Signs of Hope
Signs of Hope: Deafhearing Family Life

By

Donna West
For Martin Hughes and Winifred Joyce Hopkins
What use is a book without pictures and conversations, what use is research without image and story?
—Hedy Bach, 2007

As long as we have deaf people on earth, we will have signs
—George Veditz, 1910
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(Brigit)

This book tells a story of a narrative inquiry into deafhearing family life. It involves three families, who, over approximately four years, taught me about their lives. We embarked on the inquiry together as an act of political counter-narrative (Andrews, 2002; 2004) to commonly held, mainstream assumptions about, and hegemonic discourses of, deafness, of sign language and of family-life experience. In doing so, spaces were created that respect and acknowledge human beings—adults, children, deaf, hearing—as storytellers and that recognise narratives potentially as political and performative resistance to marginalisation, prejudice and ignorance. With a nod towards Deafhood and Deaf Theory, and a feminist-orientated, culturally sensitive methodology of collaborating with participants as equal, agentic and creative, this book re-presents stories of family life framed largely as resistance narratives. Deafhood (Ladd, 2003) seeks to address the power of discursive systems in which deaf people are talked about as broken and requiring normalisation, integration or cure, and draws parallels with postcolonial theory and minority cultural studies in order to counter the dismissal of deaf lives as lacking, impoverished and pitiable. Deafhood also celebrates deaf people’s cultural strategies of collective, artistic, performative and political resistance to what is often perceived as the never-ending campaign of science to end the ‘scourge’ of deafness. Deaf Theory (Bauman, 2002) casts a philosophical lens over the deaf body to acknowledge sign languages as textual, and the deaf person
as a visual, tactile being with an alternative sensory orientation to the world. Narrative inquiry, as a postmodern methodology, opens up dynamic spaces for deaf and hearing people to tell stories and to construct meanings woven from their personal and collective biographies, histories and cultures. The narratives at the heart of this book reveal not only the ways in which damaging and hurtful definitions of, and discrimination towards, deaf people and signing deafhearing families is troubled, destabilised and resisted, but also how pride in, and celebration of, deaf lives and sign language are affirming and essential for family life, together with a desire for this intimate, cultural, social and political re-visioning of deaf/deafhearing life to be heard.

For many of us, deafness represents loss, silence, being without, becoming lost. For others, being deaf is a genetic quirk or happenstance, an opportunity for learning, for spiritual adventure and reward. For yet others, it is the most natural thing in the world; a coming-together of generations of deaf people, a connection to a genealogical layer of signing ancestors, the continuation of a culture and way of being. Today in the UK, the majority of deaf children attend mainstream schools (some with specialist teaching, resource bases or communication support), have cochlear implants surgically fitted when they are very young, and will have little or no contact with deaf people (Mathews, 2010). There are however deaf children born every year into families who are curious about sign language, who have the resources and/or capital to investigate and pursue alternatives to medical intervention, who feel morally, philosophically and spiritually compelled to embrace ‘difference’: families where sign language is learned and used in the home, where generations come together to celebrate what a deaf child can teach her siblings, parents and cousins, where the arrival of a deaf baby is not met with grief but with a strengthened sense of connection and continuity. Amid the noise of the normalising disability discourses of the medical and popular media, the snail’s-pace and tokenistic recognition of sign languages and the legislation concerning embryo screening, diagnosis and (non)selection, there are family voices demanding to be heard—whether spoken or signed—that challenge or reject audiological and surgical intervention, that call for scrutiny and critique of ‘inclusive’ pedagogical practices, that rail against the marginalisation of members of minority cultures and ‘muted’ groups.

Within the majority of empirical research on deafhearing families, a distinct, medical/disability chronology—diagnosis, confirmation, intervention, communication, education placement—is detectable. A great deal of attention is usually paid to the period of time immediately
following the diagnosis of deafness in young children, the early experiences of (hearing) parents, and the subsequent ‘coping’ strategies that are employed (Calderon & Greenberg, 1993; Feher-Prout, 1996; Roots, 1999). Reactions to a diagnosis of deafness have often been described in terms of loss and bereavement (Kurtzer-White & Luterman, 2003; Vijaialakshmi, 2010; Valente, 2011). So ingrained is the assumption that (hearing) parents will grieve, become angry, go into denial and then accept their child’s deafness, that according to Gregory (2004), mothers in particular who do not go through these stages are often viewed by medical and educational professionals as pathologically deviant.

Due to the relatively recent implementation of nationwide newborn hearing screening programmes (NHSPs) (Young & Tattersall, 2005), deafness is now usually diagnosed and confirmed within ten weeks of birth (Young, 2008). Intervention measures are then put in place before the child is six months old. Screening by medical professionals usually takes place in a hospital setting; the family becomes ‘medicalised’ (Valentine & Skelton, 2003; Mathews, 2010). The thinking behind such early diagnosis is that it is a good thing to know your child is deaf as early as possible, in order that adaptations can be made, and services put in place. However, as Young (2008) highlights, there is an assumption that any grief experienced (if at all), will be less the earlier parents find out. This is countered, however, by the risk of harming the bond between new mother and father and their newborn (newly diagnosed deaf) baby and does not acknowledge the experiences of deaf parents.

Confirmation of deafness marks the next stage for parents who become intense targets for professional advice (Henderson & Hendershott, 1991; Densham, 1995; Lane, 1995; Luckner & Velaski, 2004). According to Gregory (2004), medical and educational professionals tend to presuppose that there is a right way to do things, and that by not following advice, parents are viewed as having failed (Fletcher, 1987; Adams, 1988). Other studies have uncovered a perceived failing in those professionals, not only to provide comprehensive, non-partisan advice to parents (Young, 2003; Luckner & Velaski, 2004; Young, Jones, Starmer & Sutherland, 2005), but also in their attitudes towards deafness and its management (Beazeley & Moore, 1995; Elewke & Rodda, 2000; Mathews, 2010). Hearing parents become overwhelmed with seductive advice that lacks both relevant, unbiased information and choice (Young, Carr, Hunt, McCracken, Skipp & Tattersall, 2006; Mathews, 2010). There is also evidence that deaf parents, largely overlooked (Nelson, Bougatsos & Nygren, 2008) and further marginalised by early services, feel that certain choices are withheld from them (Young et al, 2006; c.f. Boone, McBride, Swann,
Moore, & Drew, 1998). Despite 21st-century ideologies of parental choice and inclusion (see Evans & Lunt, 2002) there are suggestions that certain provisions for deaf children, particularly signing deaf children, are considered disproportionately expensive; that individual rights, communication requirements and inclusive social responsibility do not comfortably co-exist (see Mathews, 2010). As Young et al (2006) propose, this is in fact less about individual, informed choice and more about the framework within which deaf children are conceptualised.

While researchers are beginning to elicit from hearing parents their experiences and constructions of parenthood (Mathews, 2010), there is still a general paucity of qualitative research with families, with siblings (Tattersall & Young, 2003) or with deaf children themselves (Fillery, 2000a/b; West, 2002). Furthermore, the deaf community, deaf parents (with deaf and hearing children) and sign languages have received little positive attention. Deaf people are still, it seems, viewed by the medical/educational hegemony as members of an ‘alien’ cultural group to which you are in danger of losing your child (Henderson & Hendershott, 1991; Dolnick, 1993; Roots, 1999; Mathews, 2010). Studies of language input from deaf parent to hearing child and the resulting need for ‘intervention’ (Schiff & Ventry, 1976), as well as comparisons with language-disordered populations (Orlansky & Bonvillian, 1985) within linguistic and psychological frameworks define much of the interest. Henderson and Hendershott’s (1991) exploration of the impact of sign language within the hearing/deaf family reveals the weight of the ‘stigma’ of deafness and the way in which family sign-language use merely exacerbates the child’s deviance, while Mathews (2010: 369) records the fact that parents (specifically in the Republic of Ireland) are still advised, “No sign language if you want to get him (sic) talking.” This despite research that has highlighted ‘successes’ among deaf children with (signing) deaf parents compared with those from hearing (non-signing) homes (Easterbrooks & Baker, 2002). This despite the identification of sign language use in the deafhearing home as an indicator of ‘healthy’ family life (Luckner & Velaski, 2004). This despite the ever-increasing numbers of hearing people enrolling for sign language classes and the growing popularity of Baby Signing classes (the philosophy of which is to improve communication and to progress the hearing infant’s language development—Woll, 2008).

Deaf children are a defining family issue. Yet, there are many other unexplored avenues of inquiry. How do deafhearing families interact and negotiate roles and meanings? How do they come to terms with and embrace hearing and deaf cultures within their family? How do they find
their way, given the reported lack of non-partisan advice, information, resources and support? What are deaf parent’s experiences of raising deaf and hearing children? How do biographies intertwine in deafhearing family life? How is the deafhearing family shaped over time?

By asking for stories, I tap into and make connections with the rich oral tradition of deaf communities, whose fragile, unwritten heritage is transmitted through signs. By asking deafhearing families for stories, I also step into the world of interrupted and shifting cultural transmission, where very few deaf stories get passed directly from parent to child and where deafhearing family life embodies the vibrant and complex intersection of identities, languages and cultures. These stories—many of which are included here in this book—range from deaf childhood memories of entirely fingerspelled conversations around the dinner table, through becoming lost in the deaf-education system and fighting for access to school curricula, to imagined futures where everyone signs, where all deaf children learn in, about and through sign language, where they grow up to be parents, teachers, MPs, travellers, writers.

The re-presentation of the family stories as poetic texts is deliberately and sensitively mindful both of deaf people’s varying and unconventional relationships to written text and of hearing people’s (mis)understanding of sign language. The aim is for the words to leap from the page; to breathe life back into the stories in the re-telling.

Take the chapters in any order. The enforced chronology of a paper-based book should not deter you from reading only certain pages; nor should it deceive by giving an impression of a coherent, neat and tidy, step-by-step inquiry that adhered strictly to a research plan. The truth is, like life, research is messy, unpredictable and mostly off the page. These stories layer and lay alongside a thousand other stories that extend and spiral through time. Wherever you choose to start, you will gradually come to know the families while encountering historical interruptions, or intertexts (c.f. Lather & Smithies, 1997) along your way.

I have provided a map of sorts. Bring a compass.
This book has grown from my PhD research, funded by the ESRC, at the Graduate School of Education, University of Bristol. The wise, patient, inspiring, encouraging and supportive people I was lucky enough to work with during that period of time are therefore thoroughly implicated in the writing of this book.

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And Jim, my compass—words cannot express …
Image 1. Family tree: Brigit, Bella, Thorin and Christian

Image 2. Family tree: Georgina, Toni and Thomas

People are like, “Oh wow, how on earth do you cope with a deaf daughter!?” and I’m like, “I’m deaf, hello, I’m still a real person!” It’s not like trying to control a … lion! (Maisie).

Dora, Luke, Harper and Maisie are my *bookends*; we visit them again in Chapter Four and once more in the Epilogue. We began working together in 2006, although we have been telling each other stories for much longer. It formally started with an e-mail exchange between Dora and me. I had contacted her to ask if the family might like to tell me their story on film for a research project I was about to embark upon. Dora replied:

I can say what I have found over the years and it is this. Most of what I have read is looking at young children, diagnosis and early language and as such tends to focus on the parents and their decisions. Most of what Luke, Harper, Maisie and I have been living in recent years has been by feel, instinct and learning by our mistakes—there have been many of those and I am not compliment-seeking when I say that!

Having Maisie has meant we have adjusted how we live in almost every aspect and we have learnt as we go along. There is an enormous impact on siblings. Harper’s life has been altered to accommodate areas that we would never have been aware of and her home life is quite unacknowledged by her peers. Bright young women though they are, they cannot see it. She has to deal with her (inappropriate) guilt every time she goes out and behaves like a teenager because she knows she has opportunities that realistically are not going to be there when her sister reaches the same age. Harper is a sensitive girl and it is a struggle.

You know us very well and you know what we think. I think if you asked our wider family you might get a very different picture of how they see our lives. I suspect some think I “bang on” about deaf stuff—so dull and difficult for family harmony. I have often been told that nobody has a perfect school when I have tried to explain what is on offer for Maisie. Well get real! It makes me very angry that people cannot get it. Others find it easier to give the whole thing a wide berth and ignore it. There are others such as Luke’s sister, her husband and their children who have embraced BSL and as a result us... Dora x
Deafhearing family life: (Not) beginning at the beginning

Dora, Luke and I are sat in the kitchen. We are ready to begin, yet words, strangely, fail us. There are so many memories, anecdotes, performances and stories, we’ve forgotten how to have a conversation. As the kettle gently bubbles on the stove, the usual way we have with each other has evaporated, and we falter. We’ve come adrift in the middle of an enormous, choppy sea of family history. Dora produces a drawing. It is an incredibly complicated, almost incomprehensible family tree; a bewildering scrawl, spaghetti-ed across the page. As she attempts to unpick the partnerships and friendships, the losses and loves, we unwittingly catch a breeze. How has Maisie’s arrival, now over fifteen years ago, impacted on extended family relationships? Dora is on the left, with Luke on the right.

BRAVE SMILES

I think
I mean a deaf member of the family
particularly a child
   As adults
      we’re responsible for the children
         It affects absolutely everything that we do
And not just on a superficial level either
In everything
It affects us
And then
   that can make it sound simple
But it complicates life hugely, just
Socially
   with other members of the family
      with other friends and family
When she was little
it wasn’t the case
because she was little
and little children tend to kind of fit in and
they’re much-
there’s much less need for them to be socially interactive
But as she’s got older
I think probably
We always knew the teenage years were going to be the challenging ones
(Not just because teenagers)
but because she’s a real person now
And there was a tendency for her to be treated like
as sort of
rather an attractive little pet by members of the family
Isn’t she cute?
Yeah she is cute

And grandparents still do
Yeah
But that has carried on
you know
And
An ornament
Yeah an ornament
and they fail to see her as an emerging adult
which is what she is

Or even a person
Because if you can’t communicate
you’ve got no idea who someone is
So it’s a bit like a nice fridge
You can look at it, and say
“Nice fridge”
and that’s about it

Yeah
And to them
having her there
It’s rather like the inclusive argument for schools
Having her there makes her included
Well it sure doesn’t
It actually completely excludes her
in a bigger way than if she wasn’t there
cos you know there’s like a bit kind of you know
It’s just
It’s there
It’s the elephant sitting in the room
and people
It’s very easy for people to carry on and not acknowledge
because she’s not y’know
Some children who have great behavioural issues
and things like that
You know’d be kicking up a storm
and you’d have to take notice
But the tendency is
well she’s there, so she must be happy
because she’s sitting there with a brave smile on her face

And I know
and Luke knows
that actually she’s hating it
and she’s feeling horrible
she’s feeling really horrible

It’s fine when you’re four
and all the kids come round
and play in the sand pit
But as soon as you’re not
the gap increases as you get older
The teenage years
the gap is much bigger
So when people are here
if you don’t sign
Maisie takes herself off
She might
she’ll just go and watch a film
or take the pudding away
or help us do the main course
And it just gets
<LESS AND LESS>

But that isn’t the sum total of the effect
her taking herself away
We’re sitting there going
“Ugh I can’t relax and enjoy this”
cos I know she’s feeling horrible
and there’s this kind of racking of your brains thinking
“How can I work this out
how can I make this work?”
And the answer is actually
you can’t

We have solved it a bit
We just don’t create any of those
situations
so you don’t have any other family around
So
when my colleagues all do Sunday lunches
I don’t  we don’t
cos it would be unfair
Why should Maisie sit for four hours
with other people’s kids running around
talking to their parents
and be excluded?

Or
If you know there are other teenagers around
they’re doing whatever teenagers do and
talking about whatever teenagers talk about
which she can’t get involved in
Or it then transfers the responsibility to Harper
and it’s a burden then
And I didn’t want to … so I stopped myself
but it is a burden
It’s a huge kind of y’know
So it’s something that you kind of carry along with you
and it’s very hard to explain it to people because
they just think we’re kind of difficult
Awkward and
making problems where there aren’t any

Anti-social

Yeah
or making an issue out of it
“She’s fine look at her she’s lovely,
she looks perfectly normal”

Yeah, “nice fridge”

But then that’s a horrible thing because
she’s so bright
that she goes
“I make your life difficult”
And what, what do you say to that?

She makes it different
not difficult

Yeah
Maybe she can’t see the distinction

No … she said I make it more difficult

KNOWING MAISIE

People are often kind of sympathetic
and see it as a terrible shame
and I’ve always kind of railed against that
No it’s not a shame
You don’t have to be sorry for her
So that’s trying to put the positive spin on it
where actually it is difficult but
it’s not a shame
It’s not a shame
It’s not a shame
It’s not a shame
It’s not, erm
but it’s very sad
You know you said before
that people don’t know her

Mmm

Y’see cos we think she’s hilarious
she’s really funny
People don’t know that
Practically no-one can know that

THE THIRD QUESTION

I met a colleague
at the interval at a do at Harper’s school
and I did kind of do a double take when I
saw him in the queue
And so
The third question is
“Where does your other daughter go ..?”
You know
“Got any other kids?”

“Do you have any other children?”

And
That
changes the rest of the conversation
You can hardly say … (laughs)
I suppose I could say no! (laughs)
But yeah, so I say
“Yeah I’ve got a daughter of fifteen”
“So, is she at the same school?”

“You’ll be sorry you asked me that”

And you go
“No cos she’s deaf
She’s at a residential special school”
And then
quite a few people kinda go <JAW DROP>
and the rest go
“Ooh, so can she hear anything?”
“Got an implant?”

“Does she speak?”
“Does she speak does she lipread?”

“Does she lipread?”

And and then
if you actually answer those questions
you miss the second half
And so it’s very difficult

You pick your opponent don’t you?
I mean
that women we met at-
(the neighbours had drinks one Christmas)
Who
The third question was
“Where does your other daughter …?”
And I said
“Deaf, deaf school”
And she said
“Ooh … who looks after her here?”
I said
I said
“She’s not ill!” (laughs)
We do!
We do!
She lives with us
Fuck off! (laughs)

I said
“She’s not ill”
then she …
and then she kind of
moved on to somebody
who was easier to talk to

BANGING ON

The banging on thing is very limiting
because you
you might not wish to go into
That Area of Conversation
You might rather talk about … Rugby

But it’s also used as an identifier
I know that people say
“Oh yes you know Dora
She’s got a deaf daughter”
And they go
“Oh yes I know who you mean”

But, I mean
in you know
in a restaurant
and you know you can hear people
coming up to you in the street
in the shop
Every
Every
Transaction

“Oh I’ve always wanted to learn to sign”
You know (sigh)
“I’ve got something to do, thanks”
We got given a Braille menu at Pizza Hut … 

(laughs)

A COMPLETE UNKNOWN

I don’t know if you knew
but I had no idea at the start of
you know
When I first knew that Maisie was deaf
I had no idea what the future was

No

Not a clue
Not a clue
And I don’t think I even particularly thought about it
You’re so busy dealing with the day-to-day
that if anybody said
you know
“Imagine her as a fifteen year old
sixteen year old
thirteen year old”

I couldn’t do it

No

The picture I would have painted
would not have been the reality

Would you have been able to
paint a picture?

Probably not

No

No

I mean
it feels like it would’ve been
much more of
A Complete Unknown

Yes

I mean
We would have had
various imagined futures
for Harper

Yes
you could see sort of
what was going to happen

Cos we’ve been there

Yes

Very similar to
to our lives if you could picture it

I remember the teacher for the deaf
when she first came round saying
“Now, thinking about school”
And I was thinking
(holding baby)
School?
What are you talking about?
This is a baby, she’s not going to school! (laughs)

OPENING UP THE WORLD

But that’s the thing you see
That’s what I meant about it
opening up this world
The world was there
we just didn’t see it
and it would have been very easy
to kinda go along that rather
narrow
little
path
I don’t know who we would have been
I suspect we might not

We wouldn’t have been
straightforward
I don’t think

No but it would’ve been easy to do that
So Maisie’s made us really stop
and Look. At. Us.
Look at ourselves
I don’t know if she’ll ever know that
I wonder if she’ll ever know that
when she’s older

Two weeks later, Maisie and Harper sat down on the sofa in the living room, ready to tell all, relishing the opportunity to pay tribute, to shout, to joke, to complain. They needed no prompt; it was simply a case of who would start. Maisie is on the left, Harper is on the right.
CLEVER PERSON

I asked mum
what was his reaction
when they found out I was deaf
I was always asking that
   How did he feel?
And she said
   Of course
he was shocked
but you know
   Shocked
Not panic-stricken oh-my-god-quick-cochlear-implant-and-all-that
Like
What do we need to do?
I mean
it was all new to him
the same as mum really

And I always think that
how people react to the deaf thing
that’s part of how we judge
what they’re like      as people
And I think if they’re a good person
a nice clever person
then they’ll understand

PULL TOGETHER

We’re very close
And I don’t think that’s to do with
deaf    and    hearing
I don’t think so
it’s just

Our family
we’re very close
Very tight-knit
and I think that’s to do with
Mum’s family
and they are all very close too
   And I think that’s had
a big influence on our family 
   definitely
So we’re a strong family anyway
and I think that’s really important
that sense of togetherness
But
but also
the deaf hearing thing
I think it’s a very different experience from my friends
It’s forced us to have to pull together
Maybe
I don’t know
It’s difficult to judge how that affects …
What do you think?
Do you think that’s right?
Working so closely together almost forces-
I don’t know …

Well I don’t know!
If I was hearing
I don’t know what our relationship would be like
It’s impossible to know
But trying to imagine what it would be like
that’s really difficult
If I was hearing
what would our relationship be like
you can’t
So …

It made me think about our holidays
and we always plan for the four of us together
and that becomes
more and more important
and whereas other families do stuff
separately
we never do that
that wouldn’t work for us
There’s the communication issue
I feel
I agree
it affects the whole family
The way we choose what-
The way we choose to use our time
We realise how it important it is
to do things together
the four of us

It doesn’t even have to be a family thing
Maybe it’s hearing friends
asking if we want to go bowling
so we’d go
but then go l e s s
and l e s s
And then just stop, going, altogether.
because I’d be sat there
twiddling my thumbs
and every time it would be the same
sat there bored and left out and
Harper’d have to interpret everything everyone said
and mum and dad would be
worried all the time about us
  How we’re feeling
  Are we comfortable?
  Having a good time?
And we weren’t
so we just felt
well …
We decided to stop doing that
and that’s why we’ve become so close
And mum and dad would always feel guilty
saying
*We don’t want to go because of Maisie*
So now I feel really guilty
I stopped them from going out!
So I think that’s become the reason
*One* of the reasons why we’re so close
  Maybe … (smiles)

Our **guilt!** (laughs)

---

**NOT THINKING**

<table>
<thead>
<tr>
<th>When we visited-</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>When we visited our grandparents two weeks ago and we were prepared for a difficult situation But it was really difficult because I had such a huge responsibility to interpret everything But actually we got on really well no getting at each other at all</td>
<td></td>
</tr>
</tbody>
</table>

Normally when we’re with them
we’re at each other all the time
  You know
because the days are so stressful
that by evening time
we’re really having a go at each other
And that’s been because
I’ve felt she hasn’t done a good enough job interpreting for me
and at the same time
Harper’s feeling guilty
because she thinks she didn’t do well
And we both end up
at each other’s throats
and it’s all to do with
Interpreting Problems

But I remember
it was really tough
that time we went on holiday
with them
Two years ago?

Two years ago
The summer before last
And it was

I remember we stayed
Three. Days.

anyway
I had to interpret
and Maisie had to cope with it not being
Good Enough y’know
You wanted more
or
for me to keep up
And by the evening
the two of us would be together
just really fighting
quite angry
It was like
we’d struggled through the day
so by the night time
we just took it out on each other

During the day
we’d be just putting up with it
trying to be patient
and then by the evening
it just all had to come out
taking it out on each other (smiles)

She signs quite well
but he doesn’t sign at all

Nothing
He says
“I don’t need to learn to sign”
Right?
When we arrive at their house
she’ll just start talking away
and I’m like
What? I don’t believe this!
Then painfully start interpreting straight away
as soon as we’ve arrived!
She just
She wasn’t thinking

NICE BELT

Last October
we went to stay at our grandparent’s house
for one night
   And the next morning
   our aunt was there
       And
       Well
We don’t get on with her that well (smiles)
   And we
<TWIDDLE THUMBS STARE AT EACH OTHER>
It wasn’t that nice to see her really
Because
   like with Harper
       she’s always asking her about you know
University and
   things like that
But she never asks me
never asks me about college
   Or
It’s like she thinks I’m stupid
   And
could never do the same things as Harper
So she’ll say things like
   “Oh your hair looks nice”
   Or
   “That’s a nice belt”
A REAL PERSON

That thing about
“Not treating me like a real person”
it’s like
Because people can’t communicate with you
they don’t realise how funny you are
and so then think you’re just …
they miss so much!
And you just think
you’re so stupid!
Why don’t you learn to sign!
you’re missing so much!
I do think that sometimes

And it’s like my cousins’ll
learn French
or Spanish
But it’s not like there’s anyone French in the family
So why won’t you learn BSL?
   It’s only one more language
There’s this *horror* or *p-a-n-i-c*
but it’s just another language
and it’s difficult to learn any other language
So
I don’t get it
   I think
   it’s
   *weird*

STRONG TOGETHER

It’s special
And I think we’re lucky
Always the last-
the bottom line is
We’re lucky to have each other
I think

I know all families have their problems
and our family has had its fights
but those arguments are because of *love*

I don’t know how we could cope any better
I feel really proud that we’ve pulled together
I feel that there are new challenges now
and different situations to deal with
But I don’t feel as if we simply
face a challenge
    then move on to the next
We just
I don’t know how to describe it
but I think
we’re just strong together
We face what comes our way
and deal with it

I think it’s like
a problem comes up
and we deal with it
but we don’t sit there
waiting for problems to turn up
We just get on with things
and if something turns up
we just have to try and solve it
and move on
and you get used to it
Just shrug …

    and move on!

This was 2006. Maisie was 15 and Harper was 17. We all met again
two years later.
INTRODUCTION

DEAFINITIONS

Stumbling at the first hurdle

In writing about writing, one invariably stumbles when it comes to representation of complex entities, or defining the indefinable. This introduction, Deafinitions (c.f. Ladd, 2003) began its life as a glossary and grew from my anxiety over the ability of English text to (mis)represent sign-language-based cultural terms. At its simplest, I worried about how to write the word for the sign that is linguistically glossed as DEAF.

For almost 40 years (see Woodward, 1972), a distinction has often been made in written texts between ‘Deaf’ and ‘deaf’. The former is used as an indicator of a positive cultural Deaf identity; of a sign-language user and member of a visual, cultural, linguistic, global, minority community (see Padden & Humphries, 1988; Ladd, 2003). Deaf people proudly accept and celebrate their sensory status, and use sign languages as their preferred means of communication, interaction, learning, teaching and cultural transmission (Bauman, 2002). The use of the lower case ‘d’ in deaf is often used to describe people who are audiologically deaf, and includes hard-of-hearing and deafened people who do not use sign language as their first or preferred language (Batterbury, Ladd & Gulliver, 2007: 2900).

In A Journey into the DEAF-WORLD (Lane, Hoffmeister & Bahan, 1996), the author note explains that the gloss, DEAF-WORLD is used as a way of recognising the American Sign Language (ASL) sign used by deaf Americans to designate themselves, their relationships and their culture. This is, however, the only occurrence of a glossed term in the text. The authors elsewhere use ‘Deaf” to describe members of the DEAF-WORLD, which includes children, whom the authors view as potential members.

Deaf, deaf, DEAF?

In the last few years, Deaf Studies academics have begun to unpack and contest meanings of the term DEAF (Thoutenhoofd, 1998; Bauman, 2002; Ladd, 2003; Gulliver, 2009). As Deaf Studies finds useful parallels,
frameworks, commonalities and comparisons within other disciplines such as postmodernist feminist theory, postcolonial and indigenous studies (Lane, 1992; Ladd, 2003; Singhellou, 2007; Batterbury et al, 2007), so the accepted terms are scrutinised, rejected and developed. As academia and community link and overlap, other meanings and definitions emerge. In 2003, the term sign-language user was proposed (Jokinen, 2003) as a way of accepting and celebrating not only the linguistic status of deaf signing people, but also their hearing, signing friends and family members. Around the same time in the UK, the British Deaf Association changed the name of its publication British Deaf News, to SignMatters,¹ and its logo to Sign Community: BDA. Ladd (2003) developed and expanded the term Deafhood to describe the process in which deaf people, as members of a previously colonised cultural-linguistic community, engage in the search for their fullest identities. Batterbury et al (2007) coined the term Sign Language Peoples (SLPs) to examine parallels between signing and indigenous communities. In the US, Bahan (2008) introduced the concept of sensory orientation and rekindled the term People of the Eye (c.f. Veditz, 1910). These can all be seen as ways of talking and writing about those people and communities who exist as visual, signing people, as a way to explore Deaf Studies through various other lenses, and as a way to move away from an inherently essentialist deaf/hearing binary.

The muddle of textual representation

In the early stages of the inquiry, when writing and transcribing, I resorted to uncritical, familiar shorthand when writing the word for DEAF. In my mind, at that time, I knew what I meant. I would put off any major decisions until much later in the process of writing. Consider the following examples:

I was saying about that birthday party before, and Maisie was there … and I saw her coping brilliantly, it was an 80th birthday party and some old boy went up to her and went “I’m deaf as well” (pointing to his ear) and showed her his hearing aid and she was going “Yes, I’m completely Deaf!” (hand to ear) but it was a very cheerful conversation (Dora).

My mum is hearing, my brother is hearing, and my other brother is Deaf … (thinking) now … so for a long time there were no Deaf in my family but now more and more, two Deaf, born deaf, now (Bella).

Nick was born, and then we found out he was deaf, and that was actually hard … when I knew he was deaf it was great, OK, can get on with things,
but the family’s reaction was really weird, like Nick’s father’s parents said “Oh no, he’s not deaf!” “Yes he is” and nobody would believe me (Georgina).

I have said to Thomas, “You are hearing, you are hearing, you are hearing, you have lost hearing in one ear, yes, but you are hearing but you have Deaf-inside” (Georgina).

As I read these excerpts back, they feel comfortably situated, to me, within clearly demarcated and familiar contexts of audiology and cultural-linguistic identity. Maisie, for example, would differentiate between herself as a young sign-language-using woman and the deafened, hearing-aid-using man at the party. If she were to re-tell this story to me, she would most likely refer to herself using the sign DEAF, and to the man as DEAFENED. The “old boy”, however, may tell the story, in spoken English, of meeting a young “deaf” woman and of telling her that he, too, was “deaf”. When Bella explained her family to me, she signed that her mum and brother are hearing, and that she and her little brother, Christian are not. I realised, in transcribing this, I was making particular decisions about when to use d/D. I write Bella and Christian as culturally Deaf. They go to a deaf school, and sign language is their primary mode of communication. Yet I drew a distinction at ‘born deaf’ (c.f. Lane et al, 1996). This may be due to the idea of a process of becoming. It may also acknowledge that when young children are tested for deafness, the medical diagnosis is based on audiological assessment. In writing deaf I acknowledged a medically identified marker. Bella and Christian were born to a mother who learned sign language and who has created a bilingual, bicultural home for them and for her other hearing son, who also signs. Am I implying, therefore, that children are born deaf, with the potential to become Deaf? With hearing parents and siblings? And what of Nick, born to Georgina who is at least seventh-generation Deaf. Was Nick born deaf or Deaf? In the final example, Georgina tells me about her hearing son’s cultural identity. As a hearing boy, born into a Deaf family, Thomas—while audiologically hearing—has grown up in a Deaf, signing home and British Sign Language (BSL) is his first language. He has Deaf-inside, not deaf-inside.

I find myself at a meeting point—or point of departure—for theories and real lives. My dilemma is brought sharply into focus as I write about the lives of three families and their social, political, cultural, historical contexts. I am forced to acknowledge both the power and the limits of text.
Troubling the binary

*Personal journal:* Who am I to decide when to write ‘deaf’ or ‘Deaf’? On what basis? Through which lens? From which position? What are the consequences? Am I simply seeing the families I work with in terms of whether they are hearing or deaf and nothing else? My attempts at clarity suddenly appear as loaded terms, particularly as I am hearing (‘Hearing’?) All along, I had been trying to write sensitively, by acknowledging a difference—albeit one I felt less than qualified to explain—and now I find myself uncomfortably positioned within a hegemonic, paternalistic tradition, despite my best efforts to go or be somewhere else.

One of the key accusations or questions raised when writing about deaf and hearing people’s lives is that of essentialism. With a certain degree of shock and irritation at myself for not having seen this coming, I begin to understand the deaf/Deaf convention as one that risks essentialising, homogenising and marginalising individuals because of certain qualities, norms or essences. Butler (1990) rejects the idea of ‘woman’ as a stable, natural subject while Wrigley (1996) warns of the dangers of an essentialised and therefore legitimised (and exclusive) ‘Deaf’ identity. Suddenly, the seemingly innocent, informative, academic practice of writing deaf/Deaf is anything but: it risks creating and perpetuating an ahistorical, apolitical definition of identity that ignores other possibilities. The deaf/hearing, deaf/Deaf binaries are no longer, as Saussure (1983) intended, an effective means to organise and construct meaning through difference. Meanings become definitions. Difference becomes othering. Binaries privilege, creating potentially rigid, unbending hierarchical structures, often generated from an ideological desire for a ‘centre’ or primary term, from which all others are marginalised (Fogarty, 2005).

