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Mr Malcolm Schyvens

Attn: AGAC Project
Guardianship Division
NCAT
PO Box K1026
HAYMARKET NSW 1240

Re: draft guidelines on the participation of the proposed represented person in guardianship and financial management/administration hearings

Dear Mr Schyvans,

Thank you for the invitation to comment on the draft guidelines on the participation of the relevant person in guardianship and financial management/administration hearings (the Draft Guidelines). The remaining content is numbered for ease of reference.

1. To provide some background information on myself, I am a Research Fellow at the Melbourne Social Equity Institute and Melbourne Law School, at the University of Melbourne. My work focuses on disability-related law and policy, with a focus on legal capacity, supported decision-making and human rights. My recent book, *A New Era for Mental Health Law and Policy: Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities*, was published with Cambridge University Press in 2017, and I am currently on the editorial board of the *International Journal for Mental Health and Capacity Law*.

2. As the AGAC briefing highlights, each state and territory enacted legislation dealing with guardianship and financial administration (section 2.10). Regarding international human rights law, and the well-publicised views of the Committee on the Rights of Persons with Disabilities, all Federal, state and territory governments appear unlikely to follow the CRPD Committee call for an end to guardianship law, which it argues, 'must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others'.[1] Further, the Australian Law Reform Commission opined that substituted decision-making based on functional assessments of decision-making ability does not entail '"discriminatory denial of legal capacity" so long as it contains appropriate safeguards, and a rights emphasis' in which 'the emphasis is placed principally on the support necessary for decision-making and that any appointment is for the purpose of protecting the person's human rights'.[2]

3. In the interest of full transparency and disclosure, I contributed two co-authored submissions to the ALRC inquiry, which made a case for discarding decision-making ability assessments in favour of an assessment of whether a person's wishes and preferences were discernible, to help determine the threshold between supported decision-making and the more intensive form of representative decision-making that may be required. I also made a case for developing 'disability-neutral' emergency

[1] Human Rights Committee, *General Comment No 35: Article 9 (Liberty and Security of Person)*, 112th sess, UN Doc CCPR/C/GC/35 (16 December 2014) [7].
[2] ALRC, E*quality, Capacity and Disability in Commonwealth Laws (ALRC Report 124)*, 3.48.

response provisions, which provides some type of proportionality test concerning serious adverse effects, and guidelines for providing support in line with a person's rights.[3] A joint submission by People with Disabilities Australia, the Australian Centre for Disability Law, and the Australian Human Rights Centre, made similar arguments.[4]

4. I wish to acknowledge the pragmatic scope of the NSW Civil and Administrative Tribunal ('**NCAT**') in developing a set of best practice guidelines on behalf of AGAC, as well as the point made in paragraph 2.11 of the briefing paper that even if governments were to transition from substituted decision-making toward a supported decision-making paradigm, it seems highly likely that guidelines would be required to maximise the involvement of persons with disabilities and others, such as older persons, in the more intensive forms of support that will be required.

5. I wanted to immediately voice support for several aspects of the proposal. The use of the term 'good practice' rather than 'best practice' seems an appropriate distinction given the scarcity of evidence supporting effective practice in this area combined with the fluctuating approach to laws concerning legal capacity and disability, noted previously. Second, the work of Marie Fallon-Kund and Jerome Bickenbach, and Lucy Series and colleagues on the Court of Protection in England and Wales are important international resources. As noted, Lucy Series and colleagues' promote three essential principles to maximise involvement of persons involved in proceedings, for which the third point is worth underscoring:

   > 3. The adversarial principle: Participation – including directly and through effective representation - may be necessary to help a person to present his case and to refute expert evidence or arguments recommending measures that a person opposes.

   My comparative legal research suggests a tendency of policymakers to frame rules and procedures concerning persons with disability primarily using therapeutic and welfarist principles. In doing so, serious rights interventions may be presented as neutral, administrative steps taken by experts, rather than state-authorised interventions that raise fundamental matters of citizenship and human rights. This is in no way a novel observation, but it seems worth reiterating given the historical drag of hard paternalism in legal responses to disability.

