

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	The transition of young people from children's into adults' services – what works for whom in what circumstances: protocol for a realist synthesis
AUTHORS	Sipanoun, Pippa; Aldiss, Susie; Porter, Louise; Morgan, Sue; Powell, Emma; Gibson, Faith

VERSION 1 – REVIEW

REVIEWER	Bauer, Annette London School of Economics and Political Science
REVIEW RETURNED	14-Jul-2023

GENERAL COMMENTS	This an overall well written protocol paper of a realist synthesis on a relevant policy issue. It is interesting that some parts of the review were already conducted, and it would be good to make this more transparent from the outset. Overall the protocol is very short and it would be helpful to have some more detail on some of the (expected) challenges of applying the method, and how those will be addressed. Furthermore it would be helpful to know how the IPTs are planned to be used. It would be god to explain the role of experts, and provide a list of experts, and how the process of selection and how they were consulted. In particular it would be helpful to understand how consensus was reached. Please explain the 'On Your Own Feet Ahead' theoretical framework and this was chosen as an initial framework and starting point of developing IPTs.
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REVIEWER	Morsa, Maxime Universite Paris 13
REVIEW RETURNED	01-Sep-2023

GENERAL COMMENTS	<p>The article present a protocol for a realist synthesis about the transition of young people from children's into adults' services. It aims to synthesize knowledge about the issues: "what works for whom in what circumstances?".</p> <p>The article is well-written, well-argued and respects the stages of a realist synthesis.</p> <p>I have three minor comments to the authors.</p> <p>1) In the introduction, you mention that "Realist methodology has been applied to healthcare transition in the context of young adults with life-limiting conditions [6, 7]". Could you present the main results of these studies?</p> <p>2) In literature, there are systematic reviews and metasynthesis on transition from pediatric to adult care. It would be interesting to</p>
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	mention them in the introduction and argue how the realist synthesis can produce additional knowledge. 3) Data collection dates are not given.
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REVIEWER	van Staa, AnneLoes Rotterdam University of Applied Sciences, Research Center Innovations in Care
REVIEW RETURNED	10-Sep-2023

GENERAL COMMENTS	<p>This is an excellent research protocol to conduct a realist review evidence synthesis into the transition of young people from children's into adults' services. In contrast to 'traditional' review methods that focus on evidence without considering the context, this type of theory-driven review aims to establish what works for whom in what circumstances. While there are numerous reviews into "evidence" surrounding the issue of the transition from child care to adult care, the outcomes are invariably that there is not enough evidence. Since most reviews only consider one specific intervention and/ or a specific patient group, the results are not applicable to all young people; nor to complex interventions such as transition programmes that consist of various elements. I therefore compliment the authors that they have selected the realist synthesis methodology as this seems very appropriate for this cause.</p> <p>I am familiar with the realist review methodology that Pawson et al. proposed, and I applaud that the authors include a sixth step, i.e. the refinement of the programme theory. We developed the On Your Own Feet Ahead framework and tested it in several quality improvement programmes. Still, we very much welcome a further refinement or validation.</p> <p>The paper is very well written, clear and concise. The figures add to the explanation of the methodology, the research questions and the PICOH presented in Table 1. I have only minor comments for improvement.</p> <p>1) Please explain more extensively why you restrict the review to papers in the past 10 years (2014 and up). I understand that there will be many papers included, but for some patient groups (such as young people with learning disabilities) this may be too strict. You mention that this is done due to "the architecture of service provision following the Care Quality Commission's paper" of 2014 - but I do not understand this argument.</p> <p>2) Page 19. Figure 2 (Initial programme theories (IPT's) applied to the OYOF model). Could you please explain why you did not formulate IPT's to the central part of the model: for example about: a) strengthening the partnership between the young person and the HC-team (involving empowerment of the YP and person-centred care from the healthcare team) - this relates to Intervention #7 in Table 1; b) strengthening the partnership between child's and adults' services - - this relates to Intervention #2 in Table 1; Interventions that could be studied in this respect are: a) listening to young people's voices and experiences with the transition process, f.ex. in mirror meetings, youth advisory boards etc. b) multidisciplinary team meetings around transition in which child & adult care services jointly discuss patients around transfer. Also:</p>
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	<p>a warm hand-over in transition clinics or the formulation of a joint policy between child and adult services (aiming to align service provision). One intervention that we have applied that was particularly easy to implement and successful in closing the gap between child and adult services and create a sense of common interests (in the context of transfer within the same clinic) was: making a list of common procedures in both PC and AC, focusing on differences between both services and discussing which differences are inevitable or inherent to new regulations and treatment guidelines (and the YP should be prepared for those), and which differences could be aligned.</p> <p>I suggest you formulate two new ITP's in purple and add them to Figure 2.</p> <p>3) I have a question regarding the list of interventions in Table 1 (PICOH). You present interventions from a comprehensive programme for young people with life-limiting conditions and although I think the list is fairly complete for YP with other conditions as well, I wonder why you did not compare these with the principles as formulated in the NICE Guideline (2016). The interventions proposed in the NICE guideline are similar, but somewhat different (my summary):</p> <ul style="list-style-type: none"> - early start (13 years at latest) - make a transition plan - appoint a named worker/ transition co-ordinator - involve young people - involve parents - meeting adult care in advance (transition clinic) - provide information about services and support available in adult care - involve primary care (GP) <p>In your list, I miss the explicit mentioning of a transition plan and of active involvement of YP. Also, I find Intervention #3: "Orientation of the young person to adults' services" somewhat unclear (Table 1).</p> <p>Small thing: typo in reference #18.</p> <p>I am confident that this review could really contribute valuable knowledge to the transition field.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1 Dr. Annette Bauer, London School of Economics and Political Science, London School of Economics and Political Science Methodology Institute Comments to the Author: This an overall well written protocol paper of a realist synthesis on a relevant policy issue. It is interesting that some parts of the review were already conducted, and it would be good to make this more transparent from the outset. Overall the protocol is very short and it would be helpful to have some more detail on some of the (expected) challenges of applying the method, and how those will be addressed. Furthermore it would be helpful to know how the IPTs are planned to be used. It would be good to explain the role of experts, and provide a list of experts, and how the process of selection and how they were consulted.