A baby who undergoes a hearing test will be diagnosed as either hearing or deaf by medical professionals. The social and cultural meanings associated with that diagnosis will depend on the family and the society into which the child is born. In the same way that it is not the biological make-up of a woman that necessarily determines her status, but the cultural interpretation of her identity, so it can be argued that it is not ‘broken ears’ that determine the position of someone who cannot hear, but society’s attitude towards people perceived of as having an audiological disability. Troubling, rather than reversing, the binaries (deaf or hearing? Deaf or deaf?) is reminiscent of Derrida’s (1981) deconstructionist theories whereby binary opposites are destabilised in order to overturn a privileging structure. Focus is drawn away from the centre towards the periphery, and marginality is claimed as a potential source of strength,
creativity and knowledge (hooks, 1990; Collins, 2000). One can begin to question what lies behind established, legitimate terms and practices, through intervention, displacement and disruption. We can consider how a hearing-speaking-normal/deaf-pathological-disabled binary is perpetuated in order then to reveal the mechanisms of medical, linguistic and educational rhetoric and thus destabilise them.

This book offers the stories of families who see and experience “deaf”/DEAF as a cultural, linguistic and sensory phenomenon. The question remains, therefore, whether all essentialism is bad. Viewing deaf communities through a postcolonial lens (Ladd, 2003), it could be argued that essentialism is a positive, affirming and required tool for change. Claiming the identity of an essentialised ‘Other’ (Gayle, 1971; Collins, 2000) fosters solidarity and resistance. That is to say, strategic essentialism (Spivak, 1990) can be used to unify and rally marginalised groups into political action (Nicholson, 1997). An essentialism that focuses on culture, language, sensory experience and minority status can strengthen a deaf community (Wrigley, 1996) that by its very nature does not have a territory or homeland, but rather occupies an interrupted, linguistically embodied Deafscape (Gulliver, 2005).

Scholars have also recently debated various ways to shift attention from what might now be considered outdated ways of thinking, writing and theorising about deaf life. Deaf Theory takes its lead from Derrida’s (1974) concept of phonocentrism (Bauman, 2002; Valente, 2011) and explores constructions of sensory experience, culture and identity in order to offer a more “complete view of human nature” (Bauman, 2002: 2). Deaf Theory views deafkind through a lens of visual and spatial orientation, offering a revised, occularcentric (Thoutenhoofd, 1996) ontological siting on the perceiving, visual, tactile body. By situating itself within a phenomenological space, Deaf Theory explores embodied perception and cultural practices; for example the mythical, physical and epistemological value of light (Bahan, 2008). Combining phenomenology and deconstructionism, a Deaf Theory of sensory orientation can even begin to destabilise and radicalise dominant audiological discourse by exploring a deaf experience of sound (Bauman, 2002). A sensory politics that recognises the deaf perceiving body draws attention away from deaf/hearing, deaf/Deaf binaries and offers instead a theory of a deaf-being-in-the-world.
Back to where I started?

I am still unsure whether I have been on a journey or simply arrived back where I started: how to write a word that represents the spoken “deaf” or the signed DEAF. Wherever I am going, or have been, this text requires some kind of ‘fixing’. While grappling with theories, philosophies, politics and semantics, I keep in mind the three families whose words and signs are at the heart of this book. As I re-read Judith Butler, I recall conversations with Bella and with Thomas about deaf and hearing worlds. As I think about sensory orientation and deafkind, I return to funny, fiery and fertile late-night discussions with Toni on hybrid identities. I daydream about Brigit reading Anderson and his imagined communities. These people, deaf and hearing, deafhearing, help me to make sense of their lives, bringing theories into focus while interrogating and interrupting them. Each of them have sign language, voice; each reads and perceives the world, each experiences sound, sight, space, vibration; each moves in deaf and hearing worlds, on a nomadic, sometimes spiritual, open-ended journey. Together, they share resemblances (Wittgenstein, 1958) and reveal intersectionalities (Collins, 2000). They identify themselves and each other, at various times and in various contexts, as DEAF or HEARING, “deaf” or “hearing.” In this postmodern world, these are still very real terms. I have caught up with them, and joined them for a while, in the infinite, political, relational, caring and contingent 21st-century space of their lives. In locating a space for this inquiry, and this book, with a nod towards the politically infused textual conventions of various deaf academic spaces—sensory, postcolonial, resistant—I have chosen to write the sign DEAF and the word “deaf” in a way that stays nearest to its utterance. This book is written in English. I could use up precious space with endless footnotes, providing contextual explanations from my personal perspective, at a given time, from a particular position. I have decided instead to place my trust in the historical, personal and political contexts of identities and narratives retold here. I have decided to provide the space for readers to enter and think with the meanings behind the sign/word and its textual re-presentation. In both speech and sign, the difference between deaf and Deaf cannot be seen or heard, save through context, modification or emphasis.

I have chosen to write “deaf,” and DEAF, as deaf, and leave the rest to you.
CHAPTER ONE

HOW DID I GET HERE?

Like any good story, this one is full of conflict (Duncombe, 2002: 9).

(Not) the silent author

This chapter is presented as an autoethnographic sketch; a work-in-progress rendering of the story of how I became a researcher and writer. I have struggled to know where, how and even whether to include it in this book. With a background in critical ethnography, I was drawn to the notion of autoethnography not only as a way of recognising and articulating a kind of ‘backstory’ to the research process and my place within it, but also as a between-and-across-cultures reflexive method of inquiry (see Etherington, 2004b). Had I been interviewed by a researcher interested in the story of How I Got Here, this is the story I might have told. I am fully implicated in this inquiry, and ultimately responsible for its migration and commitment to print. I could not do that without telling you something of myself.

I chose to write this story in the privacy of my room rather than speak or sign it to another person, into a microphone, or towards a camera. As I wrote it, I noted my responses. I found my heart beating faster, tears in my eyes, a lump in my throat. It suddenly struck me how my family narrators might feel, telling me their story. I also began observing the choices I was making about what to tell, what to leave out, and why. Again, I thought of my narrators. I realised that, for all sorts of unanticipated reasons, it was vital that I included something of my story here. This was both exhilarating and terrifying. I could tell a story; I could script it, direct it, stage it, I could be in charge of a story that, until now, had had a powerful control over me. However, I was getting into deep water. I would have to treat my narrative with the same care as I did the family stories. I changed all names, places and details. It is crafted and considered. It is also an angry story, a much-needed personal corrective, perhaps a small victory even. I have mixed feelings about its inclusion here. It reveals a side to me I rarely acknowledge, barely recognise. I decided to take the risk.
Ultimately, and most importantly, I sought to align myself with Georgina, Toni, Thomas, Brigit, Bella, Dora, Luke, Harper and Maisie, who took a leap of faith in telling me their stories, and who you will soon meet. I took up the position of storyteller alongside them. I am interested in the fact that I chose to tell a ‘professional’ story, rather than a ‘family’ story. This could be seen, through an ethical lens, as exercising my right to withdraw from aspects of the work, to maintain editorial control. It could also be seen as indicative of my desire somehow to prove myself as a rigorous, mindful researcher. Having written it this way, I have written the rest of the book from a less vulnerable and exposed place. However, this chapter informs my reflexive practice in ways I could never have predicted. It serves as a reminder, as an illustration, of the ways in which various actors construct meanings based on their own social, cultural, discursive and historical backgrounds and experiences; actors who themselves have no control over this particular scripting of their role or actions. It also serves as a reminder that my own position(s)—both during the time of the story I wrote and again at the time I wrote it—were themselves hugely and quite specifically influenced by discursive, cultural and social experiences. My own act of narrative resistance in scripting and directing this particular story, I must admit, does not offer windows on to the experiential world of various other antagonists. It is a specifically positioned tale. With sufficient emotional, geographical and temporal distance (Vickers, 2007), I could perhaps in the future re-script, re-direct; I could channel still-raw emotion into a re-visioning that embraces alternative perspectives, values, sense-making processes and that deconstructs the anger and hurt, and examines the reasons for their power over my story.

One person’s invitation …

Stories are useful ways to invite readers to think into the interpretive spaces between narrator and experience. Readers, however, will respond and react in any number of ways, based on their own knowledge, assumptions, sense-making and backgrounds. However, I find myself also compelled to write into these spaces by acknowledging, recognising and deconstructing the emotionally charged, performative nature of personal narrative and the potential impacts and implications. In later chapters I take this on board, engaging reflexively within, between and across theory, experience, other people’s stories and my own, and in the chapter Signs of Hope I revisit my autoethnographic sketch and offer a critique of that very specifically situated and constructed account.
Autoethnography: A slippery customer

Autoethnography is a method of inquiry that sees the researcher as the field of study (Ellis & Bochner, 1996), placing emphasis on holistic, cultural, historical and relational experience, within a loosely ethnographic tradition (Speedy, 2007). Reed-Danahay (1997) locates autoethnography at the intersection of postmodern critical ethnography and postmodern autobiography. Autoethnographic writing, which weaves together personal and institutional storylines (Ellis & Bochner, 2000) or story and theory (Spry, 2001), tends to disrupt the more traditional academic writing genres. It seeks emotional engagement (Ronai, 1992; Behar, 1996; Jones, 2005b) and aims to “dissolve any idea of distance” between the researcher and the reader (Goodall, 1998: 2). Consequently the reader is invited in to new ways of knowing, being and acting in/on the world (Jones, 2005b).

Originally coined as a term to describe anthropological study of one’s own people or culture (Hayano, 1979), and emerging from the ethnographic turn in the 1970s from participant observation to observation of one’s participation (Tedlock, 1991; Berger, 2001), autoethnography is nonetheless very difficult to define in precise terms. Ellis and Bochner (1996) helpfully catalogue many terms and genres, from auto-observation (Adler & Adler, 1994), through ethnographic autobiography (Brandes, 1982) and personal experience narratives (Denzin, 1989) to native ethnography (Abu-Lughod, 1993). A spectrum of process, politics and purpose becomes apparent, with emphases placed variously on the self, culture and the writing of autoethnographic research (Reed-Danahay, 1997).

Speedy’s (2007) observation that autoethnography inhabits more an ethnographic than biographical tradition is helpful in distinguishing it from autobiography, life history and life story. Autoethnography is often driven by a critical, political agenda (Reed-Danahay, 1997), which situates the “sociopolitically inscribed body as a central site of meaning” (Spry, 2001: 710), thereby countering the traditional ethnography standard of privileging the researcher over the subject or field of study (Denzin, 1992). As a discourse from the margins (Pratt, 1986), writing critically about oneself as the field of study (Church, 1995) aims to democratise research methodology and cultural representation through individual self-stories that challenge and rub up against hegemonic discourses and power relations (Neumann, 1996). It also disrupts traditional notions of the ‘Other’, the subject/object of study, the researched, by shifting the traditional power imbalance in line with egalitarian, critical, feminist, indigenist and decolonising methodologies (Gibson-Graham, 1994; Pratt,
1994; Rigney, 1999; Tuhiwai-Smith, 1999). The ‘silent author’ (Charmaz & Mitchell, 1997) is no longer silent, but present, and not simply in ‘confessional’ appendices (see Malinowski, 1967; Van Maanen, 1988) or disguised in discrete publications (see Bowen, 1956), but central, integrated, exposed, situated, positioned, connected, politicised and agentic (Trinh, 1991; Neumann, 1996; Behar, 1996; Spry, 2001; Jones, 2005b).

**Self and culture (auto and ethnography)**

The researcher’s sociopolitically inscribed body, as the locus of identity constructions and of embodied experiences, speaks, through autoethnography, not only of the personal, the political and the cultural (Spry, 2001), but also of the spaces in between these (Speedy, 2007). As Ellis and Bochner (2000) describe it, connections of the self to culture are achieved, maintained and negotiated by turning an ethnographic wide-angle lens back and forth from personal-cultural experience to the vulnerable self as it navigates discourses, experiences and meaning-making. Autoethnography recognises a constant state of flux, between self and culture(s) (Coffey, 1999), between the researcher and the reader, between stories and historical, political and cultural contexts, between body and text. Writing about these negotiations not only casts light on oneself but on others’—readers’—potential, possible and imagined experiences, and on the worlds that others inhabit (Church, 1995). Writing about oneself is also therefore ‘writing culture’ (Brettell, 1997).

**Private and public**

Writing (about) oneself is also ethically complex. It exposes the researcher as vulnerable (Behar, 1996), bringing her stories into the public domain. In redressing power imbalances in research by including self-stories, unnamed, or even secret stories (Clandinin & Connelly, 2000: 63), courage is required (Spry, 2001). Some stories are riskier than others, and as Ellis (2004) reflects, it is not easy to write a resonant autoethnography that tells a happy story. Gray’s (2000) *Conversation with Dad* not only reveals his own experiences but also implicates a significant other—namely his father—who committed suicide. Wyatt (2005) tells a story of the death of his father. Richardson (2007) journals the death of a close friend. Jones (2005a) reveals a multi-generational story of adoption, loss and motherhood and Cixous (Cixous & Calle-Gruber, 1997) tells her family history against the backdrop of the Holocaust. Even when not
How Did I Get Here?

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named, others are indirectly implicated (e.g. Tillmann-Healy, 1996). However, it is the private-self-going-public that principally acts as an invitation to the reader to come close, to witness and to think with the ethnographer’s own story (Frank, 1995; Fontana, 2003).

Autoethnography therefore requires a considered ethics of the self. Remembering may take the researcher to intense physical and emotional states. Writing often incorporates different ways of writing and remembering, inserting oneself into the past (Denzin, 2006: 334) in order to experience and understand identities, lives and knowledge through writing (Shope, 2006). Vickers (2007) stresses the need for emotional, figurative and temporal distance, in order to be able to write retrospectively and to make sense of painful experiences: remembering is not just documenting what happened: it is also a painfully visceral, embodied journey into the past. Richardson’s (2007: 9) Last Writes was conceived as a way of writing in the moment, to help “endure my friend’s terrible illness and death through an honest expression of my terribly mixed emotions—sadness, anger, disgust, fear—by exploring more generally my attitudes towards death, dying and friendship.” Both engage with past, present and future in different ways, to explore and make sense of experience.

Here is a story.

So when did you become hearing?

An autoethnographic sketch

Late 1970s

Like many people I know, I have hazy, bleached out memories of learning to fingerspell. Andrew-something was his name, a small boy—tiny in fact—and a couple of years younger than me. He had dark hair, small, piercing black eyes like raisins, flying hands, and a jolting, frenetic energy. There was a box strapped to his chest, with white braces, and wires hanging from his ears. I think I knew that he was deaf. I never heard his voice, but used to watch his sister, brother and mother sign to him. And him sign to them. I remember it didn’t seem strange. Sometimes their voices sounded odd—they didn’t switch them off when they signed—but I remember intense discussions, arguments, jokes, communication. He taught me the fingerspelling alphabet and how to swear in sign.
1993: Alex

I am a Teacher. Alex was eleven when I met him. Again, dark hair, but this time, blue eyes and freckles. Alex had a friend called Laurie. The two of them used to hang out together. I think Laurie saw himself as Vital To Alex’s Well-Being. They were both loners who hooked up. I used to see them shuffling around together, in the corridors, the playground, and they always sat next to each other in class. Alex didn’t sign. Neither did his family. No-one had ever mentioned it to them. No-one was available to teach them. Alex used his hearing aids, and, after all, was only severely deaf. “Put this transmitter round your neck, make sure it’s switched to the right frequency and he’ll be all right. Any questions, just leave a note for his teacher of the deaf. She comes in once a week to help him with his English.”

I made an appointment with his teacher of the deaf, a peripatetic member of the borough’s Audiology Service, who saw Alex for an hour a week. In this hour, she checked his hearing aids and corrected his English homework. “What can you tell me about Alex? Is there anything I should know? Does he use sign language?”

“No. None of the children in the borough do. It’s policy.” Sometime later, however, all the teachers of the deaf in the borough were invited to attend a BSL Stage One course even though they would never use sign language with the children they taught. There were no courses for the children, or their families. I managed to get a place because of my growing interest in Special Educational Needs, and because of a very supportive headteacher, and I passed.

1995: London

I find myself, on the back of my BSL Stage One success, applying to work as a teacher of the deaf in a very large comprehensive school in South-East London. I was the only one to apply for the post. I messed up my interview horribly, but they offered me the job. I was also offered training on a part-time university course in Hearing Impairment in order to qualify as a teacher of the deaf. For the one remaining term I had at my old school, I stumbled upon an Open University course called Issues in Deafness. I enrolled and dived headlong into course material about deaf history, education, welfare, mental health, about sign language, about deaf culture. I started to write essays.

My first day as a teacher of the deaf was a training day. I think we were still in those days calling them Baker Days. Part of the training was
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an IT session. Something to do with timetables. There were about ten of us in the room. The walls were spotlessly white, reflecting the sunlight that streamed in through the blinds. After an introduction from someone in a tie and a moustache, we were to pair up, and work through an activity. My new boss assigned me to Sam, who had been sitting in the room with us. Suddenly, it struck me. Sam’s deaf.

There is a sign in BSL for confidence—the thumb and forefinger form the shape of the letter C, which is placed on the chest. If you are feeling confident, the C rises up towards the throat. If you are suddenly filled with confidence, the movement is fast and sure. Over-confidence often results in the C continuing to rise and float above the head like a hot-air balloon. My C-for-confidence not only dropped like a lead weight; it crashed through the floorboards, into the cellar below where it bounced comically, ricocheted into a dark corner, and wasn’t discovered again for several weeks. I have no idea how we got through that training session, let alone the whole day. That afternoon, however, a bond was formed. And over the following weeks, it was Sam who found my confidence—my lonely C—cowering in the corner of the cellar, picked it up, dusted it off, gave it a bit of a slap, and restored it to its rightful place next to my heart.

My deaf-sister, my deaf-conscience, my deaf-mentor, role-model, teacher, sanity-saver, my deaf-kick-up-the-arse; I owe everything that followed to Sam. She initiated me into deaf clubs, deaf pubs, deaf weekends. Entering deaf spaces—it’s a cliché but—there is nothing like that ‘sea of signing’ that hits you as soon as you walk in the door of deaf club. And the sound of deaf laughter; deep belly laughs, high-pitched screeches, it’s infectious. In deaf pubs the lights are on, the jukebox is blaring out God-Knows-What, but unlike hearing conversation—people shouting, bending their heads to listen above the racket, trying to order drinks—noise doesn’t matter. You can hold a conversation with someone outside, through the window, you can order a drink from the far corner, you can tell someone on the first floor balcony that you love them. And deaf nightclubs—I’ll never forget the first time I saw deaf people dancing. You tune in and feel the beat in your chest; your ribcage pulses and hums, your feet sense vibrations through the floor, you listen through your eyes and hear through your body. Quite a baptism—I proudly perfected the art of signing, and (almost) understanding deaf people while thoroughly inebriated.

I soon passed BSL Stage Two while both teaching in school and studying at university. I found myself working with an amazing group of children: Kevin, from Trinidad, Jaffar and Mahdi, newly arrived from Bangladesh, Mark, obsessed with cricket, Simon, who came out at 15,
Halitha and Kaarthik, Adilah, Sabina, Ifra, Parveen, Shazmah, Aadil and Jawad. Patiently, we worked together, as I started to find my way and learned to sign better, as Sam and I took some of the children to deaf club, as we shared jokes in Science lessons, spluttering to smother our laughter, or as we ploughed our way through *Romeo and Juliet, Lord of the Flies*, quadratic equations, plate tectonics and Beatles’ songs (signing *Ob-La-Di Ob-La-Da* at a terrifying pace is seared into my memory, thanks to Mr Phillips).

I became immersed—not waving but drowning—in Special Needs legislation: Annual Reviews, Individual Education Plans, hearing-aid technology and testing, audiology, audiometry, linguistics, classroom management, deaf awareness. Being a teacher of the deaf in a mainstream school often meant interpreting lessons (in spite of my rudimentary skills). At the same time, it meant constantly monitoring lesson delivery, language, noise levels, facilitating group work, advocacy, inclusive practice, acting as keyworker for some of the deaf children and getting to know their families. Those of us in the staff who could sign (there were only four of us) became safe people for the children to turn to. Our room became the secure space within the entire school—so large it was on two separate sites.

**First week of the new school year**

Thursday lunchtime. I was heading down the corridor of the lower school towards the canteen. A group of new, year-seven boys had gathered at the bottom of the stairs. “Miss, Miss!” As I approached, I saw Kevin. He was dressed in his PE kit, facing the wall, sobbing. Every time a boy went up to him, put a hand on his shoulder, he shrugged them off. They didn’t know what else to do, but were concerned and were trying to help. None of them knew any signs; they were a bit lost.

I reached Kevin, and put a hand on his shoulder. He was shaking, tears and snot running down his cheeks and chin. I needed eye contact, but he wouldn’t look at me. I kept my hand on his shoulder and sent the boys away. Slowly, they wandered off. Both hands on his shoulders, I turned Kevin away from the wall. I bent down, then kneeled on the floor and looked into his eyes, all puffy and sore, “What is it?”

Slowly, in between sniffs and huffs, hands shaking, Kevin told me he had wanted to try out for the Year 7 football team. The first thing I ever found out about Kevin when I visited him at his Primary school was that he was football mad. He worshipped Eric Cantona, and for years teased me mercilessly about my fondness for a certain, glamorous West London
side who looked rather fetching in blue. In his journal for today he had hurriedly written ‘fotbll’ to remind him of the trial. His form tutor had read out the announcements during Monday’s tutor time, but there had been no-one to interpret, so Kevin copied the one word he recognised from the boy next to him. What he didn’t know, however, was that to try out for the team, you had to turn up in Games kit, not PE kit. Kevin had gone to the changing room (arriving late as he wasn’t sure where it was), put on his brand new, very white T-shirt, shorts, socks and trainers, and had run out onto the field. The teacher took one look at him, shouted something incomprehensible, the other boys all laughed, and Kevin was sent back to the changing rooms.

We couldn’t stay like this in the corridor. Children were staring and we were being jostled by the lunchtime crowds. Our room was just a few doors down. “Come on,” I coaxed Kevin. As I opened the door and we entered, I saw the boss, sitting there, eating his sandwiches. “Out!” he ordered to us both. “This is lunchtime and the children are not allowed in here. They’ll never integrate into the school and the wider world if every time they get upset they come in here.”

**Getting lost**

It was my boss who eventually finished me off. He didn’t sign, wouldn’t sign, couldn’t sign. He was uncomfortable when people did sign and utterly convinced that if you talked to deaf children long enough, often enough, loud enough and clearly enough, they’d understand. He had an instant and impressive recall of the children’s degrees of hearing loss, down to the finest detail (age of onset, type of deafness, make of hearing aid). He called the severely deaf children ‘partials’.

I used to watch him working with deaf children, marvelling at the ways they had developed to convince him that they understood, and to work out what was being asked of them. They’d sign to each other under the table when he wasn’t looking. Working as a team, they’d search for clues, in his facial expression, in the books on the table, at words written down in the margins of their work. But most of the time, they’d smile sweetly and nod enthusiastically. They would try to mouth the words he articulated, getting praise for using their voice.

I was told off for using BSL with the children. My brain was becoming less and less able to deal with arguments over Total Communication and bilingualism. I thought—stubbornly and perhaps naïvely—that I should be using BSL. After all, that was the language I had gone to classes to learn. At the same time, when it was required on the timetable, I did ‘listening
work’, and incorporated using radio aids into my lessons. We played lip-reading games, and role-played television interviews with celebrities. I worked hard on literacy skills—speaking, listening and reading. But some of the children were deliberately removing the batteries from their hearing aids, or switching off their radio aids in class, to get a break from the almost incessant noise of big, mainstream classrooms. I realised that my training was providing little in terms of helping me to work with deaf children bilingually. Nor was it helping me to work with their residual hearing in acoustically unsuitable environments. I was becoming frustrated with and angry towards my boss, who I increasingly saw as a bully. He went out of his way to make things difficult for me and I reacted by digging my heels in, without the experience or the resources to deal effectively with the growing conflict. I got cornered in our office, when nobody else was about. He was a large man, and he got me up against a wall, and with his nose up close to mine, he shouted at me for five minutes. Why was I being so difficult, so uncommunicative, and why was I turning to other colleagues, rather than talk to him if I had a problem?

**Letter from my Head of Department to my University Tutor**

Halfway through my training, my tutor contacted me to ask for my comments on a letter they had received from my boss.

Donna has always had an excellent relationship with all her students and has looked after them with care and thoughtfulness. She communicates with them in BSL and although it is the natural and right language, I have been concerned about lack of training in English to help them to cope outside. She has planned and used an English language programme to very good effect. She does not use the child’s residual hearing at all, but prefers the use of BSL lip patterns. She works in silence, but has worked hard to maintain the Radio Aids. She manages her sessions in withdrawal in an exemplary manner and works very hard with the ‘mainstream’ teacher in integrated sessions. Her curriculum planning and delivery have been painstaking and of high quality, but I feel her targets have been too complicated and her approach is sometimes too rigid. She finds it difficult to adapt her work if necessary. I am sure Donna would agree that her sensitivity is a problem and although I am a firm believer in ‘Open Government’ I have found it difficult to find out what she feels. She does need to indicate to her “boss” how she feels, so there can be a two-way exchange as
she has as much to offer to an old hand as an old hand has to her.

I must stress that all the criticisms except one are very slight compared to the strengths. Donna has worked well and efficiently throughout her teaching practice and for all the time at this school. My one concern is her almost obsessive use of BSL. I would have expected her to use her voice, SSE and lipreading for some of the time to give these children more of a choice when they do not have the prop of a school or college. I feel the Total Communication policy was not being followed as much as I would have liked. Can I stress again, I am not anti-BSL, but I worry about choice.

Jawad

Jawad and I had a reading lesson. He was, at 13 years old, working his way through a Primary School reading scheme. We found a table in the corner. Over the far side of the same room, beyond the bookcase, Anita was taking a Year 7 E2L class who were reciting, as a group, English sentences written on the whiteboard. Over and over, becoming more rhythmical each time, and louder. One or two of the children were beating time on the table, with hands, pencils, rulers. There was a fierce energy to the lesson and a smiling Anita was almost dancing round the table. I turned to Jawad. Pale, with dark shadows under watery, deep brown eyes, he switched his hearing aids off. I was about to—automatically and without thinking—remind him to leave them on. But I didn’t. I stopped myself. As usual, he took the left aid out. His ear was bright red where he’d been rubbing it. “Pain,” he signed. I didn’t know what to do. This didn’t feel like school. I got up to fetch him a glass of water. We’d wait for five minutes. He closed his eyes. His bag was still over his shoulder, unzipped, and full to bursting with books, trainers, pencil cases, a packed-lunch box. As we sat there, I realised I was envious that he couldn’t hear the E2L class. My head was starting to throb. A few more minutes and Jawad opened his eyes. He looked wiped out. “Are you ill?” Shake of the head. “You want to read?” Sigh. He twisted and tugged the flimsy, dog-eared picture book out of his bag. Something to do with a cat and a dog and a missing necklace. I had planned, in my notes, to try and work on comprehension today. I’d pictured us working together; we’d silently read a sentence, and then discuss it. Or maybe even a paragraph. A page, a whole chapter.

Before I could do anything, Jawad opened the book at his bookmark, and mechanically started to bark at the words, stabbing each one with his
finger. He nodded his head in time to the syllables, and moved his mouth to the shape of the words. I tapped his hand. What was he doing? He ignored me. I put my hand on his shoulder. Still, he carried on. This was horrible. He was getting louder and faster, unwittingly mocking the class on the far side of the room. He turned the page and read on, word-by-word. I just sat there, defeated. Defeated, but impressed by his rebellion. *This is how this school wants me to read, so that’s how I am going to read. I am not signing, I am using my voice!* He turned the page. More words. And again. And again until he reached the end. He closed the book and looked at me, pained yet defiant.

Later that term, I met with Sam. We agreed (Sam had been saying this all along) that Jawad should be in a deaf school. I can’t remember how long it took, how many meetings, how many forms, but eventually Jawad left. He transferred to a bilingual deaf school in the Midlands.

**Leaving, moving on**

I left my job. I didn’t want to fight any more: I could no longer make sense of the system in which I was working. The children held a party for me. It was in our room at lunchtime on my last day. Some of the older children had been shopping to buy party food and had spent morning break either decorating the tables, or keeping me out of the way. We had Sri Lankan snacks and Indian sweets, cake, biscuits and squash. There were cards, ribbons and balloons. Towards the end of the party, as the afternoon bell flashed, Halitha stood up on a chair in front of everyone because she had prepared a goodbye speech. She started to sign. And my boss interrupted: “Use your voice!” I was speechless.

I moved to a different city, to a different school. Too many stories. *Why am I telling you this?* After only seven years of teaching, I fell ill. I was having terrible dreams. I was fraying at the edges. I wanted to teach my class of children and everything was getting in the way. I was told to make sure teenage deaf children in my class wore their hearing aids at all times and when I offered that I simply couldn’t do this, it was clear I was not complying. I was therefore not a very good teacher. I carry the guilt with me to this day. Temporal distance merely blurs the mess of memories that play over and over in my bluer moments. I try to remember the successes, the achievements, the lasting bonds that were formed in my final 18 months as a teacher, but I was falling out of love. I was also the victim of a (‘regrettable but minor’ and therefore overlooked) assault in school. My doctor advised me to quit teaching. I failed, drowning in a sea of politics, disappointment, joy, despair, confusion, beta-blockers and even
more disappointment. And anger. At myself. The system. At bureaucracy, misunderstanding, indifference and short-sightedness.

I took flight and landed, albeit with the wrong map, in the world of academia and Deaf Studies. Confronted with the History of Hearing People’s Oppression of Deaf People and encouraged to ‘academise’ my emotional responses to my place in this history, I felt myself withdrawing; uncertain, confused, inarticulate, the rug pulled out from under me. At the same time, my eyes were opened to a whole new world of being and seeing, of identity, language, communication and history. I was hungry for knowledge and desperate to learn more. A constant negotiation, on the edge, not fitting in, yet wanting so much to be there.

And so I found myself working and surviving in deaf community and academic spaces where the going—still rough—became more navigable. But rather than chugging safely in the estuary, I was now out on the high seas; the ups were huge and the downs terrifying, full of tears, doubts and some very strange dreams. But there were also times for forging deep and lasting relationships, for talking and sharing, for reflection and introspection—how did I get here?—and time to appreciate that I did get here, under my own steam eventually; guided, prodded and encouraged by a long line of generous, intelligent, insightful and inspirational people. Maybe I was finally starting to find my place.

I picked up my C-for-confidence, pinned it back where it belonged, and fell in love all over again.

Is it autoethnography?

I have called this story—one of many—a sketch, in that it is not complete, fully worked up, fixed and framed. There are rememberings and recollections, marked, erased and re-drawn, torn up, thrown in the bin, retrieved and smoothed out. It is, I confess, largely instinctive. That it is included here at all is indicative of my ambivalent desire to be visible, however uncomfortable or vulnerable that makes me feel. It has to be this way. This inquiry into deafhearing family life has made visible and legible the lives of at least eleven people, and, indirectly, many others. Perhaps they, too, have felt uncomfortable, exposed and fragile in telling me their stories. In our many conversations, I have shared my stories with them. I cannot—and do not wish to—write them all down; yet to hide away, or become invisible now would betray the spirit of our work together. In honour of their trust both in me and in the reader of this book, I join them as a storyteller.
A well-respected colleague speculated whether I could write autoethnographically as part of this inquiry. As a hearing ‘outsider’, autoethnography—as a study of one’s own culture—could not apply. As a hearing person, from a long line of hearing people, as a woman without children of her own, I was not studying my ‘own’ culture. However, asking questions, of families, and of myself, and exploring the interplay of my “introspective, personally engaged self” (Ellis & Bochner, 2000: 742) with the sociohistorical and cultural fields of deaf and hearing lives and my own personal narrative, perhaps I could write autoethnographically. This fits with Reed-Danahay’s (1997) observation that autoethnography as a term can have a double sense—referring either to an ethnography of one’s own culture, or to an ethnographically orientated autobiography. My aim therefore is to reflect on my experiences, to write about my connection to this work, to use my self to learn about others, to use my self so that others can learn about others.

This is a true story about love, respect and acceptance, about power and powerlessness, resistance, voice, ignorance, anger, patience, generosity, naïveté and denial. It is a story of how I got here. In setting it down, writing as a method of inquiry (Richardson, 1994a), I find my voice. Call it what you will.
INTERTEXT I

EARLY DEAF LIFE

Few groups in history have suffered such sustained and uncomprehending cruelty as the so-called ‘deaf and dumb’. In most civilisations they have been treated like animals, if not worse (Rée, 1999: 85).

What value deaf lives?

A great deal has been written about the histories of deaf people; reaching as far back as Ancient Greece (see Edwards, 1997; Winzer, 1997; Rée, 1999; Lee, 2004) and to Hittite society (Miles, 2008-9), covering many countries in the world, and located within social, cultural, medical and educational discourses (inter alia Lane, 1984a; Ladd, 2003; Branson & Miller, 2002). These histories span time, geography, society, philosophy, ontology, technology, science, faith, spirituality, human rights and politics. And yet, for their vastness, they are inextricably, intricately, and delicately linked to the lives of the people who told me their stories for this book. Therefore, I am compelled to set down a history of the value of deaf lives, which touches on much of the above, but which is infused with the spirit of personal, political 21st-century thinking, feeling and knowing about deafhearing life.

Early deaf life

If we have no voice or tongue and wished to make things clear to one another, should we not try as the dumb do to make signs with our hands, head and person generally? (Socrates, in Plato’s Cratylus, cited in Lee, 2004).

