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## Donor-linking provisions in New Zealand: counselling roles, concerns and needs

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### ABSTRACT

Donor-linking where those genetically related through donor conception (e.g. donor-conceived persons (DCP), donors and siblings), or recipient parents, search for and connect with each other, is increasingly common, both in identity-release jurisdictions where donors' identifying information may be released to DCP, usually when they become adults - and in anonymous jurisdictions, e.g. as a result of direct-to-consumer DNA testing. In this paper, we explore New Zealand fertility clinic counsellors' views regarding their donor-linking roles and their concerns and needs in relation to current and anticipated service provision. Counsellors believed that fertility service providers had a longer-term responsibility to offer donor-linking services to ensure the wellbeing of all parties affected by donor conception. They perceived their role as complex and multifaceted, encompassing psychoeducation, mediation, advocacy, facilitation, relationship counselling, and therapeutic intervention. They identified significant service provision challenges however, including inadequate staffing, training, time and prioritisation of donor-linking, and inadequate legislative provisions to support practice. Counsellors called for clarity in legislation addressing different contexts of donation and providing measures to ensure the recording of and access to identifying information. They expressed a need for comprehensive, funded donor-linking services, therefore facilitating choice, and services staffed by professionally trained and supported staff.

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Donor-linking; counselling; concerns; needs; clinical practice

### Introduction

Donor-linking refers to the practice whereby people genetically related through donor conception (e.g. donor-conceived persons (DCP), donors and siblings) or recipient parents, seek access to information about each other, sometimes with the intention of making contact (Kelly et al., 2019). Historically, gamete donation was anonymous, and parents were discouraged from disclosing donation details to their children (Crawshaw & Marshall, 2008). However, the frustrations of donor-conceived people (DCP) unable to access their genetic information, and research suggesting a link between genetic knowledge and healthy identity development (Allan, 2017; Bracewell-Milnes et al., 2016; Pasch, 2018), have resulted in legislative change and a shift to openness in several jurisdictions, including New Zealand. Even in anonymous donation jurisdictions, with the growing access to direct-to-consumer DNA testing (Darroch & Smith, 2021),

people connected through donor conception are more readily able to become aware of genetic relatedness and identify and sometimes contact each other, potentially at earlier ages than allowed for in many legislated contexts (Gilman et al., 2024).

In New Zealand, the Human Assisted Reproductive Technology (HART) Act 2004 specifies the right of individuals conceived through donor treatment to access identifying information about the donor when they turn 18. The Act established a mandatory register for donations made at a fertility clinic on or after 22 August 2005 to enable offspring to access information about their origins (Te Kāwanatanga o Aotearoa/New Zealand Government, 2022). The New Zealand Department of Internal Affairs Births, Deaths and Marriages division (BDM) has the responsibility for establishing and maintaining the register, with fertility clinics providing the required information to BDM for each child born through donor conception. The register includes the DCP's name, sex, and date and place

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of birth; their parents' names and addresses; and the donor's name, address, and date and place of birth. Fertility clinics hold information additional to what is on the register, recording the donor's height, eye and hair colour, ethnicity, and relevant cultural affiliation (including for Māori), reasons for donating and significant medical history (Te Kāwanatanga o Aotearoa/New Zealand Government, 2022).

It is important to note, however, that while disclosure is encouraged (Fertility Associates, 2022) this is not required by law, and donor information is not recorded on birth certificates. Furthermore, the legislation does not apply to DCP conceived outside of fertility clinics in New Zealand, for example through private arrangements such as home insemination, or for donations made in other countries. While DCP born, and donors who donated, before 22 August 2005 (when identity-release provisions came into effect) can record details they wish to make available on the register on a voluntary basis, this has had minimal uptake (Te Tari Taiwhenua/Department of Internal Affairs, 2022). By February 2022, 3,003 people were recorded on the HART register as born from donor conception, with 2,974 mandatory recordings, and 29 voluntarily recorded (Te Tari Taiwhenua/Department of Internal Affairs, 2022). The first DCP born under the HART Act provisions turned 18 in late 2023. Assuming they have been made aware of their donor conception, they will be able to exercise their legal right to access the identifying information recorded about the donor on the register by submitting an application to BDM, as well as contact the clinic directly for further information held by them. Parents and guardians of DCP can also apply on behalf of the DCP if they are under 18 years old, and DCP can apply for information about any siblings born from the same donor, with identifying information provided only if consent from these siblings has been obtained. Donors may also apply for information, such as whether any donor offspring have been born and the sex of the DCP but can access further information only if consent to disclosure is held by BDM. Those DCP born prior to 2005 can apply to BDM for a print-out of voluntarily recorded information, but only if consent has been given by the donor. When identifying information is released concerning either the donor or a DCP, the other party will be advised where possible and records are up to date. Parties can then apply to access information about their donor/offspring/siblings who share the same donor from BDM or the fertility clinic and thus make contact/link with

each other. BDM's role is thus currently set up as an information provision service.