In particular it would be helpful to understand how consensus was reached. Please explain the 'On Your Own Feet Ahead' theoretical framework and this was chosen as an initial framework and starting point of developing IPTs. - Thank you for your thoughtful suggestions. We feel that the changes add value to the protocol. We have clarified why it was important to commence stages 1 and 2 prior to publication of the protocol on page 11 of the manuscript. This was so that the IPTs could be developed and Page 2 applied to the theoretical framework, which would then inform the subsequent stages of this research. We hope this makes the process more transparent. - Thank you for the suggestion of including some of the expected challenges of applying realist methodology and how these challenges will be addressed. We have included this towards the end of the manuscript (page 15) and feel this adds value to the protocol. - We have clarified how the IPT's will be used by adding 'The selection of relevant, rigorous evidence will be applied to these IPT's in subsequent stages of this realist synthesis so that they can be supported, refuted or refined.' (page 11). - We have clarified the role of the experts, provided the professional roles of the experts, and clarified the consultation process (page 10). - We have explained the 'On Your Own Feet Ahead' theoretical framework, and why we have chosen this to guide our work (page 10). Reviewer: 2 Dr. Maxime Morsa, Université Paris 13 Comments to the Author: The article present a protocol for a realist synthesis about the transition of young people from children's into adults' services. It aims to synthesize knowledge about the issues: "what works for whom in what circumstances?". The article is well-written, well-argued and respects the stages of a realist synthesis. I have three minor comments to the authors. 1) In the introduction, you mention that "Realist methodology has been applied to healthcare transition in the context of young adults with life-limiting conditions [6, 7]". Could you present the main results of these studies? 2) In literature, there are systematic reviews and metasynthesis on transition from pediatric to adult care. It would be interesting to mention them in the introduction and argue how the realist synthesis can produce additional knowledge. 3) Data collection dates are not given. - Thank you for your constructive feedback. We have included the following changes, which we feel has improved our protocol. We have included the main findings from the realist work conducted within the context of life-limiting diseases (page 6). - Thank you for highlighting systematic reviews and meta-syntheses on transition from pediatric to adult care. We have included further clarification around why we chose realist methodology over conducting a systematic review (page 5). Due to the word limit, we will include a thorough analysis of the systematic reviews and meta-syntheses on this topic in our larger results paper, once the realist synthesis has been completed. - Data collection dates will be reported in the results paper. Reviewer: 3 Prof. AnneLoes van Staa, Rotterdam University of Applied Sciences Comments to the Author: This is an excellent research protocol to conduct a realist review evidence synthesis into the transition of young people from children's into adults' services. In contrast to 'traditional' review methods that focus on evidence without considering the context, this type of theory-driven review aims to establish what works for whom in what circumstances. While there a numerous reviews into "evidence" surrounding the issue of the transition from childcare to adult care, the outcomes are invariably that there is not enough evidence. Since most reviews only consider one specific intervention and/ or a Page 3 specific patient group, the results are not applicable to all young people; nor to complex interventions such as transition programmes that consist of various element. I therefore compliment the authors that they have selected the realist synthesis methodology as this seems very appropriate for this cause. I am familiar with the realist review methodology that Pawson et al. proposed, and I applaud that the authors include a sixth step, i.e. the refinement of the programme theory. We developed the On Your Own Feet Ahead framework and tested it in several quality improvement programmes. Still, we very much welcome a further refinement or validation. The paper is very well written, clear and concise. The figures add to the explanation of the methodology, the research questions and the PICOH presented in Table 1. I have only minor comments for improvement. 1) Please explain more extensively why you restrict the review to papers in the past 10 years (2014 and up). I understand that there will be many papers included, but for some patient groups (such as young people with learning disabilities) this may be too strict. You mention that this is done due to "the architecture of service provision following the Care Quality Commission's paper" of 2014 - but I do not understand this argument. 2) Page 19. Figure 2 (Initial programme theories (IPT's)

