Submission to the Department of Children and Youth Affairs

A Commentary on the proposed

Adoption (Information and Tracing) Bill 2016

in relation to the use of DNA testing by Adoptees and Birth Parents searching for each other

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1. Key Points

- 1. DNA testing is here to stay. It has become an integral part of researching family history.
- 2. There are currently over **7 million** people worldwide in the databases of the major DNA testing companies.
- 3. This number is growing exponentially and is predicted to hit **25 million** by the year 2020.
- 4. This exponential growth has largely **abolished anonymity**, in particular for sperm donors and birth parents.
- 5. The "right to anonymity" is not absolute and must be clearly distinguished from the "right to privacy", which is also not absolute.
- 6. Many Irish people are reconnecting with relatives via DNA.
- 7. The adoptee component of the worldwide "genetic genealogy" community is disproportionately large and increasing.
- 8. Success rates for adoptees finding immediate birth family via DNA currently vary from **21%** (non-US) to **52%** (US). These numbers will increase as the databases grow.
- 9. There is a considerable amount of **help and support** available for adoptees from the genetic genealogy community (via Facebook groups, Forums, websites, etc)
- 10. **DNA testing is the only avenue of investigation** for those people who were illegally adopted or whose birth information is grossly inaccurate or non-existent.
- 11. DNA testing should be a **routine part** of the Agency's tracing service.
- 12. The **cost** of DNA testing should be borne by the Agency.
- 13. **Professional genetic genealogists** should be an important part of the Agency's tracing service team.
- 14. There is an urgent need for **education**, **training and support** for adoptees to help them contact and (if desired) develop a relationship with immediate birth family via DNA testing (including birth parents, full & half-siblings & close cousins)
- 15. The government's dilemma always has been (and still is) to **balance the rights and responsibilities** of adopted people and the rights and responsibilities of their birth parents. There is no need for genetic genealogists to take sides in this debate, other than to point out that the solution must acknowledge the DNA revolution, and any proposed solution that does not acknowledge the DNA revolution will be doomed to immediate failure.
- 16. The genetic genealogy community has the knowledge base and skills to assist in the process, and we are **ready and willing to help the Minister** in any way we can.

2. Growth of the DNA Databases

- 1. DNA testing has been used as a tool to augment family history research since about 2003, and an entire genetic genealogy community has evolved since that time. Technical progress in recent years has made DNA analysis increasingly affordable. The AncestryDNA database alone announced its **four-millionth** member on 27 April 2017.² Altogether, the main DNA-testing companies³ have over 7 million people in their databases.⁴
- 2. These databases are **growing exponentially** as the popularity of recreational DNA testing increases and by 2020 there are likely to be **25 million** people in these worldwide databases. This will make searching for relatives considerably easier.⁵
- 3. These databases include many people born or resident in Ireland and many more deemed to have Irish ethnicity. As a result, many people are connecting with Irish relatives and identifying their Irish ancestors. This applies both to the 6 million "Local Irish" and the 80 million "Diaspora Irish".
- 4. Several leading Irish politicians have had their DNA tested and are in the DNA databases, including the former Taoiseach, Enda Kenny, and the Minister for Community & Rural Affairs, Michael Ring.⁶
- 5. It is becoming commonplace in Irish documentaries to include DNA testing and discussion of the results as part of the programme "Creedon's Epic East", "John Connors: The Travellers", "Adoption Stories", etc. Some from our Irish genetic genealogy community have been called upon to assist in the analysis of the data for presentation. The public are becoming more aware of such testing and how it can enlighten one's family history and heritage. It is a natural progression for adoptees to consider DNA testing to aid them in their search for their birth family.

² https://blogs.ancestry.com/ancestry/2017/04/27/ancestrydna-reaches-4-million-customers-in-dna-database/

³ AncestryDNA, 23andMe, FamilyTreeDNA, MyHeritage, LivingDNA

⁴ ISOGG wiki - https://isogg.org/wiki/Autosomal_DNA_testing_comparison_chart

⁵ *The History of Genetic Genealogy and Unknown Parentage Research*, by CeCe Moore. Journal of Genetic Genealogy 8(1):35-37, 2016

 $^{{}^{6}\;\}underline{\text{http://voices.nationalgeographic.com/2013/11/21/the-genographic-project-returns-to-ireland-to-reveal-dnaresults/}$

3. DNA and Adoptees

- 6. The commercial DNA databases are of particular value to those who do not know much about their biological ancestry due to adoption, abandonment, infidelity, sperm or egg donation and similar situations. In fact, a disproportionate number of those resorting to DNA to trace their family history are adoptees. In cases where the adoptee was a foundling or where false names were used at the time of the adoption, DNA information is the only information available to the adoptee in his or her search for birth family.
- 7. The following statistics emphasise the growth of the adoptee component of the genetic genealogy community and their rate of success in tracing birth family:
 - As of 12 June 2017, there were 50,361 members in the DNA Detectives Facebook group, which describes itself as a "genetic genealogy group focused on using DNA to find biological family for adoptees, foundlings, donor-conceived individuals, unknown paternity and all other types of unknown parentage cases recent and more distant". The group is full of stories of successful reunions of birth parents and children, separated by adoption or other circumstances and re-united by DNA testing.
 - A recent worldwide survey^{7,8,9} of over **1200 adoptees** (see Appendix 1) who had undertaken DNA testing reported the following:
 - o 86% were adopted from the US (14% outside of the US)
 - 52% of US adoptees had found a sibling or parent
 - 21% of non-US adoptees had found a sibling or parent
 - 74% were still actively searching for biological family
 - o 61% did not receive assistance from a "search angel"
 - o their closest match when they first got their results was:
 - a parent 2%
 - a sibling 6%
 - a 1st cousin 19%
 - a 2nd cousin 34%

⁷ These results are from March 2017 and were personally supplied in a powerpoint slideset by Blaine Bettinger.

