept and recognise the value of co-production. The 2021 Adult Social Reform White Paper, *People at the Heart of Care*,[4] sets out the Government's vision for adult social care around three objectives: people having choice, control and support to live independent lives; people having access to outstanding quality and tailored care and support; and people finding adult social care fair and accessible. Within the White Paper, co-production is highlighted as an approach to enable innovation in the sector:

> 'Embedding innovation takes dedicated leadership and good relationships, it requires consultation, engagement and co-production with people who need support and a workforce that are supported to champion and embrace new ways of working.'[4]

Given these recent policy commitments, their implementation will provide opportunities for co-production to be used as an approach to:

- improve policy
- improve service design
- improve service delivery
- improve the care environment.

In turn, the evaluation of co-production in these circumstances will enable the building of understanding and knowledge about the difference that co-production makes to care outcomes for individuals, services and the wider health and care system.

To maximise this opportunity, SCIE has reviewed the existing evidence and heard from people who have been involved in co-production, to understand what more should be done to show the difference that co-production makes.

Our evidence review considered the impact of co-production on and outcomes for individuals, organisations and communities. We searched key databases in health and social care. We also carried out internet searches and undertook cited reference searches. We focused on literature published since 2017 within the UK.

In April and May 2022, we facilitated four online sessions with people with lived experience and people who work in services to consider the impact of co-production. In terms of the latter, the sessions were attended by members of the SCIE Co-production Network and workers from a range of different organisations in England and Wales – including local authorities, national charities, and statutory and voluntary sector health and social care and

support providers – attended the sessions. Other Co-production Network members have contributed to this briefing by other means.

During the sessions, we discussed the following topics:

- the overall benefits of co-production
- benefits for people who access services and other people with lived experience
- benefits for people who work in services
- how co-production improves services
- drawbacks and challenges associated with co-production.

2. What is co-production?

The term ‘co-production’ is still not widely understood and is often confused with ‘involvement’. This means that we cannot assume that everyone shares a common understanding of what co-production is. An important part of the process of co-production is organisations and projects coming to an agreement on what they understand co-production to be and the principles that will guide its implementation.

Our online participants agreed that sharing power and joint decision-making lie at the heart of successful co-production.

Think Local Act Personal (TLAP) identifies co-production as a long-term relationship, at the top of a ‘ladder of co-production’.[5] It is an equal relationship between all those involved in the process, including people using services. People responsible for services work together with those using services in sharing ideas and spaces for decision-making about policies, services and activities.

Increasingly, it is being suggested that the focus should be placed on understanding the underlying principles and values of co-production so they can be applied in practice.[6] The principles of equality, diversity, accessibility and reciprocity (or getting something back for putting something in) are critical values for putting co-production into practice. Acting in accordance with these principles helps to make co-production as inclusive as possible. Demonstrating a commitment to inclusivity shows that co-production is genuine and authentic.[3] The four principles are:

- Equality – everyone has assets – co-production starts from the idea that no one group, or person, is more important than anyone else and everyone has the skills, abilities and time to contribute.
- Diversity – co-production should be as inclusive and diverse as possible. Particular efforts may be needed to ensure that seldom-heard groups are included.
- Accessibility – making everything accessible is a way to ensure that everyone has an equal opportunity to participate fully in an activity in the way that suits them best.
- Reciprocity – this means people get something back for putting something in.

We heard from the online participants that co-production is about partnership, equity and people being ‘on the same page’. It should have a strategic focus and involve people from

different backgrounds. It is an inclusive process, based on teamwork and trust, which requires transparency and mutual respect. People should feel that their suggestions are welcomed and valued.

Consultation alone is not co-production. Co-production is about 'doing with', rather than 'doing to', it is about challenging poor services and gaps in service provision, and it provides opportunities for people who use services to become involved in service design and innovation.

It is important to know the outcomes of the contributions that people with lived experience make. In involvement, people with lived experience receive feedback on the differences their contributions have made. In co-production, people with lived experience are aware of these differences because they have been engaged with deciding on and actioning those contributions in partnership with people who do not have lived experience.