While BDM 'strongly recommends' counselling either from fertility clinic or independent counsellors to help consider the implications of accessing information and of linking (Te Kāwanatanga o Aotearoa/New Zealand Government, 2022), the person seeking information needs to arrange the counselling and is responsible for any cost incurred. Clinics will typically suggest counselling through the clinic counsellors when an approach is made to them for information, although they currently have no legal obligation to provide donor linking counselling. Clinics must adhere to the HART Act, and the principles of the Act include that the health and wellbeing of children born as a result of an assisted reproductive procedure should be an important consideration, and that the health, safety and dignity of present and *future* generations should be preserved and promoted. How this is to be operationalised in the context of the donor-linking process and with reference to the future needs of DCP has yet to be established.

Interestingly, some form of donor linking is possible in New Zealand from the outset in that donors and recipients may ask to meet each other prior to donation and use this opportunity to discuss disclosure intention and expectations around information sharing and contact (Goedeke et al., 2023). Joint meetings facilitated by clinic counsellors between embryo donors and recipients are mandatory under the Act (Advisory Committee on Assisted Reproductive Technology (ACART), 2021); for gamete donors this is on request although this practice is more common in egg rather than sperm donation (Goedeke et al., 2023). Such meetings may set the scene for ongoing contact between donor and recipient families, and while there is limited data about this contact, there is a call for access to counselling for donor and recipient families on an ongoing basis as they negotiate relationships with each other (Goedeke et al., 2023).

While the number of people engaging in donor-linking internationally is hard to gauge, an increasing number of jurisdictions embracing open-identity legislation together with the rise in informal linking even in anonymous contexts (Hamilton et al., 2021) suggests that linking is becoming more prevalent (Kelly et al., 2019). International research on experiences of searching for and contact between parties varies, and while there is evidence of positive experiences (Blyth et al., 2017; Daniels et al., 2012; Hertz et al., 2015; Jadva et al., 2011), disclosure, the release of identifying information, and the process of connecting can have

wide-reaching and emotionally challenging effects for DCP, donors, parents, and their wider families (Rodino et al., 2015). DCP may experience distress from learning about their origins in unplanned ways, disclosure may affect relationships with families, and disappointment may arise where contact between the parties is not possible or does not unfold as expected (Blyth et al., 2020; Daniels, 2020; Trail & Goedeke, 2022). Several authors have suggested that counselling is necessary for preparing people for accessing information and linking (Indekeu et al., 2022, 2023; Rodino et al., 2015). While the Australian and New Zealand Infertility Counsellors' Association (ANZICA) has published guidelines for donor linking, these were published in 2012 and it is unclear to what extent these have informed practice in New Zealand or are relevant to the current context (the guidelines are currently under review). With the prospect of increased linking in New Zealand from late 2023 given the HART Act provisions, this study aims to explore the views and experiences of fertility counsellors with respect to service provisions and their roles, and to highlight concerns or needs they may anticipate as linking increases. Given the trend towards identity-release donation in many jurisdictions, and the increased likelihood of contact even in anonymous contexts, such research may be a relevant and timely addition to international work on donor-linking practice and policy.

## Method

Seven fertility clinic counsellors from across New Zealand were interviewed between March and July 2023, either face-to-face or online. Participants ranged in age from their 30s to 60s, and mainly identified as European New Zealanders. While the number of counsellors participating was small, it represents the majority of clinic-based counsellors in this country. There are only 3 fertility service providers (7 clinics) in New Zealand and at the time of the study there were nine counsellors employed by the clinics, all employed on a part time basis, and not all of whom had had donor linking experience. More specific demographic information is not provided given counsellors' potential identifiability, and all names provided are pseudonyms. Counsellors were interviewed by the second author using a semi-structured interview format as to their experiences of providing donor-linking services, any concerns they might have, and anticipated future service provision needs. Data from the interviews were transcribed and analysed using Braun and Clarke

(2006) well-established six step method of data analysis: data familiarisation, assigning of preliminary codes, search for patterns across interviews, revision of themes, definition and naming of themes, and finally, producing a report. Ethical approval was obtained from AUT Ethics Committee – AUTEK (approval number 22/103).