Many authors have made reference to signing deaf people, throughout history. In fact, deaf people have been a philosophical, academic and physiological topic of fascination for centuries (Branson & Miller, 2002). Many sources indicate that in the presence of deaf people, sign language occurs, and thrives, whether we are looking at Athens in the fourth century
BCE. The Weald in Kent in the 17th century and Martha’s Vineyard in the 17th-19th century (Groce, 1985), the Ottoman Empire of the 16th century (Miles, 2000), or Bali and Ghana today (Branson, Miller & Marsaja, 1996; David, Edoo, Mustaffah & Hinchcliffe, 1971; Kusters, 2012). In England, records exists as far back as the early 16th century of sign language being used at weddings and in court cases (Branson & Miller, 2002), and in 1666, an entry in the diary of Samuel Pepys describes a conversation between a deaf boy and Lord Downing on the progress of the Great Fire of London (Pepys, 1972). Signing was thought to be common in pre-Renaissance times, and evidence suggests that it flourished in monasteries when silence was to be maintained. It seems to be accepted, not only by lay people in their everyday communication, but also by scholars, that deaf people were, through signs, able to converse, and even argue and tell stories (see Montaigne, 1580). People lived in a ‘linguistic mosaic’; language switching and signing were part of everyday discourse (Branson & Miller, 2002). Various forms of manual and written alphabets, such as the Ogham alphabet—used by Druids from the sixth century BCE through to the Roman occupation—have been noted (Sutton-Spence, 2003). However, as Bragg (1997) and Edwards (1997) point out, textual evidence is at best meagre and sketchy—particularly before the advent of the printing press—and historical interpretation of the existence of visual communication methods before deaf education is wide, varied, and sometimes confused. Reliable copies of manuscripts, where available, offer some evidence that some signs used in monasteries “conform to many of the signs at present used by the deaf” (Lee, 2004: 211).

That is not to say that deaf people lived idyllic, peaceful, pre-Renaissance lives. Winzer (1993; 1997) documents the ways in which deaf people in Ancient Greece and Rome were viewed with fear and superstition, as manifestations of curses or vengeance from angry gods, and as the Divine Master’s punishment for a family’s sins in early Christian times. Deaf people were shunned, outcast and tortured, often homeless, poverty-stricken, and confined to asylums or charitable homes (Bézagu-Deluy, 1993). Winzer (1997) also provides evidence that deaf people were subjected to various, invasive examinations and procedures. In the first century CE, Hippocrates undertook physiological diagnoses and middle-ear treatments of otitis media, and his successor, Aulus Cornelius Celsus made use of a very rough knowledge of ear anatomy to prescribe various hot juices and oils to be administered to, and syringed from, deaf people’s ears (Hodgson, 1952; Edwards, 1997). The Roman physician, Galen (129-200 CE), is reported to have carried out operations on deaf people’s tongues (Land, 1931). While there is also early Christian
reference to deaf people being healed through blessing (see for example, St John of Beverley, described in Porter, 1847), Winzer (1997) also describes the ways in which deaf (and disabled) people were feared as evil beings by 13th-century Christians. Evil, heresy and witchcraft were inextricably linked under the auspices of the Inquisition, and exacerbated by fear of agents of the anti-Christ. It is not known how many deaf, blind and disabled people were burned, hanged or drowned in the three centuries of witch hunts in Europe, although Monter (1972) estimates the number of trials as in the region of 100,000.

These were wildly contradictory times. Christianity, while preaching equality and entry into the kingdom of heaven for all, excluded deaf people. St Augustine of Numidia interpreted Paul’s dictum, “Faith comes by hearing” to mean that deaf people were incapable of communion with God; they were denied membership of the church, and considered unable to confess their sins (Winzer, 1997).
A narrative epistemology

The wanderings and wonderings to secure a research identity in which I initially felt lost and confused, and admittedly feel perpetually tentative and wavering (but not irrevocably wayward) resulted in a journey that dropped me at a narrative epistemology—knowledge and knowing that is constructed through and revels in stories and storytelling (Lapum, 2008 [34]).

I can no longer recall the exact moment where I found myself thinking about narrative, and narrative inquiry; it gradually seeped into my consciousness, my vocabulary, my writing. Like Prosser (2007), my entry into this work did not begin from a conscious philosophical or methodological orientation. I have always been resistant to the idea of ‘framing’ an inquiry (within a postmodern/poststructural/social constructionist/feminist paradigm or tradition for example). This is not out of laziness or bad scholarship, but rather because I found myself engaging with a group of families who challenged, complemented, contradicted, turned inside-out or rendered redundant the many academic frames I had obediently, if apprehensively, stuffed into my bag when I first arrived at their front doors, keen to make a good impression and prove my worth. We worked together, collaboratively, over a period of four years. Therefore, the idea—as Clandinin and Rosiek (2007) put it—of a relational and continuous research experience that navigates and negotiates multiple discourses and meaning-making processes resonates strongly for me and echoes feminist, egalitarian research practices. It also chimes with a postmodern recognition of multiple, socially constructed, complex, fragmented and conflicted meanings and subjectivities that shift through time and according to context (Scheurich, 1997; Henriques, Hollway, Urwin, Venn & Walkerdine, 1984).

Narrative as a term is ubiquitous, whether sociological (e.g. Richardson, 1997; Langellier, 2001), anthropological (Behar, 1996), biological, cultural
(see Connelly & Clandinin, 1990), or poststructuralist (e.g. Lather & Smithies, 1997; Ronai, 1999) and covers a range of activities, analyses and writing practices. I am drawn to the idea that a narrative inquiry can embrace not only the meanings that are constructed, felt, known and told (Richardson, 1997), but also the very phenomena of the telling (Clandinin & Connelly, 2000). As Bruner (1987) explains, there is the life that is lived (reality), the life that is experienced (consciousness) and the life that is told (how experience is framed and reflexively articulated). This charges us to acknowledge the temporal, historical and cultural situatedness of the story, as an interpretation that evolves through time and many tellings (Ochs & Capps, 1996).

So this is my entry point, as a situated knower and as a reflexive inquirer. My views concerning how human beings make sense of the world joins hands with a political concern for amplifying voices in the margins and with a desire to explore and understand how people, deaf and hearing, adult and child, brother, mother, father, sister ‘speak/sign back’—constructing the stories of their lives as discursively situated counter-narratives of resistance (Domosh, 2003). Unable fully to situate myself in any one paradigm, I have been drawn to several, political, philosophical tenets, from a “loose constellation” of theories (Collins, 2000: 41) full of dynamic tension. At its heart, this work has led me to form, or revisit, relationships with people (see Etherington, 2007) who taught me about their lives with deaf and hearing parents, children, siblings and so on.

Why narrative?

Beginning with (more or less) a single question, I realised I was both curious and unknowing about deafhearing family life. In previous research projects, I had worked with deaf children and their deaf educators. It was during the course of this work that I got to know several children and their families. I had visited children in their homes and our research relationships relied heavily on, and benefited hugely from, being generously welcomed and trusted by parents, siblings and other family members. Reflecting on my own background, upbringing and ways of thinking about family, I recognised a burgeoning desire to learn about the lives of these people; but I had no specific, fixed questions to ask, no particular frame of reference. I simply wanted to ask, “What’s your story?” and to trust in our abilities to take it from there. Creating a narrative space where stories were invited, remembered, told out loud and listened to began a process of activism (Tuihiwai-Smith, 2005), of making sense of one’s own (and one’s own family’s) lives, as historically,
socially, culturally and temporally situated (Bruner, 1990; Lewis, 2006). I began to see meaning-making as “the construction of new maps, new understandings of human beings and their relationship to the world” (Frank, 1995: 3). These acts of construction take stories and locate them in another space in order that they can be heard, seen, read; that they can resonate and merge with the stories, meanings, histories and experiences of the audience/reader (Denzin, 1999). Stories are often told to repair, to correct, to heal, to challenge, to re-position (McAdams, 1997; Owens, 2006), to explain not only what happened, but also how what happened is understood (Riessman, 1993). Personal stories can also be viewed as threads of wider, collective cultural memory (Carr, 1986). Freeman (2002) examines the way that stories surge into and disrupt histories with new meanings. This is particularly pertinent, not only in terms of disrupting or expanding mainstream, popular, medical scripts of deafness, but also in terms of how intersecting hearing and deaf biographies surge into, infuse and disrupt deaf history.

I entered the lives of three families (as a researcher) in the midst of their “living and telling, reliving and retelling” (Clandinin & Connelly, 2000: 20). Reflecting on and constructing my own story and based on knowing many deaf children and their families for several years, I also recognised a personal and political desire to re-tell and re-present these stories with particular purpose. I shared with them my developing understanding of narratives and narrative inquiry. Throughout our working together, this understanding deepened, as we jointly became narratively literate.

**A reflexive consciousness**

In this book you find a story of how I arrived in academia and gained the confidence to undertake a PhD. My story is part of this inquiry. I wrote it in its entirety in one sitting. While I enjoyed writing it, I also discovered a story that I had previously held silently within me. Reading it back, I recognised its familiar contours, and yet I was surprised by its form and content. I uncovered and recovered memories, artefacts, images and emotions that I thought were safely locked away, that had been discarded, or that had faded to obscurity. It was surprising that I could construct an ordered account, of relative coherence, that drew on thirty years of experiences. This was a narrative written with purpose (Mishler, 1986), with personal and political intent (Ellis, 2002) and infused with repair, homage and feeling. I became more acutely tuned in to ideas of telling a story or constructing a narrative. I attended more closely to my own
story/stories and how these influenced my role(s) within the inquiry. I made myself visible and vulnerable alongside my family narrators.

Instead of “going into” the field, we might embark on a “pilgrimage” or imagine ourselves “walking with” people. In “walking with” we are embodied, self-consciously reflexive, partial knowers, conveners, ministers—not “insiders” or “outsiders” (Richardson, 1997: 185).

A reflexive consciousness reminds me to attend to and articulate my responses to the stories being told to me, and to monitor how I act on those responses (Etherington, 2007). Naples (2003) is clear that a failure to explore not only our responses to stories but also our personal, cultural and academic locations reinscribes power imbalance and oppressive behaviours. I kept journal notes so as to cultivate a more dialogic, interrelational, holistic reflexivity (Guillemin & Gillam, 2004). I would ‘write back’ to the families, sharing journal notes, offering my situated understanding. I shared newspaper articles and discussed news with them, I admitted getting lost in ideas and theories and I became embroiled in heated debates, all as ways to open my thought-processes and struggles to those who were telling me and trusting me with their stories (see Ellis & Berger, 2003). This fluid, fragmented, intuitive and somewhat ambiguous way of being with the families took our inquiry in new directions; as Amorim and Ryan (2005: 589) put it, allowing the work to grow at the extremities, as well as the centre. It was not always successful. Georgina and I met in a pub one evening, as I shared a draft of poetic re-presentations of her story. So keen was I to be transparent and vulnerable, I completely misread the signals and nearly trampled over her need to talk about Thomas (a story beyond this story). Early on in our work, I sent Brigit some of the notes I had made after our first meeting, in the spirit of open collaboration. The next time we met, she told me that even though she thought I was “brave”, she couldn’t read it: Kotre (1996) writes of the shock of seeing not only one’s words in print, but also the patterns and plots of one’s life. She was to have an even stronger reaction when she first saw the transcript of our first conversation. Bella, always curious whenever I visited, asked me so many questions, I asked if she would like to interview me about my family. She readily agreed, and relished the opportunity to ‘turn the tables’ but the formalising of her curiosity on film had the effect of stultifying our usual, relaxed, if arbitrary ways of communicating.

However, I believe that, due to the spirit in which these decisions were made, our bond of trust was strengthened. My vulnerable and (at times) faltering way of researching created dynamic, temporal, forward-moving spaces (Lapum, 2008) for reflection among all of us—on not only what we
had discovered, but also how we had discovered it (Etherington, 2007: 601).

**Deaf/deafhearing story and resistance**

Deaf culture survives on its vibrant narrative tradition. Storytelling, as with many other oral cultures, is a central strategy for cultural affirmation and the transmission of wisdom, heritage and solidarity to future generations (Rutherford, 1993; Lane, Hoffmeister & Bahan, 1996; Peters, 2002; c.f. Benham, 2007). Deaf stories as cultural praxis and celebration lie at the heart of a resistant Deafhood visibility (Bechter, 2002) and often become collective tales within a collective deaf space (Smith & Sutton-Spence, 2007). They frequently run along familiar lines and embrace commonly identified tropes; learning to be deaf, survival, journeys and communication. This unwritten literature of resistance, resilience, pride, creativity and celebration not only posits the body as text (Bauman, Nelson & Rose, 2006) and renders deaf life visible but also troubles, counters, resists, even renders meaningless, the more traditional and familiar terms associated with minority discourses such as *voice* and *silence*.

The concept of *resistance* is elastic (Duncombe, 2002). It can take on various forms, in many contexts and spaces, both public and private. At its simplest, it can be understood as a conscious (or unconscious) effort to challenge, change, counter, hinder, re-write or overthrow dominant discourses, systems or structures, be they economic, political, social, or cultural. From African-American slave songs and spirituals (Levine, 1977), to Reclaim the Streets (Jordan, 1998) or Deafhood (Ladd, 2003), resistance is about creating or providing a ‘free space’ for experimenting with new ideas, ways of seeing and being in the world, and for developing and transmitting political messages to particular audiences (Duncombe, 2002), through action and disruption. Depending on context, resistance is about survival, whether in the face of genocide, colonialism, racism, sexism or capitalism. It is about survival of cultures, languages, beliefs and traditions. For deaf cultures, deaf people, and their families, resistance is also about survival. It is about the recognition and survival of sign languages, of deaf education, of deaf stories and storytelling. It is about a survival of voice, the recognition of alternate, sensory ways of being in the world.

So what of deafhearing resistance narratives? Where and how does a signing deafhearing family fit with, contribute to, challenge, disrupt, elaborate, enlarge and trouble this seemingly monolithic yet fragile
collective deaf narrative? Georgina, a deaf mother with deaf children and deaf grandchildren, stands as a clear transmitter of inherited wisdom, epistemology and *Deaflore* (Carmel, 1996) within her family. And yet, her personal narrative also incorporates her youngest child who was born hearing and his ‘treatment’ as a child born to deaf parents. Georgina recalls poignant and significant deaf memories that resonate with and complement Breivik’s (2005) notion of an enlarging deaf *grand narrative*, yet also wishes to make visible her deafhearing motherhood.

Stories of 21st-century deaf parenthood not only resist and counter mainstream discourses of family life, but also highlight the interruptions of deaf family life, cultural transmission and heritage. Brigit, a hearing mother with two deaf children and one hearing child, wholly embraces the identities of everyone in her family, and has created a bilingual home. She rails against the discrimination and marginalisation her family has faced and sends her deaf children to one of the few remaining bilingual deaf schools in the country, yet she also acknowledges her bemusement at and frustrations with the deaf community and its structures and mechanisms. Dora and Luke, hearing parents to one deaf child and one hearing child, while having turned their lives completely around in order to reshape themselves as a deafhearing family, have to remind themselves that it is “OK to be hearing”. Ceaselessly fighting against rigid systems that ignore or cannot cater for their deaf daughter, allying themselves with the deaf community as bilingual parents, they are hearing and therefore somewhat homeless, or at best, temporary guests in the deaf world.

How does a narrative inquiry that brings together deafhearing family life and the cultural phenomenon of deaf storytelling find a place? Where do these stories fit? Do they fit? Do they expand even further what we might understand as a wider, postmodern, troubling, yet fluid and generous, set of resistance narratives? Or do they mark a tiny set of resistances within resistances; an intersecting, powerful, marginal-yet-present performance?

Resistances manifest themselves through humour, rage, sadness, disruption, table-turning, defiance, protest, celebration, spirituality, patience, care and love. They find their way into the light through the telling of stories, and in the re-presentation of those stories. I am, therefore, thoroughly implicated.

**What’s the story of your family?**

My journal is full to bursting with structured writing, random scribbles, newspaper cuttings, cartoons and pressed flowers. My mobile ’phone is
full of text messages and photographs. Going back through these pages stirs up many memories and emotions. This is a ‘heartful’ (Ellis, 1999), between-the-lines/off-the-page (Wiebe, 2002) inquiry. There is, naturally, some kind of imposed order in what follows in this chapter. As Frank (1991) points out, writing creates an illusion of sequence, of neat chronology, a biographical illusion (Bourdieu, 1994). It is time, however, to tease out the messy, layered, up-and-down journey and to tell the story of What We Did.

The families

Dora and Luke are hearing and in their mid-forties. Their eldest daughter, Harper, is hearing. Her sister Maisie is deaf. They are from London. I have known them since 1998.

Brigit is hearing and 37. She has three children under the age of ten. Bella is deaf. Thorin is hearing. Christian is deaf. We have known each other for five years, although it was through this inquiry that our relationships deepened. They live ten miles outside Bristol.

Georgina is seventh-generation deaf. She has five adult children. With her first deaf partner, she gave birth to Nick, Wesley, Jasmine and Toni who are all deaf. Thomas, from her second (deaf) partner, Jake, was born hearing. She has two deaf grandchildren and one hearing grandchild. The family live in various locations in the South of England.

Three families and me: A disclaimer of sorts

It is important to raise at this point what in general research terms might be described as ‘sampling technique’, and to make transparent and explicit the fact that all three families are bilingual, bicultural, and as such, I would suggest, necessarily highly politicised. In one way, we could be seen collectively as inherently biased. I discussed this issue with them. Their reasons for getting involved stemmed largely from their trust in me to understand the stories they wished to share. They also made it clear, to a greater or lesser degree, and in a variety of ways, that they felt very strongly that their stories had yet to be heard, and that therefore there was an urgency to this inquiry. The past few years have marked a period of extreme contradictions, of highs and lows: recognition of British Sign Language and increased numbers of deaf educators working in schools, the Human Fertilisation and Embryology Act amendments and the pressures of an inclusive-education imperative. In the midst of all this, these families felt silenced, marginalised and misunderstood. While their
narratives are full of surprises, unexpected turns, contrasts and contradictions, we shared many views and recognised familiar stories.

It is important to note, however, that this inquiry is specifically located at particular political, theoretical, historical and personal intersections, and could be viewed as excluding the many voices of those (families, professionals, politicians, academics) who do not necessarily or visibly occupy these places of intersection due to their own histories, values, backgrounds, affiliations and beliefs. This mirrors in many ways the tensions that weave throughout the work: Deafhood, strategic essentialism and postcolonial thought; Deaf Theory and bodily perception; postmodern, poststructural, critical feminist inquiry, resistances and performativity, hearing privilege and power; my choices and negotiations concerning whose voices to record and document, and whose to leave out.

Resistance as a concept is tricky and full of pitfalls; conceivably weak, reactive (Richardson, 1997) and thus counterproductive. Although I have worked to deconstruct resistances at the intersection of local, intimate, partial family narratives, Deafhood, critical feminist theory and postcolonial writing, I have perhaps lost sight of, ignored or excluded other resistances, other stories, all of equal value. I permitted myself to get ‘lost’ in a particular landscape with only a partial map. My ethical compass aligned itself only to this map. I would suggest that, despite my best efforts to be critically reflexive, my vision remained tunnelled.

I must live with my choices, and defend them. Yet I also have a responsibility here to draw the reader’s attention to these gaps, absences and silences; to recognise that these pages represent a partial act. Those with alternative experiences of language, of deafness, of deaf education, of disability, of growing up with deafness (see Reisler, 2002) also have a right to tell and perform their own (counter) narratives, and a right for those narratives also to be located within the landscape of this type of work.

Here, then, is a story, our story, my story.

**Ethical mindfulness**

The thing is Donna, I’m a bit of a weirdo, and so my children are weirdos too. We’re not exactly representative … (Brigit).

I was incredibly nervous about visiting Brigit. She’s a very clever woman; about the same age as me, energetic, beautiful, funny and smart. She immediately started telling stories as soon as we had sat down, recommending books, revisiting her own academic past, offering
interpretations of her children’s life stories. She talked about Joseph Campbell’s *Hero’s Journey*, about spiritual paths, about language and embodiment. All this before I had even thought to get my videocamera out. The next time I visited, however, we filmed for an hour. Bella was at home ill and she came downstairs half-way through filming, so there were pauses for porridge and tea. Bella then came in and sat behind the camera, watching her mother, who immediately, instinctively, picked up her hands and went from speech to sign. *This is why I film.* Even if there are no deaf people present, hearing signing people use their hands, add signs to their speech, even use signs to replace speech when the word is not good enough to articulate what they really want to say. Bella started interrupting with questions: *Why? What for? When?* and Brigit answered. When I review this tape, I can hear Bella laughing, as her mother, no longer only looking at me but also at her daughter, involves the ten-year-old child in the stories. This has been a wonderful start, and Brigit assumes I will visit again, same time next week. On the doorstep, she hugs me very tight, as we say our goodbyes. “Thank you. It’s good. It’s therapy!”

Things do not always go as smoothly. Brigit has a profound reaction to seeing the transcripts I sent her. I am so annoyed with myself for assuming she will be fine seeing them (even though we had agreed this would happen). I have tried to represent her words (and signs) as faithfully as I can, but she is unhappy at appearing so inarticulate (“Too many y’knows”). Over the weeks and months, I constantly reassure her that we will work together on editing the transcripts in order that she feels happy with my re-presentation of her story.

One day, having spent three hours at Brigit’s house, I say my goodbyes and set off for the journey home. I am halfway to the bus-stop when I find myself in floods of tears. I try to carry on walking, but stop by a low wall, and gather myself. I feign searching for something in my bag, to avoid attention from passers-by. This is silly, things have gone well! Having taken a few deep breaths, I carry on my way. All the way home, I replay the conversation in my head, over and over. Yet this is not what has upset me. It is not a ‘head thing.’ Things went well! This is a ‘heart’ thing. I am overwhelmed, but by what? Relief? Generosity? Joy?

Other times, I do not film our conversations. Brigit appears happy to talk, but we don’t seem able to move from general conversations about life and what’s going on, to sitting down and pressing record. Once, with the camera ready, but off, I confessed to Brigit how weird it felt to sit there with her, talking, warming up, and then to press record. There is always such a shift, and it takes effort to carry on having conversations once we
are recording. I look at her, press record and she freezes. She laughs and says, “Well, you’ve pressed it now!”

I have to learn to speak up, speak out. I don’t want Brigit to feel uncomfortable, so I need to say out loud that I will follow her lead, acknowledge up front how she is feeling, or suggest that perhaps today is not a good day for filming. Once, I visited and she was clearly upset about something. I stayed and we drank lots of tea. We hardly touched on the family. It was just ‘stuff going on’. This is all part of what it is like to be invited into somebody’s house, to be welcomed as a guest. You cannot expect life to pause, every time, just so that you can get what you need.

As I learned more through visiting Brigit, I became more confident with her. Altogether, we filmed three conversations, but had many, many more that I wrote up as notes in my journal. We swapped books, DVDs, plants and tea. I was also keen to start sharing her story at seminars and conferences. This provided me with a clear structure within which to broach subjects such as, “This is what I am trying to do, this is how I am working with your story, are you happy for me to share this?” And, “Here are some final questions that I would like to make sure I’ve asked you before the summer.” My voice was getting stronger. We found our way.

As soon as I had Brigit’s permission, I decided to talk to Bella about my ideas, and to ask if she would like to tell me her story. I used to give Bella lifts home from deaf club every so often, and this was a nice time for the two of us to chat (despite the inherent challenges of signing in the car at night). Bella kept me on my toes throughout our collaboration. If I went to a conference she wanted to know who would be there; “Any deaf?” and afterwards, what people said, what questions they asked. At one stage, Bella interviewed me. She also reviewed the DVDs of our conversations and the transcripts, correcting my English, and meticulously changing all the names, to protect her family identity. We spent hours discussing pseudonyms. Could she be Donna? Could I use her real name, as a double bluff? *Is it really her, or not?*

Bella took great interest in my life, my family and our research processes. In my mind, she represents genuine reciprocity, and the most touching sensitivity. One day, I had called round with some photographs. Brigit and the children were home, but Thorin and Christian were playing outside. Brigit asked how I was, and I explained that things had been a bit rough lately. I found myself telling her about a family illness, and began crying into my tea. Bella waved at me from the corner of the kitchen, “Maybe you shouldn’t talk about this if it makes you cry.” She changed the subject and made us all laugh. Every time I see her, she always asks how I am. She teases me mercilessly about my old banger of a car (now
written off) and generously offers stories, jokes and performances. I therefore offer back memories, funny stories (“What’s your earliest memory? No, not the one about your gran leaving you outside the shop in the pram, you’ve already told me that one, tell me another story!”) I also offer small gifts, honey and wobbly rides on the back of my bicycle.

A note about Thorin and Christian: Brigit and I both felt that Christian—just five years old—was too young to involve himself in our inquiry. Thorin said yes, but, as Brigit told me, might drift in and out, and change his mind. I spent time getting to know Thorin better, getting beaten at chess and draughts, reading with him, and telling him about the book I was writing. I wondered if he wanted to talk to me about family. He didn’t. Did he want to draw? A cartoon? Yes. Could it be a cat cartoon though? Of course. Thorin draws beautifully, carefully and precisely. We did try working together on a family cat cartoon one afternoon, but he lost interest and I made the decision not to keep asking. One day, as Brigit and I discussed pseudonyms, Thorin said he wanted to be Mr Nobody. He drifted out of the inquiry, and we carried on playing chess instead.

Christian features on my videotapes. He throws Pooh and Piglet at the camera. He sits on the sofa next to Bella and eats eggs. He giggles infectiously as he catches sight of himself in the viewfinder. He fetches
biscuits and presents them on a plate as Bella attempts for the third or fourth time to tell me who in her family signs. Bella relents, changes direction in her story and talks about her little deaf brother.

I was building up to meeting Georgina. I hadn’t seen her in ages, but I knew in my heart that I wanted to hear her stories. I went to see her at work. As I began signing, hands shaking, I thought, yes, she’s going to say yes. I could feel my throat contracting, my stomach flipping. Before I had finished, she interrupted: “Do you want to know the story of my family?” Later, we agreed to meet, away from work, to discuss working together over coffee. She told me, “I want to do this.” Why? “Because I’ve wanted to write the story of my family for a long time. And because I value my children so much. But this is not just about my children, this is about cousins and aunties and grandchildren too.” We started chatting about other members of the family being involved in the inquiry; about Nick (“Well, I asked him, but he says he can’t remember anything when he was younger!”) about Thomas and what’s been happening lately, and about Toni, the independent one (“Yes, but she always comes back”). I shared some of my ideas on narrative inquiry, and Georgina offered her observations. She said, “Don’t forget, the story of my family, is the story of my family, not of all deaf families. But I like the way you work.”
Georgina and I met twice for filmed conversations. The first time, we ran on to a second tape. It had begun to get dark outside, and we reached a natural pause. Georgina made tea. As we sat chatting, she began recalling other stories. I said, “Do you want to record this?” She burst out laughing and said, “Yes! I think we should!” We used up three tapes.

*Personal journal: 3am.*

I am out of kilter, my magnetic north gone awry. I feel shaken up, like a bottle of medicine, the sediment disturbed, and the insides of me all wrong. I have a lump in my throat and an edgy swelling in my heart. I am not myself. I see her in the most surprising of places. She was at the corner of my street, watching television with me, boiling the kettle with me, and something she had said on tape came out of my mouth mid-sentence, when I was talking about something completely unrelated, like … going on holiday. Didn’t Laurel Richardson write about finding herself using Louisa May’s words in her own daily conversations? Maybe G’s here because she’s under my skin and in my head, and what I need to do is put her in my computer, and write about her and about the whole experience of being with her in this work. Maybe then I can sleep …

I sent Georgina transcripts, which she carefully and painstakingly checked through (“My god, I do go on, don’t I?”). There was one story she asked me to take out. I was so disappointed; it was such a good story! “The thing is, I don’t know if my children know that story. I think it’s best to take it out.” Georgina praised my transcribing, “Well done. Only a few mistakes.” I checked in with her regarding my ethics. She told me, “The thing is, signing a form doesn’t mean anything. It’s about trust. I trust you.” So we talked more about ethics and informed consent as an ongoing process, where I would keep her up-to-date with what I was doing, and check she was happy. When we could, we met for a drink after work. I showed her the book of poetic texts I had created. She sat there, head down, and read every single word of her story, crying and laughing all the way through. “I like the way you’ve done them. Help me remember what I said—pictures in my head.”

Toni and I have known each other for years, since she was fifteen. We arranged to meet in her local café. She brought Thomas with her. Perfect. I had written him a letter, but Toni thought it would be a good idea for both of them to meet me at the same time. Over café latte and Red Bull, I talked to them about what I hoped we could do together. They couldn’t wait to get started. They were already looking at each other, laughing; “Ha! Remember when …” Over the next few months, Toni and I had three filmed conversations. In between, she lent me a folder of her writing, drawing and songs. She also got down from the attic a bag full of
photographs, toys, mementos, all of which generated stories. As always, we carried on talking outside the research conversation. General things. Life. I sent Toni the transcripts, which she happily corrected. There were always things she wanted to expand on. And because we’ve known each other so long, there were stories I already knew, but wanted to hear again. Finally, it got to the stage where I asked Toni if she was going to share her text with her mother. Had she seen Georgina’s story yet? “No, but I can’t wait! We’re gonna swap this weekend.” I took a deep breath. There were some stories Toni had told me, I wasn’t sure if Georgina knew or not. The thing is, when you told me about this, Georgina told me a slightly different version, so … does she know what really happened? “Oh yeah, she’s just probably forgotten! It’s fine. I’ll have to remind her about that!”

Image 3. Toni’s journey

Having written to Thomas, and having explained the research to him and his sister, we began meeting. At first, in the café, and then at his home. Each time, I brought my videocamera and notebooks. The first time when I suggested filming, Thomas said no. He wanted to read and sign an ethics form first. He wanted to be “covered”. The next time, he suggested writing his story. He went to the shop next door, bought a pad and pen, then sat with me as we discussed and planned how he wanted to tell his story. He began writing the story he wanted to tell, which he gave to me to type up. Amid the ethical chaos of encounters in the café I was physically sick. On another occasion, I went to Thomas’s house. We talked for hours. He needed to talk, but this was indiscriminate, and I realised most of it
was not for inclusion. We would have to hunt for the gems. I wondered whether he would consider letting me record part of the conversation, simply to help me remember better what we talked about and on another visit, I set the camera up. For the next two hours, Thomas distracted us from having a research conversation. He clearly did not want to be filmed. We worked out other ways. He would sign to me, and I would write up my notes as carefully and accurately as possible, often outside in the car, as soon as we had said goodbye. I sent these to him, and we would meet again to talk about it. He would offer comments, and I would write these on to the pages. We began crafting a story, stitching it together. Working with Thomas has been one of the most incredibly touching experiences of my life. I have known him since he was little, and we have had our fights and fun. Every so often, he would suddenly come out with something so profound, so moving, in amongst the random contradictions of his stories, a moment of insight of such poetic depth, it would make me cry. I would sit next to him on the sofa, watching him read through the transcript, pen in hand, mobile ’phone constantly vibrating and receiving texts, taking every single word seriously. I gave him a newspaper article to read once, about a hearing girl from a deaf family, and he read it from start to finish, before offering me his philosophy. He opened his heart, talking about relationships, then closed down again, just as swiftly. We arranged one more meeting. Thomas had cancelled on me a few times. Once or twice, Georgina found out and said she would have a word with him. We finalised a date and time, but then I cancelled. I was overwhelmed with work, and felt unable to walk away from it to visit Thomas. I texted him to explain, and to try and set up a new date. He was unable to commit, he had a lot going on too. I still feel bad about this.

The last time I saw Thomas was in the pub with his mum and his sister. Georgina wanted to read through Thomas’s story, and he wanted her to check it, to make sure she was happy, and to help him make decisions about what to keep, what to take out, and what to change. Georgina and I were already sat with a drink when he walked up to me, arms open wide, eyes twinkling, with a cheeky grin, and said, “Hey, you’re a poet!”

Thomas’s story continues. But that is a story beyond this one.

As for Nick, Wesley and Jasmine, they chose not to participate. I have it on authority from Georgina and Toni that they are happy that I contacted them, and happy about the research. They simply did not want to tell their story. Wesley visited one day and found the poetic texts on the coffee table in the living room. “Oh mum! Why didn’t you tell me this was how she was doing it? They’re beautiful. If I’d known … Can I read them all now?”
Dora, Luke, Maisie, Harper, my bookends. I began this journey with the four of them in 2006 and they wanted to carry on (“Do we have to stop now? We’ve got loads more stories!”). So, I packed my things, and drove to London. In the time between us agreeing to work together again and my visit a news story hit the headlines and spread like wildfire across the media. The Government’s proposed amendments to the Human Fertilisation and Embryology Act (HFEA) suddenly appeared to be naming deaf people as undesired members of society, and were bringing out the very worst of public opinion and vitriol. We were suddenly caught up in this, in the middle of our work together. Should we talk about this? I didn’t see any way to avoid it, yet I was painfully aware of how parents like Dora and Luke must be feeling. We swapped e-mails. Luke wanted guidance on the kind of thing I was interested in hearing about. In the end, with the camera set up, but not recording, I checked in one more time. Are you happy to talk about this? I think it’s so important that hearing people’s voices and objections are recorded and heard. But if you don’t want to go there, I completely respect that. That is all part of the story. “Yes, we want to talk about it.” I pressed record, and Dora said, “Shall I start? I’m happy to start.” A full 90 minutes on the impact of government legislation. After a tea break, they tried to talk more generally about the girls, the extended family, the two of them, as parents, husband and wife, but in the end, it kept coming back to HFEA.

A couple of months later, Maisie and Harper were both home and we seized the opportunity to meet. I was still reeling somewhat from typing Dora and Luke’s transcript, and losing sleep about putting them through such an upsetting experience. For my own peace of mind (selfishly perhaps) I directed the sisters towards more general family memories, revisitings, stories, and kept The Genetics Issue until the end of the conversation. They were on good form, although Maisie was full of cold. We jumped from story to story, with the usual humour, teasing and banter. And then I asked about the grandparents. I genuinely and naïvely thought it a fairly innocuous question. Silence. We had hit a bump in the road. They both looked at me. What had I said? I felt terrible. I tried to ease the atmosphere by apologising, to see where we could go with this. Maisie to Harper: “Go on! The grandparents! Go on, you start!” Somehow, the conversation jump-started, juddered and eventually gave out again. Maisie, once more: “Move on to the next thing!” Afterwards, Harper joined Dora and me as we sat drinking coffee. She seemed … Worried? Upset? Concerned? Maisie was off, sitting at the computer. But Harper wanted to say something. She said she hadn’t quite expected Maisie to say all that. A couple of weeks later, I got the following e-mail from Dora:
Hi Donna
We are having a visit from the grandparents. Tea here yesterday, dinner out last night (their treat) and they are having shopping and lunch with the girls today. Tea yesterday was stressful and a bit awkward as usual so the girls and I had a bit of a chat before the evening session. Harper and I decided that as the gatekeepers of communication we could wield our power and decide who gets through and who gets blocked. Positive discrimination meant the hearing were right down the pecking order. Maisie seized the initiative and dominated the conversation with Gran amusing her with anecdotes of student life and I talked to Pop preventing interruption. Luke acted as border patrol. It worked very well! Maisie was not the passive receiver of boring interpreted nonsense who then gave up and spent the time texting and missing the hard work of the interpreters who then did not get resentful. Result! I will be interested to hear how they have got on today. We thought you would like to know as we were probably inspired by the ‘awkward silence’ in the girls’ last interview to try and improve things. Still a work in progress! Hope you are ok and the writing is a happy experience. Keep those fingers warm. Love Dora x

Image 4. Glue

Ethical endnotes

Informed consent: An oxymoron?