> 'In co-production we don't want a "you said, we did" scenario, we want "we said, we did"!' (Online participant)

3. The benefits of co-production

Much of the research on co-production in social care has focused on the benefits of the process for the individuals involved. People with lived experience in our online groups reported that their involvement had contributed to transforming their lives. Opportunities to work alongside senior leaders had improved their self-esteem by acknowledging and valuing the expertise that comes from lived experience. One participant shared that the recognition of his expertise had enabled opportunities to create a successful business.

More generally, participants appreciated that the equality, power-sharing and shared responsibility involved in co-production contribute to finding legitimate solutions and create a powerful voice for positive change, resulting in credible services that are of benefit to all.

There has been less research into the impact and outcomes of co-production. A systematic review of co-creation and co-production identified more than a hundred empirical studies of co-creation and co-production between public organisations and citizens (or their representatives), but found only 20% (24 papers) evaluated the outcome of co-creation and/or co-production and a proportion of these assessed the outcome as being to enhance participation.[7]

Measuring the outcomes and impact of co-production on those who access services, the organisation, staff and the community is important in determining the difference that co-production can make to all those involved. Systematic evaluation studies should be undertaken to show the difference being made.

3.1 Benefits for people who draw on services

Throughout the literature, studies highlight how the involvement in co-production activities of those who draw on services results in several positive benefits for the individual. Often these are described as a benefit of becoming involved within a co-production process. These studies point to outcomes for those who draw on services, including:

- increased self-confidence, self-esteem and sense of empowerment
- better health and wellbeing
- increased engagement and trust
- higher levels of satisfaction with, and awareness of, services.

3.1.1 Individuals' self-confidence, self-esteem and sense of empowerment

Increases in self-confidence, being valued, feeling useful and being able to 'give something back' were reported widely in the literature, including studies with older people[8] and those with disabilities.[9] When looking at commissioning within health and social care with those with disabilities, participants specifically said that 'being listened to' had a very positive effect and one person commented that: 'I feel that I've … got incrementally better with everything where I've been involved.'[9]

Improvements in self-confidence and feelings of empowerment were also reported within local authority settings[10] and within the voluntary and social enterprise sector.[11]

Within Patient Public Involvement (PPI), it has been reported that those who drew on services reported perceptions of being listened to (84%), perceptions of having given something back (44%) and increased knowledge of services (52%).[12]

Increases in self-esteem, confidence and empowerment were also found in studies working with young people, including young people with a mental health diagnosis.[13]

3.1.2 Health and wellbeing

Studies from health settings reported that co-produced services and interventions resulted in those who draw on services increasing their understanding of their condition,[14] improving their knowledge and confidence and being better able to self-manage[14,15,16] and increasing their understanding of medication.[16]

Within mental health services, evidence for a reduction in the need to access acute services, and improvements in wellbeing, were reported. For example, an evaluation of a recovery college developed with the values of co-production found improvements in health as measured by the Warwick–Edinburgh Mental Wellbeing Scale (WEMWBS) and the Patient Activation Measure (PAM).[17]

3.1.3 Engagement and trust

There is an increasing amount of literature highlighting how co-production increases the engagement and trust of individuals towards the service provider/organisation.

An evaluation of co-production in Oxfordshire County Council found that people who drew on care and support and carers felt listened to and valued.[10] Similar findings of increased engagement with services and trust between those who draw on services and service providers have been found elsewhere, including the following settings:

- Within voluntary and social enterprise settings, there were improvements in engagement, with people who drew on care and support and carers feeling listened to and valued. The study authors noted how people who drew on care and support and carers felt valued because their lived experience was appreciated and considered as comparable expertise to that of practitioners.[11]
- Among those who draw on services, improvements in levels of trust in organisations were found and feelings of empowerment were reported.[18]
- Within health settings, positive changes in levels of trust between patients and services were reported[16] along with engagement with mental health services, with increased uptake of services being found among Black, Asian and minority ethnic (BAME) groups.[19]

The literature showed young people articulating feeling valued and learning from one another in a co-production project in a prison setting, expressing the formation of a professional identity and being seen as individuals who can be trusted despite previously coming from a prison environment.[20]

3.2 Findings from online participants about those who draw on services

Participants in our online groups echoed the difference that co-production makes to self-confidence, self-esteem, empowerment and trust. They noted how co-production can help people to feel better about themselves and how it supports recovery and self-management within wider society. Co-production also encourages peer learning, which helps people to communicate with each other and learn about different cultures. It develops a sense of connection between people with shared or similar experiences of support and can result in people feeling understood and believed. It provides opportunities for people with lived experience to give something back by reducing the chances that their peers will have the same negative experiences they have been through.

