Delivering quality care more efficiently inquiry

Questionnaire response 14

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Participant background

1. For the purposes of this consultation, which of the following best describes you:

   I am an interested community member

2. Which of the following care sectors will your feedback relate to? Please select all that apply.

   Disability; Health

3. What kind of care supports, services and programs do you have experience with, and in what jurisdictions?

   The participant did not respond to this question.

1. Reform of quality and safety regulation to support a more cohesive care economy

1. To what extent do differences in quality and safety regulation make it costly or complex to provide or access care services?

   Somewhat

2. What are the reasons for your answer?

   There needs to be appropriate regulation to keep people free from abuse, violence, neglect and exploitation but it also needs to be done in a way that organisations aren't so fearful of breaking the rules that they lock their clients away or take away all normal risk from the client's life. For example, a client should be free to participate in risky activities like visiting nightclubs, having sex, racing cars or bungee jumping. Part of equality is the right to make mistakes and be adventurous. But this freedom needs to be nested in a support system that doesn't enable predatory people to exploit our most vulnerable members of society.

3. To what extent should quality and safety regulations be more aligned across the different care service sectors and jurisdictions?

   To a great extent

4. What are the reasons for your answer?

   It should be the same across all sectors. Human rights are human rights and a person with a disability also needs to access the aged care, early childhood and health care systems. The only way to improve equality is to weave access and inclusion into all sectors rather than segregating it.

   Access and inclusions should 100% be integrated into early childhood education as an immediate regulation priority.

2. Embed collaborative commissioning to increase the integration of care services

1. What is your experience with collaborative commissioning

The participant did not respond to this question.

2. What are the benefits of pursuing greater collaborative commissioning?

The participant did not respond to this question.

3. What are the barriers to collaborative commissioning, and do you have any suggestions for solutions that would lead to better collaboration in the commissioning of care services?

I don't think we're at a point where these 3 sectors are ideologically aligned yet. Healthcare speaks to clients with a lot of authority, can be a bit intellectually coercive and sometimes ignore consent. Disability prioritises the lived experience and wants of the client. Aged care standardises support and sometimes infantilises clients. I'd worry about preserving disability rights with the combination of these sectors.

3. A national framework to support government investment in prevention

1. What are the main barriers to governments investing in evidence-based prevention programs across the care economy?

The government significantly under-invests in genetic reproductive services for people with genetic conditions. IVF costs around $18,600 for a woman with a genetic condition, $10,000 more than a woman without a genetic condition. On top of that, the woman with the genetic condition reduces her odds of a viable pregnancy by 50% because 1 in 2 of her eggs will be affected by the condition. That means she has to do multiple rounds of IVF just to achieve the same pregnancy rate as non-genetic condition women.

Making it easier and cheaper for people with chronic health conditions to access genetic reproductive services would drastically reduce the costs of healthcare overall, especially for genetically dominant conditions.

Here is a financial breakdown for your reference for a woman with a genetic condition accessing reproductive services through IVF Australia:
- Specialist appointments with cardiologist, endocrinologist and obstetrician to support preparation for a high risk pregnancy. 6 x appointments for a total of $3,177.25
- Genetic testing panel through Eugene $1399
- Genetic testing pre IVF to determine gene characteristics $2600 (medicare rebate outstanding)
- Pre-IVF ultrasound $385
- Egg collection hormone medication $138.20
- Pain relief $72.97 (panadine forte and numbing cream for injection site)
- 1 round of egg collection $12,936 (Medicare rebate $6287.30) Out of pocket: $6648.1
- Anaesthetist for the collection $280
- Hosptial day fee $752.85
- Egg freezing fee $350
- Biopsy fee $1075
- Embryo genetic test $4500 (medicare rebate $3000ish)
- Embryo transfer $280 (Medicare voucher used, no idea what that is but for some

reason it was cheaper)

Which makes it $18,658.37 for a woman with a genetic condition to collect and implant 1 embryo. Compare this to the $8,907.12 out of pocket cost the woman would have had for the same IVF service if she didn't have a genetic condition.

This cost continues to climb by $10,344.27 for the woman with the genetic condition when the transfer is unsuccessful. (hormone medication + pain relief + egg collection service + anaesthetist + egg freezing fee because eggs have to be frozen in order to be genetically tested + biopsy fee + embryo genetic test + embryo transfer). Remember that for a dominant gene a significant portion of the embryos created are affected so it is common to only receive 1 embryo per collection because other embryos will be discarded for genetic reasons.

2. What are some examples of successful prevention programs (this could include discontinued programs)?

   Please properly fund genetic reproductive services.

3. How can governments better support investment in prevention activities that have broad and long-term benefits for the Australian community?

   Have mechanisms for patients and people who experiences services to communicate about the costs to governments. There isn't a space for proper dialogue that doesn't disintegrate into political debate.