⁸ Preliminary results from October 2016 (based on 575 respondents) are broadly similar and can be found in Appendix 1 and here ...

https://www.facebook.com/groups/DNADetectives/permalink/1200136676724114/?match=YWRvcHRlZSB0ZXN0aW5nIDIwMTY%3D

 $^{^{9}}$ Preliminary results from January 2017 (based on 700 respondents) are broadly similar and can be found here ...

http://thegeneticgenealogist.com/2017/01/08/adoptee-testing-a-study/

- 8. Thus there is a considerable amount of support for adoptees from the genetic genealogy community and the success rate for finding birth family is high and increasing. ^{10,11}
- 9. DNA testing will reveal any close DNA matches who are already in the database. Potentially, these matches may include either or both birth parents of the adoptee. Other close DNA matches may include full or half siblings, uncles, aunts, grandparents or close (first or second) cousins. There are more people joining these databases all the time and each new member will have their DNA results compared to everyone already there. Thus additional close matches will emerge over time and in many cases all the adoptee will need to do is to sit and wait for a close match that helps him/her connect with birth family. 12
- 10. Analysis of current matches may identify small groups of related individuals that include the adoptee. If the connection of any two members of these groups is close enough (e.g. second cousins), this may allow identification one of the adoptees four pairs of great-grandparents. A group of first cousins including the adoptee might then be identified, allowing one of his or her two pairs of grandparents to be identified and possibly contacted if still living. Ultimately, full or half-siblings of the adoptee may be identified and contacted. If the birth parent or a full sibling or half sibling of the adoptee is willing to provide a DNA sample, then there will be no ambiguity about the DNA results.
- 11. Thus the usual steps involved in the process of tracing birth family using DNA can be summarised as follows:
 - the adoptee tests with some/all of the major companies results take 4-8 weeks
 - the results reveal that the adoptee frequently has some relatively close matches (2nd to 3rd cousins) within one or more of the companies' databases
 - family trees for these close matches are examined (or constructed) and specific ancestors (e.g. great grandparents) of the adoptee are identified at the point of intersection of the various family trees
 - all the descendants of these ancestors are traced and people living at the time of the adoptees birth are identified one of them will be the birth parent
 - the most likely candidates for the birth parent are identified (i.e. people who were in the right place at the right time)
 - potential birth family relatives are approached and asked to help by supplying a DNA sample. In many cases, they are very eager to help the adoptee and act as "middlemen", facilitating contact with other family members, including half-siblings and birth parents of the adoptee.

¹⁰ https://isogg.org/wiki/DNA_testing_for_adoptees

¹¹ https://isogg.org/wiki/Utilizing_DNA_testing_to_break_through_adoption_roadblocks

^{12 &}lt;a href="https://isogg.org/wiki/Utilizing_DNA_testing_to_break_through_adoption_roadblocks">https://isogg.org/wiki/Utilizing_DNA_testing_to_break_through_adoption_roadblocks

- eventually, after sequential DNA testing of potential birth family, a close family member is identified (usually a half-sibling) thus confirming the identity of one of the adoptee's birth parents
- the same process is repeated for tracing the other birth parent
- 12. Thus the use of DNA involves a combination of DNA testing <u>and</u> traditional genealogy (i.e. building family trees for any close genetic matches). Furthermore, testing several people is usually required before the immediate birth family can be identified. On average, this process has been taking about 2 years to complete but this timescale is decreasing as the database size increases.
- 13. There are a lot of people who are not immediate birth family to the adoptee (e.g. first cousins) but who would like to be available to answer any questions should the adoptee ever wish to make enquiries. This is the sole motivation behind some people who undertake DNA tests.
- 14. The general guidance given by genetic genealogists to adoptees aiming to reconnect with families separated by adoption, whether using DNA or more conventional methods, is not to rush in without the advice of an experienced genetic genealogist, social worker, or other professional support, as there will only be one chance to make the critical first contact with immediate family a success. In most cases, the adoptee makes direct contact with their genetic matches (including immediate family) and the genetic genealogist merely interprets the DNA results, assists with building family trees, and generally points them in the right direction.¹³
- 15. Most genetic genealogists do not have the professional training or experience to counsel the adoptee on how to best approach the first contact with their birth family, or how to manage expectations and emotions associated with developing this new relationship.

4. The proposed Adoption Bill 2016 – general comments

- 16. An open access system to adoptee records would be a better option than the restricted access system proposed. The reasons for this are the increasing use of DNA and the fact that restricted access is no longer a tenable solution for the reasons hereunder described. Other European countries have instituted this system and it seems to work quite well for them (Great Britain 1975, Northern Ireland 1987).
- 17. The explosive growth of both social media and genetic genealogy in recent years has let the genie out of the bottle as far as anonymity is concerned. There is no longer any

¹³ https://isogg.org/wiki/Utilizing_DNA_testing_to_break_through_adoption_roadblocks

guarantee that sperm donors' anonymity can be safeguarded.¹⁴ In the UK, legislation for sperm donors allows them access to the information about their donor when they reach the age of 16.¹⁵ And in Victoria, Australia, a new Bill went one step further and from March 2017 retrospectively gave all donor conceived individuals the right to information about their birth parents.¹⁶ Similarly, it is no longer possible to safeguard the anonymity of the birth parents of adoptees. And as the extent of social media and the size of the DNA databases increase, anonymity will be further eroded. Thus, there is no point in introducing legislation aimed at closing the stable door after the horse has bolted.

- 18. There is a need for a public discussion (globally) on the end of anonymity, the consequences arising from this, and the need (if any) to institute appropriate safeguards. This is a "hot topic" within the genetic genealogy community and clarity on the issue will emerge and evolve over time.
- 19. There is also a need to make a very strong distinction between the "right to anonymity" and the "right to privacy". The two are very distinct and separate concepts, albeit related. The "right to anonymity" is probably seen by most people as being less important than the "right to privacy". And it is important to appreciate that the loss of anonymity does not mean that a person's right to privacy is lessened as a result.
- 20. There are several areas of the proposed Bill that will be directly impacted by DNA and these areas will be discussed first.

5. Tracing of Birth Parents (Part 4 of the Bill)

- 21. Not every adoptee will want to trace and/or contact their birth parents.
- 22. For many, just the information surrounding their birth and the identity of their birth parents is sufficient.
- 23. However some adoptees will want to go further than this. They may wish to know if their birth parents are still alive. If they are deceased, they may wish to pay their respects at the graveside. If they are alive, there may be additional information that the adoptee would like to glean that only the birth parents can answer (e.g. current medical information). Or they may wish to communicate directly with the birth parents. Or they may want to explore the possibility of having a relationship with their birth family.