> ‘After receiving a mental health diagnosis and losing my career, I used this opportunity to turn the corner. It’s given me the ability to teach at university. It’s empowered me to find myself.’ (Online participant)

The participants noted that co-production challenges barriers to better care. It supports people to develop into experts by experience, which contributes to their wellbeing. It provides opportunities for people to use their skills in a new way, and it can help to turn bad experiences into something positive. This can result in people regaining their confidence; people with lived experience reported that life becomes easier when you feel heard and understood.

Participants went on to explore 'softer' outcomes that may be overlooked. Being involved in co-production creates opportunities for people to meet and work alongside people outside of their established personal networks. It can result in younger people meeting older people and learning from each other. These encounters not only help people to participate in service development, but they can also result in long-term friendships.

Participants talked about co-production enabling them to be involved in leading and designing projects, to acquire research knowledge and skills, to develop the service user-led organisations they are involved with and to achieve financial security. Participants mentioned how co-production has contributed to the development of opportunities for people who draw on care and support and carers to work with professionals (for example, in interviewing students for university courses), and equipped people with lived experience with the skills and knowledge to find employment.

Importantly, many participants agreed that we need to move away from an 'us' and 'them' mentality, and consider the question, 'What can we do together?', rather than the question of what services can do for people who draw on care and support and carers. If more people with lived experience start to work in services, this might help to redress the balance.

3.3 Benefits for people who work in services

Although fewer studies include the impact on staff involved on the impact of co-production, research is emerging suggesting that their involvement results in positive outcomes, including:

- improved job satisfaction, motivation and practice
- higher levels of trust and engagement, including involvement in future projects and dialogue with people who draw on care and support and carers.

3.3.1 Individuals' job satisfaction, motivation and practice

Within health settings, a systematic review pointed to increased job satisfaction and motivation among staff who were involved in co-production.[21]

Greater understanding of those who draw on services, resulting in changes in practice, was reported in several studies.[14,22,23,24] Within the voluntary and social enterprise sector, practitioners also thought that co-production enhanced their professional practice, and they viewed co-production as mutually empowering.[11] One participant of the evaluation commented:

> 'As a professional, working with customers on something and doing things slightly differently and seeing different points of view and working in a slightly different way, it adds to my ability to be a professional. I really enjoy the process. (Stockport Homes)'

3.3.2 Trust and engagement

Increasing levels of trust and engagement of practitioners were mentioned within a selection of the literature found. For example, a study of co-production in recovery colleges found changing power dynamics, with a reduction in the power imbalance; and a positive attitude among staff, with a suggestion of more equal relationships between practitioners and people who drew on care and support and carers.[25] Within patient and public settings, outcomes included an improved dialogue between professionals and people who drew on care and support and carers and the identification of staff training needs.[12]

3.4 Findings from online participants about people who work in services

Our online participants noted how co-production creates dynamic environments where everyone feels like they are working together. It provides lifelong learning for professionals working in health and social care, results in greater job satisfaction and helps with employability. It creates better leaders and encourages people to speak up in their roles if they are uncomfortable with anything.

The participants noted that there is great diversity in lived experience and co-production provides the means for workers to benefit from this. Professionals can develop empathy and emotional responsiveness, which enable them to support other people they are working with. Seeing that people's voices matter and sharing responsibility result in changes to the way practitioners work, and they also feel better about the work they are doing. It can result in greater enthusiasm, passion and creativity, and it can help to make workers' lives easier.