## Results

We identified five common themes across interviews. (1) Counsellors perceived fertility service providers, and themselves, to have a duty of care to provide donor linking services and while they were unclear as to the extent and scope of this duty of care, they expressed concern about how this would be met; (2) they perceived their roles in relation to donor linking as multifaceted, including facilitation, mediation, advocacy, relationship counselling and therapy; (3) they highlighted a range of challenges related to resources (staffing, professional development, funding, time and prioritisation) in addition to (4), a perceived lack of adequate legislative provisions to support donor-linking, and (5), suggested a way forward in terms of access to comprehensive, funded donor-linking services which would facilitate patient choice, staffed by professionally trained and supported staff.

### *Duty of care obligations and questions*

Counsellors regarded access to knowledge about genetic information as a right for DCP as reinforced through its legal recognition through the HART Act. For example, Harriet said that *'It is that recognition that it's about somebody's identity, and that was obviously enshrined in legal change... that people have access to their genetic identity, their lineage.'*

Counsellors believed that fertility service providers/clinics had an obligation to ensure that linking services were offered given they had facilitated donor conception as a treatment. For example, Rose commented that, *'There is a moral and ethical duty to do it'* and Anna that, *'The clinic has a duty of care to their clients, and as we know, it's really important for donor conceived people to have information about their donor.'* For Anna, this meant providing access to professional support, saying that *'I think it would be irresponsible to not provide those services, and to not have people who have experience talking to people about the implications and considerations and to support them.'*

Counsellors also felt that they had a clear duty of care, especially to DCP, as is captured by Emma, who said, *'I feel*

*like we've got a responsibility in some ways... a duty to provide something... I've got a really strong desire to hold information for children and young people.'* and Grace, *'Everything that we do, we have the best interest of future children at the forefront and centre about decision making.'*

However, counsellors also saw their duty as extending to include all the parties affected by donor conception: DCP, donors, parents, siblings, and wider families. Balancing the at times conflicting needs of these different parties was perceived to be challenging, with one counsellor, Jane, suggesting that there needed to be clearer policy guidance around the rights of each party as determined by government: *'All we can do is try to action their (the various parties) requests... (for information disclosure). That needs to be decided on a ministerial level around whose rights trump whose.'*

However, counsellors also had questions as to whether this perceived duty of care to the parties affected by donor conception should or could rest only with the clinic and as to who should be responsible for its provision. For example, Jane said, *'I don't think it's only the clinic's responsibility, and I don't think it's only the parents, and I don't necessarily know if it's the government's either. I don't know to be honest!'*

They also had questions as to the duration of the perceived duty of care, with Anna reflecting:

What are the reasonable boundaries around duty of care? People are often discharged within the first trimester of the pregnancy... to continue on with their lives. Is a clinic responsible for the welfare of everyone who passes through a clinic indefinitely? Or just for a set point in time?

Questions were also raised about the extent of this care, especially in relation to individuals affected by donor conception prior to the Act, where linking may entail a significant amount of searching on behalf of the DCP. Sam asked:

The question was, and is, how far do you look? How do you look for people when you've just got a name, and you're trying to make contact? What's considered a decent look? Is trying to do a social media, electoral role, and then a (health) number search enough?

Counsellors voiced concerns about DCP outside the parameters of clinic care and legislative provision and how they would be able to access information and donor linking. For example, Sam commented, *'There are those people who are conceived from international donations and purposeful home insemination arrangements where contact might be lost. It's a particular*

*group of people who may not be able to access any information at all...'*

In line with this, there was concern that adequate provisions for linking were not available in New Zealand, as Harriet reflects below:

That's something that hasn't really been properly addressed yet... The Department [of Internal Affairs] ... say, 'We're a registry. We hold information. We're not the people who will be facilitating the passing on of information or the flow-on effects.' There needs to be a counselling or support process within that.

Furthermore, concern was expressed about the increasing need for services as DCP reach the age at which they can access information, and as donor conception services expand, even if the increase was expected to be gradual. Grace highlights her concern about counsellors/clinics being in a position to meet the demand, saying that:

(Donor-linking counselling) has ramped up quite significantly in the last 6 months... and that is only going to increase over time. I think we're already at a point where it feels like we're heading for crisis, and I don't see a plan in place on how we're going to manage that.