¹⁴ https://academic.oup.com/humrep/article-lookup/doi/10.1093/humrep/dew065

¹⁵ http://www.hfea.gov.uk/5526.html

¹⁶ http://www.bionews.org.uk/page 787504.asp

- 24. Thus there are several situations where the Agency will attempt to trace the location of a birth parent. The first situation is related to a request for information regarding the father's name. If he has not been consulted about the adoption previously, then the proposed Bill dictates that he will need to be traced in order to obtain his consent for the release of his name. The letter he will receive from the Agency will apparently contain the following:
 - a. you are the birth father (presumably he already knew but this may be the first time he hears about it)
 - b. you can have support & guidance if desired
 - c. your child wants birth information
 - d. is this likely to endanger anyone's life?
 - e. you have 12 weeks to reply
- 25. The second (more common) situation is when the adoptee wants to contact either birth parent directly. In such cases, the Agency will act as a go-between and having contacted the parent will ask them: "do you want to have contact with your natural child? If so, we will facilitate."
- 26. There are no explicit details in the Bill regarding the nature of the tracing service that will be provided. The form that this service will eventually take is entirely up to the Minister concerned.
- 27. However, Note 3 in the FAQ states that people subjected to "informal adoptions" will be entitled to a tracing service "in the same manner as an adopted person or a birth parent". ¹⁷ We welcome this undertaking because this will really help this specific group of people, many of whom have been floating in limbo for years and levels of frustration are high. In such cases, **DNA testing is the only realistic option** as it is the only means by which the birth family of the adoptee can be discovered.
- 28. We welcome the above move, but would strongly urge the Minister to clarify that the use of DNA will become a routine part of the tracing process. Specifically, the wording of the proposed Bill obliges the Agency to use DNA testing to assist in the search where conventional means have failed to locate the birth parent. DNA data falls under the heading of "records that are likely to be relevant for locating a person" (section 19-2-b).
- 29. We would therefore strongly recommend that the Minister clarify that **DNA testing will** be used in all situations where accurate birth information is not available, for example because:

¹⁷ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

- 1. The information never existed in the first place, due to covert adoptions, illegal adoptions, or informal care arrangements
- 2. The information was entered incorrectly or deliberately falsified
- 3. Despite its best efforts using conventional means, the Agency has been unable to locate the birth parent
- 30. There are two main options for the routine use of DNA data as a tracing record. DNA testing can be **undertaken by the Agency on behalf of the adoptee** and the full cost of the DNA testing can be borne by the Agency. In this situation the Agency could assume responsibility for managing the test results and contacting any genetic matches that the adoptee may have. This helps the Government achieve its aim of protecting the birth parents' right to privacy and bolsters any written undertaking (section 41) taken by the adoptee not to contact the birth parent.
- 31. The second option is for **the adoptee to cover the cost of the DNA test**. In this situation the adoptee remains in control of their own DNA data and contacts their genetic matches themselves. However, if the adoptee finds that their parent is among their matches (which currently happens in about 2% of cases), there is potential for a breach of section 41 of the proposed Bill in this situation (i.e. the adoptee has to initially sign a written undertaking not to contact his birth parents). In such circumstances the adoptee can undertake not to contact the parent but rather have the Agency do it on their behalf ... but such an undertaking may not be necessary if the birth parent sees the close match on their own DNA Matches page and gets in touch directly with the adoptee.
- 32. If any other matches appear on the adoptee's DNA Matches page (for example a half sibling or a first cousin or second cousin), then the adoptee can safely contact these people without being in breach of the proposed Bill (which only strives to safeguard the right to privacy of the birth parents but not the half-siblings or cousins of the adoptee).
- 33. We must remember that any matches that the adoptee finds in the database are people who have willingly and voluntarily submitted their own DNA for analysis, alerted to the possibility that surprises sometimes happen and that they may find close relatives that they never knew existed. In other words, everyone who has done a DNA test and is in the database has been forewarned. And they have made the informed decision to go ahead anyway.
- 34. However, those who choose not to make their data publicly available have the ability to do so. They may have already taken measures to privatise their own information. For example, some people do not give a name and are marked as "Private", others have given a false name, others have used initials or nicknames, etc. So if any of the people who have tested want anonymity or privacy, there are ways of achieving this which they may already

have employed. In addition, some people have chosen not to supply family tree information, thus further restricting the chances of tracing who they are.

- 35. Furthermore, a match is under no obligation to respond to any message or email that they may receive. And if (for whatever reason) they do not want to have their DNA displayed publicly, they can privatise it, or remove it from public view, or even delete it completely should they so desire. So there are a multitude of safeguards to protect people's anonymity and privacy that have been built into the system by the companies concerned (all of whom will have taken extensive advice from their legal teams).
- 36. If the adoptee is to retain control over their own DNA results, this situation will require the adoptee to be **trained in contacting their matches** and in revealing appropriate amounts of information at various times during the contact, just as social workers have always advised adoptees and birth parents seeking to meet for the first time. Hints and tips, dos and don'ts, social etiquette guidelines, and other guidance for the adoptee should be developed by the Agency and made publicly available on its website, in a similar fashion to the guidance available on the *Adoption Search Reunion* website in the UK.¹⁸ This website offers guidance on making initial contact, using intermediary services, how to make contact via Facebook, and how to manage reunions.
- 37. The genetic genealogy community would be happy to assist in the development of these guidelines so that the outcome of the adoptee contacting their genetic matches can be optimized. Without this guidance, people will make *faux pas*, they will "put their foot in it", they will make mistakes, they will estrange and alienate people ... in other words, to optimise a successful outcome, adoptees need help making contact with their birth family and managing the initial reconnection. They will also need ongoing guidance and support developing the relationship with their birth family (should they wish to do so) and managing expectations (and emotions) on both sides. The Agency is well-placed to provide this ongoing education and support.
- 38. The introduction of DNA testing as a routine part of the day-to-day work of the Tracing Service would need to be **adequately resourced**. Specifically, the Minister should consider the following action points:
 - DNA testing to be routinely employed in tracing birth parents
 - The cost of DNA testing to be borne by the Agency
 - The Agency should explore options for special discounted deals with the major DNA testing companies regarding the purchase of DNA kits
 - AncestryDNA, FamilyTreeDNA, and 23andMe should be approached in this regard