From the outset, I made it my key objective to update the families (in conversation, via SMS, or e-mail) on what I was doing, thinking, writing, struggling with, presenting and learning. Toni and I spent part of an evening discussing deaf/Deaf/DEAF, Bella interrogated me about a particularly prickly conference attendee who only wished to know the precise details of Maisie’s ‘hearing loss’, and insisted I re-tell the story, again and again. Apart from Thomas, no-one signed—nor wished to sign—a consent form before telling me their stories. In terms of informing
and consenting, there seemed no single point at which we all arrived, knowing what we were all consenting to. As Etherington explains:

The researcher can usually provide information about the purposes and practices of research in advance but may not be able to provide information about processes that have yet to unfold (Etherington, 2004a).

Our ‘contracts’ with each other were constantly revisited, negotiated, clarified and absorbed into our ways of working together. Josselson (1996; 2007) goes as far as to say that informed consent is an oxymoron; that the terms on which a participant is expected to consent are largely unknowable or unforeseeable at the outset, and only develop through personal, often intimate, research relationships and through the “ebb and flow of dialogue” (Helgeland, 2005: 554). Our dialogue revolved around what Etherington (2007: 608) calls “an ethics of consequences”: What will happen to your stories? Who will read or hear them? Who is implicated? How will you feel seeing your story in print? How might this change over time? Even though Thomas wanted to read and sign a form before we began working together, I maintained this ethic of care (Gilligan, 1982; Noddings, 1986) and dialogue with him as well as the other family members. In fact, his signing of the form was a significant turning point. I recognised its worth and importance in his eyes, but at the same time acknowledged its potential superficiality. What was he really signing up for? We could only work this out by working together. He agreed (on the form) to be filmed, but later declined. This opened a door to a different way of working together; one that could not, as Josselson and Etherington both point out, have been planned, or foreseen.

**Space interrupted**

Any inquiry that asks people to tell their stories interrupts or disrupts the everyday spaces of their lives. I invited the families to draw their own boundaries (Daly, 1992: 10). Issues of privacy arise both in the spaces in which stories are told, and in the stories themselves. Mostly, I was invited to family homes; it was easier if I came to them. Sometimes, we met in cafés—“My flatmate is at home during the day” or “It’s where I feel relaxed.” Once filming was over, later conversations often moved to the pub, over a meal, outside in the park. Research conversations in the home are peppered with events and everyday interruptions, saturated with details of family life. I include my responses to these in my notes, and the videocamera picks up many of them. The doorbell rings; little brother enters the room and performs with his toys in front of the camera,
redirecting the conversation to stories about him; a conversation needs to be cut short because of a doctor’s visit; older sister unexpectedly turns up to discuss cooking the evening meal. These interruptions weave into the narrative research space. They are an intrinsic element of the inquiry, but my responsibility is to work with the families so as not to include anything that breaches our trust, our research relationship and their privacy, but to work with them to discover and uncover the story that they are happy to tell.

**Entextualisation**

When stories are told or performed in sign language, there are many complex issues relating to moving from a visual-spatial modality with no written form to a linear text (Temple & Young, 2004). BSL is a richly poetic and metaphoric language (Ladd, 2003) and everyone (adult, child, deaf, hearing) has her/his own idiosyncrasies, narration styles and turns of phrase. Not only was I stretching my translation abilities, but I was also grappling with the seemingly infinite limitations of the English language in order to do justice to the signs as I typed. I was also mindful of the theoretically and politically complex act of writing down spoken and signed stories.\(^7\) Acknowledging the idea—the truism, even—that transcription is a partial representation (Green, Franquiz & Dixon, 1997; Ely, 2007), I wondered where to draw the line between what to include and exclude: what of intonation, emotion, the passage of time, body language, eye gaze, accent, emphasis? Vigouroux (2007) talks of the transformation (perhaps entextualisation, see Urban, 1996) of the narrator’s physical and sensual presence into linguistic data. I wondered how much should be written into these scripts, and perhaps more importantly, why (Green et al, 1997). Much has been written about transcribing as a situated, interpretive and political act (Duranti & Goodwin, 1992; Edwards & Lampert, 1993; Green et al, 1997). I, with the families, tried to acknowledge the first-draft script as a tool, a construction, a part of the process, to have something to show them, to work with. These scripts often triggered new memories, or served to remind each of them what they had said. Typing up, I found myself—in watching, listening, writing, reviewing—becoming drawn into features of individual story-telling. Dora and Luke, for example, spoke quickly, often at the same time, and bounced ideas off each other. I set down the draft script in a way that attempted to illustrate this back-and-forth dynamic. Bella, in sign, employed certain BSL features, such as establishing that there was a list of stories she wanted to tell, and beginning with \(<\text{NUMBER} \)
ONE> (in English, “Firstly”). Her narrative features <ALSO> as a marker of a new story, and <MEANS> as development. I chose to retain these, specifically, rather than attempting other translations for variation, as I recognised them as a familiar aspect of BSL. Deaf narrators—Bella and Georgina in particular—also made very specific, topographical and metaphorical use of placement in many of their stories. I tried to retain this in the drafts through text placement, and chose to retain, even emphasise, this in some of the final texts. I also included pauses, laughs, smiles and gaze, particularly when omission might obscure or alter the intention or meaning conveyed through writing down speech/sign alone. This highlights a tension in the process, which Barthes (1981) refers to as losing the body, while trying to restitute it. It was not my intention to deny the transformation of live story into text, but to capture and retain certain details.

I wrote, largely, in standard English. However, in terms of what I felt to be untranslatable signs, or strongly recognisable BSL expressions, I incorporated specific non-English/decontextualised words, enclosed <thus> (such as <FEE> and <FANT>) in the texts. I also preserved cultural-behaviour referents such as <TAPTAPTAP> and some BSL expressions that do not necessarily translate directly with the same, particular meaning in English (e.g. <THAT’S IT> <FINISH>).

When signs (and indeed words) were lengthened, I stretched them (sooooooooooo excited, S-I-I-I-I-I-G-N). When spoken conversations included signs, I have also included these. Sometimes, I simply did not want to translate and elaborate too much; so beautiful or poignant is the original, pared-down expression. Georgina talks about the sudden death of her brother when she was little and looks at me:

<PLAY PLAY PLAY PLAY GONE>. Enough said.

Using draft scripts as a tool was important, not only in terms of ‘getting it right’ but also to feel sure the families were happy with what I had done, and how I had done it. The back and forth of scripts, elsewhere termed member checking (e.g. Hole, 2007), brought us together in terms not only of linguistics and translation, but also of pragmatics, culture, power relationships, epistemology and co-construction (see Vigouroux, 2007). Scripts became springboards: for new stories, for meta-linguistic analysis, for cultural unpacking, for elaboration (Clifford, 1983) and for planning how we could craft the stories in ways which restituted them, aesthetically, persuasively and truthfully.
Bella

*Personal journal:* Driving Bella home from deaf club—it’s dark and pouring with rain. The wipers flash and groan. The world is shiny and she is pointing out police cars and ambulances. Blue lights flashing, lighting the interior of the car, and casting strange, intermittent shadows on our faces. She is wondering why, whenever I give her a lift, we always see accidents, fire, police, trouble. She has decided (wickedly) that each time this happens on our way to her house, I “fail”. She shakes her head slowly, in mock disappointment, sighing. So now, each lift home is a test, to see if I can get her back without an incident, so that I can “pass”. While all this is going on, I try to grab a few moments to check in with her (sign language conversations while driving are never easy at the best of times). Is she still OK with the project? Does she have any questions? Yes. She holds a pretend microphone to my face and signs “What’s the story of your family?”

Bella is 10 and by far the youngest of my narrators. In my reading about researching with children I was intrigued by such claims as “children are more likely to be invited to confirm adults’ readings of their representations of personal experiences than to be given a chance to share their experiences independently” (Tsai, 2007: 462), and ideas that children may be surprised to find out that adult researchers can learn from them (Huber & Clandinin, 2002: 792). I talked, at length, to Bella about our inquiry. I talked to her about the power of stories, and about existing, historical and contemporary theories of deafness, sign language, cochlear implants and families with deaf children. She was witness to her mother’s story, and took on the role of camera-person. She wanted me to tell her all about the seminars and conferences I was presenting at. She wanted to see examples of my writing. When it came to filming, she had a clear idea of what her story should contain—she embodied, at ten years old, an active, agentic narrative authority (Olson, 1993; Huber & Clandinin, 2002). I have therefore treated her stories in the same way as I have those of the other family members. I have worked with her on their representation, in accordance with her wishes and ideas. Research with children—and particularly deaf children—invariably throws up all sorts of issues regarding power, voice, collaboration and consent (Christensen & James, 2000; Davis, Watson & Cunningham-Burley, 2000; Garth & Aroni, 2003; Young *et al*., 2006). At all times mindful of these, I still chose to treat Bella no differently. After all, Georgina was the only deaf mother, Luke the only father, Harper the only hearing sister, and so on. We each found our own ethical ways of working together.
hi donna, just wanted to say that bel has just gone to bed, sparkly and happy, for the first time in ages, and largely due to having a great time chatting to you! Brigit X
I cannot understand how a language like sign language—the richest in expressions, the most energetic, the most incalculably advantageous in its universal intelligibility—is still so neglected and that only the deaf speak it (Desloges, 1779: 45-6).

Another thread running through deaf history is the ongoing philosophical debate concerning language, thought, faith and enlightenment. Although Socrates drew conclusions on thinking and communication among deaf Athenians, later Greek philosophers—perhaps most infamously, Aristotle—did not necessarily concur. Aristotle believed that, without speech, deaf people were without reason (Edwards, 1997; xi Lee, 2004). He was particularly interested in the five senses, and how they might be divided into two groups (Ross, 2000): the contact senses of touch and taste, the distant senses of sight and hearing, with smell possibly belonging in either or both. According to Rée (1999), Aristotle believed that the distance senses were more noble, pure and epistemologically respectable than the contact senses. Perhaps the bizarre flaw in Aristotle’s thinking was in viewing the signed communication of deaf people as tactile (which it certainly is) without also acknowledging its visuality. His development of a ‘hierarchy of senses’, however, was to influence many philosophies of language and thought for almost two thousand years (Winzer, 1997).

By the 17th century, deafness was no longer simply part of life’s rich tapestry. Deaf people were becoming “pawns in an intellectual game” (Branson & Miller, 2002: 87). Their signs became a particular focus for philosophers, and particularly Royal Society linguists such as John Wilkins who believed that sign language was equal to spoken language and a viable means of communication and understanding for deaf people.

Now, Aristotle’s assertion that speech was fundamental to understanding and the source of all knowledge was being questioned. Scholars were engaged in the search for the perfect language; a vehicle for the mind and the soul (Wilkins, 1641). Deaf people were seen as holding
the key to unlocking the secret of the prelingual mind (Winzer, 1997). Despite the fascination for signs, however, and acknowledgement of visuality as key to communication for deaf people, Royal Society members such as Wilkins, Dalgarno and Bulwer were still very attached to speech, and to the superiority of English.\textsuperscript{xii} Practices of ‘linguistic colonialism’ (see Greenblatt, 1990) viewed sign language as the poor relation of spoken language (Nelson & Berens, 1997)—a thread that was to run throughout the histories of deaf lives.

**Educating deaf people**

Taking it for granted. That Deaf people are equal, in the faculties of Apprehension, and memory, not only to the Blind; but even to those that have all their senses … It will follow, That the Deaf man is, not only, as capable; but also, as soon capable of Instruction in Letters, as the blind man. And if we compare them, as to their intrinsick (sic) powers, has the advantage of him too: insomuch as he has a more distinct and perfect perception, of external Objects, then (sic) the other … (Dalgarno, 1680: 8).\textsuperscript{xiii}

It was becoming clear to some not only that deaf people were capable of thought, and of communion with God, but also that deafness was no barrier to education. Dalgarno (above), a teacher, in musing over the faculties of blind and deaf people had, perhaps unwittingly, tapped into one of the richest veins of deaf life in his observations of the power of sight and visuality. Other educators followed suit. In the quest to educate deaf children (albeit from the wealthy and noble classes), it was accepted that, in line with intellectual life stretching back to Roman and Greek times, knowledge was obtained through reading and writing: “Wisdom was in the text” (Branson & Miller, 2002: 67). Once it was realised that deaf people could think and express their thoughts, they could also, through the faculty of vision, learn to read and to write, and become educated. As Rée (1999: 109) puts it, deaf people were speaking with their fingers, and hearing with their eyes. The challenge, of course, was in knowing how to teach deaf signers. It was John Wallis, mathematician and educator, who realised that “little Actions or Gestures” would be required (Wallis, 1698: 359).\textsuperscript{xiv} Deaf children could then be shown “what Words answer to their Signes” (Wallis, 1698), and they could learn English as a second language. A similar method was also emerging, entirely separately, in Paris. The Abbé de l’Epée, who knew nothing about educators such as Wallis, and Braidwood in Edinburgh, was convinced that the signing he saw being used by deaf Parisians was a genuine language (Rée, 1999).
This language would have to be learnt before attempting to teach deaf children French, or any other subject. By the turn of the 18th century, sign language was being used, by deaf as well as hearing teachers, in many deaf schools across Europe (Rée, 1999; Branson & Miller, 2002).
CHAPTER THREE
THE STORY OF THE WRITING

A story of the writing

This chapter is the—or perhaps a—story of the writing of the family narratives. It focuses largely on the construction and creation of the poetic texts that are at the heart of this book. In doing so, however, it also intersects with the theories that underpin or embrace writing more generally: the creation of a reflexive, moving-about-in-time, multilayered piece of work. It also acknowledges writing across and through more than one language. It acknowledges deaf and hearing narrators, deaf and hearing readers and creative ways of re-presenting spoken and signed stories on paper.

Me writing?

The question of who tells and retells, how, for whom, and for what purpose raises the prickly issue of authorial privilege and rights (Benham, 2007: 517).

With the permission and approval of Brigit, Bella, Georgina, Toni, Thomas, Dora, Luke, Harper and Maisie, I have written their family narratives as a poetic volume (Chapter Four). I position myself, however uneasily or tentatively, as the writer of these texts. Geertz (1988: 10) talks of the burden of authorship, in terms of the tensions between the intimate view and the objective, ‘cool’ assessment in one’s writing. I do not so much experience a negotiation of these tensions; more I wish to unburden myself of the position of author (see also Shope, 2006), and to take on that of collaborator-writer.xvi While I have made decisions regarding the re-telling and re-presentation of the family stories (c.f. Richardson, 1992, who talks of ‘staging’), they are authored by the families themselves xvii The texts are produced carefully and collaboratively, from our earliest conversations, through co-editing of scripts, to consultation, mutual decision-making and feedback over the ‘final’ rendering in print. Perhaps,
then, I can find comfort in Barone and Eisner’s (1997) idea of *artistry*; necessary for the aesthetic transition of stories from private to public (Brearley, 2000). Or perhaps it is a feminist reworking of the term *author* as one who relies on—and is interdependent with—others (Richardson, 1997; Bloom, 1998), that alleviates my unease.

I am, however, further troubled by issues of language, and by what Spivak (1992) refers to as the politics of translation, when it comes to transcribing BSL. There is an inherent hierarchy maintained in the representation of a signed narrative in English. As Temple and Young (2004: 170) point out, “it is the hearing/speaking/writing communities for whom any acts of translation occur in the dissemination of the research to predominantly text-based, hearing academia.” That is to say, entire narratives are at risk of being uprooted, transformed, transported, and relocated by hearing people, for hearing (non-signing) people. The aim to amplify marginalised voices runs the risk of muting them further if the researcher/translator/writer is seen as—or takes on the role of—authoritative spokesperson (Shope, 2006). Writing, as Richardson (2003) reminds us, is never innocent. Language is a constitutive force (Foucault, 1978). It is up to the writer to decide whether to reinscribe what are traditionally considered legitimate, accurate, facile forms of academic knowledge (St Pierre, 1997; Richardson, 2003), or to trouble, disrupt and resist them in the production of reflexive, experimental, interrupted, co-constructed accounts (*inter alia* Speedy, 2001; Richardson, 2003; Gannon, 2004). Either way, I run the risk of distancing myself from my family narrators. Postmodern writing can be elitist, unrecognisable, impenetrable, dislocated. Ellis and Bochner (1996) and Denzin (1999) help, with their attention to an ethics of writing. The texts I wrote, sent back and forth to my family narrators, and re-presented here, have been read and approved—written *for* them, authored *by* them.

**Writing back**

The power of language is in the actual experience of communication as well as in what is evoked and provoked by the intellectual meaning of the words used (Ortiz, 2004: 144).

I am struck by the ways in which stories engage with various audiences/readers; particularly in terms of this book, which is informed by deaf and hearing, signing/speaking bilinguals, and re-presented, in the main, as a written text, by a hearing, speaking/signing researcher. I recognise an urge to seek out ideas from postcolonial writing as a way to make sense of cultural and linguistic contact zones and postcolonial hybrid
texts written as indigenous responses to colonialism (Pratt, 1992; 1994): *rewriting* and *rerighting* (Tuhiwai-Smith, 1999: 28). Postcolonial writers (e.g. Meddeb, 1979; 1986; Khatibi, 1990; Djebar, 1992—see Mehrez, 1992) make specific decisions regarding the language(s) they write in. At its simplest—and here the examples are largely from North African Arabic/French writing—the decision is whether to write in the language of the colonised, or of the coloniser. What emerges from these decisions is the forging of hybrid texts, or *métissés* (Mehrez, 1992: 121), which move between languages and cultures, and create new, resistant, ‘in-between’ spaces for writing and reading. Writing in the language of the coloniser, by bilingual, postcolonial writers, creates disruption. As Pratt (1994) explains, coloniser-readers are confronted by alien concepts, parodied in their own language. This creates a powerful tension and resonant ambiguity, as familiar words no longer make sense. The idea that a ‘subjugated’ bilingual writer can write to, and effectively exclude, the (monolingual) coloniser-reader is a cornerstone of postcolonial writing.

Hybrid texts demand that readers move between languages and translations; this migration is integral to the act of reading (Mehrez, 1992). As Khatibi (1990) claims, reading and writing postcolonial texts is a plurilingual act, almost at the threshold of the untranslatable. However, translation is not simply about linguistic equivalence. Postcolonial hybrid texts contain cultural referents, structures and formulas that resonate with the colonised reader. Texts become mazes of subversion, linguistically, grammatically, syntactically and culturally (Meddeb, 1979; 1986). Even when familiar terms and styles are employed (Tuhiwai-Smith, 1999), cultural meanings, which only emerge in the act of constant migration, expand and enlarge the ‘hidden’ messages that remain inaccessible or obscure to the monolingual, imperialist reader.

The tension resides, however, in the highly strategic appropriation of the coloniser’s language, idioms and ideological apparatus (Pratt, 1994) for the construction of resistance texts that directly intervene, address, confront, even parody the coloniser. Ngugi wa Thiong’o (1981), for example, believes that writing in one’s own language is the means to engage in postcolonial struggle: using the coloniser’s language—which obscures indigenous cultural practice, history, heritage, ways of knowing—simply pays homage to them. There is conflict between the liberation of writing one’s story, and the compromise of writing it not in one’s own language. As Mehrez (1992) explains, it often comes down to choosing the word over silence. Djebar’s (1992) work with Algerian women is such a case—it is the writing of their testimonials, in the language of the ‘enemy’ (French) that “liberates their stifled voices”
Without the written text, Djebar argues, these women’s voices would remain unheard. Therefore, writing them down is liberatory—*listen to us*—and resistant—*look what you have done to us*. That they are written in French is, as Mehrez (1992) explains, the reason for their power, reach and influence.

This brings us back to oral cultures. Putting to one side for now the notion of sign-language-as-text, it remains that, like many of the world’s small, indigenous, oral languages, sign languages have no written form. There are various notation systems (Stokoe, 1960; Brennan, Colville & Lawson, 1980; Sutton-Spence & Woll, 1999) that are used to annotate linguistic features of sign language lexicons, but other than by recording on film/video, sign languages essentially remain oral languages. Deaf people are not, however, monolingual; living as they do in contact zones and constantly migrating between their own language and spoken/written languages. Deaf stories as signed stories will rarely penetrate wider discourses, and reach wider audiences. Therefore, as with Djebar (1992, see above), the decision over which language to write in relates directly to who is doing the writing, and why. Deaf history is often viewed in postcolonial terms, with hearing oralists in positions of colonial power (Ladd, 2003). I am not suggesting monolinguals (i.e. non-signers) are colonialists. I am not suggesting hearing people are the enemy. I am simply highlighting and reflecting on the fact that a freely migrating bilingualism can be a source of strength and creative freedom. I have somewhat mischievously taken advantage of that fact.

**Who writes?**


This book records and re-presents the narratives of deaf and hearing people, who have told me their stories in English and in BSL. This book also tells the story of the inquiry, and locates it at the intersections of history, culture, family and narrative inquiry. This is a story of resiliences and resistances; multi-layered, intersecting, contingent, personal, intimate, imaginative and academic. In re-presenting family stories, and in the decisions I make as the writer who puts words on the page, I am articulating and making visible a resistance narrative of my own.

My first act of politics has been consciously to act (see Duncombe, 2002); to ask families to tell me their stories so that I might set them down for others to read. *Their* first act (consciously or otherwise) was to agree to
be a part of this. This created a space for talking about, crying and shouting about deafhearing life, for remembering, showing and celebrating. I have been entrusted to transmit these stories. Whether they were told to me in English or in BSL, I am writing them in English, which is my first language. I am, therefore, constantly, *seamfully*, migrating between the two.

**For whom is the writing being done?**

Hey ... Got a bit lethargic over the wkd so read email and transcript this morning, was late for work with tears! It’s beautiful, thank you so much. Have noticed 2 things need to change but other than that ... it’s poetic justice to itself. You should be proud, i am! Big hugs and love, Toni x

As I re-present family stories, my aim is to employ or emphasise certain hybrid, linguistic conventions, potentially unfamiliar concepts and referents, ambiguities, disruptions, untranslatable representations—albeit through the use of English, and enclosed <thus>—which require a certain knowledge for cultural and linguistic translation. There is a temptation to provide footnotes, explanations, translations. At the same time, I wonder; should I leave it to the reader to read, recognise, stutter, ignore, question, discover or dismiss the unfamiliar? I acknowledge postcolonial writing that, through in-between spaces of languages, creates texts that are differently read and felt by monolingual/bilingual, coloniser/colonised audiences, and that turn issues of power and ways of knowing and speaking on their heads. My position is tenuous. Do I have permission to do this? I am hearing, and I negotiate my (self)ascribed Hearing identity by attempting to move into a risky writing space where, despite my best efforts, I find myself in a *neocolonial* position of control. I am writing about, and re-presenting other (deaf and hearing) people’s resistance narratives; narratives that are demanding to be heard. Writing at the intersections of language and culture, deaf and hearing, community and academia, adult and child, personal and public, the risk is that, if too obscure, these stories will not be read/heard at all. I have done what I can to play creatively, critically, strategically and imaginatively with English textual representation; choosing words over silence.*xix*
Chapter Three

Poetics of experience

I made a note, sometime in 2007, that I wished to “produce a collective artefact of which we are proud” (Denzin, 1999: 568). Yet the permanence and authority of the printed word (Josselson, 1996) should not be underestimated. Stories, signed or spoken, exist in the moment of the telling, and live on in the remembering and retelling. In that living-on, they are dynamic and ever-changing, spiralling through time. Stories that are transferred to print are embalmed (Denzin, 1999), or fixed—like photographs taken from the stop-bath—in the moment of the printing. Our artefact, therefore, is just that; a distinct, material, textual construction of stories moving about in time (Brockmeier, 2000).

I became drawn to the idea of an aesthetic/poetic re-presentation of the family stories. Setting out texts in stanza form (inter alia Tedlock, 1983; Richardson, 1994b; 2003; Riessman, 2000; Speedy, 2001; Etherington, 2008) began as a process of tuning in to emotionally, morally, politically charged stories; those that resonated, jarred, or simply stayed with me (Richardson, 2003). I also began to attend to the ways that my narrators spoke and signed—often closer to poetry than to prose (Tedlock, 1983; Mair, 1989; Bauman, 2006). Repetition, rhythm, pace, alliteration, flashback, close-up, distance shot, symmetry, simile, silence and symbol: to write in prosaic form is almost a violation of the stories that we are trusted to take care of (Richardson, 2003). Vignettes, memories, snapshots and short stories stood as mini-narratives in their own rights (Richardson, 2003; Bamberg, 2006a, 2006b; Ely, 2007) and as such, offered titles, and demanded their own space on the page. Many stories are short, others are longer. Realising them as such—as opposed to a more cohesive, balanced, consistent re-structuring, perhaps—reflects the shifting, contingent complexities of life and the ways in which they are spoken about.

Poetic narrative re-presentation aligns itself with other postmodern forms of writing (Fontana, 2003) and challenges the idea of the traditional, conventional, acceptable, analytical, unnoticed prose format of social-science research (Brearley, 2000; Willis, 2000; Gubrium & Holstein, 2003). As Richardson (2003: 188) points out, prose is not the sole, legitimate conveyor of knowledge. Experimental writing and poetic, creative re-presentation, on the other hand, openly and deliberately reveal the constructed nature of the work (Etherington, 2002), the multidimensionality of the stories therein, the reflexive, situated, epistemologically concerned researcher (Richardson, 1997; 2003) and the writers/authors as “masked and unmasked, costumed and bared, liars and truth-tellers, actors and audience, offstage and onstage” (Prendergast,
Poetic narrative re-presentation is also, therefore, a performative act.

For the (deaf) reader

As well as following my intuition, collaborating with and honouring my family narrators and writing texts that aligned themselves to a postmodern, experimental, reflexive tradition, I also have the reader in mind. We want others to read these stories. My hope is that, by inviting the active reader in close (Tillmann-Healy, 1996)—to enter into the open, familiar spaces, the silences, the metaphorical and crystallised landscape of the poetic texts—they can engage, think with, insert themselves into, reflect upon, interpret and feel more deeply alongside (Bjorkvold, 1992; Frank, 1995; Morgan, 1996; Green et al, 1997) the stories that are included here. I am mindful, as ever, of Spivak’s (1992) politics of translation, not only in methodological, but also dissemination terms. Richardson (1997) makes a plea for texts to be accessible; qualitative inquiry needs to be read, not scanned or skipped over. I hope, therefore, that the poetic texts leap from the page and paint pictures in both deaf and hearing readers’ minds. Poetry, in written form, is visual as well as acoustic (Bauman, 2006; see also Denzin, 1999); poetic form as a visual aesthetic potentially aligns itself, therefore, with sign language. Bauman (2006: 102) recalls Appollinaire’s Calligrammes, whose lines are “freed to convey a visual image” and compels us to consider the visual, graphic poetics not only of text, but also of sign. There are ways, therefore, to recognise and exploit even the common, visual modalityxxi when constructing paper-and-ink-based texts. I have experimented with textual (as well as linguistic) strategies, playing with particular features of sign language, such as metaphorical and topographical placement. Certain stanzas, or short stories, therefore, are placed specifically on the page, to retain a sense of sign-language placement. I have also experimented with individual words and with how they are written, when representing modified signs, for example, with Maisie:

A b u m p i e r ride

And:

If the family has the right attitude
It can go smooth
I mean
Maybe not always s—m—o—o—o—o—o—t—h
Maybe more like s.m.o.o.t.h.
But generally s m o o t h
As with the draft scripts, I retained some BSL features, and particular non-standard-English in the poetic texts. Space on the page is exploited. In BSL, speakers are indicated through eye-gaze, body-shift, acknowledging (without naming) their position in the signing space. It becomes possible to harness the signing space and relocate it on the page. For example, when Georgina signs about her mother’s and father’s families, she clearly indicates them in topographical space:

But they (mother’s family)
They know me
They know I can be mischievous
They know I’m funny
They know who I am

Georgina

Not like my father’s family (smiles)
They didn’t know me
They didn’t really know me

Me

Georgina
That I was funny
They didn’t know that

When two narrators sign (or speak) the text can be manipulated to echo the spatial event of the conversation. Harper sat on the right of the sofa, with Maisie to the left:

But I do feel sometimes like I’ve failed
If you can’t stay
But also maybe
I have to just accept
Some things won’t ever change

I don’t think about it that much
If it was
You
Mum
Dad
who had to sit there
twiddling your thumbs
Imagine!
All Your Lives...
You’d be shouting
and screaming
ba/n/g/i/n/g doors
Til the whole house collapsed!

(laughs) Yeah, I can believe that!

Words and pictures

In print, of course, we are not restricted only to words. Other visual, aesthetic devices, such as images and graphics may also be incorporated to create “attention-grabbing, evocative” texts (Jones, 2006: 71; also McCormack, 2004; Ely, 2007). The decision to include images stems largely from the idea that visual texts can include aspects of people’s narratives that might be excluded from a prose rendering of research conversations (Green et al, 1997). While attuned to the metaphoric use of language in many of the stories, I also became increasingly aware of image (doors, nests, fish, plants, dials). Bachelard (1964) sees the poetic image as dynamic and active, as salient and brilliant, and therefore a new, sensual layer, or dimension, to narrative (Halford & Knowles, 2005). In terms of a phenomenology of reading, and the experience of words and pictures, according to Bachelard (1964) the subjective experience of engaging with visual narratives extends into the realms of resonances and repercussions. He explains that resonances disperse across the various planes of our lives and the repercussions give depth to our existence. That is to say, in the resonance, we hear/see, and in the reverberations, we tell—the stories become our own (Bachelard, 1964: xviii). My decision to include images is based on the following: I wished to layer and thicken the texts by bringing to them both clarity and ambiguity; I hoped to create a beautiful, funny, poignant volume that encapsulated more than a series of short stories—through a small number of images I have woven in other stories, stitched-together snippets and offcuts, shared jokes, dedications and banal observations—to create a memento of our collaboration. I deliberately confer ambiguity, and in doing so emphasise the infinite number of meanings that the texts may generate for the reader who can take the resonances, and breathe new life into the narratives that take root, and find new linkages and alignments (Davies & Gannon, 2006).

I read it today, it is brilliant.
Love the way u used the pictures.
Thank you for making me sound so poetry

Love,
Maisie x
Words are the means best adapted to signifying concepts. So a man who, because he was deaf from birth, must also remain dumb can never achieve more than an analogue of reason (Kant, 1798: 155).xxii

From its early beginnings as private tuition for deaf children of the wealthy, to the establishment of the first academies, such as the Paris Institute (1754) and Braidwood’s Academy for the Deaf and Dumb in Edinburgh (1760), the Western system of educating deaf children mirrored contemporary scholarly philosophies, and was constantly shaped by philanthropy, business, science and medicine, anthropology and evolutionism. Deaf people were increasingly seen as objects of pity, and in need of charity. The Asylum for the Support and Education of the Deaf and Dumb Children of the Poor in London flourished with the support of well-known philanthropists of the day. Education was no longer driven by a philosophical curiosity about language: it was a business (Branson & Miller, 2002).

In 1859, Darwin’s On The Origin of Species by Means of Natural Selection threw sign language into the spotlight by claiming that speech was the mark of humanity, having developed much later, and that manual gestures were primitive, and could only “aid us in forming a picture of the ancient forms of life” (Darwin, 1859: 448). The anthropologist, Tylor (1865), while acknowledging that signs could relate ideas, concurred with Darwin on their inferiority to spoken language. A binary emerged, and a line was drawn; people around the world were being categorised as either civilised or primitive. Deaf people, according to Mirzoeff (1995), were seen as being below the line. Evolutionary theories of humans and animals not only found strength in Cartesian philosophies of the duality of the mind and body but also resonated with Locke’s (1689) concept of sensory perception: that humans experience the world through the five senses. The expansion of European empires created a wave of linguistic imperialism and scientific rationalism. Deaf people were primitive, impoverished, biologically inferior, disabled, and—like women, working class people
and natives of colonised countries—dominated “by means of Social Darwinism” (Branson & Miller, 2002: 27).

**Pathology, therapy and violence**

Between 1759, the date of the first appearance of the word *normal*, and 1834, the date of the first appearance of the word *normalised*, a normative class conquered the power to identify the function of social norms with its own uses and its own determination of content. This new taxonomy categorised hearing as normal and deafness as pathological (Canguilhem, 1991: 246).

This shift in thinking represents what Branson & Miller (2002: 16) refer to as a “radical transformation of Western cosmology” and “the triumph of science over spiritualism.” Normality was the core, the centre, from which others—disabled, mentally ill, deaf, poor, *abnormal*—could and would be excluded (Mirzoeff, 1995). Prior to this, the 17th century had admired what Davis (1997) refers to as the ideal body: the unattainable, mythological body, as portrayed in paintings and sculptures of the time. In contrast, the grotesque, which adorned cathedral facades, was a symbol of all people, with a “life affirming quality in its inversion of political hierarchy” (Davis, 1997: 10). With the advent of *normal*, however, the ideal body was transformed into the normal, acceptable, even achievable, body, and anyone who did not fit was excluded from society as deviant.