### ***Navigating roles in donor-linking: Facilitators, mediators, advocates, relationship counsellors and therapists***

Counsellors framed donor-linking as encompassing a range of roles – advocacy, facilitation, mediation, relationship counselling and therapeutic intervention – in what was often seen to be a challenging field of service delivery with few specific frameworks to guide them. Sam speaks of how the work involves advocacy, speaking of the rights of DCP to access information and have contact if desired, reflecting that, *'I see myself, in terms of donor linking, as a facilitator and an advocate for donor-conceived children... I hold the place, I'm an advocate for their child or donor-conceived children.'*

The work was also held to involve listening to concerns, providing psychoeducation, and bringing the implications of linking to the fore in preparation for linking. For example, Anna spoke of how in the donor linking process:

Sometimes it's just to hear some of their (the DCP) concerns or wonderings, so (providing) some information, talking them through the process, the legislation around the time that they might have been conceived ... what the context is now, what information they might be privy to or not, what pathways they might undertake to do some linking.

So, it's that (sharing of) information, support, being there to listen as they're going through it.... get(ting) them to consider different possibilities.

The role was also presented as entailing being information-holders and providers, facilitating the exchange of information between the parties. Emma reflects that:

I describe (my role) as a post box. We (counsellors) sit in the middle and hold the identifying information for each of the people off to the side... I've noticed that most people sometimes just want to ask a question, like, 'Hey, I'm wondering if they (donor) had an interest in this (e.g. hobby)? My kid (DCP) seems to have a really big interest in this' or, 'Where were you from in this particular country?' Lots of different kinds of little questions that are meaningful to recipient parents.

Emma explains this role in information exchange between the parties as, *'facilitating contact or mediating between people. When you're acting in that post-box (role), you're having a conversation here and a conversation there... you're exchanging information.'* Sam elaborates that facilitation is also involved in setting up the linking, *'Trying to explain to both parties what each want, and create an environment where if they agree, and they feel comfortable, you (can) create a physical environment (for them) to come into.'*

Maintaining oversight over the linking process and retaining awareness of what information had been shared was often challenging for counsellors due to the complexity of managing links across various parties. Sam explained that she used a spreadsheet to keep track of what parties were involved, what had been shared with each and what type of linking had occurred. She commented:

We run the spreadsheet, which is getting quite complicated, of how linking looks: the number of families per donor, and if they are linked to the donor, or if they're linked to one another, and what that looks like. You look how many other families are there and have any of them been linked in?

Where the various parties were involved in meeting face-to-face, counsellors saw their roles as also potentially extending into relationship counselling, with Sam reflecting that *'There is an element of managing relationships that's really integral to the process'* and Emma that her role with the different parties involves *'balancing people's needs, expectations, and the need for privacy.'*

Counsellors also positioned themselves as containing emotion within and after sessions, helping the various parties involved to *'debrief'* (Sam) especially where expectations and reality might be different. At

times, their role extended into providing therapeutic intervention. Harriet, for example, spoke of the range of areas where this might occur:

Sometimes people are not receiving great news around the ease of access to information – they may learn that the donor has died, and they're not going to have any way of ever meeting the donor. There's working with people around that loss. Or they may be declined ... and feeling quite rejected.

The difficulty of managing these roles was acknowledged. Anna commented that the role is, *'a bit of everything'* and that it's *'very evolved and evolving'*; Sam that the role required *'great sensitivity, diplomacy and care,'* and Grace that linking was *'challenging and emotionally rife.'* She elaborated:

It often feels like we're holding so many parties at the same time, and different emotional responses and different motivations and different places. I think that creates this really challenging dynamic when you're sitting in the middle of feeling quite daunted yourself as to how this is all going to unfold...

This required counsellors to be *'prepared for the unexpected and treading carefully'* (Jane).

In the context of multiple and challenging roles, counsellors referred to guidelines developed by clinics or professional bodies; however, they were clear that there was no 'one manual' that guided their practice. Furthermore, existing guidelines were often referenced as out-of-date, or not sufficiently capturing the complexity of donor-linking practices, as is captured by Rose, who comments, *'There are policy protocols that have been set up. Vague, but they are (there), (they) do exist'*; Harriet, *'We have a donor linking policy and procedures that are documented. But they're constantly being updated, I guess, as new things come to light'*; Anna, *'We don't have any models. The policy is really the only sort of the guiding document and it's an evolving document'*, and finally Sam, who says:

There is no manual. It's always been a bit of a joke – you think that you have imagined all kinds of possible scenarios, and then someone will come with something, and you're like, 'what?' Okay, now I have to think about that!

