Reviewer's report

Title: 'From activating towards caring'. Shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians.

Version: 2 Date: 26 May 2015

Reviewer: Irene Tuffrey-Wijne

Reviewer's report:

This is a well written paper in an under-researched area of growing importance. The tension within intellectual disability services when a client needs palliative care, from a focus on "helping someone live to the full" to "supporting someone when they are dying", was first described by S. Todd a decade ago (eg Learning Disability Practice 2004; Int J Pall Care 2005). The authors not only present clear evidence that the issue remains pressing today, but such convincing evidence has been scarce in the literature. As such, this paper makes an important contribution to the field.

The paper is well structured and generally well evidenced. The background section is illuminating and sets the scene well. I like the way case studies and quotes are used in the presentation of findings, making this easy to read and understand whilst not losing a comprehensive overview. The discussion is relevant. The practice implications (conclusion) are sound and follow from the findings.

Before the paper is ready for publication, I have some questions that need to be addressed, and some minor suggestions for improvement.

MAJOR COMPULSORY REVISIONS

The weakest part of this paper is the methods section.

I found the terms "semi-structured interviews" and "qualitative" somewhat inadequate in describing the study design. I would urge the authors to be more specific (eg "Retrospective case study design").

I would also like to see more detail on the data collection tools (interview schedule) and its development. What were the interview questions/topics based on? Was there a theoretical research framework? (It might help to see a table or figure with the interview guide).

I gather the selection of participants was purposive rather than random or convenience? Please state. Did the sampling strategy lead to any limitations in the study? (perhaps not... I do note that saturation was reached), if so, please include under "strengths and weaknesses"). Overall, studying twelve cases with 35 1-2 hour interviews is an adequate amount for a sound qualitative study, so the findings do seem to rest on a good amount of data.
With regards to the research question (last paragraph of background section), the author states that "THIS PAPER will address the following research questions..." Does this mean that this was part of a study with wider aims than the ones addressed in this paper? If so, please state. If not, it would help to have the aim of the study clearly set out here.

MINOR ESSENTIAL REVISIONS

1) Definitions and terminology: In a palliative care journal, it is essential to include a definition of "intellectual disabilities", as this term is not universally understood. "End-of-life care" has different meanings in different countries: some (incl UK) use it interchangeably with "palliative care", whereas many others see it purely as the care in the last few days of life. I suggest changing this term to "palliative care" and clarify that it can start well before the final decline (as, reading the paper, I gather the authors are not just talking about the final days).

"Social worker" (this term is used several times, for example in Eleanor's case study): I gather that in the Netherlands, a "social worker" is like a support worker, i.e. provides day-to-day support for the person with ID. This is not the same in the UK, for example, where a social worker of someone with ID would usually only see this person in special meetings or case reviews. This could therefore lead to reader confusion. I suggest clarifying the role of the Dutch social worker in just a short sentence.

2) Background section: I missed the work of Todd here (see above) and think it should be referenced

DISCRETIONARY REVISIONS

Personally, I would find it more logical and helpful if the summary of research findings, currently the first paragraph of the "Conclusion", was moved to the beginning of the "Discussion" section. (This may be a matter of journal policy and preference though)

Overall, I congratulate the authors on a good paper and would urge them to make the suggested revisions. I cannot currently recommend publication as the revisions with regards to methodology cannot be described as "minor", but I feel that they are relatively easy to make!

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests. There are, however, only a limited number of active researchers in this field internationally, and these have begun to
meet with the view to building future collaborations and to supporting each other in their work. Because of this process, I know the authors personally, although there are currently no joint projects.