Deaf children were becoming linked conceptually with ‘savages’ in the colonies and with mentally ill people. In France, Mirzoeff (1995: 98) points out, “the deaf and the insane were dealt with by the same department of the Ministry of the Interior through the 19th century. The stigma of deafness was doubled by that of madness.” The paradox of the expansion of deaf education in Europe lies in the fact that, while it had been demonstrated that deaf people could be educated to high levels (Lane, 1984a), to become teachers, writers and philosophers, schools were also sites for the confinement and normalisation of ‘anomalous’ deaf children.

The business of deaf education became the domain of professionals, concerned with the treatment or the moral therapy of deaf children. In Britain, the emphasis was on the saving of deaf souls, whereas in France, education was more medically orientated. Children’s bodies and souls were “free game” (Branson & Miller, 2002: 122) for not only educators, but also missionaries and surgeons. Deafness was becoming a medical condition, a pathological syndrome, which needed to be treated, overcome, or cured. In France, Itard—the so-called founder of otology—began a
series of experiments on deaf children (Itard, 1842) at the Paris Institute in the search for viable cures for deafness. Following in the footsteps of Hippocrates and Celsus, he began piercing ear drums, inserting catheters into the Eustachian tube, applying leeches, blistering chemicals and hot metal to areas around the ear (Lane, 1992; Jankowski, 1997). Not content with the death of at least one pupil whose eardrum was pierced:

Itard dispensed a secret brew into the ears of every pupil in the school who was not born deaf, a few drops a day for two weeks—without effect. With other students he tried a regime of daily purgatives; still others had their ears covered with a bandage soaked in a blistering agent. Within a few days, the ear lost all its skin, oozed pus, and was excruciatingly painful. When it scabbed, Itard reapplied the bandage and the wound reopened. Then the cycle was repeated, with caustic soda spread on the skin behind the ear. All of this was to no avail. Still Itard remained relentless in his search for a cure. He tried fracturing the skull of a few pupils, striking the area just behind the ear with a hammer. With a dozen pupils he applied a white-hot metal button behind the ear … It was all a miserable failure. “Medicine does not work on the dead,” Itard finally concluded, “and as far as I am concerned the ear is dead in the deaf-mute” (Lane, 1992: 213).

Oralism

Alongside the medicalisation of deaf education came the Darwinian denigration of sign languages. Coming full circle, the dominant belief once more equated language with the spoken word; through speech alone could the deaf child express thoughts, and develop both intellectually and spiritually (Rée, 1999). Thomas Arnold, who opened an oral school, believed that signs could only convey the most basic of needs (Arnold, 1888). More and more, the voice was promoted, not only in evolutionary terms as the more refined and advanced means of thinking, expressing and communicating, but also in spiritual terms: the voice was God’s design (Kinsey, 1880). If speech was ‘better’—more evolved—for hearing people, then so it should be for deaf people. In a pre-echo of the mainstreaming movement of the 20th century, it was now claimed that “the power of speech and lip-reading [could] bring the deaf into general communion with mankind” (Baynton, Gannon & Bergey, 2007: 66). The French System, by contrast, was seen as “herding together signing deaf pupils” (Rée, 1999: 226). The campaign against sign language gained momentum throughout the second half of the 19th century, and climaxed in the now-infamous Second International Congress on the Education of the Deaf held in Milan in 1880, where votes were taken on the future of the education of deaf children and their teachers (Lane, 1984a; Baynton,
Buoyed by anthropological theories concerning the atavistic nature of signs (Mirzoeff, 1995), the congress gathered in order to emancipate “deaf people from their deafness” (Branson & Miller, 2002: 168). On 11th September, 1880, the Congress decided by 160 votes to four that signs were no longer to be used in the education of ‘neglected’ deaf children. The many accounts of what happened post-Milan document the wave of oralism that swept many countries of the world (see Lane, 1984a; Baynton, 1996; Ladd, 2003). In the post-civil-war era in the US, oralism was associated with progress, with national unity and with social order through homogeneity (Baynton: 1997: 131).xxvi Deaf, signing teachers were either removed or driven from their jobs as educators of deaf children. Various ‘offensives’—covert and overt—maintained the momentum of oralism through linguistic oppression. Karacostas (1993) describes in detail the lengths pro-oralism administrators at the Paris Institute went to in order to take control of curricular, staffing and teaching methods, gradually sapping the energy from signing deaf teachers.xxvii

Signs were not automatically, instantly and wholly abolished following Milan; Branson and Miller (2002: 154) note that they continued to be used in some countries. The shift though, was in purpose. Hearing teachers used signing more as a means to an end, to teach “literature languages.” Signs also continued to be used (in Britain, at least) for those children who were never able to ‘articulate’ (Branson & Miller, 2002). Baynton (1996) and McCaskill, Lucas, Bayley and Hill (2011) report that segregated deaf education in the US—predominantly in the southern states—continued using sign language in (largely neglected) schools for black, deaf children. And in Ireland, it was not until the 1950s that a pro-oralism policy was fully adopted: signing classes were gradually squeezed, signing children were physically controlled, coerced, deceived, segregated, marginalised, ostracised and punished (McDonnell & Saunders, 1993; Mathews, 2010).

What Milan did, ultimately, was shift the objectives of deaf education. Caught up in spirit of the times—of imperialism, of evolutionism, of professionalisation—the goal for deaf children’s education was, for the first time, fundamentally different from that of hearing children (c.f. Mathews, 2010). The main aim was for deaf children to fit into normal society, and to do that, they needed to be able to speak.
CHAPTER FOUR

DEAFHEARING FAMILY LIFE

This chapter lies symbolically and actually at the heart of the book. Here you meet and hear from three families. Brigit and her daughter Bella offer their views on family, the local community, sign language, discrimination, ignorance, the best things about being deaf, the tensions of deafhearing life, the spiritual journey they have embarked on. Next, Georgina and two of her children, Toni and Thomas, give us a window on to deaf life as members of a multigenerational deaf(hearing) family. Toni is eighth-generation, signing, singing and dancing deaf, and Georgina, who has traced her deaf family back to the turn of the 19th century, is now grandmother to two deaf children. Thomas is the ‘interruption’. Born hearing, raised in a signing, deaf home, he is both fiercely resistant to telling his story and fiercely proud of his heritage. He has now lost the hearing in one ear. Dora, Luke, Harper and Maisie then take up their story once more. Reeling from parliamentary proposals to amend the UK Human Fertilisation and Embryology Act, amendments that imply that deaf lives are necessarily less valued than hearing lives, they push through the pain and anger, the bewilderment and sadness, and compose the next chapters of their lives. These narratives are presented poetically, some long, some short, some familiar, some strange.

Brigit and Bella

Beginnings

Weaving their narrative together here, I am reminded of how differently Brigit and Bella approached the beginning of their stories. Brigit needed a clear question, other than, “Tell me the story of your family.” We started with the birth of her first child. Brigit talked about giving birth, about Bella meeting the world. She moves between the distant and near pasts (Ellis, 2009), telling the story as it happened, yet also reviewing it from a nearer past. The shift, or interruption, in her narrative occurs at a party, where Bella, either a ‘model child’, or a deaf
child, sleeps through the loud music. The turning point, however, is not that Brigit suddenly finds out her daughter is deaf, but that her deeper, unspoken sensing of something is confirmed by a friend. Brigit’s life-experiences, knowledge, philosophies, politics and parenting instinct converge on knowing that Bella has come into the world as a deaf child—a change of perspective is all that is required. Brigit was intuitively, emotionally, physically and politically drawn to sign language as a way of communicating with, teaching and learning from Bella. She wondered if Bella’s soul had chosen to be deaf; if Bella is deaf because she is a teacher. She even wondered, “What if she’s not deaf, but pretending to be, to help me on a particular path.”

Bella had her story—the one she wanted to tell—almost entirely planned in her head. She knew exactly what she wanted to say, to tell me, to show the reader. Much of her story revolved around sign: how her family sign (“lots sign in my family”), that her hearing mother and hearing brother have learnt sign, how Christian can fingerspell his name, how her little cousins are also learning to communicate visually. She also wished to make it clear that deaf is useful. Deaf people are visual, good at ‘catching’ things (visually), deaf people are peaceful, sleep well at night. Deaf people get discounts, and qualify for Hearing Dogs. Bella also told me how much she had wanted a deaf sister. Or maybe just a sister (deaf hearing doesn’t matter). When Christian was born deaf, she realised it was a happy compromise. Thorin got a brother, and Bella got deaf (and Christian likes to dress up).

**FIRST CHILD: Brigit**

It’s massive
your first child, you shift

Suddenly

I wasn’t a mother before
    I was in a family
but I wasn’t a mother

And suddenly I was a mother
and I had this most precious thing
which was my daughter
and I didn’t know she was deaf

When she was really really little
I said to a couple of people
    “D’you think she’s deaf?”
and they said, you know
    “You’re just neurotic” *First time mother* (laughs)
My sister also
she checked Bella’s hands
because she thought
    It’s an intuitive thing you know
    that the child’s a little bit different
    But you don’t know what it is …
So she checked her hands
    which she told me at a later date
she thought *Maybe she’s Downs*
and because there’s a mark on your hand
    She just did a check
    And she hadn’t got it
But it’s that whole thing
    being vaguely aware of something
    But not being able to put your finger on it
And Bella was
really really really **really** happy as as a baby
    And I didn’t have
    anything to do with
    health visitors whatsoever
    We didn’t do any hearing tests
    or any tests
    you know she was perfect! (laughs)
*We didn’t do any tests*
and I actually think
**Y e s** we could’ve brought language in earlier
But in lots of ways
it was quite good
not knowing she was deaf
when she was little
Whereas Christian
    being deaf
Knowing that from
    immediately
    It was different
    Because we already were a deaf family
    **Y’know** a deafhearing family

MEETING THE WORLD: Brigit

With **B e l l a**
    it was one of my real real concerns
    when they started doing neo-natal screening
    and it still is
I think neo-natal screening is really really risky.

And speaking to people and meeting families and parents and I can think of several different people Mothers who have disclosed that essentially they’ve just gone into a fear reaction

Because you know you’ve just gone through this immense thing Giving birth Been through labour and you’ve given birth and just when you think you’ve got a baby you’re told you haven’t!

And you know This is what people say which is like incredible!

I just think it’s really really risky because you get in the way of the bonding thing by bringing in fear of the unknown And you know it needn’t be like that But I think it’s really risky and that bonding bit is so important

But anyway we didn’t have any of those problems because I didn’t have anything to do with them and we didn’t know that she was deaf And she was a very very happy child

And also I wasn’t saying “Ball, say Ball!” that’s not my parenting so there was no issue there I didn’t talk to Bella very much I liked her being in the general social sort of talky place

Because I felt that she was my first child and I was coming up with lots of theories on the perfect way to evolve And if you look at creation myths from everywhere you start off in the chaos And I wanted her to be in the world We were living outside and I didn’t want to say
Chapter Four

And that is a tree 
And that is a branch 
And that is a leaf

It was like
The w o r l d
And it was like
Her meeting the world
And so she was happy
And there was no cause for concern

Bella usually asked more questions of me, than I did of her. Once, we even switched places, and she interviewed me. I was curious, however, to learn from her about being born into this world as a deaf child, and the sense she might make of this. Ever the pragmatist, Bella saw deaf life as “just life”, as an opportunity for her mother and brother to learn sign. Later, she also explained it in terms of genetics. Yes, there are reasons or explanations, but perhaps some of it is just a mystery, and we should leave it at that.

I THINK SHE’S DEAF: Bella

In the past when
When I was born
My mum felt I was deaf
But everyone was like
No don’t be silly
Crazy
She’s hearing!

But my mum
My mum thought I was deaf
She was sure I was deaf
But my dad said <FEE>
she’s definitely hearing!
There’s no deaf in our family!

So anyway
my mum
said nothing
<GET ON WITH THINGS SLOWLY SURELY>
til I was about 15 months
We went to see my dad’s friend
I think? Or a friend of mum and dad
One friend looked at me
and he thought I was deaf
“I think she’s deaf”
And my mum was like see!
She said to my dad
    I think she’s deaf
So my mum took me to hospital
    for tests
And they <LOOK DOWN AT ME FIND FIND FIND>
and right
Mum was right
    I was deaf!
<THAT’S IT> deaf!
And my mum said
    “I was right!”
    But there were no deaf in my family before
    Nothing
    That’s why
    So my dad didn’t think I was deaf! (laughs)
    So have to start learn to sign!
I’m deaf
    That’s it
    Just get on with life (smiles)

CHANGE OF PERSPECTIVE: Brigit

We couldn’t get information
    It was crazy
So I went and stayed in London
I thought (rubs hands)
Have to get information
    you know
    tool yourself up
    you know it’s a challenge!
    OK deaf kid right what d’you do?
I think I had a few moments of panic
Think I phoned a friend
and she just sort of said
    “It’s just a change of perspective”
    that’s what she said
    It’s just a change of perspective
And it was like O h O K
    No space for anything else
    It’s just a change of perspective
DEAF IN MY FAMILY: Bella

My mum is hearing
My brother is hearing
My other brother is deaf
Now

So for long time
There were no deaf in my family
But now more and more
Two deaf
Born deaf

Now

I don’t know why
But also I feel
I was born in the right environment
Why?
My family fine
Also they never
<LOOK DOWN ON SHAME>
deaf people
Nothing like that
or not sign sign sign
My mum when I was born
wanted to learn sign
Same when my brother Thorin born
he signed
he learnt sign sign sign
And now Christian signs too!

Because
If long time ago
That was awful
War Bad schools
would mean I can’t go to school
or Oral school

Means
I was born in the right time
Means
I can go to a signing school
Means I can sign
Teachers can sign
and learn sign
Not oral not war time
Means my mum and dad not oral
Or my mum and dad don’t ignore me
They help me
I’m equal to my hearing brother
Deafhearing Family Life

FANTASTIC DEAF CHILD: Brigit

I need to get information
I need to meet people
We found it incredibly difficult
to get information
and we got assigned
some teacher of the deaf and yeah right!
And that was really funny
The audiology people at the hospital
I mentioned sign language to them
and this woman who was an audiologist
she wasn’t hostile to it
but she hadn’t heard of it!!
I went to the library
Thinking I’ve got to get books
It was all a bit too much
Went to the Oxfam bookshop
got that autobiography of a deaf man
Read that and it was like
Aha! OK!
Yes it’s OK
I don’t have to suddenly suddenly
want my child to fit in
and not be noticed
and be a crap hearing child
She can still be fantastic
but she’ll be a fantastic deaf child
and she can shine and everything
And I was thinking
I need to meet
I need some people with deaf children
I need to meet them
see what they did
how they did it
So I asked my teacher of the deaf
if she could put me in contact with anybody
and she said that she couldn’t ...

Bella lives in a signing bilingual home, and attends a signing school. We often talked about sign. Having travelled abroad recently to the Far East, she shared her experience of different world languages, about communication (she had met a local deaf boy on holiday), about different alphabet scripts, about finding ways to connect with people. I told her
about my recent trip to the World Federation of the Deaf congress in Madrid, and my experiences of meeting and signing with deaf people from all over the world, of learning to use (some) International Sign, of seeing with my own eyes a global deaf community, of observing the contrast I experienced between being a signing person in a foreign land and a hearing-speaking person in a foreign land (I had a signed conversation in a Spanish Museum with a deaf Japanese woman).

For Brigit, signing deaf people embody the anthropological concept of muted groups. She was drawn to sign, not only for political reasons, but also in a somatic, cognitive, neuro-linguistic sense. The hand can teach the brain. “When you wake up in the morning, your hands can do all sorts of intricate things, like turning off the alarm clock and putting the kettle on, while your brain is still muggy and can’t possibly be telling your hands to do these things!”

Bella and Brigit share perceptions about the embodied nature of signing. Bella told me that if you read a story and sign it (as opposed to reading words aloud) you understand the story better, because you use a different part of your brain, you absorb, feel, sense and *know* the story.

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**DEAF LANGUAGE: Bella**

If I go to France
I don’t understand French language
  It’s the same as hearing people
don’t understand deaf language
Same
The same as abroad language

**SIGN BRAIN: Bella**

My mum likes deaf stories
  like signed stories
  Because talking stories
    you think in different way
  And reading
    looking through eyes
      and your brain
    and reading
But if you switch on   (on forehead)
And switch off        (side of head)
a different part of brain
means you don’t know what story about
Brigit told me how people became more openly hostile when she had a second deaf child (“Although my status in the deaf world went up”). It became a double shame. I found myself wondering if people had even considered her irresponsible for bringing another deaf child into the world. Perhaps. Mostly, hearing people didn’t know how to respond to her, and to her family, particularly as she had such a positive attitude towards deaf. Perhaps people saw her as irresponsible, she really didn’t know.

I was reminded of a conversation I had with Dora and Luke when they told me how Maisie had opened up the world for them. Or had opened their eyes to a world they didn’t really know was there. And maybe, before she arrived in the world, they had a particular kind of outlook, and then suddenly that outlook grew and became larger because she had come into their lives. Brigit talked about detective work, and looking at the world through a different lens. She said, “I’ve got a visual image. That family saying about opening up the world, and until you said that, I hadn’t actually thought about it opening up the world, but I had a very visual image of a door being opened.”
Soon after Brigit found out that Bella was deaf, she moved to a new area, in search of support, information about sign language, family services and bilingual education “models of excellence.” As I listened to her, I revisited my past as a teacher of the deaf, and my own feelings of shame, frustration and inadequacy.

SORROW AT THE WORLD: Brigit

We came here
and got allocated a teacher of the deaf
who was a really nice woman but
One of the first things she said she
You know she was r-e-a-l-l-y- sympathetic
and there was this whole kind of sympathy
you know “You must be in grief”
And I just felt really really angry!
What?
You know why must I be in grief?
You know
What are you saying about my kid?
**Is my kid dead?**
You know *Why am I in grief?*
When I said I wasn’t in grief
she said “Well you’re probably in denial”
and that made me even crosser
I don’t think that she really understood
I *do* think I was in denial but not of my grief
What was I in denial of?
I don’t think I even was at the time
because I really didn’t know the implications
of having deaf children
and what it would mean in terms of
how it would lead me into
situations of
meeting awful prejudice
Or of being
**More** isolated
or of feeling let down by people
I didn’t realise
that I was even going to encounter that stuff

So I suppose and that thing about
being out on the wasteland
and being quite a harsh place
I kind of believed that I was gonna meet all these fantastic deaf people you know?

There’s this door opening
And it’s all gonna be fine

So there wasn’t any grief

and I don’t know if there’s grief now

But when I see the steps that my deaf children Bella and Christian have to take
to communicate with people
that don’t take those steps towards them

When I see how much bigger people they are
When I see hearing people turn their backs
because they don’t know how to communicate

Whereas I see these children who’ve apparently ‘got communication problems’

Find new ways of communicating

New ways of communicating

It’s not grief it’s more
I don’t think that’s the way it should be

It’s not sorrow that my child is deaf
It’s sorrow at the world I live in

DEAF WHY? Bella

I don’t know (smiles)

Born that way
Just born

And my dad’s family expected me to be hearing

And my mum’s family too
And when it was true
I was deaf
my mum was really interested
to learn sign

But it was strange

Why?

I never learned to sign
until I was two two!

When they asked the doctor what to do
because they didn’t know about deaf
there were no deaf in my family before
they didn’t know what to do with a deaf baby
Should sign?
Or what?
And the doctor said
  should speak to her
  not sign
  the doctor said
And my mum said \(<FEE>\)
Said we should sign

Brigit reflected on the neo-natal screening programme, and the inherent risks as she saw them to the bonding process between mother and baby. Now she talked about her own personal experience. She was about to begin, when Bella came into the room, eating porridge. Brigit stopped herself, and said to me, “I don’t know if I want Bella to see this,” but then, “No, if I don’t want her to see this, I shouldn’t say it.” So she lifted her hands and switched to sign. When she finished, Bella waved to her mother and signed, “Why?” and Brigit explained to her young deaf daughter what the story meant to her, and to her deafhearing family. I found myself wanting to shout from the rooftops, how can sign language receive such negative press, such token recognition, when I have seen with my own eyes how a hearing mother can communicate such profound, complex issues so directly, so meaningfully, with such care, to her bright, funny, inquisitive deaf daughter?

SCREENING: Brigit

Then I had another child
And when I was pregnant with Thorin
  and because Thorin was born when Bella was two
  and we were
  we were going into this deaf world
And we were at the hospital in the audiology department
One of the audiologists
saw me in the corridor
and came towards me
  And I was pregnant
  And I was very obviously pregnant
And she asked me if I would like to have
a sort of screening
like Genetic Screening
  And I was I mean  I was obviously pregnant
  I was about six months pregnant
  \(D’you\  know\  what\  I\  mean?\)
And so I was a bit defensive
And I said “What for?” “What for?
Oh! So I can have a medically approved abortion?”
Meaning (sarcastically) Oh! I would like another deaf child
If he’s hearing you gonna abort him?
You know?

And I was very, very very cross
Why were they offering it to me?
I didn’t understand
I just felt really really insulted
Soooo I didn’t have the screening! (laughs)

THE BABY’S DEAF AS WELL! Brigit

I felt like my family <HIGHER STATUS>
in the deaf world (laughs)
But in the hearing world people just became more openly rude
Y’know
And say things like
What!?
The baby’s deaf as well?!
Oh, Jesus! (laughs)
(Bella bursts out laughing)
There is one story, or recollection, from Brigit that catches me every time I read it. Here is a woman who, by her own admission, is often seen by others (in particular other hearing parents of deaf children) as strong, opinionated, confident, perhaps confrontational. And yet, as she showed me, she can still be hurt, she can still be treated badly, she can have doubts. For so long, I saw her as supremely able, skilled, grounded, ‘sorted’: a lone parent of three children, two deaf, one hearing, who created a bilingual home for her family. Then she told me how she felt when Christian was born. I confess, I hadn’t even considered that she might have carried feelings such as these with her all those years.

A CLEARING: Brigit

That thing about guilt
Bella’s birth
My labour with her
our labour
was really really difficult
and it went on for labour proper was 72 hours
and I was being pressured to have a caesarean
and I was refusing
So I felt like I was in like a battle already
with them
I’d refused caesarean
and then labour went on and on and on and on and on
and someone said to me
used the words
“Do you want your child to be brain damaged?”
You know it was like “Oh yeah!” (laughs)
“Yes please!” (laughs)
You know?

And there was a bit of me always that wasn’t sure
if Bella should have been born by caesarean
And my sister said to me
No
if she was deaf through lack of oxygen
she would have general damage around her brain
and she’s clearly a very bright child
This is not connected with the birth
This is her way you know

So I knew that
but I still wasn’t sure
So when Christian was born
and he was deaf (smiles)
it was just like a clearing
It was like Aha

It was nothing that I did wrong
D’you know what I mean?
It’s like
This is the way it should be and
and so that was good

GOOD LUCK: Bella

But

<AWFUL WHAT>
My mum told me
some people
when their baby is born deaf
they think it’s terrible
“Oh no, deaf!”
and they p-a-n-i-c p-a-n-i-c p-a-n-i-c
and think it’s terrible!
And I think, what? What for?
Also my mum
when she went to a course
and they said
“Oh poor you, shame, another deaf child, poor thing!”
And my mum said
“No, maybe I’m lucky!”
Most hearing parents
They don’t know about deaf
but my mum she said
deaf means what
Different!(smiles)

DEAF MEANS: Bella

(Donna): “Bella, deaf means what?”

Deaf means
More experiences
Plus means good
Noticing catching things
Secret things
Can spot quickly
Like in school

_Secret things_

Can spot easily

Catch them

But you know some clubs
Not allow deaf (huh?)

Like horse riding

So I would need a friend to go with me
and maybe they say

*Oh sorry!*

I don’t know how to teach deaf

So if I could switch to hearing
I could go and learn horse riding

<LEARN LEARN LEARN LEARN LEARN>

then go back to deaf

And then deaf ask me
if I know how horse ride
and I could say _Yes!_

I learnt how
I can horse ride easy _finish!_ (smiles)

Also sometimes I like to show off

Like I can sleep in _peace_

Like at night
if it’s r/a/i/n/i/n/g h/a/r/d
and hearing can’t get to sleep

Plus

deaf can sign

can have hearing dog

deaf school

dead family centre

deaf club

dead people visual

dead means laugh

dead sleep peaceful

_hearing people always_

<TALK TALK TALK> all the time

dead people more peaceful

more quiet life

That’s why I want deaf me

_C h o o s e_  

<THAT’S IT!>
Deafhearing Family Life

BLESSDED: Brigit

I was just thinking
There’s lots of different
There’s lots of different forms
There’s lots of different forms that can
assist you
in seeing deeper into the world
But having deaf children
has been a m a z i n g
in terms of as a tool of focus
Almost like
it’s via that
to be able to unravel some of the
   The illusion of this world
   And get to what’s underneath
It’s been really helpful
I mean as in
   it’s almost like your identity
And this
But this
   Well it’s not more personal than being a woman
   but it’s the depth
   the depth it gives you

It’s very interesting
   and it’s very useful
   for just pushing away
   loads of the of the pretence
   And actually seeing what’s going on
   And working out
   And seeing the psychology of people
   And how messed up the world is
   And also and clarifying things
   Just clarifying things about What Life Is
You know

Is my child’s life worth something less?

But for that detective work
it’s very useful you know
   I’m blessed, I am! (laughs)
   I am blessed
BROTHER HEARING: Bella

Sometimes
Me and my brother Thorin
He’s jealous of me
and I’m jealous of him like I’m jealous of him
But sometimes he’s jealous of me
like
if there’s a storm through the night
in the morning
he’s really tired
and I ask
“Why? What happened?”
And he (fed up) tells me
There was a big storm
R/a/i/n and thunder«
And he’s jealous
cos I didn’t hear it
I can’t hear
Or if we go on holiday in the van
and we sleep in the van
if it’s raining
it’s worse
the metal roof
And the rain is really loud!
Means he can’t sleep
Tossing turning
But I’m fast asleep! Zzzzzzzzz
All through the night!
And then I wake up
and see my mum and my brother
sleeping because it’s stopped raining
and I think
“Why are you sleeping for such a long time?”
And then he tells me
“Because it was raining
I couldn’t sleep!”
So then he falls fast asleep
and it makes me laugh at him
and he gets a bit grumpy and says
I want the same as Bella!
I want to be deaf!
I was invited to tea, and we all sat round the table, eating delicious food, signing, laughing. Brigit admitted to me, however, it is also difficult. And once she’d admitted that, she said she felt better. She conjured up an image of a Kraken (an in-joke between us) who can sign, cook, answer the door and paint, all at the same time. But the Kraken is also a monster. And for Brigit, when it is difficult, she is fearful of becoming monstrous with her children, of contorting her body when she is signing, and that is difficult. It is also difficult when, as a parent of deaf children, you become a member of a fragmented community of other parents of deaf children, while none of your friends—“your natural community”—has deaf children. I breathe a sigh of relief, that we can share stories of difficulty as well as of celebration. Bella too, complains. She can’t go to the same school as Thorin, and she is envious of his education. She sees deaf education as impoverished. There are out-of-school activities that are far harder for her to participate in, because people do not know how to accommodate a deaf child. She looks at her hearing brother and tells me that she wishes she had a dial on her chest. She could switch back and forth, she could learn things, gain experiences, go to clubs as a hearing girl, then once her head was ‘filled up’, she could switch back to deaf, to her peaceful, visual existence. I am deeply moved by this. This is not about hearing, or not hearing. I have lost count of the number of times I wished I could have my own dial, in order to shut out noise. This is about opportunity, about prejudice, about people’s inability to take steps towards deaf children, about inequality.

**DIAL ON CHEST: Bella**

Sometimes I wish
<DIAL ON CHEST>

  can switch to hearing or deaf
  
  **Wish**

  “Why?”
  Why?
  
  Maybe hearing
  School more better
  Higher than deaf
  
  **So**
  <SWITCH TO HEARING>
  <HEAD FILL UP>

  Then <SWITCH TO DEAF> That’s better!

Means I can switch between the two
I can be deaf

  and I can be hearing
IT IS DIFFICULT: Brigit

You must be in grief

I felt like it was totally inappropriate
   actually I still think it was inappropriate (laughs)
But you know
the grief that I would understand now
is a bit like saying
   actually it is difficult
There is a bit of me that would like
a really easy life! (laughs)
   And not just in terms of
   being able to
   cook and talk at the same time
But
Every coin has two sides
and I think that there’s loads of top prizes
   having deaf kids
But there’s also really tricky things
   and one of those is
suddenly feeling
I’m not coping
   Because I am trying to cook dinner
   I am trying to cook dinner
and I have got Bella going <TAP TAP TAP>
   and I am trying to keep eye on everything
   and Thorin is shouting something to me
   and this is going to burn
   and I just AARGH (claws hands)
   and behave badly

And I do
I stop cooking

And I’m saying to Bella
What is it?
Is it an important thing you’ve got to say to me?

And she’s kind of going <BACK AWAY NERVOUS>
And I see it in her face!
And it’s like, oh no!
I’ve been a monster
   d’you know what I mean?
And also meantime
I have stopped cooking
and I could have not become a monster
and simply asked her what she wanted
and it would have been the same amount of not-cooking-time
not letting things burn
I don’t need to shout at Thorin
I could just say
“Thorin come and have a look at me
come and have a look look at what I’m doing”
So that’s me
not having the resources
to be able to Deal Perfectly With Every Situation

As Brigit explained, yes, doors open, but others close, and some are slammed.
TRUST: Brigit

I think parts of me started closing down. But when it came to Christian I removed myself rather than have that difficult situation which essentially meant that you know we weren’t getting early years services One of the things I kept repeatedly saying is *Your research is shoddy* You know *Why?* You give a child an implant You back it up with speech therapy *What’s your budget?* *58 thousand pounds?* *On speech therapy?*

Give that to my signing child! Give them 58 thousand pounds worth of speech therapy and then tell me cochlear implants work Because maybe they do Maybe they do

But look You’ve got a little badge that says you’re a scientist Maybe the cochlear implant is a fantastic thing But then **do your research** Don’t get this *<IMBALANCE>* Then let’s look at outcomes *What’s your outcome?* Intelligible speech? And is that it? Is intelligible speech your simple outcome? Which is a great outcome And it’s very useful thing *But are there other things that happen in a child’s life* Are there effects of major surgery? At an early age? You know? And how does this traumatising a child? And how does it affect them? I mean we **know** there are language delays with children that undergo operations and what we’re actually trying to do is stimulate all the stuff that goes on in the language centres Now would it be more sensible Would It Be. More. Sensible. Given that British Sign Language
as opposed to gesture
has be shown to stimulate all those pathways

Shall we get them all going first?
Or I mean

Why is there no conversation about this??

And why when I ask these questions
do you go “AAARGH” and shut that door!?

Why am I being viewed as a trouble-maker?
Why will you not have a conversation?
I don’t trust you
Maybe a cochlear implant is a great thing
but I can’t put my children there
because I don’t trust you
And it’s the same as I wouldn’t let you babysit
if I didn’t trust you and
My major role (hand to chest)
as a parent
is to protect my children
and therefore (laughs)
I keep them away from people I don’t trust!

Maybe you’ve got something really nice
in your bag for them but I don’t know
Why do you look frightened of what I’m asking?
You know?
I don’t know
I don’t know

So I don’t know! (laughs)

It’s misinformation
It’s agendas and what’s really going on
So the cochlear implant stuff
Who’s paying for it?
Who’s paying for their research?
You know
Why are they, as well?
You know
Why are they doing this research?
And why are they spending so much money?

You know I don’t know! (laughs)
At the heart of Brigit’s and Bella’s narratives is a resistance to ascribed identity, as well as a celebration of hearing and deaf life. I had been reading Wittgenstein’s theories of games and family resemblances. Then Bella offered her perspective on her deaf/hearing, blonde/brown-haired, born upside-down/right-way-up, storytelling, artistic family. She unwittingly tapped into postmodern, rhizomatic theories concerning identities and intersectionality, of shared features and experiences, and of networks of differences. Brigit talked of balance within her deaf/hearing family, and paid tribute not only to her deaf children, but also to Thorin, deaf sandwich, bilingual boy.

At the time, I had shared my observations of Thorin with Brigit—how, to me, he appeared to move fluidly in deaf and hearing spaces. I think I was reflecting on the brief periods of time I had spent with Thorin at deaf club, in the car, in the garden, playing chess, and wondering what it was like for him to go to deaf club as a hearing sibling. Then Brigit said, “But he doesn’t always want to. And that is fine as well, because the thing is, it’s a journey, isn’t it? And you have these ideas of what it is, and Bella was my first-born, and then I expected Thorin to just, come into it, or whatever, and then realising that he’s got his journey as well.”