6. I would also like to draw attention to several elements of the guidelines:

   a. **Section 3.2** states that 'A decision not to seek the views of the person should, however, be supported by evidence from an independent health professional'. Several questions arise here: how should independence be assessed? Are there grounds to challenge evidence from an independent medical professional? What are the grounds used by doctors when determining it is not appropriate to seek the views of the person: is it the likely harm that seeking such views would cause, or a perception that the person simply could not offer any views to speak of? Do the reasons for such a conclusion need to be provided to and recorded by Tribunals? This broad directive appears to be premised on a view that independent medical professionals will act neutrally to determine whether it would be harmful to seek the views of the person. This may be the case in many if not most instances. Many doctors have longstanding relationships with individuals and their families, and understand

[3] See <https://www.alrc.gov.au/sites/default/files/subs/130. org centre for disability law policy nui galway.pdf>; <https://www.academia.edu/10027685/Submission_to_the_Australian_Law_Reform_Commission_Equality_Capacity_and_Disability_in_Commonwealth_Laws_2014_>

[4] See <https://www.alrc.gov.au/sites/default/files/subs/111. org people with disability australia and the disability rights research collaboration university of sydney final.pdf>

contextual factors beyond the individual's medical circumstances. However, it is also the case that medical professionals are no less susceptible to widespread discriminatory attitudes toward persons with disabilities than the rest of the community, including maintaining the 'soft bigotry of low expectations'.[5] There is clear evidence of discrimination toward persons with intellectual disabilities in the Australian health system,[6] and others with disabilities. Many women with disabilities, for example, have undergone involuntary or coerced sterilisation at the hands of uninformed doctors.[7] It is reasonable to assume that many doctors will be similarly uninformed about communication supports for persons with disabilities, older persons and so on, particularly in light of developments around supported decision-making in recent years. Given the profound impact that a guardianship or administration arrangement can have on a person's life, and the general spirit of the guidelines in recognising the shift brought by the CRPD from a medical/welfare framework to a rights-based framework, steps must be taken to avoid presenting clinical power in terms of neutral, administrative decision-making, particularly when the results can be a restriction on fundamental rights.

b. Regarding **Draft Guideline 10** directing Tribunals to collect data and report publicly on the rate of appointment of representatives, Article 31 of the CRPD is relevant. Article 31(2) of the CRPD requires disaggregation of data where appropriate with the aim of CRPD implementation. The discussion at section 5.28 on the collection of data is welcome (and data on participation rates of the person in hearings, is disaggregated regarding: face-to-face participation, hearings by videoconference and hearings by telephone). It would be helpful to provide additional specificity about other types of disaggregation of data that are desirable or may even be required unequivocally. It would seem appropriate, for example, to disaggregate data along lines of gender, race, and disability types, and perhaps in terms of the different forms of communication used during each year, so as to better understand how guardianship and administration is working in practice. This understanding can help on several fronts, including monitoring against over-representation of particular groups, better understand what supports may be useful for the individuals presenting before tribunals, their use between jurisdictions, and so on. The disaggregation of data that occurs for those who are Aboriginal and Torres Strait Islander may be particularly important (discussed below).

c. Regarding **Draft Guideline 14,** the emphasis on allowing and promoting the involvement of an assistant for the relevant person, be they family, disability advocates, friends or others, is welcome. There is not always material available to lawyers, or non-legal advocates, to assist persons with disabilities in legal proceedings. We attach for your consideration, a 'supporter protocol' that myself and my colleagues developed for disability support persons (discussed below) as part of a project on access to justice for persons with disabilities in the criminal justice system. Although developed to assist 'Justice Support Persons' who assist accused persons with cognitive disabilities in the *criminal justice context*, the materials may be useful (see Appendix A).

[5] Graeme Innes, 'Graeme Innes: If you could choose the legacy you leave behind, what would it be and why?' Wheeler Centre, 28 November 2015 <https://www.wheelercentre.com/broadcasts/graeme-innes-if-you-could-choose-the-legacy-you-leave-behind-what-would-it-be-and-why>

[6] Council for Intellectual Disabilities '#DeadlyDisabilityDiscrimination sees Health Minister act on preventable deaths' http://www.nswcid.org.au/deadlydiscrimination.html

[7] Stella Young, 'The involuntary sterilisation of children with disabilities should be challenged', *Ramp Up* (ABC) 19 Jul 2013 http://www.abc.net.au/rampup/articles/2013/07/19/3806737.htm

d. Regarding **Draft Guideline 18**, which directs that 'the person should have a genuine opportunity to participate in an oral hearing before a determination is made', this provision could be clarified with an additional reference to the person having an opportunity to communicate their will and preference, with communication supports that may be necessary to do so.

e. Regarding **Draft Guideline 25** which refers to the training of 'members and registry staff about strategies to involve persons who are the subject of applications'; this guideline could be strengthened by promoting the employment of persons with disabilities as trainers. There are several rationales for employing persons with disabilities in delivering or co-delivering training, including obligations to ensure active participation of persons with disabilities under the CRPD,[8] the expertise of trainers with disabilities on communication needs, ableist attitudes that hinder involvement, and in conveying the implications (both positive and negative) of being placed on a guardianship or administration order. During our own work on unfitness to stand trial laws, trainers with disabilities were employed to assist in the training of 'disability justice support persons'.[9] The new 'disability justice support person' role involved non-legal advocates assisting accused persons with disabilities during criminal proceedings. Most training participants, including lawyers who worked alongside the disability justice persons, reported that the training sessions led by persons with disabilities – including persons with intellectual, cognitive and psychosocial disabilities – were particularly useful.

