

TRANSCRIPT OF PROCEEDINGS

THE HON JULIA GILLARD AC, Commissioner

THE ROYAL COMMISSION INTO EARLY CHILD EDUCATION AND CARE

**MONDAY, 27 MARCH 2023
AT 6.00 PM**

This transcript is intended as a guide only and as an aide memoire with respect to the audio-visual record, which constitutes the official record of the hearing on 27 March 2023

SARAH ATTAR, Counsel Assisting

< HEARING RESUMED AT 6.00PM

< PROFESSOR MARK MON-WILLIAMS SWORN

COUNSEL ASSISTING

Thank you Professor. Just a few introductory questions by way introducing yourself to begin with and thank you for joining us this morning so early. Do you currently hold a Chair in Cognitive Psychology at the University of Leeds?

PROFESSOR MON-WILLIAMS

I do.

COUNSEL ASSISTING

And are you also a Professor of Psychology at the Bradford Institute of Health Research?

PROFESSOR

I am.

COUNSEL ASSISTING

And amongst other roles you're a professor of Vision Science at the Norwegian Centre for vision, I understand?

PROFESSOR MON-WILLIAMS

That's correct.

COUNSEL ASSISTING

And a Turing Fellow at the Alan Turing Institute.

RPROFESSOR MON-WILLIAMS

That's right.

COUNSEL ASSISTING

And am I right that that's the UK's National Data Analytics and AI Centre.

PROFESSOR MON-WILLIAMS

Yeah, that's right.

COUNSEL ASSISTING

Do you have a post-doctoral fellowship from both the Universities of Edinburgh and a connection to us from University of Queensland I believe?

PROFESSOR MON-WILLIAMS

I do. I spent three very happy years that University and as I said sort of said my son was actually born in Brisbane almost 25 years ago, 25 years ago to the day when we had a preliminary chat. So very proud to have those connections to Australia.

COUNSEL ASSISTING

And as I suggested to you last week, that's enough for us to claim you as one of our own.

PROFESSOR MON-WILLIAMS

Excellent.

COUNSEL ASSISTING

We've had some sessions, while you would've been asleep I imagine earlier today in Australia where we've started to look a little bit about where, within South Australia, government departments have tried to start linking data sets, and we've had an initial discussion about the importance and the benefits of, of linking data. Can I ask you to give us a, just a broad overview to begin with about born in Bradford, which is what we've asked you to come to speak to us about today, and then we'd really like to try and pick your brains essentially about how, uh, data linkage is, is best done and to look at some tangible examples, where Born in Bradford has been able to link data.

PROFESSOR MON-WILLIAMS

So Born in Bradford is a longitudinal birth cohort study. So, over a four year period, we recruited pregnant mothers across the whole of our district, that's the district of Bradford. Bradford's the sixth largest city in the UK. It's located in the north of England and it's a very diverse sort of population. It has socioeconomic diversity, so we have some of the wealthiest wards outside London but we also have the most disadvantaged wards outside of London. So large socioeconomic diversity. We also have large ethnic diversity. So we have pretty much a bi-ethnic population with half the population being white British in heritage and half the population being South Asian in heritage, particularly from Pakistan, from the Mirpur region in Pakistan. And in fact, if we look at the mothers within the born and Bradford project, we can split the mothers of South Asian heritage pretty much down the middle, so half were born in the UK and the other half were born in Pakistan and then came across typically age 15 or 16,

and often for arranged marriages. So this allows us to start disentangling effects of socioeconomic position, ethnicity culture, and that broader milieu, so we can start really properly understanding what are the various factors that influence family' lives, particularly that influence outcomes for children, young people. So for that four year period, we recruited all the pregnant mothers, followed the mothers all the way through their pregnancy, followed the children through the birthing process and then we've been following the children as they go up. It's probably one of the most richly described populations that exists anywhere in the world. So we have all genetic information on the 13,818 children within our cohort but we've also tested these children to oblivion, so that's taking blood samples, taking urines samples, doing lots and lots of sort of cognitive tests other tests. It's a very, very richly described population. But one of the things that happened within the project sort of as an afterthought, was asking mothers to consent for us to link up their different records and access their, their routine data. So just the data which happened, you know, so every time they go to the GP or they turn up in accident emergency, or the children in school doing a test or the, local authority, our local sort of government obtain sort of better information. So we have all these rich sort of data sets. And because we had the consent, we could then pull all those data into one place. And that's probably been the most powerful sort of a tool that we've had to really properly understand how different factors intersect and interact to determine outcomes to children and young people.

COUNSEL ASSISTING

You've described starting off with the, the primary purpose being, I think you said, just testing everything that, that you could with the cohort that you were looking at. And I think they were children born 2007 to 11?

PROFESSOR MON-WILLIAMS

Correct.

COUNSEL ASSISTING

Prior to the Born in Bradford study, had there been any studies that had the cultural diversity and breadth of the group that you have been following?

PROFESSOR MON-WILLIAMS

No. So we were founded very much on the principles of the ALSPAC studies. So that's the Avon longitudinal birth cohort sort of our study that was located down in Bristol. It's a fantastic piece of work and, you know, inspired the born in Bradford project. But actually at the time of recruitment, Bristol was far more homogenous. It's quite a diverse population now, but at the time of recruitment for ALSPAC, it was quite homogenous and quite middle class and quite white British, so I'd say it lacked some of the diversity of socioeconomic position and ethnicity that we really needed to properly understand some of the complexities that play out across

large parts of the UK. So that's, that's one of the sort of powerful elements within Born and Bradford, just that ethnic and cultural and socioeconomic diversity.

COUNSEL ASSISTING

I'm interested in the reception when you initially commenced and your focus was on that, that really broad range of medical testing and I assume that ran the gamut from urine testing to measurements and weights and, and all sorts of things. When you initially started that within this cultural group, what was the reaction like to the request for the collection of that type of data initially?