MY FAMILY WHAT? (For Wittgenstein): Bella

I think in my family
What?
girl girl boy boy
And
hearing deaf hearing deaf
But
girl girl boy boy
Or
brown hair blonde brown hair blonde
Also
My mum have on her face
And Christian too
Have lots <BEAUTIFUL SPOT>
near eye
near ear
lots of <BEAUTIFUL SPOT>
And my brother have too
Don’t know where got that from
Who?
Don’t know from who
And
When I was ready to be born
they realised
I was upside down
My head was here
and my legs down here
They had to turn me
up the other way
so my head down
my legs up
And I think maybe
72 hours of labour
and they thought
Soon she will be born
but it was really painful
I refused to be born
(shakes head stubborn)
I won’t be born!
(frowns, shakes head)
I want to stay!
So the nurse said
You’ll have to have an operation
but my mum refused
and carried on
So they said
We’ll have to use forceps
on my head
to pull me out
and mum (weaker)
said no
And she had pain through the night
really determined
then phew
eventually I was born
And Thorin
what happened
everything was fine
but when he was born
and out
the cord wrap round his neck!
and his face was blue
and the nurse said
we have to pick him up
put him over here
and cut the cord
And mum didn’t want that
    She was holding him
    and then
two natural doctors came in
    and touched Thorin
and mum was breastfeeding him
    and very gently
    slowly
    they cut the cord
and he was still alive!
But he could have died
    That was really bad
    and then Christian
well that was perfect!
    he was born
Christian’s birth was perfect
    but also
    when Christian
    and Thorin
    were born
they really cried and cried
    And I was really calm
    <NOTHING CRY NOTHING>
    But
    Thorin was the one
    who nearly died
    so that means
    it’s really strange
    We’re all different
There’s nothing like <SAME>
    But
    inside
    inside
    like inside
we’re all good at art
    My mum
    the same as me
    My mum
    My granddad
    My great granddad
All the way back really far in the family
    All good at art
    Good at maths
    Good at making up stories
    My mum is really good at telling stories
    I think my family what
really good at art
My brother Thorin is good at art
I love art
My mum loves art
My granddad loves art
My great granddad loves art
My aunty loves art
Most love art
Strange how my family
mostly love art

DEAF SANDWICH: Brigit

He’s deaf sandwich
but he but he’s
He’s deaf sandwich
I’ve had to see that
But he’s also Bilingual Boy
d’you know what I mean?
I think he’s quite cool you know
and I know that I’ve got a bit of a propensity to show off
But he
moves into the deaf world incredibly well
And so that’s about being a sibling you know
as a sibling he moves
so I think that as a family
they’re actually
as siblings
there isn’t that <SEPARATION> you know
And I mean
I think my family is perfectly balanced (laughs)
I was saying something to somebody the other day
Oh, you know
I’ve got a deaf boy
and then another boy who’s hearing
so they’re both boys
and then I’ve got a deaf girl
so there’s deaf and deaf boy and boy
So for balance in my family
I need a hearing girl!
And then I went
“Oh, that’s me! (laughs)
I’m the hearing girl!”
I hadn’t realised!
cos I’d just been looking at them
and actually
there are <FOUR PILLARS> to support
but the <FOUR PILLARS> are there
| girl deaf | girl hearing |
| boy deaf | boy hearing |
So they’ve got boy boy
They’ve got deaf deaf
Thorin and I’ve got hearing hearing
So I’ve got to look at my relationship
As a hearing person
<MEET IN MIDDLE ONE TO ONE> with Thorin
and be his hearing support
Because Bella and Christian are deaf
support with each other
Support is a funny word but
Bella and Christian do <BALANCE>
for identity or whatever it is
defaf deaf you know
And Thorin and Christian are boys
so I need to do girl things with Bella
And I’ve gotta do hearing with Thorin
I do do hearing with Thorin
Cos we sing together and things

So I’m the hearing girl (smiles)
So I don’t need to have another baby after all
Bit of a relief at my age! (laughs)

He’s deaf sandwich
But I think he’s got it
I really think he has
and some of his signing’s quite funny
but it seems to be totally understood
I do sort of feel for his isolation in it all
I feel with Thorin
Sometimes
He does get all these things put on him
that Bella well she gets it in a different form
But he’ll say things
and Bella’s going to me
“What’s he saying?”
and I’m saying to him
“Why don’t you sign!!”
and I’m thinking
“I’m not telling you what he’s saying!”
“You can tell her!” you know?
and you know
He’s in school all day
where there’s no question of signing
he’s just and it’s all very spontaneous and f↓l↓u↓i↓d
and then he comes into our home
and he is bilingual
and he’s really great at it
but you know
his essence
his essence isn’t deaf
his essence is a hearing child
So he’s spontaneously coming through <CHATTING>
but our environment isn’t
so he has to adapt
Thorin you know needs to be reminded
though he does go into deaf
he goes into signing
There’ll be times when
if he wants to make that bubble around us
and he wants to sign to me
and he doesn’t want others to know
you know
It’s not just me deciding I want a bubble of communication
he does it very naturally
So he is bilingual you know
He’s bilingual
But he doesn’t always want to
and that is fine as well
because the thing is
it’s a journey, isn’t it?
And you have these ideas of what it is
And Bella was my first-born
And then I expected Thorin to just
come into it or whatever
And then realising
that he’s
He’s got his journey as well

But at the same time
I also need to let him not be continuously accommodating
because I don’t want him to get resentful
I don’t want him to get trapped in or something like that
and celebrate his ability to mix and move
But he’s got needs as well
if I just see Bella and Christian’s needs
I’m conspiring with this idea of them as disabled
And Thorin has got needs
Thorin is very sensitive
we’re all sensitive
he’s very sensitive
So to always prioritise the deaf ones’ needs
is to cement them as disabled
We’ve all got needs
and we all need to adapt ourselves
Bella and Christian need to adapt
as much as Thorin needs to adapt
But the first time I said that about deaf sandwich
I kind of said it for Thorin
To acknowledge
acknowledge something he was feeling
I think I told you that thing
he turned round to me
when he was quite little
and just said
“Why did you never tell me Bella was deaf?”
And it was just such a thing for me
It was like
Just not taking care of him enough
I guess it’s just keeping Thorin visible in it all

DEAF LIKE FISH: Bella

I feel like deaf like fish

Can swim in water
But out of water can’t
And some animals can walk on land
But underwater can’t
And deaf can in water
And like penguins
Can both
Can walk on land
Then dive into water
You Donna lucky
Know how to sign
All round the world
You can go underwater
On land
Maybe up in space! (laughs)
CIRCLES WITHIN CIRCLES: Brigit

I want my family to
   I want my family to be a *family*
   and not to be in separate worlds
   and that’s like Bella’s Venn diagram
So it’s like
  
  <MIXING MOVING>
I don’t want those worlds
   I want them to inhabit one world really
It’s like you know
We’re lonely you know
Some people are great
   and are well-placed in the world
but a lot of us
   when we peel off the layers
   are really lonely
and it’s a horrible thing you know
for anybody so

We’re just people aren’t we?

Georgina, Toni and Thomas

Beginnings

Toni was so keen to tell me stories, she couldn’t wait to get started. And yet, almost from the start, she seemed to falter. She had memories of her grandfather, fond recollections of her grandmother, funny stories about school. As if she was standing back from her life, looking at it from the top of a hill, choosing that which was in the sharpest focus. And yet no sooner did she start, than she paused. I waited for her to expand. I offered my own stories, shared memories. Unlike Georgina, who signed for hours with hardly a pause (a long, continuous, epic narrative) Toni and I had dialogue; reciprocal negotiation. In between our meetings, she made notes for me and for herself. She read and commented on the scripts I sent her. One day, she presented me with her “life in a bag,” a holdall full of songs, mementoes, diaries, photographs, drawings. She trawled through her souvenirs and talked round them: short stories, sense-making. We reflected on her family life as a solid foundation, the nest Georgina built. How each child was encouraged to leave when they were ready, to pursue their own path, in the knowledge that the nest was always there, <HOME THROUGH MOTHER>.
Toni smiled and laughed her way through memories of Thomas, of living in the Peaks, of moving from school to school. Yet I was struck by her loneliness, her rebellion, her resilience, her pain. I am not sure if this comes across in her story. It is often present in what she didn’t tell me. It is there in her travels, her love of the countryside, her bunking off school, her craving for hugs, for self-expression through music, her struggle to survive university. I want to pay tribute to her guts and determination, her unshakeable loyalty to her family, and her ever-optimistic openness to those she meets along her path. Toni is still searching for something.

Thomas, like his sister, was very keen to be part of the inquiry. Yet, from the moment we began, he resisted telling me his story. Most of what appears in this text is constructed not from scripts of filmed conversations, but from Thomas’s own writing, and from my notes taken from what he signed to me. His narrative is highly censored, not only through what he didn’t tell me, but also through what he wanted taken out. I struggle to know what to write about Thomas. His story is so complex, so fragmented, so minimal. And yet, there comes across a profound, contemplative, poetic self-observation. The reader is left to imagine what happened next. I cannot possibly tell you. The Thomas-scape is tricky terrain.

Georgina. We talked for hours and hours. As she said, she has wanted to tell her family story for a very long time. This is but a small part. I am so glad I simply asked, “What’s the story of your family?” She covered five generations almost without pause. She wanted to celebrate her family, and not only her children, as individuals. She wanted also to touch on, and pay tribute to the extended family. If only we had had more time. Georgina’s story is also a window on local deaf history, laced with recognisable characters, events and cultural referents. At its heart, however, it is a story of a deaf mother, and the journey she embarked on with her five children. It is at times very angry, hurt, regretful: we laughed and cried all the way through.

MY FAMILY: Georgina

“What’s the story of your family?”

My family
I was trying to think back
about my family
And I think my family <WHAT IS IT?>
D E A F
And that’s powerful
Deaf Family
Because it’s not just my immediate family
It’s my cousins
  aunts
  uncles
E-v-e-r-y-o-n-e
And as a family unit
  we’re deaf
And going—back—through—the—generations
  we’re all deaf
And I think that’s our bond

_Bond Forever: Toni_

_(Donna): “Tell me about your family”_

It’s interesting
When you’re growing up
you never really think about **family**
you know
as you grow up
It’s more like
  “I don’t like my sister, she breaks my dolls”
or silly arguments and fights
And it’s only later
when you meet others
from hearing families
and you realise
   <Wow>  (hand on chest)
<i’m really lucky!>
Without them
my life would be
<BAM>
SO different

I think we’d be the same people
but we wouldn’t have the same connection
The first thing
as soon as you’re born
   it’s SIGN
and you connect
<Finish>
<Bond forever>
I value that SO-O much!

ME, GEORGINA: Georgina

And so thinking about my family
I wasn’t actually thinking about deaf
but when I stopped to think
going back to when I was a girl

   I used to get so excited
going to see my grandmother grandfather
   Because we could communicate
   Because they were deaf

Compared with my father’s family
who were hearing
And when we had to go there
I had <Churning in gut>
   felt nervous anxious
And when I arrived
<What do?>
Because, I’m not Georgina
When I was there
I wasn’t Georgina
I’m just the deaf girl in the family
on her best behaviour

But they (mother’s family)
They <i-know> me
They know I can be mischievous
They know I’m funny
They know who I am

*Georgina*

Not like my father’s family  (smiles)
They didn’t know me
They didn’t really know me

*Me*

*Georgina*
That I was funny
They didn’t know that
didn’t know

And my grandmother and grandfather deaf
have a special place in my heart
and my deaf aunts
special to me

*Deaf Family*

GRANDPARENTS: Toni

I remember
a long time ago now
but when I was growing up
I idolised my grandmother
I’d always be asking my mum
if it was OK to visit my grandmother
she only lived round the corner
So mum would drop me off there no problem
And if my grandmother was cooking
or doing the washing up or whatever
I’d go chat with my grandfather
but the thing was
he didn’t sign
he fingerspelled everything!
I remember this one time
I’d asked him to tell me a story
And I remember
it was something, to do with war-time.

*But*
he fingerspelled the whole thing!
and I was only about seven at the time
or eight maybe
So I was still learning English
I was still building up my understanding
So I had to try to link
each spelling
to the word
to the sentence
and put it all together
I could understand individual words
but couldn’t quite put it all together in sentences
You know?
whole-string-of-spelt-words-coming-at-me-really-fast
And at the end I had to think
So … what was that story about? (laughs)
But now of course
it means I can get fingerspelling with no problems!
So it was really useful (smiles)
That was my grandfather’s way
That was how he did it
Absolutely his (smiles)

ROUND THE TABLE: Georgina

When we were growing up
I remember
we all had to get together
and sit round the table for meals

Father         Mother
Me          Brother

Sister

Round the table
And that was when we would all watch conversations
And my father would be fingerspelling
And my mother would be signing
And we’d all join in
But
My father
He was a very strict man  very strict
You must sign properly
and if we signed while we had our knives and forks
he’d cuff us
and make us put our cutlery down
Must sign properly
And also he’d complain
   “You sign too much
   You should fingerspell more”
   Fingerspelling is good
   Signing bad
My father was a lovely man
but he was strict
   \_very strict\_  \_very strict\_

MUM AND DAD: Georgina

I remember my mum telling me
when they got married
my mother moved to Scotland
and they lived with his mother and father
I can’t imagine myself in her place
   I can’t imagine myself in that position
But I can picture what it must have been like \_My god!\_

   My mother was from a deaf family
   where everybody signed
   and she got married
and moved to Scotland
and really
she was completely lost!
She was so lonely \_Really lost\_

And my mother
she realised
she would have to teach my father
who people were
   I mean
   My father
   He knew the people around him
   But he didn’t actually know \_who\_ they were!
   So my mother would ask people who they were
   and then tell him
   “That’s your uncle
   your mother’s brother” \_things like that\_
And my father was like
   “Really?” \_<FANT FANT>_\_
And my father would call his father Jim
and my mother would say
   “You can’t call him that \_he’s your father!\_”
   “But I’ve always called him Jim!”
My father didn’t really know who they were
My mother had to teach that to him
So I think really
there wasn’t any proper communication at home
I’d expect him to know that (smiles)

Toni said her grandfather would have been proud of his two deaf great-grandchildren. I wondered if she would say more about this. Coming as he did from a hearing family, and growing up in a particular time, could we ever assume that deaf pride is a constant, that deaf is always celebrated, never a shame?

DEAF PRIDE: Toni

Grandfather was from a hearing family
a Scottish hearing family
and we’re going back a long time
and mostly the attitude towards deaf was
<PATRONISE POOR THING SHAME>
or <BRUSH UNDER CARPET>
hide away
So there was nothing like the deaf pride we have now
But my family was always proud
all the way down the generations
We had that pride
So when my grandfather met my grandmother
and how he felt when his children were deaf?
I mean this is a good example
My grandmother
on my father’s side
it was her 60th wedding anniversary
so The Entire Family
came together
On my father’s side that is not my mum’s side
and Sophie and Fraser were there
and it was so sweet
and they were running round and
there were four generations from two families
All there you know? wow
From two family lines
And it was lovely
And everyone was mixing
And Fraser was running round
And I looked after him
And then someone
an elderly relative
came up to me
“Oh whose child?”
“Oh, it’s my brother’s son”
“Hearing?”
“No, deaf”
“Aww shame”
And I was a bit like
What?
It’s brilliant that he’s deaf come on!
should be cheering!
So some do have that attitude you know
Deaf? Oh shame …
So I don’t know
what my grandfather’s reaction would have been
whether he would have got that pride
from my grandmother’s family
Deaf Signing
I don’t know
And he died
when I was ten, nine or ten

A VERY QUIET CHILD (IN LOVING MEMORY): Georgina

When I was growing up
I was actually a very quiet child
And when I tell people that
they don’t believe me
but it’s true
I was quiet
and very well-behaved
and I would listen
and do as I was told
and that’s how I was brought up

My brother died when I was 12
and that was a terrible day
He was 11 and I was 12
we were both young
but I think when he was killed
the awful part was to think that
someone had died in the same house
and you know
Suddenly he was just gone
That was the really awful part
and I think that really hit me
that I woke up the next morning and felt guilty
I felt guilty because I was living
and because my brother had stopped living
but I was still living
and moving on
And I think even though I was only 12
I started to think
I have to start living for today
Or, what’s the point otherwise?
So live for today
I have an opportunity to live
that my brother didn’t have
so I think that had a big impact on me
and I learned a lot from his dying
when I was 12
So after that
I became I started to think
I don’t have to be the quiet and passive good girl
the girl my dad wanted me to be
because he was always telling me to behave
and that’s why I was always so good
But I think
by the time I was 13
I thought hang on
and I started to come out of myself a bit more
I have to start enjoying myself more!
I can start to enjoy life more
But I really, really really missed my brother
We were so close
My sister was five years older than me
so we’d never been that close really
But there was only 14 months between us
And we were always playing together

<PLAY PLAY PLAY PLAY GONE>

And mum and dad were really worried about me
and they bought me a puppy
because they were so concerned
And they didn’t really realise
what I was feeling
and they’d lost a son
but now their daughter was kind of
/shutting herself off/
And they didn’t really know
what I was going through

That’s when that started
you know Live For Today
You have to
And take what life throws at you
And don’t let it get you down
Just move on
And I learnt that very young

SWEET LITTLE DEAF GIRL: Georgina

I went to a hearing Nursery
and I’ve got a photo of me somewhere
with such a miserable face!
and my mum said to me
All the photos of you
when you were growing up
you always looked so miserable!
but now you’re always laughing
Such a difference!

But at hearing school
I remember that photo
I was
really really sooo miserable
because I simply had
No Idea What The Teacher Was Saying

But she’d spend all her time
being nice to me
Sweet little deaf girl!
(pulls face)
bugger off!
Inside I’d be thinking
What are you doing that for?
Frowning
Thinking
What for?
What for? (smiles)
Music, singing, popular songs, nursery rhymes are part of family life. Georgina’s mother would sing songs for the children, and later, Georgina would learn the words of popular music, and sign them to her children. The “silent world of the deaf” is a myth.

MY MUSIC: Toni

Mainstream music
that is really close to my heart
because when I was growing up
my mum used to put on records
and put on her hearing aid
and sign the songs for me
    She knew the music already herself
    and she would
    you know
    Like Beatles songs
    Like Yellow Submarine
    She would sign those songs to me
and that’s why
I know the words
to some sixties music
because mum would sign them to me
again
    and
    again
    and
    again
And I’d happily sit there
    and watch
    and take it all in
Even now
sometimes in the car
she’ll start signing a song
and it’s like “Oh wow, I remember that one!”
(bursts out laughing)
and I’ll join in!

But there’s also the music in my head
My songs
And I remember writing my first song
when I was 11
    I think songs
    for me
    are what I’m feeling at that point
you know

Here
Now
Just get that out on the page
And when I read them back
I remember exactly what I was feeling
I remember exactly how I felt
So there are lots of songs (laughs)
There’s a huge file! (smiles)
They all show the phases of my life
How I was at each point

TEACHING OR FISHING: Georgina

I really really wanted to be a teacher
I wanted to teach deaf children
That’s what I wanted
And at school
I always volunteered to look after the younger children
at lunchtimes
watch over them when they were having a sleep
Oh (hand to chest)
I used to love looking after deaf children!
I felt really close to all of them …
So that’s what I wanted
But my teacher told me I couldn’t
But I’m deaf!
I can teach deaf children!
< DEAF ALREADY SAME EACH OTHER>
No
Impossible
SO disappointed!
And around that time
we had to start thinking
about what job we wanted to do
when we left school
And I was still saying
IWANTTOTEACHDEAFCHILDREN
<FINISH>
But no!
So everyone else was deciding to
go-off-do-typing
And the time got nearer and nearer
and they said to me
Come on!
you have to decide

**What you want to do**

And I said

I told you what I wanted to do
I want to teach deaf children
and you said no!

And they told me
I had to think of something else
So in the end I said
OK
I want to do fishing
and my teacher said
  Don’t be silly!

And I said
  No It’s all right
  Fishing is easy
    Just sitting on a boat
    Don’t need to communicate with anyone
  It’ll be fine!
  I’ll do fishing, easy!

But right at the end of term
  In the end
  I said  (grumpy)
  Oh all right
    I’ll do typing

**HOME THROUGH MOTHER: Georgina**

It’s strange
I was thinking about this
this morning (smiles)
I was tidying up
putting things away
and I was thinking
It’s like with Thomas
when he says
  “Oh I want to come home
    I miss home”
I have to try to explain to him
Your home is here
and it always will be here
so when you go away
you do miss home
  And Nick misses home
    And Wesley misses home too
And Jasmine misses home
And Toni misses home
But don’t forget
**Home is always here**
and you will come back
but you need to find your own way
a new life
and it feels like a bird’s nest (smiles)
I’m encouraging them to fly
to leave the nest

Image 12. Nest

And Thomas doesn’t want to go
He’s straight back
So I keep encouraging him
Find your path
or let go
And sometimes I look to where they’ve gone
and I go there too
see if they’re OK
I will go to see if they’re happyoku?
Then I’ll leave them and come back …
So I was thinking about that
and when Nick visits
He says “Oh!!” (hand to chest happy)
But this is not the house he was born in
This is just a building
But it’s
**<HOME THROUGH MOTHER>**
I think
Mother Mother
Because mother is here
I think
So the children go
but I’m still here
I will always be here

Georgina began to focus on each of her children and early encounters with audiologists and teachers.

HE IS DEAF: Georgina

Nick was born
and then we found out he was deaf
and that was actually hard
when I knew he was deaf
It was great
  OK
  can get on with things
But the family’s reaction was really weird
Nick’s father’s parents said
  “Oh no, he’s not deaf!”    “Yes he is!”
And nobody would believe me
I felt like
Wait a minute
He is deaf     He’s had a hearing test and everything
He is deaf
And they were saying
  “No no, he can’t be deaf!”
And they went
  on
  and
  on
  and
  on
And I just felt
really alone
with Nick
He is deaf
But it became really negative
  Why they were so negative?
    I don’t know
    It was weird
BUT *HE IS HEARING*: Georgina

But when Thomas went for his hearing test
and they said he was hearing
my mum burst into tears!
My mum!

She cried when they said Nick was deaf
and she cried when they said Thomas was hearing!
She said
“He should be deaf!”  *I know!*
I remember
they handed Thomas back to me
and I just looked at him
and I couldn’t see Thomas
I could just see a *hearing label across his chest*

But then I started to think
This is what it must be like
for hearing parents of a deaf child
*Of course!*
They can’t see past the ‘deaf’ label
and how they’re going to cope with that
< DEAF DEAF DEAF >

So I was able to empathise
It was the same
seeing the big hearing label on my baby

I remember
I put Thomas in his seat in the car
and strapped him in
and just sat there looking at him
You’re hearing??
How?  
What for? 
Why? (at a loss)  
What for? 

I drove home  
and I remember  
my mum was doing the washing up  
and I told her  

He’s hearing  
and she started crying  
and I was crying  
and I remember sitting there  
watching TV  
and just staring at it  not really watching  
just going over it all in my head  

Hearing  
Healing  

It’s very powerful  

So  
What do I do?  Should I sign with him?  
in my work  
I tell parents  
they must sign with their deaf child  

Does that mean I should <VOICE> with him?  
That’s fair isn’t it?  

What’s best?  
Best for me?  
Best for him  
Best for family?  

I had to think about him  
and the family  
(looking down to baby)  
YOU HEARING WORLD  
WILL GIVE YOU BACK HEARING WORLD>  
You hearing world  
but you are also part of this family  
with my other children  
I can talk to them  
if they have any problems  
we can talk about it  freely with ease  
But (to baby)  I can’t do that with you  
But I can talk to all my children  
and you are also my child  
and so I want to do the same for you  
so I will sign
But it wasn’t
Straightaway
Definitely
I am determined to sign
There was a lot of thought went into it
about the family as a unit
his brothers and sisters
Thomas was part of the family
I didn’t want him to be apart from that
We’re a unit
a family
and that’s the most important thing
togetherness
So I signed to him
I signed to Thomas
and it was lovely
and he grew up signing

HE’S MY BROTHER: Toni

I was seven
and at first
I didn’t really like him
because he was a boy!
I didn’t like him
And I think
I remember mum coming home
and telling me he was hearing
and we were all in shock Huh!
But I think for us brothers and sisters
we were like
Oh well
He’s still our baby brother
So we just carried on signing to him
So did it affect anything
that he was hearing?
No!
He’s my brother THAT’S IT

Thomas. A way in with him was to talk about the process of the inquiry, the ethics of storytelling in a family, the risks involved. Suddenly, and without warning:
BLOODY ANNOYING: Thomas

It is difficult
when my mum
tells people about me
    When I was born
    Finding out I was hearing
So when I meet them
in the pub
or wherever
They know really personal things
    about me!
        Small world …

WEIRD: Thomas

Wherever I go
People come up to me
    I know you
        I remember when you were this big!
Someone showed me a book
and there was the story of the family tree
and a picture of me when I was a baby
and at a football match with my dad
    I was just sat there with my gran
        and people are coming up to me
        saying they ‘know’ me
What a weird thing to happen in your life

However, Thomas was also keen to begin reflecting on his Hearing-Mother-Father-Deaf (HMFD) position; how he found himself resisting the traditional ‘role’ while at the same time enjoying the responsibility of defending his parents.

INTERPRETER, NO: Thomas

I can overhear
in restaurants shops
    “What does your mum want?”
    “Ask her yourself…”
Ooooh, you can’t sign? Better use pen and paper then!”
One day I shared a newspaper article with Thomas about a young hearing woman with deaf parents who described her life as swimming in a river between two banks.

HMFD: Thomas

Swimming in the river?
Something is missing in that
that’s not the whole story
“So what is missing?”
W…e…l…l…
It’s like

It’s not-
Yes I can move in both worlds
But it’s like
You don’t know your fate
You don’t know where life will lead you
But you just take a path
and see where it leads

“Do you have more paths
Or more choices
Cos you move in both worlds?”

Maybe
but also
my deaf friends
they move in both worlds too
Same as me

DEAF HAVE INSIDE: Toni

I remember moving back here
Thomas would have been seven
and Thomas was sleeping
and sometimes mum would sleep next to him
and this one time
Thomas was having a bad dream
But instead of shouting out in his sleep
he was signing
He was signing!
And mum was really taken aback
He was sleeping
He was dreaming
And he was signing
   No voice
   Just signing!
And that really hit mum
You know
   it’s there
   \textless{} DEAF HAVE INSIDE\textgreater{}
For him
signing first
speaking second
always
I think it’s naturally inside him
   And when he was little
   he wanted to go to a deaf school
       but he couldn’t because he was hearing
Thomas was very resistant to the idea of signing to me, let alone filming. I wondered about his early memories, what he remembered about growing up. He “didn’t remember anything”. He did want to tell a story. But it would have to be written. So this is what he wrote.

**MY LANGUAGES: Thomas**

Language  
BSL  English  
Which was first language  
BSL

**ABOUT ME: Thomas**

I have been through a lot of things  
In my life  
when I was young  
From 3-7 years old  
I lived in The Peaks  
Memories I have from then  
The house  
A beautiful  
Five bedroom house!!  
It was quite a nice village  

We moved back here  
When I was 7 years old  
We lived with my gran

**WHOLE FAMILY DEAF: Thomas**

Until I was 15  
I was fully hearing  
But whole family deaf  
My first language was BSL  
I learned BSL  
I was 1-2 years old  
English speech I learned  
When I was 4-5 years old  
In school
50-50: Thomas

How do I feel about my self
In between the deaf world
And
The hearing world?
To me it’s 50-50
But not split down the middle of me
It’s different ways
Everyday

Dora and Luke had talked to me about Maisie leaving home at eleven years old to go to a residential deaf school. Some of the most poignant family stories, particularly from Harper, centred on Maisie only coming home at weekends. Georgina’s children have all left home at various stages in their lives, for education. I had no idea what that would do to a family, to a parent. I had no direct frame of reference. Through tears, Georgina told me what it was like.

AWAY TO SCHOOL: Georgina

I wanted Nick to enjoy his education
and he went to a PHU
I think at about 8
he started to really stress
He was so frustrated
because he really wanted to learn
and Nick was bright
a really bright boy
who just learnt so quickly
he took it all in

And then he reached a point
where he wanted to carry on learning
but he had reached the top (level)
and they weren’t teaching him any more
and he got more and more frustrated
So I decided to try Mary Hare …

But poor Nick
the decision to send him to boarding school
that was so hard for me
but I was only thinking
what best for him
I knew in the end
it was the best thing for him
rather than sending him to the secondary PHU

My god
just impossible

I went to have a look around
and I just thought what!?!?
What the hell is this??
You educate a deaf child
by sending them into a hearing classroom
on their own
then they go back through the same work
with a teacher of the deaf?
Come on!

And the hearing children are just
going straight through the work
and getting on with learning
while my child would be held back?
What’s the point in that?

And Nick was so bright
I knew he wouldn’t be happy
He would be frustrated
So he tried for Mary Hare
Nick’s first day
I dropped him off (hand to mouth, looking teary)
that was sooo hard
I dropped him off
and Nick was sobbing and shaking
and I just had to go
and I cried and cried and cried
   Every.
   Single.
   Day.
And my mum came round
   “What’s the matter?”
   “I miss Nick”
When he went away to school
the house was just
   Empt y
   quiet
Then I realised
Nick was my friend
He would talk to me all the time
He was my friend even though he was only 11
I missed him
I really really missed him (hand to chest)
I planned
   I think it was a special day
   a speech day something like that
So I planned for all the family
to go in a minibus
And I think it was a really bad idea
   (hand to head shaking head)
A bad idea
There was me
My mum and dad
My sister my brother in law
   Wesley
   Jasmine
   Toni
And we arrived
and
the first thing I saw it was such a shock
Nick
hands in his pockets
Talking! what a shock!
And I looked at him
and picked his arms up by his sleeves
and said
   “Nick, hands out, sign”
and he started signing good
but then his hands would go back in his pockets
and he’d start talking again
   “Hands out! Hands … Sign!” that was a shock
   A really big shock
I had to remind him to sign
Then Nick started crying again
He was crying and crying and crying
and my mum looked at me
and she was saying
“Be strong! You have to be strong!”
and I was thinking
“I’m trying!”
I had a lump in my throat
But I was trying
and it was so hard
But then he came home for half term
and that was lovely
and the house felt back to life again
    chaos
    and the biscuits were all gone
Everything gone!
Every packet was empty!
So the house was a l i v e
Mad … Crazy … Chaotic
And then he went back to school
    and it settled down again
    and I started to get used to it

BECAUSE WE SIGN: Georgina

I was thinking
    thinking about what you said
about signing
And I think
all my children
    all sign
and
    <FEEL NEGATIVE FEEL THREAT NOTHING>
But when something happens
I see in all of them Oh! (hand to chest)
They react from their own gut …
They don’t react because I have told them
“Sign language is a language”
and
    this
    and
    this
    and
    this
Chapter Four

No that doesn’t happen
But because we are a unit
A family
Because we sign
We are deaf
Sign is our language
without me having to tell them
“It’s a language”
We-just-all-sign-together
as they’ve grown up
Like with Nick
maybe school said something to him
and he thought
“Cheek!
The teacher told me I should use my voice
But I sign
Cheek!
The teacher told me to speak
What a cheek!”
But that reaction was from his own gut
What are you saying that for?
I’m signing

THE HEARING WORLD: Toni

I was always so keen on the idea of
   It’s my life! YES!
   Finally
   No responsibilities
Leaving this behind me
and going to uni
But
when I was there
   Hmm
I realised
   Hmm

This is the hearing world
The Hearing World
   It sounds like a really bad political label
But that hearing environment
   It’s f-i-n-e
you know
and it’s O… K…
and I can get on
But
Every Day
_E v e r y. D a y._

_With no signing?_ (shakes head)
<br>_<ME HAVE STRONG DEAF IDENTITY MUST SIGN>_  
So I could go for maybe … two weeks
But
whenever I had a few days off
I’d be out of there
back here to sign
(fill up my signing again)
I’d soak it all up like a sponge!
until I was full
and ready to go back
and get on with uni life again
And once my tank was empty again
I’d come back here
fill up again

NICK REALISE WORLD HEARING: Georgina

Nick (smiles)  
He went to the PHU  
then I think (smiles)  
a bit later  
maybe when we was about six or seven  
he came home  
<br>_<TAPTAPTAPTAPTAP>_  
_<FANT>_  
“Yes, so? They’re hearing … and?”  
“Yes, it’s all right …”  
“RACHEL MOTHER FATHER HEARING!”  
Yes! Right!  
And I said to him  
You’re lucky  
Your family are deaf  
All your family are deaf  
You’re lucky!  
And I explained to him  
The world is hearing  
And we’re deaf  
And Nick (trying to make sense of this)  
“You mean next door, hearing?”
“Yes!”
And then I think next Saturday
Nick and I were at the shops
<TAPTAPTAPTAPTAP>
“That man there, is he hearing?”
“Yes” (penny drops)
And then a car went past
“Is he hearing too?”
“Yes!”
And that’s when it really hit him
Oh! the world is hearing! not deaf!
And not just a small number of hearing people
No Oh!
And when I look back
to when I was growing up
looking around and realising
wait a minute!
hearing hearing hearing
All these people are hearing
And I’m deaf
OK
I was out on my bike
With a hearing friend
And I realised
how many hearing people there were
And the penny finally dropped
I’m deaf they’re hearing
And we’re different (nods)

WELCOME TO UNIVERSITY: Toni

October
There was a Halloween party in the halls
And nobody in the house talked to me
in all that time
Nothing
My house-mates didn’t talk to me
since the day I arrived
But
they invited me to the Halloween party
so I thought
OK
give it a go
OK
Deafhearing Family Life

At least they’re making a bit of an effort

So anyway
I got dressed up and everything
and went downstairs
and sat down in the room
and there were lots of people there
and there was music playing
and drinks all laid out
and so I sat there
And nobody said hello

Nobody

Nobody (OK…)

So I waited
I waited for the right moment you know
and more and more people were arriving
And so I turned the music off
and I turned to everyone and said

Hello.
My name is Toni
and I live here.
I’m deaf.
But I’m also human.
It’s not very nice to walk in here
And to have nobody even say hello to me.
So I’m just saying hello.
I live here.
I live here with all of you.
But I’m not going to stay living here
if you don’t talk to me.
I’m somebody nice to know.
I like to go out
have a drink
I’m one of you!
I’m a first year!
I’m not going to take this!
And I turned the music back on and left

Enough
And three of four of them came after me
“You’re right”

Yes …
But I had to stand up
and say something
before they realised that Come on! … no!
Do you have any idea
how hard it is
for a deaf person
to stand up
IN A ROOM FULL OF HEARING PEOPLE
to say something???

A few years ago, following diagnoses of dyslexia and later dyspraxia, Thomas became seriously ill. He developed a blood clot in his ear. Georgina told the whole story of the night she followed him in the ambulance and the hectic and terrifying confusion of not knowing what was happening to her son. Having just received helpful and somewhat reassuring news from a private psychologist about Thomas’s dyspraxia, and having somehow found peace and a sense of understanding about her youngest son, their lives were once more thrown into chaos. Thomas has spent much of his life coming to terms with his identities. Once more, culture and audiology clash and cause disarray.

