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Dear Editor,

# Re: McEwen et al., "Moving on from Quality Assurance: Exploring Systems that Measure both Process and Personal Outcomes in Disability Services"

We are writing in our capacity as researchers at the University of Kent involved in the development of the Adult Social Care Outcomes Toolkit (ASCOT) [1–3]. The ASCOT measures social care-related quality of life (<a href="www.pssru.ac.uk/ascot">www.pssru.ac.uk/ascot</a>). The ASCOT offers different approaches for data collection, including self-report, interview, mixed methods, proxy-report and easy-read format [1, 4–8].

The authors of the article "Moving on from Quality assurance" select the Adult Social Care Outcomes Framework (ASCOF) in England [9] as an example of a quality system that measures a combination of process and personal outcomes for people with disabilities. There are, however, factual inaccuracies in how the ASCOF is described that may affect the authors' analysis and interpretation. We briefly outline these below.

The ASCOF includes the ASCOT in its entirety, and does not just use some of the items, as stated by the authors (p.9). All eight ASCOT items (see Box 1) are collected in the ASCS. For the purposes of the ASCOF, the ASCOT is collected by self-report via a postal or interview survey. The ASCOF reports personal outcomes (quality of life) for some of the items individually, as well as the overall ASCOT quality of life score (see Table 1). Most of the ASCOT-related indicators are found in Section 1 of ASCOF, Enhancing quality of life for people with care and support needs. There is also one ASCOT indicator in ASCOF Section 4, Safeguarding and protecting from harm. The overall ASCOT measure, which draws upon the scores for all eight aspects of quality of life, is the overarching indicator of quality, ASCOF 1A (social care-related quality of life).

### Box 1. ASCOT quality of life domains (see <a href="https://www.pssru.ac.uk/ascot">www.pssru.ac.uk/ascot</a>)

Food and drink
Personal comfort and cleanliness
Accommodation comfort and cleanliness
Personal safety
Control over daily life (choice and control)
Social participation and involvement
Occupation (doing things I value and enjoy)
Dignity

Table 1. How the ASCOT maps into the ASCOF

ASCOF indicator	ASCOT items / measure
Section 1: Enhancing quality of life	
Indicator 1A	ASCOT (overall score)
Indicator 1B	ASCOT (Control over daily life)
Indicator 1I	ASCOT (Social participation and involvement)
Indicator 1J	ASCOT (overall score, adjusted)
Section 2: delaying or reducing the need for care	
Section 3. Ensuring people have a positive experience of care	
Section 4: Safeguarding	
Indicator 4A	ASCOT (Personal safety)

Since one of the aims of the ASCOF was to consider individual/personal outcomes [10], it is important to consider the central place of the ASCOT as an overarching outcome indicator in the ASCOF. The analysis presented by McEwan et al in Table 3 does not consider the detail of the constituent indicators in the ASCOF. Instead, the analysis shows only the descriptive subject headings for each of the ASCOF sections, rather than the actual indicators (outcome measures) that are described in detail in the ASCOF Handbook [9].

Due to this omission, the analysis is limited and potentially misleading. Table 3 (p.8), for example, indicates that the ASCOF does not consider social inclusion. However, ASCOT *Social participation and involvement*, which is reported in the ASCOF as indicators 1A and 1J (overall ASCOT score, with and without adjustment) and also as a standalone indicator ASCOF 1I, captures quality of life with regard to social relationships and inclusion. The omission of these ASCOF indicators in the analysis is also evident in Table 4 (p3), which states that there are no indicators of social inclusion in the ASCOF. This overlooks that Indicators 1A and 1I both relate to social relationships and inclusion captured by ASCOT *Social participation and involvement*.

Similarly, Verdugo *et al*, 2012 outline that emotional well-being includes the concept of safety – but Table 3 (p.8) does not consider the ASCOT domain of *Personal safety* either as ASCOF Indicators 1A or 4A/B. The same applies to a number of other ASCOF indicators based on ASCOT (see full detail in the Table 2 below). There is a considerable degree of overlap between the domains of quality of life proposed by Verdugo *et al* (2012), and the aspects of quality of life captured by ASCOT, even if they do not correspond exactly.

Table 2. Mapping quality of life domains (Verdugo et al, 2012) to the ASCOF indicators derived from ASCOT

QoL domains <sup>1</sup>	ASCOF indicators	
Personal development	<b>1A</b> (ASCOT overall score, incl. Occupation ('doing things I value and enjoy'))	
Self-determination	1A (ASCOT overall score, incl. Control over daily life)	
	<b>1B</b> (ASCOT Control over daily life)	
Interpersonal relations	1A (ASCOT overall score, incl. Social participation)	
	1I (ASCOT Social participation)	
Participation	1A (ASCOT overall score, incl. Social participation)	
	1I (ASCOT Social participation)	
Rights	1A (ASCOT overall score, incl. Dignity, Personal safety)	
Emotional well-being	1A (ASCOT overall score, incl. Personal safety, Dignity)	
_	<b>4A</b> (ASCOT Personal safety)	
Physical well-being	1A (ASCOT overall score, incl. Food and drink)	
Material well-being	<b>1A</b> (ASCOT overall score, incl. <i>Accommodation, Food and drink, Occupation (incl. employment)</i>	

<sup>&</sup>lt;sup>1</sup> From Verdugo *et al*, 2012.

Our concern is that the analysis presented by McEwan *et al* in Table 3, as it is currently presented by the authors, does not adequately consider the range of indicators in the ASCOF, especially those that relate to personal outcomes derived from the ASCOT, although there are other relevant indicators that have been omitted (e.g. ASCOF 1E proportion of adults with a learning disability in paid employment that relates to "material well-being"). The omission does not reflect the way in which the ASCOF seeks to consider personal outcomes, in a way that corresponds (even if it does not precisely overlap with) the domains of quality of life identified as important.

Despite these limitations, we support the authors' conclusions that there are challenges that relate to the measurement and use of personal outcomes measurement in adults with disabilities. There is clearly a need to ensure that data collections are inclusive and accessible. Mixed methods

approaches and easy-read formats are ways of addressing this.<sup>1</sup> There also needs to be caution and robustness against potential sources of bias.<sup>2</sup>

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<sup>&</sup>lt;sup>1</sup> A report of the adaptation of the ASCOT in easy-read format and its acceptability and feasibility for personal outcomes data collection in adults with intellectual and developmental disabilities is provided here [6, 8].

<sup>&</sup>lt;sup>2</sup> The issues of potential bias related proxy response and/or help to complete the questionnaire in the adult social care survey (ASCS) is discussed here [11].

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