PROFESSOR MON-WILLIAMS

So, really enthusiastic and that's, so one of the big problems that was playing out that sort of time were really high infant mortality rates. So Bradford at that stage had one of the highest infant mortality rates within the UK. So it was a real pressing need. And I guess that was one of the sort of really important sort of things that we learn almost on a sort of daily sort of basis - that populations are particularly unhappy about government coming along and saying for abstract reasons, 'we just want to hold a whole bunch of sort of data on you', understandably. But when you actually start grounding it in, in issues such as infant mortality or undiagnosed autism, or, you know, issues that everybody cares about and can see are still really, really sort of important for us as a society, then it's a very, very different sort of conversation. So grounding this particular project within the issue of infant mortality meant that it was welcomed, you know, across the district, and, and I've gotta sort of say that, you know, people within the district are incredibly proud of Born and Bradford, incredibly proud being part of Born in Bradford as well.

COUNSEL ASSISTING

You mentioned that it was something of an afterthought that after that initial testing phase, that the project moved on to linking other held data sets and then linking that in together with data that, that you had collected. How, how did that come about?

PROFESSOR MON-WILLIAMS

So it was actually done, I mean, it was an afterthought in terms of setting up the whole project, but it was actually done at the point of recruitment. That was important, that at the point that mothers were recruited they were asked to consent to, as I say, being tested to oblivion and the children being tested to sort of oblivion as the children were sort of growing up. But also they were asked at that sort of stage to consent to us just accessing their data records. I mean, I don't think anybody really envisaged at that stage just how insightful the routine data, would be. Just, you know, we just, weren't really thinking about sort of a power connected routine data sets at that stage.

COUNSEL ASSISTING

And the connection of those data sets that's now what you're referring to as the Connected Bradford Database, is that correct?

PROFESSOR MON-WILLIAMS

Well, so not quite. So we basically proved the principle if you like, in the connected Bradford, data sort of set. And then we could use the, effectively what we then did using the connected, sorry, sorry, using the Born in Bradford data set was show the power of the connected data sets to really shine a spotlight on really sort of important issues and issues that actually lent themselves to interventions, things that we could actually go in to, to, to make sort of people's lives, sort of better. So off the back of that, we then set up another project, which was the connected Bradford sort of project. And that was then to link all of the records for everybody across the whole of the district. So that of course includes sort of born in Bradford but Connected Bradford is much, much larger. So everybody across the whole of the Bradford sort of our district, uh, we took all their health records and linked them with education, social care sort of, policing and the like, and that's the Connected Bradford sort of data set.

COUNSEL ASSISTING

Was that the first of its kind in terms of the scale of that linkage?

PROFESSOR MON-WILLIAMS

Yeah. So nobody else has managed to do this anywhere in the UK, but obviously there's lots of interest now in picking that up and scaling it up, but to our knowledge, it was definitely unique within the UK. We don't think there are many places anywhere in the world that have managed to, to do it previously.

COUNSEL ASSISTING

In terms of the breadth of data that you are now able to capture with the Connected Bradford database in your view, what were the, the key enablers that required that to come together.

PROFESSOR MON-WILLIAMS

So, uh, so I think it's really important, we touched on this already, that this is all co-produced with communities, and it's very important to take the communities on the journey with you. So rather than this just being, you know, a bunch of individuals sort of coming and saying, we're gonna do this to you, or even with you, it's really sort of working with those sort of communities to help them understand what we're sort of doing. And again, by grounding it in very specific sort of projects, we could really then start communicating with our communities as to the benefits of these particular approaches. So for me, that's really at, at the heart of everything we do, that whole co-production and, and winning hearts and minds to allow this to happen.

COUNSEL ASSISTING

As you mentioned, you and I were able to connect at last week, and I believe, if I remember correctly, that you told me the connection between the project and community was so strong that there a community events where people are encouraged to come together under the, the guise of Born in Bradford, have I remembered that correctly?

PROFESSOR MON-WILLIAMS

Well, so there's lots of Band Bradford events that we hold like picnics in the park where the whole sort of community come together, which are wonderful sort of celebrations. Every couple of years we book out one of the mills, so this used to be the wool capital of the world, so we have these huge mills, which no longer act as mills but of them sorts, sort of mill has been converted to a big art gallery, lot of David Hockney artwork there. So we book out the whole of the mill, and again, we invite all the community and we celebrate all things, sort of, Born in Bradford. So that's one big sort of, part of the, sort of our work, but then we also really try and engage with specific communities. So I've already sort of touched upon the idea that there's huge amounts of diversity across the district. And really what that means is that it's very, very challenging for the policy, sort of, for makers who sort of sit in the sort of centre of Bradford to try and write policies that are actually going to be effective in all of the different parts of our district. So right now I'm sat in the Bradford Royal Infirmary in an area called Manningham. So Manningham's a very deprived area, but its an area that's predominantly South Asian in heritage. Now to the south of the city, we have an area called Holme Wood, equally deprived, but it's predominantly white British in heritage with quite a large Roma community within it. Now, a policy that works in Manningham almost by definition is not gonna work in Holme Wood and sort of vice versa. Now I cycled in today from an area called Wharfedale and that's again, predominantly white, British, but now very, very affluent. So again, policies that are fit for purpose in Holme Wood or Manningham them, aren't going to sort of land appropriately with, within Ilkley. So the question is, how can we take policies, you know, so, so saying you've got brilliant sort of local government trying to make sort of people's lives better and they'll often want to enact particular policies. The question is how can we then tailor those policies for the context of those individuals in our communities? So we've been using our connected data sets to really engage with those communities to first test our understanding of these sort of other places, because sometimes the, the, the view that we have, you know, within, within local government or central sort of government might not actually tally with people's lived experiences. So for example, in one of our areas, it looks like they have very, very low burglary rates. Well, actually it turns out we have really high burglary rates to the extent where people don't bother reporting burglaries anymore. You know, so a quick look at your sort of data can lead you to misleading conclusions. So really important to test your data set with those communities. But in that process, you can then start to, you know, effectively create a sort of a map of a sort of a place, and start engaging with communities and saying, well, this is to us, what looks like is happening within your area, and some of the priorities. And then you can engage those sort that are communities to really start understanding what their priorities are

