rainbow families queensland

29 April 2022

Email to: Legal Affairs and Safety Committee

lasc@parliament.qld.gov.au

Dear Committee

Inquiry into matters relating to donor conception information

Thank you for the opportunity to provide a submission regarding donor conception information. Our submission is made on behalf of rainbow families across Queensland, with a focus on representing the voices of the LGBTQ+ community as well as those of our children.

About Rainbow Families Queensland (RFQ)

RFQ supports, celebrates, and advocates on behalf of LGBTQ+ parents and carers and their children, across Queensland. RFQ has a vision of a community where every family is included, respected, and valued. As a community organisation run on a volunteer basis by LGBTQ+ parents, we act as a support network for parents and carers as well as their children. We advocate on behalf of our community and are a strong and consistent voice for LGBTQ+ families to address discrimination, raise awareness and promote acceptance.

Families in which one or more parents or carers identify as LGBTQ+ are known as rainbow families.

Our families are created in many ways, including through donor conception, surrogacy, step-parenting, and co-parenting.

Community survey on donor conception information

To inform the Committee on the views of our community regarding donor conception information, RFQ published a community survey in April 2022. 112 people participated in the survey including:

- 89 parents of donor-conceived child(ren)
- 16 intended parents of donor-conceived child(ren)
- 9 people pregnant/their partner is pregnant with donor-conceived child
- 2 donors, and 1 intended donor[1]

The results of this survey are summarised below, and the full survey results are available at the following location: <https://docs.google.com/forms/d/1ANiq0rLpOACk5IIYL-ZAzE58diu9wUlOnSw76MASSPE/viewanalytics>

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[1] Survey participants were able to select all that apply – some participants had experiences as both a donor and a parent of a donor-conceived child.

Survey participants

The survey results indicated that the majority of our community members who use or intend to use donors are (or will) access anonymous donors through ART clinics.

Of the survey participants who are parents or intending to become parents of a donor conceived child or children 79 (70.5%) used or intend to use an anonymous donor through a clinic, and only 2 had used or were intending to use an anonymous donor through a private arrangement. A further 37 parents were using or intended to use a known donor, with a minority of these using a clinic (13.4% of sample). Other survey participants used the open text to provide additional responses about their arrangements.

The gender of survey participants was mostly female/woman (87.5%), with 4.5% identifying as man/male and 6.3% identifying as non-binary, and 1.7% other. 6.3% of the sample (7 participants) were transgender or gender diverse.

With regard to sexual orientation, 69.4% identified as lesbian, 10.8% as bisexual, 5.4% as gay, 4.5% as queer and 9.9% identified as another orientation.

It is important to note the limitations of our survey which mostly represents the views of lesbian parents who used or intend to use anonymous donors through clinics. Gender diverse, non-binary parents and gay fathers are not significantly represented in the sample.

We also did not hear from anyone who has a variation of sex characteristics (intersex). Intersex Human Rights Australia or Intersex Peer Support Australia can best speak to the issues for people born with variations of sex characteristics.

Child’s right to access information

Our community strongly identified with a statement that “Donor conceived children should have the right to access information about their genetic origins.” A total of 96% of the survey participants either agreed or strongly agreed. Many expressed views such as:

> *‘It is the children’s choice not the parents. There should be access and openness around this method of conceptions for so many reasons.’*

In general, our communities are well informed about the importance of our children knowing where they came from. Our children are in a different situation from DCP adults born 30 or 40 years ago. For a start, donor conception usually does not take place after years of infertility and is often seen as the primary (not secondary) way to start a family. Further, there is almost never an opportunity in a two mum, two dad, or single parent household to ‘hide’ the fact of a child being donor-conceived. This sets the experience of our children apart from the devastating experiences of some donor-conceived people (DCP) in the past who misled or lied to about their genetic origins.

As one of our survey participants expressed:

> *‘DCP who were lied to and found out as adults have rights and need to be heard. But the experiences of the next generation, who have been raised in queer, DC-affirming homes without stigma and with access to info about their genetic background (often including relationships with their donor siblings and even with their donor/s), are quite different.’*

Central register

Most survey participants were in favour of the government creating a central register to record information about donor conception, with 75% showing moderate support or strong support. However, some had reservations with 14.3% being neutral, and 10.7% being against this proposal.