¹⁸ http://www.adoptionsearchreunion.org.uk/contact/reunions/

- AncestryDNA data can currently be transferred for free to other companies
- Agency staff to be trained in the basics of DNA testing
- Professional genetic genealogists to be employed by the Agency to assist in tracing endeavours
- 39. Throughout the tracing process, which may be long and protracted, the Agency should manage expectations and provide ongoing guidance and support to the adoptee. This phase of the search is often fraught with frustration, impatience, disappointment, bouts of hopelessness, feelings of just giving up, disenchantment, and exhaustion. Many adoptees do not complete this phase and "drop out" from further searching.
- 40. If the Agency does not employ DNA testing as part of its tracing service, adoptees will take this on themselves. This would be a less than optimal scenario. The ability of the adoptee to negotiate the minefield of tracing and making contact with potential birth family would be significantly hampered without Agency support. The risk of a negative outcome would be much higher.
- 41. Thus it is imperative that **the Agency nurtures the continued engagement of the adoptee** in collaborative working with the Agency. And providing a comprehensive DNA testing and advisory service as part of its overall service is essential. Failure to do so would significantly reduce the effectiveness of the tracing process.

6. Support for Contacting Birth Family

- 42. One of the most disappointing aspects of the proposed Bill ¹⁹ (and the associated memo²⁰ and FAQ document ²¹) is the total lack of detail regarding the support offered to the adoptee in contacting their birth families.
- 43. There are multiple examples of how government agencies have failed adoptees in the past, and how these adoptees have had to use their own methods to search for their birth families (e.g. Private investigator, DNA testing, etc). Without professional help, the search undertaken by adoptees may be clumsy, ill-conceived, not thought through, fraught with pitfalls and dangers, and ultimately may cause unnecessary distress to the adoptee and/or their birth family. But this can potentially be avoided with the proper support and guidance.
- 44. We have previously stressed the imperative of the adoptee remaining engaged with the Agency. We would go further and stress that such engagement should continue even if the

¹⁹ https://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s.pdf

²⁰ https://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s-memo.pdf

²¹ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

adoptee refuses to sign the written undertaking (section 41) not to contact his/her birth family. And it should continue even if the adoptee decides to choose his own search methods. There is still a lot the Agency can do to support the adoptee even if it cannot release information relating to the birth parents. The Agency has a responsibility (according to the current Bill) to protect the privacy of the birth parents, but the same responsibility does not extend to half-siblings (or cousins). Adoptees who have never met a single blood relative are often thrilled to meet even a predicted third cousin. Parents may not want contact but half-siblings (or cousins) often do welcome such contact. The Agency should help facilitate these connections if it cannot facilitate contact with the parents.

45. If the Agency does not provide the necessary advice and support for adoptees, they will start knocking on doors, they will inadvertently invade people's privacy, and they will cause distress and harm (to themselves or others), especially if their level of frustration by being blocked by the Agency makes them more desperate than ever to make contact.

46. Rather than a written undertaking not to contact their birth parents, it would be better to teach people how to contact them in a respectful way, observing social etiquette, cognisant of the rights and sensitivities of the birth parents and their families. The Agency should provide support and guidance in this regard via a variety of different methodologies, including (for example):

- one-to-one work with adoptees
- regular workshops (e.g. see Barnardos' Post Adoption Services)²²
- online training programme
- user support groups
- social etiquette guide
- Hints & Tips factsheet
- Dos and Don'ts guide
- publish Success Stories illustrating key learning points
- and so on ...

47. Such educational activity should build on the resources already made available by the global genetic genealogy community^{23,24,25} and should address such questions as: how do you make first contact? What do you say initially? When do you mention that you are adopted? How do you break the news? How will people react? What can of worms might you be opening? What potential situations should one remain mindful of? For example, was there rape or violence involved in their conception? How traumatic was the adoption for the mother?

²³ https://isogg.org/wiki/DNA_testing_for_adoptees

²² https://www.barnardos.ie/adoption

²⁴ https://isogg.org/wiki/Utilizing_DNA_testing_to_break_through_adoption_roadblocks

²⁵ https://isogg.org/wiki/Adoption_success_stories

- 48. The Agency should establish an Advisory Committee, made up of representatives in the field, including adoptees, birth parents, adoptive parents, social workers, adoption activists, genetic genealogists, tracing experts (search angels), legal experts, etc. The Advisory Committee could advise on the general running of the Agency as well as educational programmes for adoptees, public awareness campaigns, etc
- 49. There is a burgeoning need to support adoptees in searching for and making contact with their birth family. Too much of this activity is currently happening "beneath the radar" and that is not a good situation for anyone concerned.
- 50. In addition, the adoptee and their birth family will need ongoing support in building the new relationship, managing expectations and emotions, dealing with upsets and setbacks, and working to achieve the most successful outcome possible for each individual and particular situation.

7. The new Register (Part 3 of the Bill)

- 51. There are several concerns regarding the need to introduce the new Register (RACE).²⁶ It is not clear why there is a need for this, in particular because it appears to duplicate the work of the NACPR.²⁷ Why reinvent the wheel? We are concerned that this will divert valuable resources away from the other aspects of the work of the Agency, in particular directly supporting adoptees in their requests for information and the tracing of birth family.
- 52. We are also concerned that people who have already made an entry on the NACPR will be invited to re-enter their information on the RACE. Not only is this an annoying duplication of effort but it raises concerns about what happens to those entries in the NACPR which have been made by people who have since died.
- 53. It appears that only certain entries will be transferred over to the new Register (i.e. those where there is a "no contact" preference from a natural parent). However, it appears that "no contact" preference entries from adoptees will <u>not</u> be transferred. This could potentially result in a breach of the adoptee's right to privacy. Furthermore, "yes contact" preferences from natural parents will not be transferred. This could potentially delay the tracing of a birth father in relation to the release of his name to the adoptee. Also if these "yes" birth parents have since died, if their "yes" preference entry is not transferred from

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²⁶ RACE, Register of Adoption Contact Enquiries ... which is a partial duplication of the currently existing NACPR

²⁷ NACPR, National Adoption Contact Preference Register

the NACPR to the new RACE, there is a risk that the adoptee will never know that their birth parent wanted to get in touch. Such information would be crucial for the wellbeing of many adoptees. Therefore, if transfer of entries is to be undertaken, it seems preferable to transfer all entries from the NACPR to the new Register.