and where they see this sort of a potential to, to, to drive sort of a policy change. So we have a program of work that we call Act Locally, which allows us then to go into those specific areas. And we've a particular methodology where we base everything around food. Food security is, quite, quite a big sort of issue for a number of our more disadvantaged communities. So we go in and we help with community sort of meals. And we start to talk about data, sort of science, using the analogy of cookery. So we then work with those communities to start helping them sort of understand what the different ingredients that you need in order to, to create sort of successful policy. And then we work with them to create a sort of recipe. And then that sort of recipe has some very sort of a clear, you know, outcomes, meals, if you like that they want to produce. But that sort of process turns out to be very powerful and we start off just very local, so just get people in their sort of comfort zones and then we bring in more people so in the end we have very senior policy makers coming to join with the sort of community to talk about the place and the policies within that sort of place and how they can now be sort of tailored on the basis that connected sort of our data, so that they're really fit for a purpose for those individuals who live in that locality.

COUNSEL ASSISTING

Commissioner, I'm conscious of the time. Did you want to touch on anything at this point before we move on?

COMMISSIONER

Yes, I would like to. I just want, you've done a great job describing Born in Bradford and Connected Bradford. Can I just be clear for the record, how many people's records are the subject of these connection processes in Connected Bradford?

PROFESSOR MON-WILLIAMS

So it's a Venn diagram because we have different data sets. So probably our largest sort of our data set is several millions. We have all the ambulance service sort of our data. I don't know how it is in Australia, but here we have different, different services have a different footprint. So, we have, so you can imagine a venn sort of diagram. So for probably, for about 700,000 sort of our people, we have all of the various sort of mixes sort of our data. So let's, let's say everybody who lives in the Bradford sort of district, we have all of their data, but, you know, we have fuzzy boundaries. Like, you know, if you looked at Google map, you work out where one area sort of stops. So, so you sometimes have a child who lives in this area who goes to school over on the other side of the boundary sector. So our data set contains, I don't know, maybe one and a half sort of a million individuals, but there's a sort of subset about 700,000 of our Bradford sort of citizens for whom we have all of the connected data.

COMMISSIONER

Right. And you spoke before about the community consent involved, the individual consent. On the other side of the table, was it hard to get the various information holders, you know, the GPs, the schools, the police, to even with, when you could evidence individual consent to make the data available? Was that a hard process?

PROFESSOR MON-WILLIAMS

Yes, exactly and it's a really good sort of question. And I think it's really important to actually sort of almost think in, in three levels. So if you go to an individual school or individual police officer or a health sort of visitor, they're desperate for this to happen. I mean, they are so frustrated because they see the complex issues playing out in children on people's lives and their inability to connect with their fellow professionals to work together is a constant source for frustration. So it's very, very easy to get people on the ground. I mean, in fact, they're just, you know really sort of championing this. It's also relatively, so not that easy, but relatively easy to get, so I work very closely with Kirsten England, who's the CEO of our local authority, passionate advocate for all of this work, because she can clearly see how this can help her, you know, tackle some of the really wicked sort of problems that are playing out across her district. But there's also that middle layer of the people who actually hold a particular sort of data set where sometimes 'computer says no' is the easier response to give. And actually we found that sort of a pincer movement, so kind of getting sort of people on the ground to start sort of driving forward some of the desire for sort of change, but then having individuals who can unblock this, has been very, very sort of very powerful. What I would say is I think we've got quite good methodologies now that we'd be very happy to sort of share about maybe perhaps you might call it a playbook or sort of cookbook about how to engage with the relevant sort of people. We've made lots of mistakes. It's taken us a long time to get here, but I think we've learnt from those mistakes and we've got a pretty good idea now as to how other areas could and should go about this approach. But, but you're right, it wasn't easy. We have been very fortunate to have good colleagues down in Bristol who haven't managed to link in the health data, but did manage to link together local authority and police sort of data and start using that to retransform their services. And that's just been a fantastic piece of work. We're now working with them to help them get health into, into their sort of data system, while they're sort of supporting us to actually create a tool that our practitioners can use to sort of share the, share the sort of our data. But they did sort of something really sort of smart, which is find new legal sort of pathways for sort of our data sort of a sharing cause what they pointed out was, well, they basically found all of various bits of legislation, which placed responsibility on various organisations as to what they had to do. And then they just flipped everything on its head and said, we cannot carry out our duties if we do not share information with this organisation. And then the question they put to their lawyers was 'can we share information on that basis' to which of course the answer was, yes, you can, if you like, if you cannot meet your statutory responsibilities without sort of doing this, then there's a perfectly good legal pathway. So that, that was sort of transformative when we started being able to frame things in that way.

COMMISSIONER

I'm just going to come back to what you've said about the legislative framework in a minute, but just before I do, apart from the will to do it, did you have to build, you know, technological solutions? I mean, I imagine this data in many people's hands is being updated, you know, in real time there's another ambulance call out or there's another, you know, incident at a school of, you know, chronic non-attendance or something like that. I mean, how has it made easy for the data collection, people, you know, who are on the ground with proper jobs, things they're, they've got to be getting on with to also interface and get the data through?

PROFESSOR MON-WILLIAMS

Yeah. So I guess it's relatively for us. So I sit here in Bradford Royal Infirmary where we already hold all of the medical records. So we've got a very secure data environment. I mean, this is perhaps the most sensitive sort of information that exists anywhere we, we could argue. The National Health Service is very well respected and trusted. So that, that also, I think, was sort of relevant for us. So people are much more comfortable sharing their data with NHS. And we have great big servers that can easily just sort of better pull information through. And actually technically it's very, very straightforward to run. Once you have the data sharing agreements in place, actually the technical elements of it, I'm not trivialising it, but they're really not that sort of difficult. This is, this is, you know, in 2023, this is not difficult to, to sort of have sort of real life sort of data streams coming in and the data be linked. So yeah, that was a big advantage for us, the NHS. I mean, I am thinking about how we do this sort of nationally, and I do think one important principle - So I sit on the, the Cross Whitehall data improvement across sort of government sort of a group. And a lot of the thinking there started off originally trying to think, how'd you do this sort of nationally. And I think we've sort of gone away from that. And I would argue strongly that it, you're better to do it sort of district by district. And then, and then sort of bring it up for sort of at a centre. Otherwise you start, you know, if it's very top down, you start getting interoperability sort of issues where typically districts have pretty good data infrastructure for us, as I say, particularly around the NHS. So you can then use that as, as a sort of building block, and then, then you pull everything into, into that sort of place and then sort of share that, that upwards, if that makes some sort of sense.