Reasons cited in favour included:

- To safeguard the right to information of the DCP
- Increased transparency, easier access to information, including medical records
- Standardises approach – more consistent procedures and outcomes
- Distrust of for-profit clinics managing the process, and fears that clinics might lose records or cease to exist
- Current challenges locating donor siblings
- Assurance that the maximum number of families is enforced

Those against the proposal or with reservations noted:

- That the process of the clinic providing information is sufficient
- Concerns with government inference with the lives of LGBTQ+ people – "It's not the government's business how my child was conceived" and "the government shouldn't be trusted with that information"
- Concerns about perceived incompetence of government managing the registry, including risk of data breaches
- Equality concerns, i.e. there is no register for accidental pregnancies for straight people
- Impedes the privacy and anonymity of the donor

Information recorded on register regarding the DCP and family

As mentioned above, not all participants agreed that there should be a central register.

Of those who thought that information should be kept on a central register, most agreed that the following mandatory elements should be recorded:

- Date of birth of child (82.6%)
- Place of birth of child (67%)

There was some support for recording the following details:

- Sex assigned at birth of child (47.7%)
- Name of the person who conceived the child (41.3%)
- Name of the child (39.4%)

Only 1.8% thought there should be contact details for the recipient family recorded on a central register.

Information recorded on register regarding the donor

Of those who thought that information should be kept on a central register, most agreed that the following mandatory elements should be recorded:

- Name of donor (55%)

- Date of birth of donor (66.7%)
- Ethnicity and physical characteristics (63.1%)
- Medical history/genetic test results relevant to future health of child/descendants (87.4%)
- De-identified information about donor siblings – e.g. sex and year of birth (70.3%)
- Name of each ART provider who has obtained sperm, eggs, or embryos from the donor (51.4%) and the date of donation (51.4%)

There was some support for recording the following details:

- Place of birth of donor (45.9%)
- Contact address of donor (28.8%)

Private vs clinic arrangements

There were mixed views about the extent to which private donor arrangements, made outside of a clinic setting, should be legally required to be recorded on a register:

- 40.2% thought that it should be mandatory
- 32.1% thought that it should only be voluntary
- Around 27.7% were unsure or provided a specific response such as that it depends on the circumstances/relationship between the parties.

The benefits noted were:

- To ensure the right to information of the DCP
- A safeguard if one party decides to withhold information should the relationships between parent(s)/donor break down
- A DCP should have the same right of information even if their parent(s) did not use a clinic
- Reduces the change of too many families using the same donor
- Makes it clear that person is ‘donor’ and not parent (in case of family law disputes)
- Improves access to information about donor siblings

One survey participant who had been a donor noted that:

> *‘I have been a private donor and while I have a great relationship with the parents and children, I can see where there may be times that relationships do break down, and ultimately the children should still have the ability to know who their genetic parents are.’*

Those who indicated that private arrangements should not be included:

- Right to privacy of all involved
- That the private arrangement involves different circumstances and agreements between the parties – usually parties know each other, and often have ongoing contact anyway

- Double-standard – single parents who do not know or choose to not reveal the biological father are not subject to this
- Increased red tape - parents often avoid clinics to "get away from the clinical side of things and paper work"
- Difficult to enforce
- May involve people taking risks to avoid being on the register

Another survey participant thought that:

> *'They are private arrangements. Should be handled privately as such. Not forced. There is no register for private arrangements and accidental pregnancies at the pub on a Saturday night!'*

Voluntary register

There were fewer reservations about a voluntary register such as that available in Victoria, where donors, relatives of donors, donor-conceived persons, parents of donor-conceived person, relatives of donor-conceived persons, descendants of donor-conceived persons may apply (for free) to receive information.

Around 81.3% of survey participants supported the idea of a voluntary register.