### **Challenges of resourcing: staffing, professional development, funding, time and prioritisation**

Counsellors expressed a significant range of concerns around the provision of donor linking services to do with resourcing challenges. This included a concern around access to funding for services and who would

provide this funding. For example, Sam commented that:

(There is) anxiety around what might this [donor-linking support] look like? How is it going to be resourced? ... If you're a provider, and you've had a really big programme over a long period of time, you're now thinking about all the potential families that might come back to you for linking.

Some counsellors drew parallels to adoption services, which are government funded, but also reflected on the differences as adoption services are publicly funded services from the outset, whereas fertility services may involve a mix of privately and publicly funded services. Sam elaborated that adoption services are, *'Paid for by the government, it's part of the Oranga Tamariki (Ministry for Children) business thing. (For) clinics, it's a little bit different because we've got a mix of public and private.'*

Some felt that since the legislation was introduced by government, services should, at least in part, be funded at this level. Anna said, *'I would like to see it done by both clinics who have been involved in these arrangements, but also something more centralized as well, like the HART register is funded by the government.'*

Counsellors also expressed concern about funding for staffing, reflecting on the limited number of counsellors employed in clinics and the likely challenges involved in extending their services to provide donor-linking, especially given the part-time nature of many counselling positions, as is reflected by Anna, *'There's just not enough (fertility counsellors) at the moment. So, the main issues that come to mind, at least initially, are just manpower, woman power, counsellor power! You know, having enough trained people to support that linking'*; Harriet, *'All of our counsellors are part time... and have a clinical role with patients going through fertility treatment'* and Rose, *'We simply won't be able to absorb the work with the hours that we've got. It will become untenable.'*

Furthermore, counsellors reflected on the perceived lack of suitably trained staff, and access to funded professional development to ensure safe service delivery. Grace reflected that:

It's probably the part of the role where I feel less comfortable, and I think that is because I don't have a background in this area. I don't feel like I have training and I am learning on the job.... The onus currently falls on the individual to upskill and find their own professional development. The issue I see is a workforce not equipped currently to provide that service and that there are very few counsellors trained in this area.

Counsellors were concerned not only about a lack of funding for donor linking services in general and for suitably trained and qualified staff, but also expressed concerns about the time demands of donor-linking counselling with respect to their existing workloads. For example, Jane commented that, *'(Donor-linking) is very time consuming, and that's not really taken into account in terms of our (workload)'* and Grace that, *'There's a strain on resources now. Even in its current capacity, it is stretched and that is only going to increase over time.'*

Given that other services they provided were often perceived to be more time pressured, for example, in terms of meeting immediate support needs of clinical patients, counsellors spoke of difficulty in prioritising donor-linking. Rose commented that, *'Unfortunately, it [donor-linking] doesn't take priority, because I've got people in front of me that are doing ongoing [fertility] treatment. This work is always either squeezed in or unfortunately isn't priority.'*

Where counsellors did prioritise donor-linking, this came at a personal cost, such as working overtime, as is illustrated in Anna's comment below:

Anna: I see it is an important and significant part of what I do as a counsellor, but I wouldn't say it's the biggest thing that I do. It's such an emotionally charged thing that it has to be prioritized.... Even if it means coming in a little bit early or leaving a little bit late to make sure that next step happens, that it doesn't drag on forever.

### Challenges related to legal provisions

In addition to resourcing challenges, counsellors spoke of a frustration about the lack of legal provisions and the inequitable access to information for different groups of donor-conceived individuals e.g. those whose parents had accessed cross border fertility care, had undertaken private home insemination, or had conceived prior to the HART Act provisions. Emma commented that:

I've always had a bit of a bugbear about the (people accessing) international fertility treatment because they're a different cohort altogether. There's no space for them on the register. There's no information kept on those guys, for those children, unless it's at the clinic at the other end. The insemination in the community is the same. I'd love for there to be some way of capturing that [donor] information.

Anna commented that:

You've got people who were conceived back before the HART act. So, the current [donor linking] situation is quite interesting, because you're supporting people

for linking in two very different systems. And the HART register, depending on whether it's voluntary or mandatory, are very different beasts.