COMMISSIONER

Yes, yes, it does. We had a discussion earlier today, our time, about the difference between data collection systems that are under a legislative framework where people have got a duty to collect and a duty to share versus dealing, with a research program where you've got an ethic committee style approval. From what you've said, and I just want to confirm this for the record, you haven't purpose, you haven't sought purpose specific legislation to enable all of this information to come together. What you've done is you've utilised current specific legislative frameworks. There might be one for the police, one for the NHS, one for education, but reimagined how the duties is that those organisations have, can only be realised if they do data sharing and you've got legal advice that that's all sufficient.

PROFESSOR MON-WILLIAMS

That's absolutely correct. And you also make very important sort of pointer as well, which is there's one sort of data set, but actually that data set can be used for two purposes. So one sort of purposes is to connect our practitioners on the sort of ground and allow them to deliver to their public sort of services more effectively. And that then requires the data be anonymised if, sorry, to have a sort of, to, to have a sort of name and sort of attached to it. So that if I know paediatricians particularly concerned about a, child, they can then find out what the sort of police's or social sort of cares worries are potentially around that sort of about a child. So that's, that's one really important use of the connected data set, but the other use is you can then pseudonymized the sort of data and use it for research sort of about purposes, the same sort of data set and the pseudonymized data set. Then you just put all kinds of safeguarding in place. So as a researcher, I can never get even down to a small sort of group of individuals. I can never get to any way of actually identifying individuals within it. So two very distinct sort of purposes. And as you say, the research sort of side, well, then you've just got all your standard research sort of governments and ethics committees, and all of the great infrastructure that exists to protect people within that sort of area. and then as you say, the other aspect, which is public service sort of delivery, for us has been covered by existing legislation.

COMMISSIONER

And if I could just follow up on that, we discussed quite a bit earlier today, the difference between, you know, anonymised public health style data, you know, enabling you to see that in a particular community, perhaps one domain of child development has gone forwards or gone backwards and then make a set of policy decisions based on that. We talked about that, but we also talked about the real time joining up of data sources so that someone working with a family would have a more complete data set. And from the point of view of the family, they wouldn't be constantly retelling the same story, you know, that perhaps their child was diagnosed with this health condition, but there's also, you know, these issues in the family and, and these issues with school attendance or whatever. In our discussions earlier today, we did talk about the potential that people might be more resistant to that kind of joining up, because it is, it does mean that a series of services that they connect with are going to have a lot of information about them. People may be sensitive about that. They may be sensitive about being stigmatised because of that. You seem to have overcome that, which seems quite remarkable. Can you just talk, talk us through that?

PROFESSOR MON-WILLIAMS

Yeah. And again, I think it's worth sort of saying that, well actually, I, I just come back on one sort of point, and I guess this is the sort of, you know, we all tend to look at the sort of world through our own experiences. So, you are sort of imagining, you know, you are sort of a child, some health sort of a problem so you are going to do everything you can to make sure that every, you know, sort of a service is aware of that. So we often just use health and education as a canonical example. So, my sort of children were healthy, but imagine my sort of child I know had, had sort of deafness. I would've been at the school making sure that the school were properly accommodating my child's needs etcetera, aet cetera. So that's that, that's all great and that's almost why when you look at, you know, rates of autism diagnosis or support

for health problems within our middle classes, there aren't any issues there because effectively we are the glue that sort of sticks the bits of the sort of system together. But as soon as we start going to our disadvantaged communities, that isn't sort of a case. And I think I sort of mentioning to sort of Sarah, so just, just down the road, there are schools here who have, have been about to exclude a child cause that child has never done what the child has been asked to sort of do year after year after year turns out the child was sort of deaf, but the school had no understanding of that at all. Or one of the examples that I gave in the sort of written sort of evidence was glasses and classes. So within Bradford, we're fortunate, we have a vision screen program. So at the point of school entry children come into the school and our orthoptics that have got a team go in and they check the eyes of the children within the school, sort of premise and any child who fails that decision sort of first screening gets a letter back to the sort of a parent. Now people imagine, including sort of middle classes, that information is, is obviously shared with the school, but it's not because that's deemed to be health information that can't be shared with the school. Now that doesn't matter in that area I was talking about before, Wharfedale, this affluent middle class sort of their area. So you look there, well, that letter goes back to this family, the family then say, oh, there's a vision sort of problem. And they take the child out to local optometrist or the hospitalised service child, gets their glasses, child sees properly, childhood development sort of proceeds sort of nicely. But when we look to the data in disadvantaged communities, the third of the children are not going anywhere near the hospitalised service or, or local optometry. We can see this in our sort of our data, sort of our set and that's for a multitude of reason, we do quite a lot quality work trying to understand it, but to a lot of our families, they don't have English sort of spoken at home. So its all well and good sending a letter back or often they come from a culture where you have to pay for health services, and these are disadvantaged communities that can't afford. It's kind of like, you know, oh no, I've had to choose between getting this pair of glasses without a really good understanding why that's sort of important or feeding my family. Or some of our children are being brought up in perfect lives. Now at the point the school know that this is an issue they're fine. They basically perhaps use a family support sort of worker and take the sort of child to the optometrist. But the problem is they can't because they have no information about which sort of children failed that separate screening test. So, it's these type of examples that sort of show you why it's so important, but actually, you know, our different sort of services work, work together. And as I say, actually, what's surprising when you start talking to people about this, you know, we talk, we talk a lot to our communities about sort of data sharing and saying, what, what do you mean? So a lot of, you know, they trust the schools, they trust the NHS and they actually find it really difficult to believe that information is completely sort of siloed between those sort of organisations. So, it's quite surprising when you actually go out into communities actually there's far more appetite for this than you might sort of imagine. But you asked for some specified reflections on how you have those sort of conversations. And for me, it gets back to that point that, that I've, I've mentioned a couple of times before it's about grounding it. And it's about actually explaining what it is that we're trying to do here. Because ultimately these are trusted sort of services that should be sort of working together. It's almost bizarre the way we managed end up with these very, very sort of siloed sort of organisations. And it's taking through, a very sort of specific example, so I think I sort of said to Sarah, SEN (special education needs) and disability and autism are massive sort of issues, and occupy a lot of people's thoughts because our services are just not fit for purpose right now. And being

