Author's response to reviews

Title: The 'placement' of people with profound Impairments across the lifespan: re-thinking age criteria

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Author's response to reviews: see over
RE: Response to Reviews
The ‘placement’ of people with profound Impairments across the lifespan: still life
Gibson et al [8176530471116035]
March 7, 2014

Dear Dr Ursula D'Souza,

Thank you for these valuable comments, which we have used to substantially revise the paper. Below please find a point-by-point response to the comments provided by the editor and each of the reviewers. Changes to the manuscript have been made using track changes.

Editor’s comments:

We agree with reviewer 1 that generalisability to western countries needs to be discussed. Also reviewer 2 points out comparisons with other models and we would like to see these arguments expanded together with how the recommendations will be able to influence policy or bring about practical changes. Thus we would appreciate if all these points could be addressed before we can make a decision on your manuscript.

Response:

• Generalisability: We have made substantial additions to the manuscript to demonstrate the commonality of the issues across different countries. This includes a new section on pp 7-9, and 30 additional references throughout the manuscript.

• Models and Practical Change: We have addressed this comment in two ways. First, we have expanded and contextualized the arguments critiquing age–based criteria for discharge and transfer. Second, we have clarified the intent of the paper in the abstract, background and summary, and modified the text to maintain this focus (See Response to Reviewer 2). Our goal in writing the paper was to raise the issue of age as a problematic criterion for transitioning young people to adult long term care facilities, which we hope will stimulate further debate and ground research into this important area. The purpose was not to conduct a structured review of evidence or recommend new delivery models. The almost complete lack of research with this population on the issues of institutional transfer renders such a task premature, but certainly we contend that the need for research is pressing. Thus to address your comment regarding how the arguments contribute to practical change, we have revised the paper to focus on the need for focused interdisciplinary research and policy debate that includes all stakeholders (families, clinicians, policy makers).

Please can you also adhere to the following editorial requests:
1. Provide an abbreviation section based on the following instructions:
http://www.biomedcentral.com/bmcmed/authors/instructions/debate#formatting-abbreviations

Response: There are no abbreviations used in the text so we have not included this section.

2. Include an acknowledgement section as follows:
http://www.biomedcentral.com/bmcmed/authors/instructions/debate#formatting-acknowledgements

Response: Added on p.17

3. The title needs to be changed to reflect the debate and we think that the "still life" needs to be removed.

Response: The title has been changed to: The ‘placement’ of people with profound impairments across the lifespan: re-thinking age criteria

4. Please remove "commentary" from the manuscript and replace with "debate".

Response: this change has been made in the abstract pp. 5 and 15.

Reviewer One Comments: Rob Imrie
This is a very well written and crafted paper and it is thoughtful and thought provoking. Its intent is to question age-related, and categorised, practices relating to where people are located within care settings and places, with a focus on children with profound impairments being moved on to adult institutions as they reach 'adult hood'. The paper has good flow and it is fluent and well structured. I feel it would benefit by making a few qualifications to some arguments and a clearer contextualisation of the subject matter.

1. The main issue for me is to ensure that the reader will be conversant with the broader issues/debates about the shift of people from one care context to another. The paper does not say much about how and why such 'age regimes' exist, and how one might begin to explain them. As a reader I need to know a bit more about how and why the institutionalisation of movement, by age category, has taken hold, and a bit more about how far it is specific to Canada or a more general part of 'western care systems'. So, think about a more careful contextualisation - it will help the reader.

Response: Thank you for this helpful comment. We agree that arguments needed further explanation and contextualization. We have extended the Discussion on pp 7-9 to locate the remarks in the Western cultural context and have grounded this discussion with regard to how the ‘problem’ of placement transitioning is constructed and critiqued in the extant
interdisciplinary literature. We have also included some examples of age-based policies from North America, Europe and Australasia.

2. I think the paper could useful draw attention to more evidence to back up the claims being made - so, on page 7 of the manuscript, first paragraph, a number of assertions are made - and I agree with the sentiments in them - but what's the evidence. The paper would benefit by embedding some of its claims a little bit more carefully in the evidence that backs them up or not - in other words, soften some of the assertive style.

Response: We agree and have softened the language in this section and throughout the paper. As per our response to the editor, we have made considerable additions to the manuscript to provide more evidence to ground the claims and focus the discussion.

3. Is the age criterion always a problem and in every instance, for every child? The paper does not really say anything about this and children with profound impairments seem to be treated as 'undifferentiated' in relation to how the care regimes, based on age, operate. I'd like to see some engagement with my observation here.

Response: We have addressed this comment in the new section in the Discussion, pp. 7-9, and throughout the paper to qualify the statements and focus on individualizing care needs.

Reviewer 2 Comments: Jane Coad
1. I am not convinced that the question posed by your team is well defined in terms of alternative models suggested. The paper is well written with an acceptable title but it is not really an argument but more a description and some discussion. A new proposed model without a strong evidence base to suggest it is then proposed. I did wonder instead if this could be a narrative review as clearly the team has undertaken a wide/comprehensive search. Some update is required like Noyes reference (See now Fraser et al). To clearly show that a review strategy and synthesis of work would help this paper to be more well defined. A number of models can then be shared for real debate. The team do use useful reporting methods but this could be enhanced to be a really exciting paper. This would balance the discussion and critical edge more to this paper.

Response:
• Thank you for the Fraser et al reference, which we have now included in the introduction.
• Thank you; these comments have helped us to focus the paper. We have done some rewording to clarify the intent of the paper, which was not to propose a new model (without evidence), but rather start a dialogue and provide a rationale to ground creative research. We disagree with the suggestion that the paper “is not really an argument”, but acknowledge that it is a largely a theoretical argument that examines the values and assumptions that underpin current practice but are seldom discussed in any kind of depth. This is what we see as the major contribution of the paper – challenging entrenched values and asking if things could and should be rethought. The paper was not intended to be a
structured review or synthesis of the literature, but rather a debate paper to stimulate discussion and establish the need for research in this field - research that does not presume individuals need to be separated according to age. Nevertheless we acknowledge that the paper needs to make these points more clearly, and that the argument would benefit from further engagement with the literature. We note that Professor Imrie (Reviewer one) made some similar comments for the need to back up some of the claims. See our response above regarding changes that have been made to extend and enhance engagement with the literature.

2. The methods of searching for evidence are not clearly defined and data quality trail not evident but could be as I have suggested in Point 1.

Response: We did not complete a structured review as doing so was outside the scope and aims of the paper, which are conceptual/philosophical in nature. We trust that the revisions clarify the aims.

3. The writing style is a real strength hence I have not rejected the article but asked for reconsideration. It flows well and could be developed further. There are some minor tensions around using some terms like 'Persons' (Page 3 for example) and 'These children'.

Response: We have changed some of this usage but we are not clear why these terms are problematic and ask for editorial guidance and/or suggestions for changes.

Sincerely,

Barbara Gibson, PhD, PT
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