Secondly, they spoke of their frustration around New Zealand legal frameworks which cite access to genetic information as a principle but fail to put in place mechanisms that make it more likely that disclosure occurs (such as birth certificate annotation recording that the person is donor conceived). Anna reflected that:

There's no mechanism to ensure a person is advised about their conception. You wouldn't know to go to the HART register to try and find out information about your donor if you didn't know that there was a donor; you don't know what you don't know. It makes it challenging if you're contacted by someone wanting to link with, for example, genetic half siblings conceived through the same donor, because you don't know who's been told, who hasn't been told.

This situation raised significant dilemmas for counsellors around privacy and rights. For example, Harriet reflected on the difficulty of reaching out to the various parties affected by donor conception with information held by counsellors, saying that:

There's a question around if we can't contact the patients themselves, the recipients and parents. Is it okay, if those donor conceived people are over 18, to try and contact them directly when they (the DCP) possibly may not know they're donor conceived, but they need this medical information? There are questions around privacy law.

Furthermore, the lack of centralised record-keeping across clinics, such as recording donors, presented challenges, as Grace reflects below:

The impact of the serial donors, the fact that we have no central register for donation in New Zealand, and so that potentially they may be donating at all the clinics, as well as donating outside of the clinics, and the ability for DCP in the future to be able to access adequate information and support from some of these known [but unregulated] donations that happen.

### ***A way forward: a funded wraparound service***

Counsellors advocated for a funded, government-supported service that could offer comprehensive donor-linking services, as illustrated by Emma, *'There needs to be some provision in the law for an actual process... For people to come and receive counselling'* and Harriet, *'I would like to see something where people don't feel that there will be a huge cost around making the inquiry (about information held and linking) and*

*being well supported through that inquiry. There shouldn't be a financial barrier to accessing support.'*

Such a service was envisaged to include staff to manage the administrative tasks of searching for information and appropriate record-keeping, with Sam commenting that *'Searching for people is probably not the best use of counsellors' skills; that could be someone else in an organization doing that.'*

Having staff manage practical tasks was seen as way to free up counsellors' time to focus on counselling and as an effective use of their skill base, as is evident in Anna's quote below:

If you had an administrative team who did the very straightforward path and then you had the counsellors that were involved at points where their skill sets would be useful, like if they [donor parties] were going to meet, conversations around the implications and the pathways.

Counsellors hoped for a service that emphasised the value of counselling and made such services possible, while not being prescriptive. Harriet suggested that, *'There needs to be a counselling process or support process. I don't know that it should be mandatory, but I think it should be mandatory to offer it and have it available.'*

A centralised and funded service would ideally also make provision for professional development for counsellors. For example, Anna suggested *'some form of a postgraduate course'*, Jane, *'formalised training'* and Grace, *'a certification' in order to 'say I feel equipped.'* Counsellors also called for *'peer support'* (Sam) and the opportunity to be able *'to talk about those things, in a confidential way with other people.'* (Harriet)

Counsellors were somewhat divided in terms of the service location, with some suggesting an external rather than clinic-based system, and others advocating for client choice, as is reflected by Sam, who commented that, *'Sometimes clinics are the best people to do it... particularly when linking is happening between donors and across families... because we're often still in contact with those families'* as well as Harriet and Emma below:

Harriet: Having choices is really important for people. I really think we need to hear (DCP) when they say that they don't feel that the clinics are the right places, and the clinic counsellors are not the right people to be offering that service further down the track, that there needs to be a sense of independence.

Emma: It would be really nice to have a centralized, independent, specialist-based place.

Nonetheless, government support, including for funding, was deemed essential, as was the introduction of legal provisions to facilitate linking. This could include birth certificate annotation, which would make it more likely

that DCP would become aware of their donor conception, and legal provisions spanning the range of donor conception trajectories, including cross border reproductive care and private arrangements. Grace said, *'I think it would be wonderful, being that there is a legislative framework around this, that the government would respond by setting adequate supports and systems in place.'* Finally, education provision for people affected by donor conception was seen as important in setting the scene for services. Anna commented that, *'Providing more resources – webinars, workshops, or books tailored to the New Zealand environment would be fabulous.'*

## Discussion

Our study, similar to that of Rodino et al. (2015), suggests that counsellors believe that providers and legislators have a duty of care to provide donor-linking services. However, both Australian and international research to date suggest somewhat inconsistent approaches to donor-linking (Adams & Lorbach, 2012; Crawshaw et al., 2015; Indekeu et al., 2023; Kelly et al., 2019) where responses to requests for information vary widely from refusals or release of basic information only, through to more open services that include counselling and facilitation. In Australia, Kelly et al. (2019) found that few Australian clinics have any kind of formal donor-linking policy, that highly discretionary decision-making remained largely at the level of the individual practitioner, and that there appeared to be an inconsistency and reluctance in service provision. While the participants in our study felt that clinics were supportive of linking and recognised its value and their role, they also indicated that resourcing and access to sufficient and dedicated staff time and professional development were of concern and affected their ability to give priority to donor linking services.