Our online participants felt that co-production also results in increased productivity and reduced wastage. Involving people who draw on care and support and carers from the outset takes away ambiguity and confusion and results in trustworthy services. It also allows for effective scrutiny, auditing and governance.

3.5 Benefits for organisations

More needs to be done to evaluate the outcomes of co-production for social care services, providers and commissioners. More published studies into the outcomes of co-production have been produced in the health sector than the social care sector. These have identified:

- increased uptake of services[17,19,22]
- decreased hospital admissions[22] and reduced non-attendance rates (providers gained knowledge and reduced post-discharge events)[16]
- changes in practice as a result of introducing co-designed outputs, including: consistency in clinical assessment and the identification of patient problems that were previously missed; changes to clinical pathways; fewer hospital visits and admissions; and a reduction in the number of patients failing to attend appointments.[23]
- capacity building within organisations, changes in service delivery and changes in the service development process.[12]

3.6 Findings from online participants about benefits for organisations

Although the online participants said that it can sometimes be difficult to pinpoint the difference that co-production makes to services, they mentioned a range of different ways in which it has impacted on the health and social care landscape, helping to change the mindsets of people involved in health and social care, keeping things relevant in a rapidly changing world, building trust and increasing credibility.

Participants identified that co-production is a valuable way of encouraging input from people who draw on care and support and carers and has a part to play in scrutiny, governance and regulation. Organisations like SCIE and Shaping Our Lives have demonstrated that they really listen to disabled people, and the guidance and information they provide contribute to service improvement. The National Institute for Health and Care Research (NIHR) has published guidance on co-producing research and practice examples that aim to promote co-production in this area.[26]

One participant mentioned that co-produced guidelines about bedwetting she was involved in developing are still being talked about and used many years later, which has made a huge difference for children, parents and families.

Participants noted how co-production has played a major role in the development of social prescribing. At a local level, involvement in the recruitment of future care staff leads to a more responsive workforce.

The opportunities that co-production provides for continued personal and professional development enable people with lived experience to make effective contributions to decision-making boards, and one participant briefly outlined how co-production had led directly to the opening of three crisis cafes in his area.

Although it can be difficult to achieve a culture shift, and to get people who use services to work co-productively with front-line teams, participants gave the following examples of co-production in the areas of planning, delivery and outcomes:

- a national personalisation panel, consisting of people with lived experience, which set up a working group to ensure that people did not lose their entitlement to support when the Independent Living Fund was stopped
- National Institute for Health and Clinical Excellence (NICE) guideline teams looking at social care and assessments, and what guidelines mean to patients
- a county-wide task and finish group to design a co-production toolkit (which is currently at an advanced stage and aims to launch during National Co-production Week: 4–9 July 2022)
- a borough-wide children and young people's plan, designed by the young people in the borough
- a collaborative research study looking at Mental Health Act assessments and the development of research questions in other research projects
- the design of a genetic centre, including the design of the car park and transport links.

3.7 Benefits for the community

To date there is currently only a limited amount of published literature on the impact of co-production on, and outcomes for, the community. But a systematic review looking at the impact of co-produced health promotion approaches reported increased knowledge and awareness of the targeted health issue or services among the community.[27] A project entailing co-producing a film about autism in the Somali community was found to have increased awareness about autism and the availability of artificial intelligence support so that people have better daily life experiences.[28]

4. Priorities for co-production in social care

Our participants identified that if the Government is to meet its policy aspirations relating to co-production, then there is a need for greater consistency in co-production, and universal understanding of co-production, including a need for greater flexibility. At times, things can change at the last minute, and at other times, it is important to change things to accommodate people.

To meet the aspirations, co-production needs to be properly funded and resourced. The skills and experiences of people with lived experience involved in co-production should be recognised in terms of rewards and recognition, but many organisations fail to do this or fail to build the relationships that are essential for meaningful co-production.

People with lived experience often have access needs, and several participants reported that these needs are not properly addressed. It can also be difficult to manage different access needs. Several participants mentioned that co-production activities they have been involved in have proved to be traumatic, and that aftercare and support networks should be created to respond to this eventuality. Co-production needs to be conducted in a safe space that protects everyone involved. People involved in co-production should also be provided with the training they need to perform their roles effectively.