Few participants had experience of using a clinic to obtain information, but those who had commented:

> *'We have been given the bare minimum.. sex and dob. I get v the feeling the clinics aren't that helpful.'*
>
> *'It is impersonal and awkward – all voluntary.'*

Some survey participants were already using social media to connect their child/ren with donor siblings. Overall, the experiences appeared to be positive for people who had made connections outside of clinics, but some felt it would be easier and better regulated through a voluntary register.

> *'I found one of my son's donor siblings in a Facebook group. We met up for a playdate and it was fantastic to see them together. It would definitely be easier if there was a central registry. My son's donor has maxed his family limit so there has to be at least 10 children in Queensland conceived from this donor, but I have only been able to contact one. Both myself and the mother of my son's donor sibling would love to be able to connect with other donor siblings.'*
>
> *'We joined a Facebook group of siblings that was unregulated and had a challenging experience (poor boundaries/questionable conduct re of donor contract).'*

RFQ's contends there is value in creating a voluntary register, as long as the information is free to access, it is properly resourced, and there is sufficient access to free/low-cost counselling for all parties (further explored below).

Child’s age

While access to information is currently available through clinics at 18, our community supported facilitating access to information when the child is mature enough to understand or make decisions about the situation. Some participants thought this could be as young as 12 years old. 21.6% thought that 16 was the appropriate age. Only 29.7% believed that 18 years old should remain the age to receive information.

RFQ supports the right of the child to autonomy over their lives and decisions and is of the opinion that allowing access earlier, at least at the age of 16, but preferably based on the maturity and understanding of the child regardless of age.

Retrospective access

While in principle survey participants supported facilitating access to records already in existence (63.4%), only 40.2% felt that the DCP’s right to access to information about their genetic origins should take precedence over the donor’s right to anonymity, such as where the parties had previously agreed it would be an anonymous arrangement for life. Around 20% were unsure about this issue.

Survey participants’ comments included:

> *‘The psychological and ethical implications of withholding a known part of someone’s genetic identity should be more highly considered than a donors anonymity considering the donors biological roll (sic) in the child’s creation’*
>
> *‘If it weren’t for donors anonymity then there wouldn’t be many donors. I value and read my donors profile carefully. The only time I think a clinic should intervene would be to ask for exceptional things eg bone marrow match.’*

Several survey participants felt that the DCP’s right to know their origins trumped the donor’s wishes, and in particular if there is a medical/genetic issue that emerges. However, some participants noted that one way to achieve the necessary flow of information would be to retain anonymity of details such as name and address while providing key genetic/health information to donor conceived children.

Others felt that donations are a ‘gift,’ that agreements made in the past should be honoured as it is “unethical to disregard the wishes of the donor as they stood at the time.” Some participants were more comfortable with the donor being able to volunteer the information, as some will have changed their attitudes to the donation over time.

Several participants were also concerned that this would limit the number of people willing to donate in future, exacerbating a situation where finding donors was already a challenge in Queensland.

On balance, RFQ is of the opinion that there are some situations where the DCP’s right to information should trump the wishes of the donor at the time of donation, but that not *all* information should released to the DCP or their family if the law is retrospective. Key medical/genetic information records should be available regardless of the intention of the donor at the time of donation.

Past donors who had originally agreed to be anonymous could be sent information about the rights of the child to know their origins (and the negative consequences for those who do not have access) and given an opportunity to change the nature of their donation to being open to information sharing and/or contact.

Counselling

Quality, affordable counselling for donors and parents at the time of agreeing to the donation, and DCPs at the time of accessing records, was highly valued by our community. 79.5% thought that counselling for donors and parents was important or very important, and 88.4% thought counselling for DCPs was important or very important.

There was strong support for community organisations being funded to deliver free/reasonably priced counselling (81.3% agreed or strongly agreed).

Actual experiences of counselling varied. While some commented it was ‘helpful’ or ‘invaluable’ others felt it was ‘perfunctory’ or a ‘box-ticking exercise,’ or at worst ‘invasive, disrespectful and insulting.’ High costs were also noted by a number of survey participants.