HARD TIME FUCKED UP: Georgina

I was thinking about this recently
We went to a party
and someone deaf went up to Thomas
  “So, you lost your hearing?”
and Thomas immediately
  “I don’t want to talk about it”
He really didn’t want to talk about it
It was hard it was a very hard time for Thomas
It was difficult to explain everything that had happened
to the school
to deal with their attitude
  But also his vision
  for what he wanted to do in the future
  had gone
Suddenly he realised
  <CAN’T CAN’T CAN’T>
I think he was confused about who he was
  Am I deaf?
or hearing?
  Which am I?
And it was difficult to take all that on board
  Really difficult
I remember that psychology assessment
When it was over
we both left
and we looked at each other
and just smiled and nodded to each other
  Now we know (smiles)
  Now we’re clear
  We understand
Then the next thing happened
He really didn’t need that too
I just thought that was so unfair for him
There was no need for that
  But that thing happened out of the blue
  and just threw everything into chaos
For Thomas everything was fucked up
  That was difficult
  It was a hard time

YOU ARE HEARING: Georgina

I have said to Thomas
You are hearing
You are *hearing*
You *are* hearing
You have lost hearing in one ear
Yes
But You Are Hearing
  *But*
  You have deaf culture
deaf inside
  You have sign
  and that’s so great
  *<wow>*

*But*
You *are* hearing

One thing I began to tune into was the way Thomas preferred to talk
not about his mother-family, but his father-family, about hearing aunts and
uncles, about cousins. Commenting on this however was met with silence.
I wondered how much Thomas needed to balance his story by referring to
his ‘other’ side of the family, whether geographical or emotional distance
permitted him to remember and tell me stories, whether that was safer. He
wouldn’t say. These are very moving stories. Unfortunately, most have
been omitted at his request. The funny story in the supermarket is
profoundly, if unwittingly symbolic (Georgina and Jake, Thomas’s father, are separated). It was later discussed in the pub, and Georgina and Toni said it wasn’t exactly true. It represents an amalgam of events, perhaps even more poignant in the way that Thomas chose to tell it.

FUNNY STORY: Thomas

I was in the supermarket with my mum and dad
They were both holding my hands but they walked off
in different directions
They were both holding my hands and I was crying out
but they couldn’t hear
They only stopped when my arms completely popped out!
(laughs)

That’s how I remember it
That’s my memory
I’m not sure if it’s true
But that’s how I remember it

Georgina and I had been filming. It was dark outside, and she went to make tea. Sitting back on the sofa, she started chatting away, asking me questions about teaching. We began remembering, and talking about, deaf education. This took her back to when she was a young mother, when Nick was born. She stopped. We both burst out laughing: “Do you want to me to film this?” “I think you should!” I was reminded of Dora who laughed at the memory of the teacher of the deaf who visited her when Maisie was a baby to talk about school. I had also been talking recently to Brigit about being told that she “must be in grief”. How do peripatetic services respond to and support deaf mothers?

YOUR CHILD OR MINE? Georgina

Peripatetic teachers! (exhales sharply)

I remember it started with Nick and we found out he was deaf and straight.away.
they gave him hearing aids
and I was quite shocked
<WHAT FOR HEARING AIDS?>
He’s deaf

I’m deaf!

but they fitted ear moulds and everything
and I was thinking
What’s going on?
It was like being ordered
You Must Do This
Like This

So they gave him hearing aids
and when we got home
I took them off him
and threw them in a drawer
and the peripatetic teacher came Oh my god
and she met my sister
and then me
and I think it completely threw her
because we were both determined to sign <STRONG SIGN>
And she was a bit like
“Oh, all right, you can sign”
But at the same time
was telling me I must speak
I must do this
And this
And that

I was feeling a bit (ugh)
because I had this vision of me
enjoying my baby
and bringing him up
and everything like that
and she had just barged in on us
with her hearing aids
And because Nick kept chewing through the leads
we had to keep going back all the time
So we had to keep doing that
and the peripatetic kept visiting every week
just interrupting
On and
on
and on
and then the Toy library started
and hearing tests as well
and I just started to think
Wait-wait-wait-wait-wait hang on!
I’m bringing up my baby
and everything has been interrupted
but I’m deaf
and he’s deaf
and then Wesley deaf too
and I thought

*I’m going to have to go through all those interruptions again*

And so my happy vision
of bringing up my children
my own way
I feel they barged in all over that …
I remember
we had a trip to a farm
a whole group of us would go every year
it was really nice
and we always enjoyed the tractors
and sitting on the trailers
    having rides
    it was lovely
I remember back then
Nick was really naughty
I was having to be really strict with him
    and hold on to him
    and tell him off
    “No, if you do that again
    you won’t be allowed to go on the ride”

And Nick was sulking
and I said “No”
and the peripatetic teacher came up
and interrupted me
and said to me “No, don’t … it’s fine”
    And I told her
    “I’m sorry
    but he’s been naughty
    so I’m telling him off”

And she just barged in
and I thought *hang on*
Is this your child
Or my child?

He’s mine
and I’ll tell him off if I want to
    (No, not “if I want to”
    but if he’s naughty I will tell him off)

She interrupted
and I started to think
Who are you?
Who are you?
Getting angry with me(!)
And another time
Wesley was a baby
I remember
and Wesley really hated hearing aids
Really really hated them
so I didn’t bother with them
and one day
Wesley was in the pram
and the teacher saw us and said
“Oh hello!”
and then she bent over to look at Wesley
and turned
hands to her face in horror
“Oh, but WHERE are his hearing aids!?!?”
And I was about to say-
I felt like wait a minute
I feel like you’re treating me like-
You talking to me like that
takes me right back to
being a little girl
and the headmaster shouting at me
“Where are your hearing aids?!?”
It felt exactly the same!
And I remember with Toni
I just said no.
Just leave us
don’t bother coming
just leave me with Toni
Oh ... peace of mind!
They gave me the hearing aids
“Happy?”
“Yes!”
Then I took them off her
and just threw them in the drawer
because I just knew they would
Keep
On
and
on
and
on at me
Fuck off!
It’s so stupid
So stupid
Oh you must make sure they wear hearing aids
You must do this
Must do that

It’s crap
Just crap, you know?
And if I look back
I wish I had been stronger
So I feel
that interruption
I feel <DAMN>
I wish I had had more time with my children

All stories have their turning points. I knew that Toni left Mary Hare before taking her exams. That’s how we met. But I didn’t know how to ask her about what happened. Clumsily, I signed something like, “Your ear??” She smiled and told me the story of how one day she suddenly became medically too deaf for a school for deaf children. Later, Georgina gave me her version of events.

LOSING HER HEARING LOSS: Georgina

The nurse …
She had a really serious face
and she put her hand to her chest
and said
“I’m really really sorry”
And I was thinking
What’s going on?
And she said
“Her hearing loss is gone”
And I thought huh? (wicked laugh)
I asked Toni
and she said
she just woke up and all the hearing had gone …
and school
panicked-and-sent-her-to-the-doctor
and-checked-her-hearing
and both ears
the hearing had just vanished.
And I said
“What about hearing aids?”
and Toni said
“There’s no point”
and Mary Hare agreed because she had
   Absolutely
   No
   Hearing
   At
   All
And I thought
   “Really … ?” <FANT> Weird
But for me it was like she hadn’t really lost anything because she was already profoundly deaf
But then the Nurse gave me a brown envelope and the letter explained what had happened and then it said that they recommended Urgently that Toni have a cochlear implant And my immediate reaction was NO WAY! And a bit later on I mentioned it to Toni and she was the same NO WAY! And then when we came home I talked to Nick and Wesley and they were the same too really against the idea NO WAY! We all had the same gut reaction <IMPLANT WHAT FOR?> Poor thing Toni The school They were really bad They started putting up posters everywhere advertising cochlear implants saying they could help you hear Then one day one of the boys at school who had an implant he was playing football and the ball hit him in the head and he collapsed and had to be rushed to hospital and Toni saw that and that made up her mind and in a way poor boy But thank you! So that made up her mind
NEST: Georgina

Home feels like a nest
Like a bird’s nest
<WATCH WORRIED PICKUP GENTLY BRING BACK TO NEST>
<TEACH TEACH TEACH>

OK?
Off you go fly again
And I know they don’t come back to stay forever
it’s like their safety net (nods)
I believe that
I help them
and encourage them
to make their own choices
and do what they want to do
L-e-t-h-e-m-g-o

I think that’s what family means

MUM: Toni

What can I say about my mum?
Difficult to know where to start
When I was small
I mean
my mum was always there
as I was growing up

So I think for me
<LOVE> <VALUE>
I realised what my mum meant for me
when I moved to university
I think it took me about two or three weeks
and then whew I want my mum!
So when I went home
we were supporting each other
and I realised then that
she’d been supporting me anyway all this time
I just didn’t see it at the time (smiles)

So we were there for each other
all t h r o u g h that time
and now
I think because I came back here
we’ve become tightly bonded
I don’t actually see her that much
but she knows I’m here
she knows she can text me about anything
I will be there
   The same for me
   I can text her
   Any reason
   and she will come (smiles)
We’ve become very closely bonded
We both know that
even though it’s unspoken same wavelength
And when we do meet up
So much to talk about!
   Sometimes it’s family stuff
   or I just tell her
   what’s been going on for me
   or needing to get work stuff off my chest
   All sorts of things
But when we’re together
there’s no stopping us
we have to tell each other everything
I think we trust each other to listen
   and what she tells me
   she knows it doesn’t go any further
   it’s just between us
   and vice versa (smiles)
It’s a family thing
and it’s our connection to each other
We have such a strong bond

and when people talk about my mum
they tell me stuff about her
I just think
   YES!
   That’s my Mum!
   Sooooooooo proud! (big grin)

My mum is my closest
my best friend it’s so true
When I get to the point
where what I really need
is a Proper
Big
L o v i n g
H u g
It’s her I turn to
I asked Thomas one day if he’d heard about the genetics furore in the newspapers. Yes, his mum had mentioned it. I then asked Toni how she was dealing with it.

PURE DEAF: Thomas

I talked to my mum
about the genetics stuff
She told me
they have identified
one of the genes that causes deaf
But her genes?
ALL DEAF

ALL THE WAY DOWN THE STRING OF DNA

It’s all deaf!

So they can never get all that
It’s like she’s p-u-u-u-u-r-e deaf! (huge grin)

THANKS A BUNCH: Toni

The eugenics stuff that’s happening <BLOW TOP>

It affects me
because of who I am you know
and if I want a child (through IVF)
I mean
I’m a lesbian
so if no, not if
I want children
I’ve said this many times before

I WILL HAVE CHILDREN

But if that Act happens
Oh great
Thanks a bunch!
I’ll-have-to-do-it-the-‘normal’-way!?!?

You know? (laughs)

It means they’ll force me to take an option
I really don’t want to take (shakes head)

As a deaf lesbian
HELL-O!

and from a deaf family

I would actually rather use genetics and see what that gives me than have that taken away completely you know what I mean?

So if they give me embryos
and they’re hearing
then that’s fine
But no way do I trust them
I won’t let them destroy my connection to a baby
It’s Hitler all over again, isn’t it? (wry smile)

In the end, Thomas and I found ways of sharing stories with each other. I think he rather enjoyed the opportunity to philosophise. This is his parting shot:

LIKE LIGHT REFLECTING OFF PLANTS: Thomas

How I feel
about
the deaf world

and
the hearing world
I feel 50-50
Because every morning
I wake up
and look in the mirror
and see 50-50 in so many ways

Like how light reflects off plants
Like light reflecting off a plant
It was from an art class
we learned to look at things
really carefully
and to see the different ways
light reflects off plants
I always remember that filed it in the back of my head
And then
it popped up
when I was thinking
about being 50-50
and different every day
and I knew it was the same
like seeing myself in the mirror
looking really carefully
and it was just like looking
at the way
light reflects off plants

Deaf - inside?
Deaf person who can hear?
No
50-50
I’ve always said that
50-50
Split down the middle?
No
It’s not down the middle
It depends
And sometimes it’s across the chest
and sometimes its diagonal
It really could be anywhere

MY FAMILY—EPILOGUE: Georgina

When my family all get together
Ooooooh!
Such an exciting energy
and it’s soooo nice
Everyone s-i-g-n-i-n-g
catching up
But some people
they don’t seem to have that
and maybe they haven’t seen their family
for a long time
and they’re all asking how they are
But they don’t have that
you know
that s:p:a:r:k:l:e
that excitement
that e~n~e~r~g~y
There’s n o t h i n g
And even if it’s been a long time
it’s like
there’s no. extra. information.
Nothing more there
But my family
We’re all so excited to see each other
to find out what we’ve all be up to
catching up chatting       siiiigning, you know? Yes!
L o v e l y
Each one of them is special
Each one is
Special
To
Me
Dora, Luke, Harper and Maisie (Part II)

Beginnings

Dora, Luke and I met shortly after the HFEA amendments had spread all over the news. I wasn’t sure they would even want to talk about this. Neither were they. There was no emotional or temporal distance; this was happening, here and now. I expected that we would have a short conversation about its impact, then move on to revisiting and layering the family story. As it turned out, Dora and Luke spent much of the time sharing with me their reactions, their frustrations, their anger and pain towards the Act’s amendments. It was only when the tape ran out that we were able to pause, to take a break, and to think of, and to tell other stories.

Maisie and Harper were both away at university. We had to plan our meeting very carefully, to fit in with their being home at the same time as each other. After many e-mails and SMS messages, we found a date just before Christmas. Short and sweet (as always), the two of them chatted away to each other, and shared new stories with me. We revisited earlier events and touched on difficult, uncomfortable family stories. There is enormous wisdom contained within their narrative. Through talking to me, and with each other, we jointly made new sense of deaf and hearing ‘identity’, deaf and hearing ‘worlds’. Some things never change. Attitudes that are stuck, remain stuck. “Shame” will always somehow get passed down through generations. But it is also possible walk away from stuckness, to move into new spaces where, as they told me, deaf hearing doesn’t matter. Forever strong together, their sister-story, their family-story spirals through time (Brockmeier, 2000), revisiting the old, worn-out, tired and faded, alighting on established and new relationships, always forward-moving, optimistic, resilient, funny, sad and wise. Maisie and Harper chose first to look back.

DEAF HEARING FANT: Maisie and Harper

Really
I never remember actually ‘realising’
Huh she’s hearing
and I’m deaf
No …
It was more like
Oh
deaf hearing <FANT>
deaf hearing <FANT>
  Signing
  Speaking
  Communicating
It was never
  She’s hearing
and I’m deaf
means we Different
I didn’t really think about that
it wasn’t an issue
so I never remember sudden realise
<PENNY DROP>
Nothing like that really
It was just very smooth
Mmm
No
I don’t remember thinking about
us being Different
  But I do remember a point where
  it felt like a more integrated life
  and that’s just how it was
  made up of different parts
  Do you remember Learning To Sign?
  and your sign language developing?

Sorry
I was blowing my nose
and didn’t see what you said
(sighs and smiles)
Do you remember
learning to sign
or all of us learning
teaching each other?

I don’t remember
formally teaching you
It was more like teaching you naturally
We didn’t ever sit down and I’d say
OK, today I’m going to teach you the signs
  for this
  this and
  this
Like
how to sign dog
and how to sign cat
I would just sign
and she would just pick it up naturally
and we just signed to each other
and learned it the same
so it was just a natural way of teaching really

That’s what I feel

LIKE CHRISTMAS PRESENTS: Maisie and Harper

I remember feeling
understanding in my head
that there was \textless SEPARATE\textgreater  \textit{difference}
of \textit{experience}
I know that really
Mum taught me sign
but I always knew
that Maisie would always have
new information for me
so she would go to school
she went to school
and picked up lots of new signs
and then come home
and teach me
So I always felt a little bit like
I had to catch up
but not in a bad way
just \textless TAPTAPTAP\textgreater
“What’s the sign for this?”
or
“What’s that mean?”
So that information was always from \textbf{you}
You were the one who was going out
and bringing information
back to the family

Like Christmas presents
I’d bring them home and say
Now
This is what you’re learning today!
Just like that! (smiles)
and sometimes I’d be signing
and she’d go
“Don’t you know the sign for \textbf{that}?!”

More like \textless STOOPID\textgreater
Yeah, more like that, actually! (laughs)
and that was all part of

\{Our Sister Relationship\}
HOPE FOR OTHER FAMILIES: Maisie and Harper

Attitude is so important
If mum hadn’t had such a great attitude
   if she’d been a bit
     unsure
   less open to signing
then we wouldn’t have been A Signing Family
But because she was so up for it
knew it was the right thing to do
we all moved forward together
But also that English was important too
   and if we hadn’t had that
then things would have been very different
   A    upper right
But nooo we all had both languages
went from strength to strength t-o-g-e-t-h-e-r
   Great!

I think
I’ve talked to other brothers and sisters
who’ve had deaf brothers or sisters
and they tend to say things like (sigh)
Oh-I-can’t-be-bothered-with-signing
Moaning or complaining about it
but that just doesn’t make sense to me
   The way mum taught me
to understand the situation
   I never thought to complain about it
It was just more
This is what I have to do
so I just rolled up my sleeves and did it!
But not   Oh-if-I-have-to
   Or
Oh-I-can’t-be-bothered-to-sign-today
I-can’t-learn-today-sorry
   I’m-too-tired-to-sign-today

No never
That seems different
from some other families I know
   like their understanding of the situation
didn’t match ours

If the family has the right attitude
it can go smooth
I mean
maybe not always s-m-o-o-o-o-o-t-h
maybe more like s.m.o.o.t.h.
but generally s~m~o~o~th

Definitely
I feel my family is such a good example
I’m not saying we’re perfect
and m a r v e l l o u s
but attitude
When you think about it
three hearing and one deaf
we still get along we all sign
it’s a bilingual home
we’ve grown up bilingual
And I hope other families can have that too (shrugs)

THE SCREEN: Harper

It’s not easy
In some ways
it’s double the work
and the double the possibility
of b.r.e.a.k.d.o.w.n
But if … No-
When it works
Oh, it’s p:e:r:f:e:c:t Am-a-zing!
I feel so proud of all of us
when we can all communicate with each other
and when I think of other families who ...
I think How can they not do it?
you know
Why?
I feel like I want to remove the screen in front of their eyes
so they can seeeeeee! (laughs)

The John Humphrys Interview: The moment when the world seemed to
go completely crazy.

H/F E A/R: Dora and Luke

When when kind of
it sort of came up
from one e-mail
and then it just exploded everywhere
And I really kept my distance
and (to Luke)
you got much more involved in it
much more quickly
And I can remember
saying to Luke
“I don’t want to read them
I don’t want to know about it
I don’t want anything to do with it”
But I very sneakily read
every e-mail that came through
I only found out
about a month or two later

I think it just struck
Very. Deep. In. Me. that ...
because the question is
Had I been in that position
Had we been in that position
What decisions would we then have made?
That’s why I really struggled
going- thinking through the whole thing
I would now think that I would
I understand it so differently
to how
I would’ve understood it then
And of course
that’s the position of most people
in the position of having IVF
    They won’t understand it
    They won’t know it and so
we’ve done an awful lot of thinking
and talking about it
even though
I’ve been pretending
I was ignoring it

PONTIFICATING: Dora and Luke

I think
I think that’s one of the things
that’s come out of this whole thing
The people who’ve been pontificating
and giving their views
have absolutely no knowledge
    at all
about the deaf community
    or deaf people
    and have never met one
And what they’re saying is
    “I don’t wanna be deaf”
That’s actually what they’re saying
    and that’s irrelevant
to the whole debate
They’re saying
    “I don’t want to be deaf”
and they’re not even saying
    really
    (although they think they are)
    (but I don’t think they are)
    “I don’t want to have a deaf child”
because
I think if they had a deaf child
they’d be saying something different
and that’s what they’re saying
    “I don’t wanna be deaf”
but they don’t-
I don’t know how you would ever
manage
to get people to see that
because it’s t-o-o big a leap
They’re trying to
Save Future Generations
from something
that
you don’t know what it is
It keeps coming back to
deaf is different
It’s really hard to understand
if you haven’t met deaf people
and you need to spend
a significant amount of time
with them

I was thinking about Blunkett’s comment
saying that there was no deaf community
You know
Because there’s obviously
No Asian community
No Jewish community
No Catholic community
Because he was saying
We’re All One Community
Well that’s absolutely spot on, isn’t it …

Thanks Dave (!)

FUCKING SELECTION: Dora

Phrases like
“Playing God”
Well God’s been played
It’s all been done
It’s there
It’s in the dish
It’s all happened
You can’t do some of it
and not do the rest of it
OK! so get rid of deaf people
You’re gonna find other things coming up
you know
What sort of human race are we out to create?
And there’ll be things we don’t know about
People will slip through the net and
we won’t be in any position
to cope with difference
I had to think very hard about it
I came down on the side of no selection
    I get a bit bothered
    I don’t know if people are being misrepresented
some deaf people saying
    they would actually choose to select a deaf embryo
But there was one e-mail
WHAT’S-THIS-ABOUT-FUCKING-SELECTION
YOU-GET-WHAT-YOU’RE-GIVEN-THAT’S-IT
    Not by picking and choosing
    No selection
    No. Selection.
Then you’ve got the same odds

But
the idea of
    just
    flushing away deaf embryos
Is so brutal
It’s so brutal


There was confusion about
whether you have to have testing
    if you test for some awful hereditary disease
d’you also have to test for deafness
V-e-r-y muddy
    and I think the angle
    the angle was wrong
I think it came across too much
that they wanted to have a deaf baby
Not … Reserve The Right
and it was very difficult
to make a pithy statement
There was nothing you could have
as a slogan
on a banner
because you-have-to-have-four-or-five-ex-plan-a-tor-y-sen-ten-ces
before you can get to the nub of it
and that’s really difficult
So you cannot hope to influence
the person on the street
epecially in a hurry
to get their heads round this
Particularly if they’ve never been
involved in the deaf community
So it’s really difficult
So
The only awareness the public got
of deaf people in all this was
“Oh, they wanna have deaf babies”
And then there’s the silly confusion between
choosing an embryo that already exists
who is deaf
And getting a wire brush
and deafening some seven-year-old
which is completely different
And that only came out months
months further on

CHOICES: Dora

All the curiosity

Oh gosh
Did you hear any of that last week?

and
and
people thinking
that it would be a good thing
And that actually
as parents
we would think that it was
would be a good thing
and had we known
and had we been able to …
And people
    seeming to not realise
        what they’re saying
You know?
    Where are you gonna end?
    Where’re you gonna stop?
And people not realising
that that’s what they’re actually saying to us
that we might have been pleased
    to have been able to make that choice
And I’m really pleased
that we have not been in the position
to have been able to make a choice
Because when you make the choice
you don’t know what the reality’s gonna be
And the point very strongly for me is
    and it’s what I’ve always said is
You never know what child you’re getting
You never know what child you’re getting
You never know what the life of that child is
You never know what illness is out there
You never know what accident is out there
You don’t know what that’s gonna mean
    And it’s completely
misrepresenting I think to people
    that they can control that
and design what they want
when actually
they may not like what they get
even when they’ve made some decisions in that
    So it’s much better that it’s left alone

Gaps and silences. We trod lightly. Unspoken feelings, and fears. No emotional distance here. Later, with some temporal distance at least, Maisie and Harper did respond, and fiercely. We had fun, shouting at the world.

CLOSED MINDS: Maisie and Harper

I completely object
to the idea
of trying to
wipe out deaf people
And that seems to have come from the idea
that deaf equals disability …
I don’t understand the issue fully
but it seems that
they are trying to…
prevent deaf from being born
What?!
Deaf is a disability?
   No! it’s a culture!
and people don’t understand that
   It would be like
   preventing Aboriginal births
   or Native American births
So trying to prevent deaf births?
That’s really really oppressive
I found the whole situation
completely depressing
   People don’t understand what-
   the deeper meaning of what they’re …
   trying to say
   It’s like their minds are
   completely closed
   And you can try to open them
   but they are totally stuck shut
   But those people
   It’s like they are completely ignorant
   they know nothing at all about deaf
   but they can make all the decisions
   about who has the right to life
   You?     no!
   You?     no! 
   You?     no!
It’s the same as Hitler!
It’s the Nazis all over again!

And people were all talking about the issue of
‘Choosing A Deaf Baby’
But people would normally be allowed to
choose a hearing baby
   So actually
   why is it any different
   to choose a deaf baby?
It’s not stopping people from choosing
It’s making the choice for them!
   I think
it’s that whole Science thing
And people can’t seem to separate
science from real lives
And I think people like to use
the Science Argument
It’s like
It is that Why question
So why do you think
some deaf people
might actually want to choose a deaf baby?
Well
maybe you should try to
understand deaf people
before you throw your hands up in horror
or make decisions to stop that choice
Oh, I’m shocked!
because I am such a pure person
and therefore I have the right to criticise
Everything I Don’t Understand
Aaargh!

That person who mentioned deaf
she doesn’t understand deaf as culture
even though
there’s a whole pile of books on the subject now
She’s ignoring all that
University Deaf Studies
Studying deaf culture
She’s ignoring that too!
It’s being studied at university
The proof is there
<HAVE>
PhDs
Academic research
like your work
It’s all there
and it’s still being ignored!
They still see deaf as disability <THAT’S IT>
the same with BSL too
they just won’t admit it
that’s what I feel they’re doing
totally. ignoring. deaf:
They’re completely ignorant of the situation
That’s what I feel (shrugs)
So instead
we want deaf to
M—A—R—C—H
a n d …
TAKE OVER THE WORLD!!!
    Yes!
    Oooh how scary(!)

(both burst out laughing)

Maisie and Harper had set the world to rights. They were very satisfied. However, their joyful, wicked rants opened a door to a more philosophical reflection on their relationships—with each other and with the wider world.

OUR WORLD: Maisie and Harper

Because we’re three hearing
and one deaf mixed
all together at home
but really
I never thought of Harper as hearing
    and me as deaf
and us being different
it just didn’t occur to me
I never thought about it

And people who say
Oh!
hearing and deaf
But I never said
Oh!
She’s hearing and I’m deaf
Never

    I feel like
    from the middle
    No, not …
    It’s like
Here’s the deaf world
    and here’s the hearing world
And it’s separate it’s not-
When I go to deaf club
I feel
OK Time to get ready
Roll up my sleeves
and be a signing person
and sometimes I feel quite relaxed
and sometimes I have to get ready to sign
and I do feel different or
in some way mixed

You’re in the hearing world
and I’m in the deaf world
But together
away from that
we’re separate
Huh!

We have our world
When we’re both here
Just-getting-on-with-things
the fact that she’s hearing
I never think about it
But I suppose when we go out
you know
Into The Hearing World
out with hearing
I don’t usually talk about
me being deaf
and Harper being hearing
deaf hearing
deaf hearing

I know that’s a difference
But
I feel that’s wrong
I feel it’s difficult to explain
if you’re trying to talk about
Different and Same  hmm
It’s easy to say
Oh deaf separate <FINISH>
But hang on  not really that simple
or hearing means the same thing
or in the deaf world
talking about hearing people
oh hearing-talking-his
it’s more complicated than that

So when we’re here
{together}  as a family
it’s only when we go outside
into the world
that you feel that separation
SISTER THAT’S IT: Maisie

I normally just say you’re my sister
And then they ask me if you’re deaf or hearing …
   they ask if you’re deaf or hearing
   and I just tell them
      but I normally just say
      she’s my sister
(teasing)  and then I say
   She’s hearing
   but her signing’s OK you know
   it’s a bit rubbish sometimes
   and it needs a bit of tweaking …

(sighs and smiles)

But no
You’re just my sister
<THAT’S IT>  (shrugs and smiles)

A 2D(EAF) IDENTITY: Harper

S o m e t i m e s
when people are genuinely interested
you still get the same results
   Like when I’m talking about my sister
   if … for example
   I didn’t want to talk about where she went to school
because I knew where the conversation would lead

But then
when the word is out
   “d e a f”
I’ve lost my chance to tell the story
because deaf is out there
It is like a 2D person
   and so I have to get out my pencils
   and colour her in
   to show people
and then I’ve lost the story I actually wanted to tell
   I think it’s different now
   I still try to avoid actually saying
   “My sister’s deaf”
and (to Maisie)
that doesn’t mean
I don’t talk about you
but
sometimes I just try to bypass it
or not bring it up
    or try to not pause
    so they don’t get a chance to ask about it
But I think now I’m older
it’s easier to have an interesting conversation
but I still get nervous
maybe I really like the person
and then they go and say something stupid like
*Oh, can she lipread?*
and I just think (sigh)
*Oh, sorry, I’ve got to go now*

I remember Laurel Richardson writing about the way she would find herself quoting from her participants. This has happened so many times, I still remember certain phrases from conversations: “Nice fridge”, “The elephant in the room”, “Sausages from a factory”, “The teenage years”, “Have I got my family right today?” At the same time, there are expressions or terms that occur, or emerge, across families, such as *shame*. These are stories about attitude, ignorance, unthinking prejudice. They are also stories of acceptance, of *identities*, of willingness to find ways to communicate, to take on challenges, to look beyond the surface of things and to really see what’s going on (I am quoting Brigit!).

**FUNNY STORY: Dora**

I was at the gym
    (which is funny in itself)
and they had the music programme on
I’d never seen before
and all these music videos
and there’s a little signer in the corner
signing some of the songs!
and she was having a *great time*
and she was really dancing
and getting into it
    And there was a woman
next to me on the exercise bike
the gym’s very *<small>*
so if you’re next to each other
we were the only two in there
    you sort of *have to* say something

And I went
“Oh there’s a signer!”
and she went
    “Yes not all of them
    but some of them are signed
    I don’t really like it”  (laughs)
And I thought
    Oh! what shall I do now?  
(Luke): Kill her, obviously
And so she said
I don’t really like it
    cos I like to watch the band
        I like to watch the video
        and it’s distracting
and I thought I’d just be open about it
I said
    Oh well that’s interesting
        cos I’d never seen it before
        and actually    my daughter’s deaf
        and you know    I was just curious about it
But I had a choice to make
Shall I say something? Or not?
    And I could’ve just left it
    and I thought, “Well I’ll see what happens”
And it completely shut her up
    she didn’t know what to say after that
        And she’s never spoken to me again!
        Ever!  (laughs)

THAT SHAME WORD: Maisie

I remember
When I first got to university
and I was getting to know the people (hearing people)
    In my halls
        there are two deaf
        but the others are hearing
So I bumped into the boy opposite me
and we got by writing notes to each other
we sat down and starting chatting
by writing notes
and so then he asked me something
    so how come you’re deaf?
And I wrote
    Well, I was born profoundly deaf
and he wrote
    Oh that’s a shame …
and I thought
Oh really?
A shame?
A shame?
And that made me so !mad!
and I wanted to write
don’t patronise me
it’s not a shame
I’m very happy actually
But I just wrote
I’ve got to go
and that was that

50 % (NOTHING CHANGES REALLY): Maisie and Harper

Last weekend
Mum’s brother and his family were here
and
I feel …
That is where I feel like I’m sat there
twiddling my thumbs
And I just take myself off
and my uncle
he doesn’t sign at all
even though he passed level one before
it just seems like he gave up
just a bit lazy really
and not only lazy about that
I think he’s lazy about lots of things
But he just carried on talking
and mum was signing
and Harper was signing
so they were telling me what he was saying
but I didn’t want to keep asking
What’s he saying?
because it was mum talking to her brother
and I felt I should just stay out of it
and leave them to it
And also
if I keep asking
What’s he saying, what’s he saying?
I’m still only getting 50% of the conversation
so I still don’t actually get what they’re talking about
so in the end I just feel
Oh well
And I’m not blaming anyone
it’s just I feel he’s a bit lazy
and if I do want to have a conversation
it still has to go through someone else
it’s not one to one
always there has to someone else there
So I just leave now (sighs and shrugs)
That last weekend
that was really frustrating
I just gave up and walked away

\textit{Just leave}

Before
I would sit there
thinking twiddling my thumbs
\textit{Oh please talk to me, just once (!)}
but now I know they won’t
so what’s the point me sitting there
waiting for something that’s never going to happen?
so I feel I can just leave
and mum agrees
I can please myself, why not?

I think she feels
feels the situation b-u-i-l-d-i-n-g u-p
when people are sitting one side of the room
talking together
and mum and I are trying to sign \textbf{everything}
And dad (and sometimes me as well)
forget to sign
And it’s like \textit{Oh shit!}
it’s too late now to start interpreting that
and then I know that you’re sitting there
p.a.t.i.e.n.t.l.y
just w-a-i-t-i-n-g
and it feels like time’s running out
until she is \textbf{completely} fed up
and that’s fair enough
Why should she stay?
So I do feel there’s a steady build up of frustrations
But it’s good
I think it’s important
that you don’t feel you have to
if they can’t sign
that you just have to sit there
there’s an equal responsibility
And if they don’t accept their part of the deal
then why should you stay?
but I do feel sometimes like I’ve failed
if you can’t stay
but also maybe
I have to just accept
some things won’t ever change

I don’t think about it
that much
If it was
You
Mum
Dad
who had to sit there
twiddling your thumbs
Imagine!
All Your Lives…
You’d be shouting
and screaming
/b/a/n/g/i/n/g doors
til the whole house collapsed!

(laughs) Yeah, I can believe that!

ALWAYS AT PARTIES: Dora

We went to
a kind of dinner thing
about ten of us there
a few weeks ago
and the bloke next to me
he must’ve been about sixty
and he said
Well…
(you know the conversation we talked about before:
“And your other daughter ..?”)
and I said about deaf
and he went
You could actually see the cogs going thinking
I don’t know what to say now
eerrrrrrrrrrrr
What did I used to say when I was nine?
I’ll try that!

“So you think it’s worse to be blind or deaf?”

and  (I’d had a few)
and I went
“I’ve got NO idea!
Why don’t you go and ask a few people
if you’re really interested!
or we’ll talk about something else …”

THAT’S THE SHAME: Maisie and Harper

I feel
we have
very separate
relationships now
with our grandparents
  I feel
  I visit
  I go to see them
And
you
don’t
because it’s hard!