The commitment to co-production in the Government's health and social care policy also provides an opportunity to build the evidence and understanding of co-production as individual policies are implemented. However, there are currently challenges in determining the outcomes and impact of co-production in social care, due to the lack of a definition and understanding of co-production principles, and the limited amount of research studies and evaluations currently available that include the outcomes and impact. A rapid evidence assessment on co-production and co-creation within the UK found that of the 33 articles considered, 18 articles mentioned a definition that referred to some of the four principles suggested by SCIE but only one of these 18 articles mentioned all four principles.[29] There is also an increasing number of studies using terms such as co-production but not actually involving those who draw on services.[6]

Other opportunities to be taken include focusing on co-production outcomes and impact, rather than the co-production process and output. Within public services, one researcher found that 35% of the studies they looked at included the outcomes of co-production[5] but while there has been a significant growth in published articles on co-production within health policy – 25% between 1994 and 2019 – there has been a lack of studies examining the

impact of co-production.[21] This lack of current evaluation to determine the impact of co-production is also beginning to be noted within local government and voluntary settings.[11]

Existing studies also highlight enablers and barriers to measuring the impact of co-production. Enablers include:

- resourcing of evaluation, including resourcing related to a need for funding in general and the resources for staffing and staff time and training[12,14,22]
- skilled facilitators to lead the co-production process including evaluation[8,22,30] and to build relationships and support communication between different groups of stakeholders
- the involvement and support of management to enable the impact of co-production to be measured[14,22,31]
- shared outcomes considering the impact on the people who use services that have been developed through participation.[14,32]

Conversely, the following have been identified as barriers to measuring the impact of co-production:

- resourcing issues, including a lack of staff, a lack of staff time and a lack of funding[12]
- the complexity of data and the introduction of quantitative approaches where statistical evidence is used to evaluate impact[12]
- a power imbalance between organisations and those who draw on services, which several authors have highlighted[33,34]
- determining evaluation outcomes, such as a tension between quantitative and qualitative approaches, including how qualitative evidence is viewed and the applicability of some quantitative approaches,[31,35,36] as well as the difficulty of defining co-production and the comparability of evidence.[37]

5. Recommendations

Co-production sets out a way of working where those who draw on services and their care professionals work in equal partnership to develop services that better meet people's needs. Increasingly, the values of co-production are being viewed as an approach to develop services that are innovative.

There is an increasing knowledge base about co-production, and while this is progress, more needs to be done to realise the full potential of co-production in social care. As social care policy increasingly recognises the importance of co-production in implementing policy ambitions, we must take this opportunity to deepen our understanding and knowledge about the difference that co-production makes. SCIE therefore recommends the following:

1. Evaluation of the impact of co-production in adult social care should be undertaken as standard for relevant projects and programmes of work, including focusing on people who are underrepresented in the current evidence base, for example people from Black, Asian and minority ethnic (BAME) communities and unpaid carers.
2. Evaluations of co-production in social care should be refocused onto assessing outcomes and impact and move away from the co-production process and output.
3. A more universal understanding of co-production should be developed.
4. Greater consistency in co-production in social care.
5. More investment in resources for the evaluation of co-production, including resourcing for staffing, staff time, remuneration for people with lived experience and the provision of training.
6. People with lived experience should be involved in identifying the outcome measures to be considered in co-production evaluations.
7. Skilled facilitators should be used to lead the co-production process (including evaluation) and build relationships and support communication between different groups of stakeholders.
8. Managers and leadership should be involved and provide support to enable the impact of co-production to be measured.

To co-produce evaluations fully, SCIE also recommends the following when undertaking evaluations with people with lived experience:

9. Greater flexibility in the evaluation process, recognising that, at times, things can change at the last minute, and it is important to make changes to accommodate people.
10. Access needs should be properly addressed and managed, to ensure evaluations are accessible.
11. Evaluations should be conducted in a safe space that protects everyone involved, and appropriate training should be provided.

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