54. Lastly, we are also concerned about the future integrity of the NACPR. Note 6 in the FAQ states that the NACPR will be discontinued but the data retained.²⁸ It would be very unfortunate if the NACPR was decommissioned, or the data was lost or could no longer be used. In effect, it would mean that the preferences of all other entrants (i.e. other than natural parents with a "no contact" preference) would be ignored or discarded.

55. Regarding the new Register, it would be helpful if individuals could have the option to edit their own entry on the Register, so that information (including contact preference information) can be updated directly by the entrant.

56. It would be helpful and informative to have an annual report published and made available to the public (via the Agency website) regarding the entries on the new Register (RACE) and the existing NACPR. The report should include anonymised aggregated data on the following:

- 1. number of total entries and annual entries (year by year; since 2005 for the NACPR)
- 2. data on who submitted the entries (adoptees, birth fathers, birth mothers, other family members)
- 3. data on type of enquiries number (%), broken down by subgroup (adoptees, birth parents, etc)
- 4. data on contact preference number (%) of "yes" and "no" preferences, broken down by subgroup (adoptees, birth parents, etc)
- 5. number (%) of cases in which birth families were re-united, cases in which birth families were identified but re-unification was not achieved because of death or a request for privacy, and cases in which birth families could not be identified
- 6. anonymised examples & case histories of the above
- 7. critical analysis of the work of the Agency, including an assessment of the major hurdles experienced by a) Agency staff; b) adoptees; and c) birth parents

8. Requests for information (Part 5 of the Bill)

57. A clear distinction needs to be made between the desire to obtain information and the desire to have contact with birth family. Many adoptees do not desire contact with their birth family but instead simply wish to know of any current medical information that may be

²⁸ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

relevant to themselves and their own children; or may simply wish to know the names of their birth parents and where they came from in order to attain a sense of roots and belonging, or even to trace their genetic family tree (as opposed to the family tree of their adoptive parents).

- 58. The proposed Bill discusses the different types of information that may be requested by an adoptee (section 23-1), and this includes:
 - 1. copy of Birth Certificate not applicable until after 2035 (i.e. 2017 + 18 = 2035)
 - 2. Birth Certificate information (23-1-g), birth father's name (23-1-h), and copy of Adoption Order (23-1-i)
 - 3. Non-identifying information (relating to the adoptee's early life, medical information, etc) section 23-1-a through 23-1-e
 - 4. Other additional non-identifying information not included above section 23-2
- 59. In addition, there may be Contact Preference information available via the NACPR.
- 60. The process for receiving this information as described in the proposed Bill ²⁹ (and the associated memo³⁰ and FAQ document ³¹) is not terribly clear. A flow diagram would have been helpful. Appendix 2 below includes a summary of the apparent process involved.
- 61. In brief, an adoptee asking for information will experience the following:
 - Release of non-identifying information³² (items 23-1-a to 23-1-e) will be relatively quick (immediately following the initial review of their request for information whatever the waiting time happens to be for that initial review of the request)
 - Release of birth cert information (except father's name) & copy of Adoption Order ...
 - Will be immediate (if birth mother is not on the Register)
 - Will take 12 weeks following initial review (if birth mother <u>is</u> on the Register she will need to be contacted)
 - Release of father's name ...
 - o Will be immediate if he was previously consulted and is not on the Register
 - Will take 12 weeks following initial review (if he was previously consulted and is on the Register)
 - Will take many months (i.e. >12 weeks) if he was not previously consulted and is not on the Register (he will need to be traced and asked)

 $\underline{https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf}$

 $^{^{29}\ \}underline{\text{https://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s.pdf}}$

³⁰ https://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s-memo.pdf

³¹ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

³² see also pages 7 & 8 of the FAQ at

- Release of Birth Certificate will <u>never</u> happen for those adopted before the Bill is passed (unless perhaps both birth parents agree?? There is no provision for this in the current Bill).
- 62. Of particular note is the fact that only the birth mother can sanction the release of the birth certificate information (or Adoption Order), and only the birth father can sanction the release of his name.
- 63. Since so few birth parents are likely to register (the NACPR has at least 10,000 entries, which is not a huge number), in the majority of cases, most information will be released fairly rapidly. However, in many cases, the birth father's name will not be released without a tracing search first (which may be protracted).
- 64. So adoptees should receive non-identifying information and birth cert information fairly quickly, but may have to wait a long time to receive their birth father's name.
- 65. There are several circumstances where the information may not be forthcoming:
 - 1. The information never existed in the first place, due to covert adoptions, illegal adoptions, or informal care arrangements
 - 2. The information was entered incorrectly or deliberately falsified
 - 3. The birth parent blocks the release of the information
 - 4. The Agency takes too long to process the request for information (in particular in relation to the name of the birth father) and the adoptee abandons collaboration with Agency staff
- 66. In these circumstances, the adoptee may turn to DNA testing and undertake their own search to obtain the information they desire. The risk here is that they do so without the help, guidance and support of the Agency. This increases the risk of harm that the Government wants to avoid. It is important that the Government does everything within its power to keep the adoptee engaged with the Agency in order to optimise a successful outcome for all concerned. To this end, requests for information should be processed quickly and tracing searches should be expedited. The Government should allocate (or divert) appropriate resources to ensure that this happens. However, this seems unlikely to happen under the proposed Bill.
- 67. The proposed process for providing information to the adoptee is overly bureaucratic and resource-consuming. An open access system would be much less so. We are concerned that the proposed system is not an optimal use of the Agency's limited resources. The

proposed system will divert resources away from areas where they could be more gainfully employed (e.g. tracing activities, direct support of adoptees, etc).