applied to the OYOF model). Could you please explain why you did not formulate IPT's to the central part of the model: for example about: a) strengthening the partnership between the young person and the HC-team (involving empowerment of the YP and person-centred care from the healthcare team) - this relates to Intervention #7 in Table 1; b) strengthening the partnership between child's and adults' services - - this relates to Intervention #2 in Table 1; Interventions that could be studied in this respect are: a) listening to young people's voices and experiences with the transition process, f.ex. in mirror meetings, youth advisory boards etc. b) multidisciplinary team meetings around transition in which child & adult care services jointly discuss patients around transfer. Also: a warm hand-over in transition clinics or the formulation of a joint policy between child and adult services (aiming to align service provision). One intervention that we have applied that was particularly easy to implement and successful in closing the gap between child and adult services and create a sense of common interests (in the context of transfer within the same clinic) was: making a list of common procedures in both PC and AC, focusing on differences between both services and discussing which differences are inevitable or inherent to new regulations and treatment guidelines (and the YP should be prepared for those), and which differences could be aligned. I suggest you formulate two new ITP's in purple and add them to Figure 2. 3) I have a question regarding the list of interventions in Table 1 (PICOH). You present interventions from a comprehensive programme for young people with life-limiting conditions and although I think the list is fairly complete for YP with other conditions as well, I wonder why you did not compare these with the principles as formulated in the NICE Guideline (2016). The interventions proposed in the NICE guideline are similar, but somewhat different (my summary): - early start (13 years at latest) - make a transition plan - appoint a named worker/ transition co-ordinator - involve young people - involve parents - meeting adult care in advance (transition clinic) Page 4 - provide information about services and support available in adult care - involve primary care (GP) In your list, I miss the explicit mentioning of a transition plan and of active involvement of YP. Also, I find Intervention #3: "Orientation of the young person to adults' services" somewhat unclear (Table 1). Small thing: typo in reference #18. I am confident that this review could really contribute valuable knowledge to the transition field. - Thank you for your detailed and thoughtful comments and guidance. We have clarified why we chose to restrict the review to papers in the past 10 years (2014 and up). This was due to a significant policy document in the UK from which change in practice was starting to be reported (page 11). Prior to this, it would not have been appropriate to include papers from the UK as practice would have been different, hence this was applied to all papers. - Thank you for your insight related to the IPTs as related to the OYOF theoretical framework. The IPTs provided were meant as examples, not an exhaustive list, so this has been clarified (page 10). We agree that IPTs relating to the young person and the healthcare team should have been included so we thank you for highlighting this. We have included two additional IPTs in Figure 2, representing this. It is our intention to include a thorough presentation of all of the IPTs as related to the framework in the results paper, also linking them to the interventions, as you have done, in Table 1. - We have amended Table 1 to include an intervention related to the NICE Guideline (2016) on making a developmentally appropriate transition plan. Thank you for highlighting the need for this (page 8). - Typo in reference has been amended. We hope you find our manuscript suitable for publication. We know of no conflicts of interest associated with this publication. As Corresponding Author, I can confirm that the manuscript has been read and approved for submission by all of the named authors. We look forward to hearing from you in due course.

VERSION 2 – REVIEW

REVIEWER	van Staa, AnneLoes Rotterdam University of Applied Sciences, Research Center Innovations in Care
REVIEW RETURNED	11-Nov-2023
GENERAL COMMENTS	I am satisfied with the answers to my queries and the adjustments made in the manuscript by the authors.