Participants clearly perceived their professional role in donor-linking to encompass psychoeducation, facilitation, advocacy, mediation, relationship counselling, and at times, therapeutic intervention. The latter sits in contrast to Rodino et al. (2015) work where counsellors viewed themselves as mediators or intermediaries rather than as therapeutic counsellors. However, while participants in this study regarded their role as more all-encompassing, as in Rodino et al.'s study much of their learning was based on their own clinical experiences although participants generally seemed to feel anxious about and ill-prepared for donor linking. For example, participants perceived that there were insufficient structures to inform their work despite having access to ANZICA's 2012 donor-linking

guidelines (ANZICA registration being a requirement for counsellors employed within New Zealand clinics). Partly participants' anxiety might be related to the relative recency, and for some, a lack of experience of donor linking work, but guidelines were also not seen to be addressing the complexity of the field and were potentially out-of-date (Note that ANZICA guidelines are currently being revised). Participants also pointed to a perceived lack of professional development and resourcing to equip them to work in donor linking service provision, and indeed, Indekeu et al. (2023) have highlighted that donor linking counselling skills are distinct from the skills needed to work with people at the start of their fertility journeys or donation – they suggest donor linking is a new specialisation in the area of donor conception. These issues are of concern especially given the limited number of clinic counsellors in New Zealand and that most of the counsellors are not employed full-time. This increases the risk those affected by donor conception requiring support/donor linking may not be able to access it, particularly given that referral to professional psychosocial care outside of fertility clinic services, as in Indekeu et al., 2023 study in the Netherlands, may not be possible given the lack of knowledge about donor conception issues in general healthcare. Furthermore, the risk of staff burnout in the context of staff shortages and resourcing challenges is very real, and participants clearly feel compromised by their inability to provide the level of support they feel ethically bound to offer.

One of the ways in which participants perceived their needs and those of people seeking donor linking could be addressed was through the setting up of a specialised donor-linking service. Crawshaw and Marshall (2008) indicate the need for a responsive, flexible 'helping' service available for each stage of the process, and one in which the skills mix of the workforce includes good quality administration staff; professionals experienced in search and contact work; and trained and experienced counselling staff to help manage the impact of the contact process. Kelly et al. (2019) and Rodino et al. (2015) suggest that a potential solution may lie in transferring responsibility from clinics to an outside, specialist-based intermediary service dedicated to providing all parties with ongoing support in information release, linking and the consequences of contact. In Victoria Australia, the Victorian Assisted Reproductive Treatment Authority (VARTA), is a statutory authority which not only regulates fertility treatment provision, but also manages both central and voluntary registers, and supports people involved in donor conception with linking services, including facilitating the

exchange of information, correspondence and contact between consenting parties. VARTA 'paused' their counselling services in 2023, but state that their board has recently approved a new psychosocial counselling model (Victorian Assisted Reproductive Treatment Authority (VARTA), 2023). The extent to which this will provide support to those related through donor conception on an ongoing basis is unclear.

Similarly, in the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA), a statutory body responsible for maintaining the register, has provided limited support to individuals seeking information about a donor or siblings, and intermediary services to facilitate contact between identifiable donors and DCP or siblings. As in New Zealand, 2023 was also a landmark year for donation in the United Kingdom with the first DCP born since legislation came into effect turning 18. The HFEA has provided two free sessions for each party seeking information, and one free session facilitating face-to-face contact if desired (Human Fertilisation and Embryology Authority (HFEA), 2023). However, due to financial pressures, these arrangements are in place until September 2024 only, and while the HFEA will continue to provide information, funding for a commissioned support service will end (Human Fertilisation and Embryology Authority (HFEA), 2024).