- 68. In addition, the proposed system is likely to cause delays in obtaining information. Such delays will cause frustration for the adoptee and may reduce their confidence in the Agency, which in turn may lead to the adoptee abandoning collaborative working with the Agency and undertaking their own search for the information they want. In effect, the delays in the system will drive the adoptee "underground". And this will increase the chances of a negative outcome, resulting in harm or distress to the adoptee and/or their birth family. Time is of the essence in these cases, as many birth parents are elderly and the worst possible outcome would be if a birth parent (or adoptee) died while the case was held up in the system. (We are aware of a case where a 44-year-old adoptee used DNA to identify her 102-year-old grandmother.)
- 69. In situations where the adoptee has clearly expressed that they do not wish to have contact with the birth parents, we are concerned that the process described of contacting birth parents to notify them that an adoptee is searching for information is a breach of the adoptee's privacy. The adoptee's right to privacy should be respected as well and this is not adequately addressed in the current Bill.
- 70. In addition, forewarning the birth parents may deter adoptees from contacting the Agency in the first place. If the adoptee does not want the natural parents to know that they are seeking information, they may turn to alternative methods for obtaining that information (e.g. Private Investigator, DNA testing) and thus the real opportunity for working collaboratively with the Agency is lost and the risk of a negative outcome is increased.
- 71. Furthermore, this process of notifying the birth parent in advance to "warn them" that their natural child is seeking information may be seen to be stigmatising of the adoptee. Moreover, asking the birth parent "if the release of the information is likely to endanger anyone's life" is unnecessarily alarmist on the part of the Agency and is likely to cause distress to the birth parent. It also suggests that the adoptee may be some sort of deviant. It is obviously not the intention of the Bill to give this impression but the wording certainly needs to be improved and a better explanation of it offered in the FAQ document.
- 72. Contact from the Agency may also be seen as intrusive by the birth parent. They may have put the adoption behind them many years before, and may not welcome notification from the Agency that reawakens painful memories associated with the trauma of giving up their child. If the adoptee has already signed a written undertaking not to contact the birth parents, why do the birth parents need to be informed that the adoptee is merely seeking information about his/her birth?

73. We are concerned that the written undertaking not to contact the birth parents (as currently described in the Bill) may be seen as infantilising and stigmatising of adoptees. This echoes the sentiments expressed in the review by the Adoption Rights Alliance.³³ We are also concerned that many adoptees will be offended by this treatment - it will alienate them, and will ultimately discourage them from engaging with the Agency and working collaboratively with it. Instead they may turn to alternative methods of tracing their birth family (e.g. Private Investigator, DNA testing, etc). Thus a real opportunity to work collaboratively with the Agency would be lost and there would be a consequent increased risk of harm and distress (to the adoptee, the birth parents, or other family members) resulting from the adoptee's unsupported efforts.

74. In any case, the written undertaking not to contact birth parents does not appear to be legally binding and is therefore probably unenforceable. In addition, it is not mentioned in the offence section of the Bill. This raises the question of its utility. We note that a previous suggestion to include a "Statutory Declaration" was shelved after the Joint Oireachtas Committee on Health and Children following legal advice could find no convincing reason for its inclusion.³⁴

75. However, we are encouraged to note that the written undertaking **does not preclude contacting siblings or cousins**. We welcome this aspect of the Bill because it does not impede using DNA testing to search for immediate family members other than the birth parents (i.e. siblings, cousins, aunts, uncles, etc). Therefore, the adoptee using DNA testing to find birth family will remain within the law (if the Bill is passed in its current form). It would be important to emphasise this point in any future Government memo or FAQ relating to the Bill so as to reduce the risk of any unnecessary challenges to the right of adoptees to undertake DNA testing.

76. Children, grandchildren and other descendants of an adopted person should have access to records, particularly if the adopted person is deceased. In some circumstances, other relatives of the adopted person (e.g. siblings, nephews, nieces) should be allowed to access the records. The Bill (and any associated memo or FAQ) should be explicit about this and define under what conditions the records can be accessed. The Government should look for examples from the open access systems of other countries.

³⁴ Adoption Rights Alliance Briefing Note, March 2016, page 14 – available at http://www.adoptionrightsalliance.com/ARA%20Briefing%20Note%20&%20Amendments%20to%202016%20Adoption%20Bill 17-03-17.pdf

³³ Adoption Rights Alliance Briefing Note, March 2016, page 14 – available at http://www.adoptionrightsalliance.com/ARA%20Briefing%20Note%20&%20Amendments%20to%202016%20Adoption%20Bill 17-03-17.pdf

9. Recommendations

- 1. Incorporate DNA testing as a routine part of the tracing procedure.
- 2. Include dedicated DNA-trained staff (including professional genetic genealogists) as part of the Agency team to assist with tracing birth family.
- 3. As a matter of urgency, develop training packs and educational materials and courses to assist adoptees using DNA to trace their birth family, and (most importantly) how to go about making first contact with their immediate birth family (half-siblings & first cousins) and building a new relationship with them.
- 4. Publish an annual report of aggregated data from RACE & NACPR, as well as an annual Agency report, in order to efficiently monitor progress.
- 5. Revise the current proposals to allow an open access system to adoption records.

We, as signatories of this submission and as members of the genetic genealogy community in Ireland, are ready and willing to assist the Minister in any way we can to achieve these recommendations.

Paddy Waldron Maurice Gleeson Martine Brennan Gerard Corcoran Finbar O Mahony Margaret Jordan

10. Sources & Links

"Adoptee Testing 2016" Survey – available at ...

https://www.facebook.com/groups/DNADetectives/permalink/1200136676724114/

DNA Detectives Facebook group – available at ...

https://www.facebook.com/groups/DNADetectives/

Question & Answers: Adoption (Information and Tracing) Bill 2016 - available at ... https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

Explanatory & Financial Memorandum: Adoption (Information and Tracing) Bill 2016 - available at ...

https://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s-memo.pdf

Adoption (Information and Tracing) Bill 2016 - available at ...

http://www.oireachtas.ie/documents/bills28/bills/2016/10016/b10016s.pdf

Adoption Rights Alliance Briefing Note, March 2016, page 14 – available at http://www.adoptionrightsalliance.com/ARA%20Briefing%20Note%20&%20Amendments%20to%202016%20Adoption%20Bill_17-03-17.pdf

Appendix 1 - "Adoptee Testing 2016" Survey

In October 2016, genetic genealogist Blaine Bettinger created a survey asking adoptees a series of nine questions relating to their experience with DNA testing. The full survey is available here: https://goo.gl/forms/ggJfMppw9T9xuCYY2

The table below describes preliminary results of the survey (based on 575 respondents) from October 2016. They can also be found here ...

https://www.facebook.com/groups/DNADetectives/permalink/1200136676724114/?match=YWRvcHRIZSB0ZXN0aW5nIDIwMTY%3D

Source Citation:

Blaine T. Bettinger (blainebettinger@gmail.com), Preliminary Results of "Adoptee Testing 2016" Survey (October 29, 2016).