able to talk to people about how different organisations working together can start to really tackle these sort of problems really then, you know, flips everything on its head. So suddenly this isn't seen as some nefarious, sort of a government sort of approach, it's actually sort of seen as government taking a sensible approach to actually effectively delivering public services. So I think it's very much about framing it and it just goes back to that central point, I keep making it's about taking communities with you, explaining why you're doing what you're trying to do. And actually when you do that, it's, it's, you know, how little resistance there is. In fact quite the opposite is a massive appetite generally. Like why isn't this already happening?

COMMISSIONER

And final question for me at this stage, can you explain the funding source that's made all of this possible. Presumably here has been, well obviously for the Born in Bradford, there would be a series of costs to be doing the checking, but for Connected Bradford, there's obviously the costs of bringing the stakeholders in the community, bringing the stove pipes together, how has that cost been met?

PROFESSOR MON-WILLIAMS

So it's a patchwork quilt for us. So we're very generously supported by the Wellcome Trust, the very large medical sort of our charity for all our Born in Bradford work. Originally it was funded by MRC, Medical Research Council, which is the UKRI's arm for supporting medical research. And then as the children went up into adolescence, the Wellcome Trust picked up quite a substantial tab for us to be able to do that piece of work. But then we'd get quite a lot of different sort of pots of funding. So the Alan Turing Institute funded us to drive forward the Act Locally work. Because it's the national sort of centre for AI and data analytics, they could see the value of not just doing data science, but actually applying data science to important issues. But then we have various other pots. So we're quite generously supported by Department for Education, so a national department for education. And that would be particularly around, for example, the autism work. So they will specifically fund a piece of, of work on that. So as I say, it's a bit of a patchwork quilt. And the other thing that's perhaps worth saying is, we're also, so we sit, you know, we are an NHS organisation, so, you know, that's well supported. Local government. Again, you know, a lot of this is just partnership working that, that, you know, local government already got a team of data analysts, collating all this data, so then it's just a case that, of pushing those sort of data through, but then just joining up, you know, the NHS analysts with the local authority analysts, and there are police that are analysts. So a lot of that then is already sort of funded through those organisations. Does that make sense?

COMMISSIONER

Thank you. Thank you very much

COUNSEL ASSISTING

In terms of the extent to which practitioners can access at present identified data. What's the current scope of that in terms of practically speaking, you've given us an example of, we'll come back to the glasses in a moment, but, but at the moment, if a GP wants to try and look beyond what services might have been accessed within the GP clinic, for example, what identified data can he, or she presently access?

PROFESSOR MON-WILLIAMS

So, that's the piece of work that we've not yet done. So that's the piece we're just about to do. So Bristol have done it. So Bristol have got their data tool, if you like, that allows sort of somebody in police, who's got sort of concerns about particular sort of family to flag those sort of concerns with social workers and with educational authorities. So that's the piece of work that they've already sort of already done. So that's the piece of work that we are now about to do within sort of a Bradford. But rather than trying to throw a sort of switch on all of this and suddenly have, you know, do this right across the piece, what we're doing is actually just sort of focusing in on very, very specific project and that's around undiagnosed autism. So undiagnosed autism is a massive issue for us in this district. And again, it gets back to that sort of point I was making before that it's kind of easier to get everybody on the sort of same sort of page when we actually ground sort of things in a very, very specific sort of, sort of piece of work and a piece of work that people really care about. And, and actually, we, I mean, we picked that because it's a burning issue within the, but the point is you can pick any of any, any area because of really the sort of central sort of technical legal sort of ethical sort of issues are all the same. You know, it's the same principles that you have to play through. But rather than try and play those sort of through multiple sort of conversations and multiple stakeholders for us, it's been much easier just to focus it in, on this specific sort of topic and then play everything through here on the grounds that once that's all up running and we've sort of proven sort of principle it's then fairly easy to then just start, you know, migrating that to, to, to other pieces of work. So, sorry there's a caveat to that. So we have done some of this, but with say Connected Brad sort of data sets. data sets that we've already got with specific consent around them, but in terms of just generally using the Connected Bradford data set to do that, that's what we're just about to do with, the piece of work around undiagnosed autism. And there's a couple of sort of massive advantages to that we sort of a feel. So one sort of huge advantage is we've shown that education data are real indicator of children who have undiagnosed autism, but not currently getting their needs met. So actually being able to come at this through the education, sort of data and trigger multidisciplinary teams who can then go into schools to assess those sort of our children, is going to be very, very, sort of very powerful. But the other thing that we think is going to be very, very powerful is, our paediatricians or our child psychiatrists, not just seeing a sort of child for the sort of first time and not really having any understanding of how that sort of child's sort of their issues are playing out in their normal environment, being able to pull through all of the educational records, that show actually how that sort of child is coping within sort of our school. So, typically right now, when a child turns up for an autism assessment, it'll take a couple of weeks and a large amount of time. It's just trying to understand how that sort of child behaves in their normal environment. Of course, this is typically happening in a hospital, right in a hospital ward where sort of children already not sort of behaving in, you know, in a normal way, because it's

an alien and, and somewhat strained sort of environment. So the ability for our paediatricians or child psychiatrist to pull together those incredible sort of insights from the school we think will really start sort of speeding up sort of process. So that's the, the, the, the first piece of work that we're doing

COUNSEL ASSISTING

Is an end point then you'd like to get to one in which a practitioner is able to look into a particular, just stick with a medical example at the moment, but they're often easiest, is able to look at the person presenting to them and rather than having to, having to take perhaps an entire history again, from that person, they might be able to access records that might indicate, for example, what other mental health service has been offered before, who they've seen, whether a referral was taken up, uh, cetera, is that, is that really a high point that you would hope to get to?