f. Regarding **Draft Guideline 27** on participation of Aboriginal and Torres Islander People, this provision could be strengthened beyond ensuring panel members have 'access to training', to instead *require* that they undertake at least a base-level of training which promotes awareness of specific cultural considerations relevant to Aboriginal and Torres Strait Islander people. Given the over-representation of Aboriginal and Torres Strait Islander people noted in the briefing document (section 9.3), as well clear evidence of the negative impact of racial discrimination Aboriginal and Torres Strait Islander health,[10] and the particular disadvantage confronting Indigenous persons with disabilities,[11] some degree of mandatory training would seem a minimum requirement to promote culturally safe and respectful practice. Materials from the health sector, such as the Nursing and Midwifery Board of Australia and Congress of Aboriginal and Torres Strait Islander Nurses and Midwives joint statement on culturally safe care,[12] and the materials of First People's Disability Network,[13] could provide the basis for such training.

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[8] See Article 4(3).

[9] Bernadette McSherry, Eileen Baldry, Anna Arstein-Kerslake, Piers Gooding, Ruth McCausland, Kerry Arabena, *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities Addressing the Legal Barriers and Creating Appropriate Alternative Supports in the Community,* Melbourne Social Equity Institute, 2017 <https://socialequity.unimelb.edu.au/__data/assets/pdf_file/0006/2477031/Unfitness-to-Plead-Main-Project-Report.pdf>

[10] Australian Human Rights Commission (2005) Social Justice Report 2005. Page 10; Yin Paradies, Ricci Harris, Ian Anderson (2008) The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda. Cooperative Research Centre for Aboriginal Health Discussion Paper Series: No. 4.

[11] Scott Avery, *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First People's Disability Network, 2018.

[12] Nursing and Midwifery Board of Australia and Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, 'NMBA and CATSINaM joint statement on culturally safe care' February 2018 <https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/position-statements/joint-statement-on-culturally-safe-care.aspx>

[13] Scott Avery, *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First People's Disability Network, 2018.

Once again, thank you for the opportunity to provide feedback to the AGAC Project. I hope my comments may be of some assistance. Please feel free to contact me regarding any of the content in this submission.

Kind regards,

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Appendix A: SUPPORT PERSON PROTOCOL

The researchers of the Unfitness to Stand Trial Project (2015-17) developed a protocol to clearly define the disability justice support person's role. The protocol set out guiding principles for the program, as well as ethical and professional obligations expected of the Disability Justice Support Person. For more information on the Project, please visit the Melbourne Social Equity Institute website: https://socialequity.unimelb.edu.au/projects/unfitness-to-plead

Guiding principles

1.1. The supporter's primary role is to support the client to participate effectively throughout the criminal justice process by facilitating accurate communication between client and the court, and between the client and their legal representatives.

1.2. The supporter must remain impartial and neutral.

1.3. Throughout the process the client must consent to the supporter's involvement.

1.4. The supporter should exercise discretion and judgement in accepting any case and should not accept cases which are outside or beyond their professional scope or expertise.

1.5. The supporter must work closely with the defence lawyer to determine appropriateness in accepting cases.

1.6. The supporter's role must be transparent throughout.

1.7. The supporter must have a clear and comprehensive understanding of their responsibilities and duties.

1.8. The supporter must conduct themselves in a professional and courteous manner at all times.

1.9. The supporter must conduct themselves in court in a manner that facilitates accurate and coherent communication between the client and the court.

1.10. The supporter must keep appropriate parties (particularly the legal practitioner) informed of any difficulties that may arise in the course of the assignment, including difficulties communicating with the client and any issues regarding consent.

2. When does the support role begin and end?

2.1. Legal practitioners will identify appropriate cases for supporter involvement.

2.2. The supporter will not become involved unless the client can give instruction to the legal practitioner.

2.3. At the suggestion of the client's legal practitioner, a supporter may offer assistance. The support relationship commences when the client gives (written or verbal) consent to accept such support.

2.4. Written consent from the client to accept support should be sought in the first instance.

2.5. Where written consent is not practicable to obtain (for example, where literacy issues arise) verbal consent may be obtained. Verbal consent may be obtained only when the purpose of the support and the research project have been discussed with the client, and the supporter and the client's legal practitioner are satisfied that the client has provided informed consent to receive support.