There are also three state-funded services internationally that use DNA tests to facilitate contact between DCP and donors particularly for those born/donating prior to identity release provisions: UK DonorLink (which became Donor-Conceived Register DCR in 2013); the Dutch Fiom KID-DNA database established in 2010, and the recently set up Belgian Vlaams Afstammingscentrum in 2021 (Indekeu et al., 2023). While these provide information and support to people genetically related as a result of donor conception, challenges have also been identified, such as financial constraints limiting the number of staff and a lack of ability to provide post-meeting ongoing support for Fiom (Indekeu et al., 2023) and uncertainty of funding streams for DCR (Crawshaw et al., 2016). Nonetheless, these various services may offer examples of what could be established in New Zealand.

The participants in our study however, had mixed feelings about setting up an external agency, with some suggesting that clinic-based support may be preferred, at least by some parties, and especially where contact with the counsellors had been maintained longer-term. This raises the prospect of having a system of centralised funding and professional support, but with the flexibility for service delivery in a

range of settings. This may also allow recognition that DCP, donors, and parents are a diverse group who may require different psychosocial support at varying times and possibly from different sources (Indekeu et al., 2021, 2022). For example, diversity may stem from parents accessing treatment overseas or through informal means where national limits for offspring per donor may not be respected or identifying information is not recorded, leading to additional complexity in searching for and linking. People discovering donor conception through DNA testing may experience significant psychosocial challenges which need to be addressed (Grethel et al., 2023). Further, given that DNA testing may make individuals connected through genetic relatedness aware of their donor conception and opens the possibility of connection with a far wider web of genetic relatives and at possibly earlier ages than has typically been the case (Gilman et al., 2024), it is imperative that the needs of these groups are recognised and accommodated.

One way in which to achieve this could be through legislative support, as also called for by the participants in our study. Legislative support could address issues around access to information about donor conception (e.g. considering mechanisms such as birth certificate information; establishing registers for all donors), the rights of the various parties (including where donor conception occurred outside of New Zealand and/or through private arrangements), and the responsibility for follow up (clinic-based, and/or governmental responsibility). These issues have been highlighted previously as of potential importance in supporting the longer-term wellbeing of all those affected by family-building through donor conception (Blyth et al., 2020; ESHRE Working Group et al., 2022; Goedeke et al., 2016) and clearly require attention.

In November 2022, a group of concerned researchers and practitioners brought together a group of key stakeholders: academics; fertility clinic counselling, medical and social work staff; the Department of Internal Affairs; the Ministry for Children; the Advisory Committee for Assisted Reproductive Technologies (ACART); the Ethics Committee for Assisted Reproductive Technologies (ECART); the consumer organisations FertilityNZ and Donor Conceived Aotearoa, and donor conceived people and their families. In a two-day meeting stakeholders aimed to address practice and research needs around donor conception in New Zealand. There was strong support for a public awareness campaign highlighting legislative provisions and the application process, and establishing systems to ensure that adequate support mechanisms

are in place to support those seeking information and linking. This present study underscores the need for such provisions from the perspective of counsellors. Following on from the meeting, there have been efforts from some clinics to pre-emptively reach out to parents whose DCP will be coming of age soon to explain processes and services available, and the donor linking guidelines are currently being revised. Nonetheless, more work remains to be done.

### Limitations

Our study had some limitations, including the small number of participants, and from only one country. However, the 7 counsellors represented the majority of counsellors employed in clinics at the time, with only two counsellors not participating. Donor conception in New Zealand operates within a legislative framework that encourages access to information, requires donors to record identifying information, and may provide the opportunity on request for donors and recipients to meet prior to donation, potentially making the prospect of donor-linking more likely. However, the findings of this study are relevant not only in New Zealand and identity-release donation jurisdictions, but also in other contexts given that donor anonymity is increasingly becoming impossible, and that informal donor-linking is increasing.

### Conclusion

Psychosocial support for people engaged in donor-linking is in its early stages, and there is need to consider the best way in which to provide appropriate and effective support to guide future service provision (Indekeu et al., 2021; Rodino et al., 2015). This is particularly important at the current time in New Zealand given that the first DCP born under the HART Act provisions are now able to request access to identifying information about their donors, and there are few mechanisms in place to support them, their families, siblings, and donors. Fertility service providers have a duty of care to call for clear legislative provision and provide support around donor conception practices. Comprehensive, appropriately resourced services facilitating information-exchange and access to supportive counselling from a choice of service providers are needed to help all the parties affected by donor conception: donor-conceived persons, parents, donors, and their families, manage the implications of this form of family-building.

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The authors report there are no competing interests to declare.

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### Data availability statement

The data that support the findings of this study are available on request from the corresponding author, SG. The data are not publicly available due to containing information that could compromise the privacy of research participants.

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