PROFESSOR MON-WILLIAMS

That's very much our vision and where we're trying to get to in the shortest possible time. Its perhaps worth just sort of saying you know, of course, with appropriate sort of safety measures within that. So I'm not talking about any practitioner being able to access any information, but rather practitioners, you know, so within our schools who already have sort of people handing really sensitive information around sort of safeguarding. So we're talking about those individuals being able to see relevant information across other services where other professionals are flagging their sort of concerns. So I think we talked about this before Sarah that every serious, and I put it my written evidence, that every serious case review that we have in the UK almost inevitably starts with the words, 'if only this organisation had shared this information with this other organisation'. It's just, you know, it's literally costing children's lives and there is just no excuse for it in 2023. We should be able to automate a process. And one of things that we can see in our data is, you know, the threshold to get onto a particular sort of service's books is really quite high. And that's just because the need is really going up. So there'll be a lot of children that social care are really quite concerned about, but they haven't quite hit the crisis at a point that means that they act. Yet when you zoom out and you suddenly realise, hang on, the police are also really concerned about that sort of child and the school is really concerned about that child, and the paediatrician is seeing that sort of child turn up in accident and emergency, suddenly, although that child hasn't hit the threshold on any individual service, suddenly you can, you can leap to action. And often of course, that's the point of which you can often work with a family because once, you know, once the wheels really come off and that family's in crisis, it's so difficult to really try and get that sort of family back on sort of track. So it's very much our sort of vision that trusted practitioners within single organisations can start to see and share relevant information with other similarly trusted professionals.

COUNSEL ASSISTING

You've explained that up to this point, you have facilitated the, the current level of data sharing within existing legislative frameworks. At least in your jurisdiction, do you envisage that you could reach the end point without further substantial legislative reform.

PROFESSOR MON-WILLIAMS

Yes.

COUNSEL ASSISTING

And is that because of some of the features you teased out earlier that, that at the moment, a lot of these agencies have their own robust frameworks and, it can be reimagined as an integral part of, of delivering your particular service, to responsibly share information.

PROFESSOR MON-WILLIAMS

Yes. And perhaps even going beyond that, actually currently organisations, you know, are breaking the law, if you like. That actually they're unable to meet their legal responsibilities because they're unable to share information. As I say, what Bristol did brilliantly is go through all the relevant laws and sort of say, if this information isn't shared, then there's you know, a clear sort of case that we're not meeting our, our responsibilities.

COUNSEL ASSISTING

I'm interested in teasing out some of those examples you raised in, in terms of you painting a picture for us as to what changes or, or what different directions that the work of Born in Bradford was able to steer. And if we go back to the glasses in classes example, was that an example of, of born in Bradford staff, looking at education level data and trying to be creative about what it was suggesting in terms of reading difficulties?

PROFESSOR MON-WILLIAMS

So well,, so looking at two data sets, that's a really important point. So, you couldn't see this just by looking at health data and you couldn't see it just by looking at the education sort data. When you put those two data sets together, you could suddenly sort of see the interconnections and interactions. So big problem, within the Bradford district, are the poor levels of reading. We're far below the national average to the point where the Department of Education actually set up a specific initiative. There were 12 areas I think, the opportunity areas. When Justine Greening was Secretary of State in the UK she selected the 12 most disadvantaged areas from an education and social mobility perspective, and then sent in sort of teams and put funding in sort of place to try and tackle the issues that were sort of playing out in those areas. For Bradford, the inability to learn to read in a timely fashion was a massive problem so we were tasked with trying to understand that sort of problem. So we could then look across health and education, and we could look at the sort of children who, who were really sort of struggling to read. And what you could see there is that large numbers, those sort of children I described previously, who had been identified within health as having a vision sort

of a problem, but that then never got a pair of glasses, effectively and what we could then show is that those same children were way below the reading age of the children, of their peers effectively, including the peers who did get the pair of glasses. So it wasn't the visual deficit per se it was the fact that they had a visual deficit, which wasn't being corrected. Now that was game changing for us because, you know, I get on very well with the Department for Education, but prior to that, whenever we were having conversations, with policy makers about that, they'd say, yeah, we sort of know, but you know, that's really that's health, right. Eye service is their health and we've really got to focus on reading and writing. But of course, the point at which I could go back and say, look, you know, that reading that you really care about that's being directly impacted by these children, just not sort of seeing. Suddenly got sort of people realising that actually going that's a health problem and not an education sort of a problem isn't, you know, a sort of tenable sort of argument. And it was game changing because suddenly our Department for Education and our Department for Health and Social Care started coming together to say, oh, actually, maybe this is an area that we should be collaborating around. And what we could then do is sort of a trial where we could then sort of, connect up the health and education. The school were then aware of which of our children weren't getting their pair of glasses and then we could work with the schools that those sort of children then had two pairs of glasses, one to take home, one to stay in the classroom. So then we could do some CPD within the schools, the school understood why it's really important these children wear their glasses when they're in a classroom. And then we could show that that had a positive sort of impact on, on those sort of our children. And interestingly, the positive impact is both in terms of their visual development, right, that's health, but in terms of their reading, right, that's the Department for Education. And, you know, there's lots of different examples like that, but it's just a nice way of sort of demonstrating you cannot cut a child in the middle and say, that's the health bit over there and that's the education bit over there. These things are intrinsically sort of joined up. We've got a great big neon sign in our building which says 'everything is connected' to remind us that everything in a child's life is connected, but unfortunately our public services often are not sort of connected. And for us, that's the power of the sort of a data – you can start just to connect with different sort of services and take a genuine whole system approach to supporting childhood development.