Examples of positive experiences were as follows:

> *‘As a parent, it helped us navigate the story of how the child came to be in age appropriate information. It helped us to discuss what was important for our children to know and when.’*
>
> *‘In order for my partner and I to receive gametes (sperm) we had to attend two counselling sessions and pay for a report. We actually loved these sessions! The psychologist really boosted our confidence to be good parents and we walked away feeling like, "yeah, we've got this!"’*

Examples of negative experiences were as follows:

> *‘Our counsellor was awful. We knew we wanted a donor conceived baby, we had studied and researched and talked for years but instead of feeling reassured or open to discussion, we felt judged and condemned. I fully respect that many people may WANT counselling, but no couple comes to that conclusion lightly and in many situations, it’s simply not necessary. Who is a counsellor to tell me what I want or do not want? Or what I do or do not understand.’*
>
> *‘As a potential parent, I received very basic and unhelpful mandatory counselling at an ART clinic before I could access sperm. There was insufficient time to discuss questions. And I felt unable to be authentic as it was a tick box exercise to access sperm. It wasn't real counselling.’*

Unfortunately, some had experiences of a counselling service was not appropriate or tailored to the needs of the LGBTQ+ community:

> *‘The counselling we received was pretty basic, and very aimed at heterosexual parents.’*
>
> *‘The counselling we went through as prospective parents at a clinic was woeful. Very hetero-normative and “let’s grieve your fertility” rubbish. And we knew waaaay more about donor conception, the viewpoints of DCP, the language of family etc than the counsellor. So I agree with counselling in principle but it has to be good quality.’*
>
> *‘For those receiving donations, I think the counselling possibly could have gone into more depth on what it means to be a non bio parent. It would be good to have more*

> *information and support networks for people and for appropriate community organisations to be funded to provide this support and maintain these networks. Eg rainbow families Qld.'*

Counselling is most effective where it is free, accessible and by choice. A system should be established which facilitates choice of provider and does not serve as a gate keeping exercise for potential parents. Referrals to organisations such as RFQ may be beneficial for people trying to conceive.

Striking the right balance

Access to donors in future was seen by many participants as a significant risk of creating a new legal framework in this area. On one hand, the community felt that that DCP's rights to know about their genetic origins were of paramount importance, but on the other hand over-regulating the ART clinics, attempting to overly intrude on private arrangements or entirely disregarding donor privacy could discourage people from becoming donors.

Consideration should also be given to the implications of the common practice of using foreign donations in Queensland, such as international sperm donations. Additional regulations may reduce the availability of foreign donations. In circumstances where there is insufficient supply in Queensland, potential parents may be required to travel to other jurisdictions to conceive, negating the potential protections afforded by regulation.

RFQ therefore urges the government to proceed with caution and take a balanced approach to these issues.

Recommendations

1. A central register should be created to support the rights of the child to receive information about their genetic origins.
2. Mandatory information recorded on the central register should include the date and place of birth of any children conceived through donor-conception, the name and date of birth of the donor, the ethnicity and physical characteristics of the donor, medical/genetic information of the donor, de-identified information about donor siblings, the name of ART provider and date of donation. It should be possible to provide further information on a voluntary basis.
3. Private arrangements may be included on the central register on a voluntary basis.
4. The register should be retrospective with respect to access to information about key medical/genetic issues which could impact on the health of the child or their descendants.
5. The government should provide a voluntary register, ensure it is properly resourced, and provide access to non-mandatory free/low-cost counselling and support for all people accessing the register.
6. A DCP should be able to access information at 16 years old, or when mature enough to understand and make decisions about the issue (whichever is sooner).
7. Community organisations that are inclusive and competent on issues regarding the LGBTQ+ community should be funded to provide high quality, free or low-cost counselling to donors, parents and DCPs.
8. That a review of the register be conducted after a period of five years including to evaluate the impact of registration on availability of supply.

Thank you for considering this submission, and our team would be pleased to discuss any aspects of the submission further.

Yours sincerely

Heather Corkhill

Rainbow Families Queensland Steering Committee