Company Tested With: 39% tested at 23andMe	Quality of Initial Matches: When You FIRST Received Your Results, What Was Your Closest Match?		
90% tested at AncestryDNA	when four first received four results.	, what	vas Tour Closest Water:
30% tested at Family Tree DNA	Parent(s)	2%	Thus, 33% of these test-takers
	Sibling(s) or Half-Sibling(s)	6%	initially had a half first cousin
	Aunt/Uncle/Niece/Nephew	5%	or closer as their closest match,
	First Cousin(s) or Half First Cousin	19%	68% had a half second cousin
Testing Coverage:	Second Cousin(s) or Half Second Cousin	36%	or closer, and 90% had a third
55% tested at only one company	Third Cousins	21%	cousin or closer.
0% tested at two companies 5% tested at three companies	Fourth Cousins	9%	
	Other	1%	

Finding Family:

52% have found at least one sibling or parent 48% have not yet found a sibling or parent

69% are still searching for biological family 31% are not searching for biological family

Search Angel Assistance:

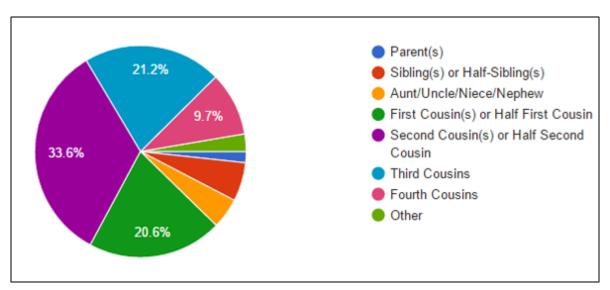
42% received some assistance from a search angel 58% did not receive assistance from a search angel

Country:

80% were adopted from the United States 20% were adopted from outside the United States

Future Analysis: Does testing at a particular company, the number of testing companies tested at, search angel assistance, and/or country adopted from (U.S. vs. non-U.S.) affect the probability of success?

Preliminary results from January 2017 (based on 700 respondents) are broadly similar and can be found here ... http://thegeneticgenealogist.com/2017/01/08/adoptee-testing-a-study/



Percentage of each type of ancestor of the adoptee found on initial DNA testing (interim results based on 700 respondents)

The full results (based on 1200 respondents) were presented at the American Adoption Congress on 7th April 2017, and were not substantially different from the interim results. Extracted data from the final results are presented in point 7 within the document.

We are very grateful to Blaine Bettinger for permission to use the data from his survey.

Appendix 2 – Process for Requesting Information

Here is a summary of the apparent process for getting information from the Agency. This was extracted from the current wording of the proposed Bill:

Those adoptees applying for information <u>after</u> the Bill is passed, and who are <u>>18 years old</u> (i.e. from about 2035 onwards) can automatically obtain a copy of their **Birth Certificate** and other information about their birth (e.g. early life, medical info, etc). Their birth parents will be notified of this 12 weeks in advance of the release date (if their names appear on the Register).

For those who were adopted <u>prior to</u> the Bill being made Law, and who are <u>>18 years old</u> (i.e. born before c.1999), the following process applies:

- First they must sign a Written Undertaking (WUT) not to contact their birth parents (WUT not necessary if the parent in question is willing to have contact, or is seeking contact, or has died) see section 41
 - o If they do not, no information will be released
 - The implication (which is not clearly stated) is that the Agency will assume responsibility for any tracing & contacting of the birth parent
- Next, TUSLA (the Agency) will see if there is an entry (with contact details) for either parent on the new Register (RACE) ³⁵
 - o If there is an entry, then that parent is contacted and notified that their natural child is seeking information about their birth. They will be given advice and support. They will also be asked if this will endanger anyone's life and be told that they have 12 weeks to block the release of the information.
 - If the parent has "no compelling reason" to block the release of the information, it will be released:
 - If the birth mother has been contacted, the information released is not a copy of the birth certificate but rather her name and other details typically found on a birth cert EXCEPT the father's name - see section 23-1-g and page 7 of the FAQ³⁶
 - If it is the birth father that has been contacted, the information released is his name – see 23-1-h ... BUT apparently he cannot consent to any other birth cert information being released

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³⁵ RACE, Register of Adoption Contact Enquiries ... which is a partial duplication of the currently existing NACPR, National Adoption Contact Preference Register

³⁶ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

- It appears that a copy of an Adoption Order can only be released once the birth mother has been contacted. Birth fathers have no say in this. However, this is not clearly delineated in the proposed Bill. See 23-1-i
- It is not terribly clear how the Bill proposes to manage the release of non-identifying "other" information, relating to early life, medical information, etc ... items 23-1a through 23-1-e. Is it subject to the same process? Can either parent consent to its release? Or can it be released without the need to contact either birth parent? Apparently the latter applies.
- If either parent feels someone's life would be in danger as a result of the release of either parent's name or other birth cert information, then the release can be blocked and the case can go to court
- o If there is no entry for the parent on the new Register, then ...
 - If the birth father was previously consulted about the adoption (i.e. 18+ years ago), then his name can be released
 - If he was not consulted about the adoption, then he becomes the subject of a tracing search so that he can be located, contacted, & asked if anyone's life will be put in danger by releasing his name
 - If there is no entry for the birth mother, then ... it looks like the information (i.e. birth certificate information and or a copy of an Adoption Order) can be released WITHOUT the need to locate her and contact her.