COUNSEL ASSISTING

That data linkage enabled the trialling of the supply of two pairs of glasses to, to various children identified from or selected from various schools. Is that something that's been able to be scaled up nationally? And, and if it has, what insights can you share with the commission about how best to scale up or roll out these types of programs?

PROFESSOR MON-WILLIAMS

Yeah so when we first got the sort of positive results back, we trialled it across hundreds of our schools and the immediate response of the Department for Education was 'fantastic, let's do this nationally', which is great, right? I mean, that's what you want to hear as a scientist, but actually we tried to roll them back a bit. Again, that point I made before, which is, is that, you know, different areas have different sort of context. And you know, within the UK, actually just

the way that we organise our health services differs. So in fact, you know, family services fall under slightly sort of different jurisdictions in different sort of other places. So actually what we persuaded the Department for Education to do was actually roll that out in different localities around the UK first of all, just so we could work through what the principles, and the principles are the same, but what would it look like within this area in terms of their ophthalmic service sort of provision versus this other area? And that was really powerful. So we did that and we worked across sort of six different areas this last year so we could properly understand how you would make the basic principles work under different organisational structures, which then, I think, will get us to where we want to go, which is the, you know, the national coverage, but in a way that properly recognises that different areas are configured in slightly different ways. And for us, within the Centre for Applied Education, that's very much our goal. We proceed in a sort of scientifically rigorous sort of manner. I mean, sometimes it's, oh, this is great, this is really exciting, let's just like, you know, do this sort of nationally. And often you get one shot at that and then it's 'why didn't it work', so for us, it's very much, and it's frustrating sometimes, especially for policy makers, who are 'let's just do this now' and it's like 'no, just wait a year', let's work out, you know, so it's really promising findings, fantastic, but now let's work out how you actually make that really sort of successful in different localities. And then you'll get to where you want to go you know, sort of faster. Sorry, did that answer your question, Sarah?

COUNSEL ASSISTING

It did. Yes. In relation to both the, the glasses example you gave us and also the, the data linking that's being done around risk of autism and accessing educational records in your written submission, you speak in both cases of taking services into schools. So, optical tests could be undertaken in schools and glasses could be provided. And in the case of the autism workers, I understand that clinicians were sent to the schools rather than children being taken out. How significant is that taking of the services to a local community in your view, in terms of, of the, the successful delivery of these types of services?

PROFESSOR MON-WILILAMS

So I think it's absolutely game changing and we saw that, I mean, we have the evidence for it. The autism program was unbelievably successful. So to put this in context, pre pandemic, you thought that taking your child out of school and trying to get them up, you know, to the hospital I'm sat in right now, isn't that smartest idea. You know, we've got quite a lot of diseases in hospitals typically. So again, you know, for your average sort of middle class family perhaps it's not so bad, they can come up and they can pay our extortionate parking fees and they can, you know, take time out of their schedule. But again, for some of our disadvantaged families, just finding their way up to the hospital, you know, lot of our families, taking a day off work to get a sort of child to come along to sort of a clinic is, is huge. Now our assessments often take two weeks, that's, you know, a parent having to take sort of two weeks off to try and get this sort of child up. Well, one of the biggest issues that we have in, in paediatrics in the hospital is, is DNAs, you know, just did not attend, which is costing us a fortune in the health service. You know, just sort of means that lots of sort of families are not having the needs of their child met. There's also particular cultural sort of issues that sort of play out in some of our areas. And

that's the stigma that's attached to mental health services. And a lot of our autism services are delivered through CAMs, which is Child and Adolescent Mental Health services. So families will not engage with CAMs because if their community find out their child has a mental health problem, then they will be, they'll be ostracised. So that's a huge sort of barrier, but as soon as we put a team into a school, then actually that destigmatizes it because there's no stigma attached to a child having an educational sort of issue. So suddenly what we found is we had a hundred percent attendance rate from families where we know that actually if we're bringing them up to the hospital instead of our CAMs services it would have dreadful attendance rates. So it's absolutely sort of a transformative, but also of course what's happening is delivering services in the child's normal habitat for want of a better word. Children are comfortable there, which means that the clinicians can really observe the child in a much more satisfactory sort of setting for carrying out an assessment than is normally the case when we bring them up into our clinics. So normally two weeks for us to carry out these assessments. What we found is these assessments could be conducted in one day within the school.

COUNSEL ASSISTING

That's the autism assessments? Sorry to interrupt you.

PROFESSOR MON-WILLIAMS

The autism assessments. So what takes two weeks within the clinic was taking a day within the school setting. And of course the school were able to really participate in that, which meant that they'd prepared their families, because it's very important to carry out that sort of family of interviews during that process. But it also meant that from day one, the teacher's insights could be brought into that assessment sort of a process, but we could then immediately start offering advice about how the school could accommodate that child's needs. So from the moment that our multidisciplinary teams turned up and did the assessment, the school could spring into action and start putting the appropriate sort of support in place. In our current systems, they come up to the hospital, have their two week assessment, and then you get put on another waiting list to then start sort of thinking about how, how the child's needs could be sort of supported. All of that suddenly happened in one place. So for me, it's incredibly important to start exploring how, you know, we're not going to relocate hospitals there, but there's just huge amounts of benefit in starting to deliver services within schools, especially in our most disadvantaged communities. And of course, schools are, you know, the place where, you know, Monday to Friday, nine o'clock to four o'clock, you will find children and young people. If you want to effectively engage with children and young people, they're a pretty good sort of, kind of place to start. So for us, this is, yeah, really, really important, really critical.

COUNSEL ASSISTING

Would you say that the, those local linking of services to particular communities has been just as important for the enduring legacy of Born in Bradford as the, the linking of data?