2.6. If, at any stage, the client withdraws consent to receive support, the support relationship ceases.

2.7. If, at any stage, the legal practitioner or the supporter believes the client can no longer consent to receive support, the support relationship ceases. In the event that the client can no longer consent to receive support, this does not preclude the supporter providing assistance to the legal practitioner, as to how communication and accessibility may be enhanced. However, the legal practitioner is under no obligation to accept or have regard to such assistance.

2.8. If the client ceases to be a client of the legal organisation or an affiliated legal organisation, the support relationship ceases.

2.9. If the criminal proceedings against the client are resolved, the support relationship ceases.

3. Ethical and professional obligations

3.1. The supporter will conduct themselves responsibly and professionally, using reasonable skill and care in the performance of their duties.

3.2. The supporter must consider at all times the potential for conflicts of interest to arise, and the need to act in the public interest.

3.3. The supporter must promptly notify the [COMMUNITY LEGAL CENTRE] of any matters, including conflicts of interest or lack of suitable qualifications or experience, that may disqualify or make it undesirable for them to continue involvement with the client.

3.4. The supporter must disclose any vested or material interests she or he may have in a client's case as soon as they arise, whether or not they may justify disqualification or make it undesirable for them to continue involvement with the client.

3.5. The supporter must treat any information coming to them in the support role as confidential, including the fact of having acted in a support role for a particular client.

3.6. The supporter's duty of confidentiality does not preclude disclosure when legally required to do so, or when failure to disclose information could render the supporter liable to prosecution.

3.7. The supporter must not use any information or knowledge gained during the course of their work to benefit themselves or anyone else improperly.

3.8. The supporter must make appropriate efforts to facilitate communication between people who have differing communication and cultural characteristics.

3.9. The supporter must respect the professional and ethical obligations of other professionals, particularly legal practitioners working for the partner organisations.

4. Supporters and legal practitioners: working together

4.1. The supporter will work actively with legal practitioners to develop and provide support that is appropriate to the legal services provided.

4.2. The supporter will offer assistance only in accordance with the legal practitioner's legal obligation to follow the accused's instructions and promote her or his interests. It is up to the legal practitioner to determine how this obligation is met.

4.3. The supporter will receive training, developed in consultation with legal practitioners, so as to avoid undermining this professional obligation.

5. Tasks within the supporter role

5.1. The supporter must assess the client's communication needs.

5.2. The supporter may spend time with the client to develop and identify effective ways to communicate.

5.3. The supporter may recommend special measures to enable effective communication with the client.

5.4. The supporter may sit with the client in the lead up to the trial to answer questions and provide reassurance.

5.5. The supporter may suggest ways to create a comfortable and safe environment for the client in order to facilitate ease in decision-making and communication.

5.6. The supporter may ask case workers, family members or others who know the client well (within the bounds of privacy and confidentiality constraints) whether there are any prior assessments or knowledge available about the client's communication needs.

5.7. The supporter may facilitate communication:
- during experts' assessment of a client on behalf of both prosecution and defence (insofar as assisting with communication);
- during familiarisation/preparation of the client for court;
- during pre-trial court appearances;
- with clients during the trial or when the client is informed about the trial outcome (subject to approval by the court);
- and in other settings as the need arises.

5.8. The supporter can work with the client and the legal practitioner to suggest ways of simplifying questions, which may also be communicated to the judge. Depending on the client, this might include requests to:
- avoid putting questions in the negative ('you were at this place at this time, weren't you');
- avoid tagged questions ('when you saw this happening, it was night time wasn't it?');
- avoid leading questions, or to consider prior to court proceedings whether the use of leading questions is likely to produce unreliable responses from the client;
- avoid leading questions combined with gestures from the questioner ('you were in the house, yes?' asked by a prosecutor who was nodding).

6. Tasks outside the supporter role

6.1. The supporter must not give legal advice.

6.2. The supporter must not offer an opinion about the truthfulness of the information provided by the client.

6.3. The supporter must not offer an opinion about the client's ability to understand truth and lies.

6.4. The supporter must not offer an opinion about the accuracy of the client's recollection of events.

6.5. The supporter must not assess, offer an opinion or contribute directly to the assessment of a client's fitness to stand trial (even though she or he may provide assistance toward communication between the person and the court).

6.6. The supporter is not an expert witness.

6.7. The supporter's role is not to provide the court with evidence, oral or written, about a client's unfitness to plead or the supports likely to be needed at any trial.

6.8. The supporter is not an interpreter.

6.9. The supporter must not enter discussions, give advice or express opinions about any aspect of the case that could contaminate the evidence or lead to an allegation of rehearsing or coaching any witness (including the client).