For those who were adopted <u>prior to</u> the Bill being made Law, and who are <u>less than 18</u> <u>years old</u> (i.e. born before c.1999), the following process applies:

- The adoptive parent may apply for non-identifying information
 - o It seems this will be released without the need to contact the birth parents
- The adoptive parent may apply for a copy of the Adoption Order and/or a copy of the Birth Certificate
 - Note 27 of the FAQ states that this will only be released if the "birth parent agrees or where the birth parent is deceased". It is not clear if the consent (or death) of one or both birth parents is required, or if only one of them needs to give consent / have died for the cert to be released ³⁷
 - Note that the option to obtain the adoptee's Birth Certificate expires as soon as he turns 18. Thereafter, both the birth father and birth mother would have to be contacted to release a) the father's name, and b) all other birth certificate information, respectively. The Birth Certificate would <u>not</u> be released to the adoptee aged 18+.

³⁷ https://www.dcya.gov.ie/documents/publications/20161125AdoptionInfoTracingBillFAQs.pdf

Appendix 3 – biographical information on authors

The authors of this submission are all members of ISOGG, the International Society of Genetic Genealogy, but the views expressed in this document are their own personal views and are not necessarily shared by ISOGG.

ISOGG was founded in 2005 by DNA project administrators who shared a common vision: the promotion and education of genetic genealogy. ISOGG is a global volunteer organisation with over 12,000 members in 80 countries. Our mission is to advocate for and educate about the use of genetics as a tool for genealogical research, and to promote a supportive network for genetic genealogists. ISOGG Ireland represents the global Irish diaspora in genetic genealogy and administers surname and regional DNA projects and organizes conferences and lectures. We organize an annual DNA conference (Genetic Genealogy Ireland) at the Back to Our Past conference in the RDS and have published over 50 lectures to our dedicated YouTube channel.

Maurice Gleeson

Maurice Gleeson is a psychiatrist and pharmaceutical physician as well as a genetic genealogist. He is administrator of several Surname DNA Projects, including the Gleason, Spearin, Farrell, Boylan, & Maloney Projects. He also works with adoptees and with people of unknown parentage and has appeared on Irish TV as a consultant for the TV series Adoption Stories. He authors several blogs (e.g. DNA and Family Tree Research) and is a regular contributor to genealogical magazines. His YouTube videos on genetic genealogy are very popular. He has organised the DNA Lectures for "Genetic Genealogy Ireland" in Dublin and "Who Do You Think You Are" in the UK since 2012, as well as given talks all over Ireland, the UK, and internationally. He was voted "Genetic Genealogist of the Year 2015" (SurnameDNA Journal) and "Superstar Genealogist, Ireland" in 2016 (Canada's Anglo-Celtic Connections). The views expressed here are his own.

Paddy Waldron

Paddy Waldron has degrees in mathematical sciences, economics and finance, but in recent years has concentrated on local history, genealogy and particularly genetic genealogy. He has lectured widely on all of these subjects. He is a Visiting Research Fellow in Economics at Trinity College Dublin. He is co-administrator of several DNA Projects, including the Clare Roots Project and the Clancy, Durkan, O'Dea & Waldron Surname Projects. He has been involved in a number of adoption cases which were solved using DNA. He has served on the committees of the Clare Roots Society, Kilrush & District Historical Society, Council of Irish

Genealogical Organisations and various similar bodies. The views expressed here are his own and not those of any of these bodies.

Martine Brennan

Martine Brennan BA, Dip. Counselling, Dip. Psychotherapy, Genealogy Researcher, Member of the Guild of One Name Studies (Brennan), Founder of The Kerry DNA Project (Facebook) Contributor to Radio Kerry, TV & Radio Documentaries, The Upper North Street School Project, Poplar, London, The Slave Name Roll Project, The Beyond Kin Project, Ireland Reaching Out www.martinebrennan.com

Gerard Corcoran

Gerard Corcoran is Director of Smart Cities for Huawei Technologies in Western Europe and is volunteer coordinator of the International Society of Genetic Genealogy in Ireland. In the former role he is on the advisory Network of Smart City Dublin, Sandyford, and Dun Laoghaire. In the latter role he is co-administrator of the Ireland DNA Outreach project and the Irish Midlands DNA Project and organiser of the annual ISOGG day out for speakers and volunteers of Genetic Genealogy Ireland. In 2008, he submitted a report to the Department of Foreign Affairs on the Ireland US Strategic Review advocating for the use of Genetic Genealogy as a tool to connect the Irish Diaspora and the establishment of a Diaspora Centre in Ireland. In 2014 he made a submission titled "Capture the Full Value of our Genealogical Heritage" to the Oireachtas Joint Committee on Environment, Culture and the Gaeltacht. In 2016 he supported the Genetic Genealogy component of the new Irish Diaspora Museum, Epic Ireland and in the same year supported the landmark TV documentary on the DNA of the Irish Travellers. He is a member of the Genealogical Society of Ireland with responsibility for contacts with the Genetic Genealogy Community and has lectured frequently on Genetic Genealogy in Ireland. The views expressed here are his own.

Finbar O Mahoney

Finbar O Mahony, BA, Dip. Psych, MBA, DBA
(F. Psych. Soc. Irl., FIPD, FIITD now retired)
Retired lecturer in Strategic Management and Business Policy and lecturer in Human Resource Management and also in Organizational Development, DIT
Former Board member of the Clans of Ireland
Project administrator of the O Mahony, Hartnett and Moriarty yDNA projects,
Council Member of the O Mahony Society
Former Director of a branch of the Samaritans
Lecturer in the use of Genetic Testing for yDNA surname projects
Member ISOGG

Margaret Jordan

Margaret Jordan was a second level teacher of Physics and Mathematics for over 25 years. She has successfully used DNA testing to identify her father's birth father. She has been a professional genealogist for over nine years and is a member of AGI (Accredited Genealogists Ireland) and APG (Association of Professional Genealogists). She is a Fellow of the Cork Genealogical Society. She is also a member of ISOGG. She specializes in Genetic Genealogy and uses it to help adoptees to find their birth family. She is a voluntary administrator of several DNA Projects, most notably the Ireland yDNA Project (which she cofounded in 2006), which (June 2017) has over 7,600 members worldwide. She has given talks on DNA and has written published articles on the topic. The views expressed here are her own and not those of any of the bodies mentioned.