PROFESSOR MON-WILLIAMS

Absolutely. I mean, at the end of the day, this is all and people can, the data is essential, but effectively we're just talking about people communicating. I mean, people think about data and like GPT-F and all this sort of, you know, sort of clever sort of fancy stuff. Actually what we're talking about is just what used to happen, right. And, you know, I'm old enough to remember when, when, you know, you just, you know, the clinician would just pick up the phone to the school teacher and social care worker, because things were smaller and easier to manage at that stage and you'd just have a conversation. All we're talking about is using modern technology to start dealing with sort of some of the pressures of everyday life to allow those sort of conversations to happen. The end of the day, this is just about connecting people so that people can work together effectively to support the needs of a child and young person. You know, you know, at the end of the day, the social care worker, this teacher, the health visitor, they all want the same thing, which is to support that family, see those children thrive within their communities. The problem is right now, they're all operating in silos, almost tripping over themselves to try and provide support to these families and the data is just the way of connecting them up. There's nothing particularly magical about the sort of data. I prefer almost the word information, just about getting that information sort of sharing happening across our, our services.

COUNSEL ASSISTING

Professor, I could ask you questions all day, but I'm conscious of the time. So I'll throw over to the Commissioner.

COMMISSIONER

Just really one question. Thank you for all of that. But in the connections that, that have been built, is there a connection to early childhood education and care? I mean, obviously the remit of the Royal Commission, and we are thinking about, information systems from the point of view of what is learned about children and also what is needed for children's development in the zero to five age range. So, you know, obviously in the youngest age ranges, there are series of checks that are normally carried out and people are quite connected to that system. Then you know, people with their return to work can be connected to the childcare system. Currently in south Australia, we have universal access to preschool for four year olds. So people are connected to that system. Many people would connect to an early learning program in addition to that now, but there's not universal access, that's one of the things that the Royal Commission is thinking through. So, you know, what line of sight would people working say in early childhood, an educator in preschool or a community nurse who's doing a child check for maybe a 12 month old, how would they be connected with the system that you describe?

PROFESSOR MON-WILLIAMS

So, I mean, that's just a microcosm of the problems, in fact, things are even worse, sort of zero to five. At least when children get up into mainstream education, there are some structures, but for us in the UK that sort of nought to five is like the sort of wild west where our health services

have got really important insights, our social care, our nurseries and it's very, very sort of disconnected. So for us that nought to five and, and all of our evidence, one of our specific MRC programs is called Act Early because it's our belief that the earlier that you act the greater the potential to really change the needle on some of these issues. So for us, that's where the biggest sort of prizes are probably on offer in that sort of preschool. And the other point to make is that often there's really rich information that's collected in those first few years of life, and then it doesn't get passed on to school and that's just that's criminal effectively. So, let me just give you an example from one of the pieces of work that we did. So, we are really into co-production. So one of the exercises that we did sort of pre pandemic is we brought together a whole bunch of educational practitioners and said, look, we've got all the health data, we've got all the education data. What are the questions you would love to sort of ask on this? And actually a couple of the sort of questions that people came up with were they were really interested in the impact of pre term at birth on children's development and they were really interested in age at point of school entry. So England is really rigorous that this sort of, you know, sort of arbitrary sort of cut off point, that's the time your child has to go up to school at age four. Which means of course, that actually the oldest child is 11 months older than the youngest child turning up to the school in this sort of place. And our education colleagues were sort of saying, there seems to be quite discrepancy there. Can you, can you do some research on this? Well, we already knew a lot of the research, so there was already quite established that actually younger children at the point of school entry have a smaller sort of a risk factor of adverse sort of outcomes relative to the older sort of children. And of course, it's well documented that children born very sort of preterm are at elevated risk of a number of problems that impact on their development. But what we realised is that actually there were a large number of children within Bradford who had what we called the double disadvantage. So, had they been born on term they'd have ended up going to school a year later, but because they've popped out maybe sort of three weeks early, they basically had marginally elevated risks because they were born three weeks premature, but they were now going to school a year earlier than they would've been if they managed to hang on in there for another sort of three weeks. So we then said, well, what happens there is these children get absolutely hammered in the education system. It is this sort of double disadvantage. But then what we realised is that this information that we could see, we could see these children were being born prematurely, this would be really useful information for people within the nurseries to know about because this child is at elevated risk of special educational needs type sort of a problems. But the nurseries have no information. Again, if they're lucky, the parent might flag that up. But even our parents, even our middle-class parents typically don't think to volunteer that information to our nurseries, even though it's really invaluable. And then all of that information gets lost as children go up into school. So the school are sort of going, this child seems to be sort of struggling in that reception class. And then, you know, it's not until the end of primary into sort of secondary that somebody goes, hang on, this sort of child is really not thriving. But we could see it right back there. This child had got elevated risk. So that's incredibly invaluable information that could really allow us to put support in place from the outset to support that child's needs with all of the evidence that, that won't allow that child to sort of, you know, stay on a, on a normal sort of a trajectory and all the evidence that if you don't put that support in place, that child's just going to fall further and further behind and have all of these long term life sort of consequences. So I'm really delighted that you are looking at

that nought to five year period, but I would sort of say that everything I'm talking about is really, really relevant, if not more relevant to that sort of a stage.

PROFESSOR MON-WILLIAMS

Thank you. That's very helpful. Thank you.

COUNSEL ASSISTING

I have no further questions specifically, Commissioner.

COMMISSIONER

No, no, I have no further questions either, but that's been absolutely fascinating. Thank you so much for making yourself available and for everything that you are doing. That's certainly been a great way to end what has been a big day talking about data and information systems, but very, very useful. So thank you so much for getting on the line and for your submission.

PROFESSOR MON-WILILAMS

No, it's great, as I said to Sarah before, you know, we hope that we can stop other people making some of the mistakes that we made. We are passionate about this. I mean, we can sort of see the difference it makes to children and young people's lives. And anything we can do in our community to stop some of the bad things that are playing out over this next then count me in. So if we can ever help with anything, do just let us know. And can I just say you've done very, very well. I know it's the end of your day now, so I'm not sure which is better, but I'm waking up, you must be falling asleep now. It's been a real pleasure to chat to you and just tell you a little bit about what we're doing. And I say, if we can help at all in any way, please let us know.

COMMISSIONER

Thank you very much. That's fantastic. Thank you. Thank you Professor.

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