I never visit them!
I know I should really
but

last time …
after that
we were both really mad with each other
It was really t.e.n.s.e.
and I don’t think we realised
how the communication issue had got to us!

That was the absolute peak
and we haven’t been away with them since
not the four of us um
But we are seeing them again
after the new year

Oh yes (!)
I’m really excited about that (not)

But I do expect
a few days before they get here
the stress levels in the house
will start to b-u-i-l-d u-p
Particularly you and mum
I’m expecting that
I’m guessing that will happen
Am I right? (smiles)

(teasing) possible …

So it’s a bit differ-
No. Nothing’s changed.

No …

HARPER NOW: Dora and Luke

Harper’s <LESS AND LESS> exposed
to deaf
Going away
whole terms at a time

So when Maisie comes up
she’s gotta interpret
do the cooking
arrange the accommodation
and everything else

And so whenever she goes for a pee
or something
if Maisie’s in a room
full of hearing people
it’s very difficult
Maisie feels left out

But also
Harper’s gotta go through that whole thing
all over again
hasn’t she?
educating her peers …

Yes
Who are slow to learn!
   Lovely people
but they still go through that
“Oh I’d love to learn to sign”
and then do nothing about it
they can’t quite take the next step
make the next leap
or see what a toll it takes on Harper

Cos it does

So it’s worked out really well for her
the getting away
having a break
   having her own space
doing what she’s interested in
Definitely time for her to do that
They do have a really nice time together

Yeah they do

But a bit like us
You never quite get away from it
and I’m sure Harper doesn’t either
and y’know
there’s always gonna be issues
with boyfriends
   or prospective partners
you know
Should they sign?
Are they really gonna connect
with Harper
and her family
if they don’t?
And at what stage of y’know
is this after the first date?
or should we wait a week?
or the beginning of the next academic year?
you know (laughs)
   It’s an extra pressure on any relationship

I’m gonna get you a pipe
and instead of
“So … what are your prospects?
   and your intentions?”
you need to have a conversation about BSL
   Yes
   and if they want
to ‘ask for her hand’
   It’ll have to be in BSL! (laughs)

COMING HOME: Maisie and Harper

We’ve just come back home
and it just feels n-o-r-m-a-l
it looks normal
they’re both signing away
   same as ever
Coming back
it’s just the same
doesn’t feel any different really
   feels exactly the same to me

I think the only difference is
it feels like
   a t−s−u−n−a−m−i
   a big wave’s »crashed« over
and then things take a while to settle
and then we all poke our heads out
and look around
and check everything is OK
and then everything goes back to normal again

When does the tsunami happen?

   You know
   when we first get back
   and everyone is so e:x:c:i:t:e:d
   and then the next day we argue

But really
it does just feel the same
their signing just needs a bit of oil really
that’s all

   True
   it’s a difficult question really
   I feel some things have changed
in some ways  but
I  can’t  pin it down
I’d need to give that some thought

You feel it’s changed <FEE>
I feel it’s exactly the same
But maybe that’s cos I’ve been asleep
most of the time
   (You know I’m joking, right?)
   Sorry
It’s the same as mum said
The family argues
but
I don’t feel they’re bad arguments
   They’re healthy arguments
   that’s what I feel …
   (lip pattern: maybe)

Yes
Get it all out!
then laugh about it
throw things, have a meal

Throw?
   What?
Tomatoes!
   When!?!?

Always dad done that!

(both laugh)

I am often struck by the ways in which Dora and Luke speak, and the ways in which their choice of words, turn of phrase, emphasis and poetic repetition reveal the depths of their stories. I think Luke found our conversation very hard at times. Dora talked far more than him; we were all agreed on this! Yet when he spoke, he did so quietly, in measured tone, but with an edge in his gentle voice. A great deal of emotion, anger and frustration, I feel, is encapsulated in his words. In 2006, he compared people’s reactions to his deaf daughter as one might remark on a new fridge: all you can say is, “nice fridge”. And here, he talks about factory settings, learned defaults. It was Luke who had thought long and hard about the HFEA. He wanted me to write H/FEA and FEA/R together. He had made notes on what had been going on in the news. It is in what Luke and Dora don’t say that I am able to appreciate the enormity of their positions. As hearing parents with a deaf daughter, where have their voices
been heard? And if you’ve only got a few minutes, how on earth do you begin?

A LEARNT DEFAULT: Dora and Luke

But it still
still affects
everything
most things we do
even when they’re not here doesn’t it?
There’s lots of things that
although we can go a few weeks
without signing

Yeah I think it’s different

Which is
which is weird
and so you get in a kindof
you can kind of
relax
whereas there’s a learnt default
which is always y’know

Don’t put music on
If in doubt sign
Don’t talk if Maisie’s in the room

I think there’s less of that

But when Maisie’s here

Oh when Maisie’s here

There’s a learnt default
and then all of a sudden
having not relaxed from that
for
a.g.e.s
then weeks go by
when you can actually
go back to the original setting
which is talking hearing
not signing

But that’s something about
recognising who we are too
we are hearing people

That’s what I mean
but you can actually relax to
you know
factory settings
not always-
Chapter Four

Factory settings? Not always having to Modify Everything You Do According to Language Awareness Everything Else

I think that I am coming to see that actually deaf and hearing mixed situations are difficult and we try have tried to make them work as best we can but with Maisie as an emerging adult now she takes on a responsibility now Not- she can’t do it all but she’s starting to take on responsibility for being the deaf person in a hearing family in a way that we were always trying to make it all right for her and I think I think that’s a change there

Oh yeah I think there is a change that she also has a part to play which is great! and it’s right and how it should be but that that she needs to do her bit as the deaf person in a hearing family the same as we really really tried to be the hearing the hearing people with a deaf person And it’s not easy

I think we do forget sometimes it’s OK to be hearing we can stop apologising or we should be able to stop apologising for it And that’s actually gonna be
the best way for the family
to continue to grow
    if we can do that as well

Image 19. Strong together
The indications are that the congenital deaf-mutes of the country are increasing at a greater rate than the population at large; and the deaf-mute children of deaf-mutes at a greater rate than the congenital deaf-mute population (Bell, 1883, cited in Mirzoeff, 1995: 70).

The enthusiasm for oral methods of educating deaf children was, as Branson and Miller (2002) point out, carried along on imperialist and evolutionism waves in 19th-century society. If deaf children could be taught to speak, and lip-read, then they could fit into normal society, and their souls would be saved. However, oralism was not able to solve the ‘problem’ of deafness altogether. Deaf babies were still being born, and illness still caused people to be deafened. The eugenics movement of the late 19th century, arising from the fear that “individual variation [in humankind] would accumulate into a composite national identity” (Davis, 1997: 18), turned its gaze on marriage between “congenital deaf-mutes” (Bell, 1883, cited in Mirzoeff, 1995: 225) and campaigned vigorously for the prevention of marriages between deaf persons (Stokes, 1917: 63).

Alexander Graham Bell’s research data was largely taken from the population on Martha’s Vineyard, which had a particular pattern of hereditary deafness at the time (see Groce, 1985). He concluded that the use of sign language among deaf people led to intermarriage and “propagation of their physical defect” (Bell, 1883, cited in Mirzoeff, 1995). Martha’s Vineyard also signalled to Bell the dangers of the creation of a Deaf Nation, of the Formation of a Deaf Variety of the Human Race. However, many of the statistical and genetic conclusions of people like Bell and Stokes (1917) were flawed. By Bell’s own admission, his predictions were worst-case scenarios (Mirzoeff, 1995); ignorant of Mendel’s concept of recessive genes, he was unable to comprehend why only one in four children was born deaf to families with patterns of hereditary deafness (Groce, 1985). He also appears to have overlooked, or chosen to ignore, the other fact that Martha’s Vineyard consisted of hearing and deaf sign-language users, and not an entirely deaf variety of
humankind. However, fears of deaf matings filtered through to educators, and deaf boys and girls began to be kept apart in the playground, lest they form strong social bonds that might lead to marriage, and to having deaf children (Branson & Miller, 2002).

The early 20th century saw a rapid growth in what became known as the eugenics movement. Mirzoeff (1995) reports in particular on the situation in the US, where by 1914, doctors were granted power to perform sterilisation procedures on anyone deemed ‘unfit’ to have children. Deaf people were on this list, along with ‘feeble-minded’, ‘epileptics’, ‘inebriates’, those who were ‘criminalistic’, ‘diseased’, ‘blind’ and ‘dependent’ (see Laughlin, 1922). In a very short time, eugenics had gone from trying to stop deaf people from signing (oralism), to trying to stop them having children (segregation and assimilation), to making absolutely sure they could not have children (non-essential, surgical violence). In just over a decade, eugenics reached its height in Germany with the introduction of Hitler’s 1933 Sterilisation Act,xxviii and 1934 Law for the Prevention of Offspring with Hereditary Diseases (Biesold, 2002), which legislated for the compulsory sterilisation of anyone with an hereditary disability (Kevles, 1985).

Hereditary disability once more included feeble-mindedness, epilepsy, severe physical deformity, alcoholism, blindness and deafness. The mid-1930s saw forced terminations of pregnancies, prohibition of ‘risky’ marriages, and mass murders of disabled people, in both hospitals and killing centres. The disabled, already “concentrated” in centres originally designed for education or service, were the first non-political group to be murdered wholesale by the Nazis (Friedlander, 1999). Concentration camps did not have to be built for them since existing institutions, such as schools for the deaf, were easily converted. From 1933-1945 in Nazi Germany, remedial deaf students were no longer offered special academic courses designed for their educational needs. Instead, they were selected and delivered for “mercy killing.”xxix By 1939, according to Kevles (1985), approximately 17 000 deaf people had been sterilised.xxx It is believed also that at least 1600 deaf people were killed in ‘euthanasia’ centres and in death camps during the Nazi era (Mirzoeff, 1995).

Technology, bureaucracy and management

Deaf education had become the agent of normalisation, guided by medical and technical advances in hearing impairment, and swept along by a new found “mania for testing” (Branson & Miller, 2002: 48). Testing covered both hearing loss and language ability. Language ability was
measured in terms of speech, or through speech performance: “People who were deaf did not stand a chance … In many cases, deaf children and adults were not actually identified as deaf but were assumed to lack spoken language because they were ‘idiots’” (Branson & Miller, 2002: 48). Misdiagnosis often resulted in deaf children being placed in homes for the ‘mentally defective’ (Hodgson, 1952). At the same time, deaf children’s hearing loss was also being measured. The first audiometers were developed to test hearing during the 1930s, and hearing-aid technology began to emerge. This kind of technical advance was the next great hope for oral education since it had failed thus far to produce well-educated, well-spoken students.

Subtle changes in the discourse of deaf education appeared. Children were now being referred to as hearing-impaired. In addition, their degree of hearing loss would result in further classification. Partially hearing (not deaf) children, by 1947, were moved from special schools to Partially Hearing Units (PHUs) within mainstream schools. Severely and profoundly deaf children who remained in special schools were often seen as capable of nothing more than a basic education. The continuing emphasis on technological remedies to impairment and efforts to produce fully integrated, speaking children meant that education standards slipped. This was not, however, identified until the 1970s in the UK, with the publication of Conrad’s (1979) damning report on the levels of language and cognition of deaf school leavers. In the first half of the 20th century, due to a severe lack of funds, deaf schools began closing down, and by the middle of the century, it was becoming hard to find places for deaf children to go to school. Education, now funded by the state, had become a major administrative and bureaucratic issue (Branson & Miller, 2002). As the 20th century progressed, more and more deaf children were placed in mainstream schools under the proviso of the 1981 Education Act. Mainstreaming, geared towards ideologies of choice and individual rights, saw increasing numbers of deaf children placed in large hearing classrooms (Lynas, 1986). At the same time, educational and medical discourses of deafness reinforced the idea of deafness as disability (Bauman, 2004); mainstreamed deaf children were expected to adjust to the hearing school environment while becoming objects of corrective audiological, pedagogical and otological intervention (Lane, 1992).
Cochlear implants

In the 1980s, a new device was developed, claimed as superior to the various hearing aids on the market, designed initially to provide a sensation of sound for people for whom hearing aids were not useful. The cochlear implant is a device that is fitted under general anaesthetic. It is designed to stimulate the auditory nerve by means of electrodes that bypass the ‘non-functioning’ or damaged parts of the inner ear and send out over a million electrical impulses per second (Chorost, 2005: 81). The implantee wears a processor, and this sends sounds to the transmitter, which is attached magnetically to the skull. The transmitter sends radio wave signals to a receiver, fitted beneath the skull and connected to the electrodes that are in turn fed to the auditory nerve (Zdenek, 2008).

By 1987, there were around 500 people fitted with the device (Slee, 1987). By 1988, that number had risen to more than 3,000 (Randal, 1988). Initially for use on adults, by 2006, there were more than 112,000 people worldwide with cochlear implants. In the US, the implant was cleared for use on children over the age of two years in 1990. The minimum age had dropped by 1998 to 18 months. Recommendations for implantation of children aged six or seven months now exist (Valencia, Rimell, Friedman, Oblender & Helmbrecht, 2008; Valente, 2011), and it is estimated that in many countries around 90-95% of all children born deaf now have cochlear implants. Because of the risks of trauma or destruction of the cochlear, and the potential loss of any residual hearing, implants were originally intended for profoundly deaf adults (and later children). As the technology advances, however, researchers are investigating ways to implant deaf adults and children with a range of hearing losses, using finer drills and a variety of electrode arrays (Berrettini, Forli & Passetti, 2008). Bilateral implantation, particularly in infants, is on the increase (Van Hoesel, 2011).

When parents opt for cochlear implants for their children—often presented as “an uncomplicated medical miracle cure” (Valente, 2011: 641)—they are increasingly told that they should place their children in mainstream settings for them to benefit more fully from the implant. For implanted children in signing/deaf school settings who have implants, the shortage of speech and language therapists necessary for post-implant rehabilitation is such that this provision is often not available to those children unless they re-locate to a mainstream school (Sutherland, personal communication, 2007). A review of parent-and-child perceptions of cochlear implantation, three years post-surgery, revealed that “implantation was seen to have had an effect on educational decisions and this was generally in the direction of mainstream provision and oral
education” (Archbold, Lutman, Gregory, O’Neill, & Nikolopoulos, 2002: 37). There can be little doubt that cochlear implantation is radically, rapidly and irreversibly altering the landscape of deaf education, and of deafkind.
CHAPTER FIVE

REFLECTIONS

I do not claim that my way of making sense has any more validity than ways in which the storytellers themselves make sense of their lives, but rather that what I bring to the exercise of sense-making will be different from what each of them brings (Etherington, 2008: 37).

This inquiry, situated at the intersections of various political, methodological, ethical, reflexive and theoretical paradigms, requires interpretation, response, reflection; not only as a way of bringing narrator-author voices together in a re-storying of the narratives contained in this book, but also as a way of inviting readers and audiences to come close, by offering ways of thinking with, and across (Frank, 1995; Etherington, 2008; Martin, 2011), stories of family life. In this chapter, I add my voice to those of Brigit, Bella, Georgina, Toni, Thomas, Dora, Luke, Harper and Maisie—becoming “an acting and feeling character” (Ellis, 2009: 78)—by reflecting on, and looking deeper into their stories, and showing how I, in collaboration with them, made sense of what they showed me.

Easier done than said

One makes oneself accountable by an engagement that selects, interprets, and orients. In a practical and performative manner, and by a decision that begins by getting caught up, like a responsibility, in the snares of an injunction that is already multiple, heterogeneous, contradictory, divided (Derrida, 1994: 93).

I am struck by Derrida’s reference to responsibility as I consider an interpretation of deafhearing family life as it has been shown to me over the years. Lather (2000) writes of mobilising thematics, of situating rather than categorising. Etherington (2008) describes her interpretive, meaning-making process as blending the voices of participants with her own personal and theoretical responses. Jones (2005a: 113) places her own narrative, and those of her participants, alongside feminist theories, to “tell and tell on” stories. I did not expect to feel so daunted. This is very real; I
tiptoed, lurked, crashed about and held back for so long. Yet, I am caught up in the responsibility, to myself and to the families, and to you, the reader.

I also acknowledge, however, that we have all been interpreting as we have gone along. We have embarked on a strange, poignant, funny, heartbreaking and joyful process of reflecting, disputing and illuminating, and have arrived together as the creators of the stories, and the stories of the stories, you now read. Dora remarked once, “It’s only when deaf comes into it that it all goes a bit wonky.” Brigit suggested, “Why don’t you interpret my children’s stories as a hero’s journey?” Bella’s philosophy on her family echoes a wider, Wittgensteinian evaluation of resemblances. Thomas’s self-recognition, “like light reflecting off plants”, resonates with postmodern theories of multiple, contingent and shifting identities. We have shared these observations and interpretations with each other along the way. So I embrace, albeit tentatively, Derrida’s accountability, to select, reflect, respond and orientate.

However, this fixing on the page does not sit well with me. Ellis (2009: 107) reminds me that “meaning is not permanent”. I have, therefore, crafted a personal response based on interpretations from all of us—the families and me—which does not offer generalisations, or explanations, but which, like Lather (2000: 307), devises a “hopefully resonant spectacle” through which the reader or audience is drawn into the temporal, contingent sense-making process.

The risk in such an offering is that the unknown—or unknowable—reader demands or requires a sociological backstory. Richardson (1997; see also 2004) draws our attention to her concerns about Louisa May’s poetic narrative and its omission of certain biographical detail or subtext that the reader usually expects. There is, of course, no simple answer. Each of my narrators has crafted their story with an audience (whoever that may be) in mind. I choose to respect their narrative strategies, their biographies, the gaps, the silences, the juxtapositions, the framings, the structures. I offer my supportive voice: having eased the families into the limelight (Chase, 2005) as authors (rather than subjects), I now offer my reflections.

Storying stories

I was drawn to the idea of reflections, rather than interpretations, or analyses, for what follows. Analysis conjures up images of isolating small chunks of talk or unusual terms (Willis, 2000: ix), of chopping or reducing data into segments (Riessman, 1993) that neatly fit, or fluidly convert into
themes (Salmon, 2006); of simplified homogeneity (Mauthner & Doucet, 1998), of categorisation (Chase, 2005), of displacement, of a reductive, seeking-out of neat and tidy answers (Frank, 1995) within a mental space of “bodiless rationality” (Calvino, 1996: 74). The contextual, situated and performative nature of the stories risks being obscured or lost altogether. McCormack (2004) refers to a process of storying stories, where understanding and experience are viewed in light of, and in juxtaposition to, the cultural, linguistic and social resources and discourses that narrators draw on in order to construct a sense-making narrative. Storying stories, therefore, reveals the life in progress and emphasises the researcher’s personal, intellectual and emotional responses as “sources of knowledge” (McCormack, 2004: 221-222). Storying stories, as a reflexive act, makes visible the researcher’s position and interactive voice within the inquiry (Tierney, 2002).

There is always and forever the risk not only of making the ‘wrong’ interpretation (see Borland, 1998), but also in reductive misappropriation of participants’ voices, or violation of ‘sacred’ or untouchable stories. The temptation, therefore, is to let narratives stand on their own, to tell their own story (c.f. Ellis, 2009). While I feel protective, proud and moved by the family narratives, the political, ethical and passionate impulse, I realise, is to share my reflections, not only with you, the reader, but also with the families—a new-found, tentative, negotiated sense of understanding, as opposed to an academically authoritative and analytical statement of truth. My responsibility, I decided one day as I took a very long walk, was to create a personal, positioned response, based on my own journey with the families. It was not to present a single, definitive, expert interpretation, but to offer an orientation, or a new layer of meaning.

Personal journal: I visited Brigit—it was just over two years since we had started filming conversations, and I was excited to show her my attempts at rendering her story into a poetic text. I was also quite nervous, but I think she was too. It was a beautiful sunny day, and, with the windows open, and the curtains gently swaying in the warm, spring breeze, Brigit sat quietly, with a cup of tea, and read the entire piece. I, too, sat quietly, trying not to pay too much attention for fear of making her feel awkward. At one stage, she looked up from her story, smiled and said, “It’s gonna take me ages to read all this.” I started playing over possible reactions in my head. What if she doesn’t like it, is disappointed? What if she hates it? Wants to pull out? Change it altogether? Once or twice, she stopped and said, “That bit doesn’t make sense.” When she finished, she closed the pages and put it to one side, got up and silently went to make more tea.

When she came back, she began flicking through to see what her daughter had said. “Ha, you’re a penguin!” and, “It’s funny, because that’s
not exactly true, that’s not exactly what happened.” And, “This is actually very poignant, to see how she remembers things, and what she has chosen to tell you.”

We then talked again about the idea of fixing stories in print. Brigit thought she seemed younger in the texts. How things have changed. Fixing stories—sometimes you become the story, in the telling, but other times, you tell it, then move on, it’s out there, it’s been said … left behind. In the end, she said, it’s fine. It’s fine. We wondered whether anyone would read it. We talked about the stories becoming a book, an exhibition. Did she want to be involved in any more conversations about how I would write about her story? No. “This is my consent. It’s fine.”

A balance needs to be struck. As Richardson (1997) explains, our participant-narrators rarely articulate or frame their stories with reference to larger discursive or philosophical structures, paradigms or features. That is the ‘job’ of academia. There is a tangible conflict, particularly when an inquiry lies—however uncomfortably—at an intersection of feminist, Deafhood, postmodern theories and methodologies, where voices in the margins are amplified, demanding to be heard, and the role of academic ‘expert’ is necessarily destabilised (Haraway, 1988; Harding, 1991). I do not want to claim, or adopt, a position of knowing, above, or remote from, my family narrators. Engaging in this inquiry with them, listening and watching, writing back, checking, sharing and caring, has allowed me to make sense from their stories. I have also been able to make more sense of my own. Our positions, Hoskins and Stoltz (2005: 106) believe, can be understood as compatible perspectives. This then permits acceptance of the researcher’s explicit-knower position as contributing more transparently to a process of sense-making that can be extended to the audience.

The power of the interpretive story lies in its ability to draw threads together from stories told through time and to blend and shape a readerly text. I have chosen to preserve much of the chronological/sequential structure of the family stories, in order to minimise my interference, and to retain and reveal the moving back and forth of the storytelling act. My distilling is in the final selection of the texts, in the placing of words on the page and in the choice of titles.

I do not wish to reiterate everything that has already been said—so passionately, so poetically, so personally—by the families themselves. Nor do I wish simply to provide a summary. Instead I follow Ellis’s (2009) suggestion to pay attention to my emerging, continuous introspection, reflection and understanding, and to offer ‘re-visions’ of the story of the stories. I sense what Ellis (ibid: 13, 232) describes as the “distant” and the
“near” past, as well as “selves in motion.” Revisioning of personal, interpretive reflections therefore casts an eye over these pasts, and my place within them, and attempts to create more of a dynamic text-in-motion—re-examined, re-visioned—that “marks and holds scenes in place, at least for this moment” (Ellis, *ibid*: 13). I re-read my notebooks and take new notes. I revisit the literature on deafness, deaf history and theory, on family experiences of deaf life, and I note resonances, contradictions and gaps. I find myself scribbling in the margins, highlighting and commenting on metaphor, contradiction, rhetoric, on discursive and narrative strategy, on common threads that run through and across families, on the upsetting, the funny, the angry, the obscure, the poignant, the beautiful. I doodle, draw and photograph as images are conjured from the words on the page. I observe the long story, the short story; the stories with a beginning, a middle and an end, and the stories without; the fragmented, static and circular, the performative, the arbitrary, the poetic, the mundane. Through this process, understanding, perspectives, memories and emotions are once more brought to the surface.

**Travelling with the map**

As I look back, my understanding, experiences, perspectives and responses have shifted, grown and altered to the extent that I could easily get lost. While this is sorely tempting, I have decided, therefore, to use my map, to revisit the stations along several of the lines, and to keep a travelogue as I go.

*Image 20. Travelling with the map*
The Deaf History line

The Deaf History line of the *intertexts* runs deepest underground; a thread that weaves through the entire book, and through the lives of all the families, in various ways. Through our conversations, I have learned to see this line as a history of fundamental—however well-meaning—misunderstanding of, and harm towards, deaf people, deaf children, sign language, communication and deafhearing family life. The single, master-narrative, chronological, unidirectional trajectory is apt; it shows the past and the present, time passing, current events, and indicates the future (albeit, obviously, under construction). Yet there is a detectable, tangible sense of circularity, or stuck-ness. Similar to Brockmeier’s (2000) concept of circular time, there is repetition, or return. Perhaps the Deaf History line is *not* progressive, but faltering; the traveller could alight at any station and see the same walls, the same people, the same platforms. Deaf children today are *not* subjected to painful, unregulated, potentially lethal experiments, deaf women are no longer persecuted as witches and deaf people are *not* murdered in killing centres. British Sign Language has been officially recognised by the UK government. xxxv And yet, the *foundations* of the line appear always to made from similar materials, by the same kinds of people.

As Brigit remembered, the offer to screen her when she was very obviously pregnant with Thorin, was based on a grand assumption that she would not want to bring another deaf child into the world. Within her social circle, the attitude is very much that having two deaf children must be just bad luck. When Maisie was younger, Dora and Luke regularly encountered people who asked who ‘looked after’ her, and Harper, Toni and Brigit each talked about the ‘Shame Brigade’. Thomas told me about the numerous times he has overheard derogatory remarks about his mother and other deaf members of his family. His own dyslexia and dyspraxia were largely overlooked, because he had deaf parents (c.f. Preston, 1994). Georgina also talked at length about how deaf children in deaf families each encounter, at some stage, ‘The Hearing World’ and its prejudices, superiorities, exclusionary attitudes and practices.

The arrival of a deaf child in the family marks a significant interruption. The arrival of a child is surely a turning point in anyone’s life, but when that child is diagnosed as deaf, life takes a different turn. As Georgina explained, home life became a series of interruptions, of instructions, of services, of scoldings, when all she wanted to do was have time with her babies. Brigit was told how she must be feeling by a visiting teacher. Regardless of whether parents are hearing or deaf, parenthood becomes something of a battle, over hearing aids, over communication,
over access, over money, over education. These interruptions, as well as encroaching on family time, are also manifested as interference on young deaf bodies and minds, whether that is by upsetting the parent-child-family bond, disrupting language development, or broaching the subject of cochlear-implant surgery. Brigit’s battle, she recalls, began at Bella’s birth, and has continued ever since. She signs with her deaf children, she has refused cochlear implants (“still experimental”), as have Georgina, Dora and Luke. Yet rather than being offered other choices for her children, Brigit has effectively become more isolated as the alternatives she seeks are rarely available or accessible.

Further along the line, Dora and Luke’s story begins once more. Government legislation concerning the amendments to the 1990 Human Fertilisation and Embryology Act threw deaf people into the public spotlight. The story that hit the headlines served to reinforce the misjudged, disempowered, voiceless position of deaf people, and their families, within mainstream-society discourse. I wrote above that deaf children are no longer experimented on, although there are very strong claims in the literature that implantation on children is experimental, unethical, dangerous, disabling, sometimes fatal, (see Komesaroff, 2007; Valente, 2011) and that deaf people are no longer murdered in killing centres, although the wording of the HFEA amendment recommends—if hypothetically—discarding deaf embryos and refusing deaf egg/sperm donors and therefore raises very sensitive issues concerning the right to life. From the stories here of family life, it is clear: being deaf is not a life-threatening condition. This book, if nothing else, re-presents voices from deafhearing families who object, from their very hearts, to the idea that a British government could even consider sending out a message that their deaf children should never have been born.

The Deafinitions line

On, then, to the Deafinitions line: a philosophical, reflexive and cyclical journey. It is largely informed by my own ongoing struggles with the spaces in between language, representation, identity, postmodernism and narrative. It is complicated by the relationships between visual, spoken and textual language, by the politics of translation, and by the tensions between concepts of Deafhood, Deaf Theory, postcolonial writing, feminist becomings, and by the complexities of deafhearing research. Here, I reflect on how the families’ narratives reveal their own philosophies, meanings and ‘Deafinitions’.
Viewed through a postmodernist lens, deafhearing family narratives reveal multiple, shifting and contingent meanings and understandings of self, of family, of community, of the world. Each narrator uses the sign DEAF or the word “deaf,” yet these terms are embedded in multiple contexts, histories and politics. When Georgina told me, in our first recorded conversation:

My family <WHAT IS IT> deaf

she was not simply telling me that the members of her family are deaf: within that one sign lay many meanings, life-histories, struggles, evenings at deaf club, friendships and celebrations. When Thomas lost the hearing in one ear, he talked about becoming deaf. He used the same sign DEAF as his mother when she described her family tree. Born into a deaf family, he was already ‘deaf-inside’ while being ‘hearing-world’, and now he was telling me about ‘becoming deaf’.xxxvi For Toni, deaf is togetherness, roots, family, hugs, filling up her signing tank, but also living, working and singing in the hearing world.

Bella’s meanings of deaf range from the practical to the spiritual. Largely, deaf equates with sign, but she and her brother are the only two deaf people in her extended family, who all, to greater or lesser degrees, also sign. She has some hearing signing friends. She signs with me, with her neighbours. Most recently, she told me that the hearing children in the school she was soon moving to are also learning to sign. However, deaf signers do have the advantage; they are more visual, theirs is a visual-spatial-tactile existence, they notice things. Bella believes she just happened to be born deaf. It may be down to genetics, but there are no other deaf in her family apart from Christian, so there is no concrete, biological reason. It is just the way her life is meant to be, who she is. When Maisie and Harper were younger, deaf also meant sign. Maisie’s gift to her family was to bring home new signs. Now, Maisie and Harper rarely refer to each other as deaf or hearing. They are sisters, “that’s it”.

Within deafhearing, signing families, the binary is blurred or contested. Thorin, as Brigit explained, moves in both worlds. He even creates new spaces where he signs privately to his hearing mother on the way to school. Harper is hearing, yet “rolls up her sleeves” as she moves into deaf spaces. Thomas, raised in a deaf family as a hearing boy with sign as his first language, firmly resists the binary. Analogies such as swimming in the river between two lands, or descriptions such as ‘half and half’ or ‘50/50’ are questioned. He is Thomas. Like looking at the way light reflects off plants, different every day, from infinite viewpoints, things
change, alter, can be seen in different ways, with different colours—“plants aren’t just green”. He embodies the intersection of deaf and hearing worlds, but this intersection is “fluid, dynamic and changeable” (Preston, 2008: xi).

Bella and Christian are deaf, but that is not their single identity. They have many threads, which are constantly being woven, pulled tighter, picked at, braided together. Maisie and Harper examined the deafhearing ideological binary in terms of their relationship and their family. Maisie reflected that it is other people who need to demarcate their difference in terms of deaf and hearing, and that determines which world they ‘belong’ to. When they are together, as sisters, they have their world: “deaf hearing doesn’t matter.” Each family represents a binary crisis, in that, within deafhearing family life, a single, fixed, either/or essence is challenged and destabilised.

However, deaf also has other meanings, other impulses. Deaf has minority, cultural, linguistic, sensory status, and deaf identities are performed in specific ways. Deaf and hearing people sign together, yet only deaf people can be deaf. The audiological condition is acknowledged, not only in terms of its impact on the deaf body through intervention and categorisation, but also in terms of claiming a political identity. Despite postmodernist theories of identities, or categories of belonging (Collins, 1998), signing deaf people also claim a strategically (or otherwise) essentialised deaf identity. Whether that is Bella self-identifying in the face of ignorance or bullying from hearing children, and her desire to go to deaf club every week to be with other deaf people, whether it is Toni’s acknowledgement that, despite spending much of her time in the hearing world, she cannot survive without her deaf family, her deaf community, her deaf language, or whether it is Georgina’s ascribed position as voiceless deaf mother in the peripatetic education system, there is a unifying, imagined community that renders deaf lives intelligible, regardless of age, generation, family. Marginalisation, muting and misunderstanding of signing people is a thread that not only links Georgina to Maisie, and Toni to Bella, but also links them to deaf people around the world, and through history.

**Bella’s Venn Diagram**

Before
My family hearing
In hearing world

Then
When I was born
Chapter Five

Deafworld come over to hearing world
Then Christian born too
deaf

Before
|deaf world|
|hearing world|

separate

Now
{cometogether}

Image 21. Bella’s Venn diagram

Deafhearing, bilingual families articulate mutual dimensions of intersectionality (Slack, 1996; Collins, 1998). Although this concept originated from Black Women’s studies and concerned social hierarchies such as class, race and gender collectively within the family (Collins, 1998; 2000), intersectionality here illuminates the multiple, historical, medical, political and ideological systems of marginalisation and discrimination visited upon deafhearing families. However, intersectionality also chimes visually with Bella’s Venn diagram (image 21). As she sat with her mother one day, drawing deaf circles, hearing circles, as she explained to me how her hearing family now intersected with deaf people, so we can see deafhearing families at the intersection of culture, history, audiology, family. The concept of ‘becoming’ is viewed in a new light; a continuous, rhizomatic life-journey. As Thomas said, “You don’t know your fate, you don’t know where life will lead you, you just take a path and see where it leads.” Doors open, paths spiral, identities grow, morph, fade and intertwine.

In line with Butler’s (1990) theory of performativity, the deafhearing binary is deconstructed and becomes unreal, irrelevant, impractical or
unrecognisable. Ladd’s (2003: 422) call to hold off poststructural (‘hearing’) explorations of interstitial zones of identities until the Deafhood Grand Narrative has acquired sufficient weight, sits uncomfortably at times with the negotiated, contingent and shifting expressions of deaf meaning explored in the family narratives. While there is clearly acknowledgement, acceptance and celebration of deaf identity and sign language, together with the recognition of a larger history of oppression of deaf communities in which deafhearing family life is often absorbed, subsumed even, the stories the families choose to tell also reveal desires to enlarge the 21st-century, social-constructionist lens through which deaf (and signing-hearing) people are viewed. In that way, their acts of resistance can be understood not simply in terms of what Davis (2008) presents as (inherently problematic) ‘offset’, or counter-models of deaf life, but more as flexible, non-hierarchical, post-identity orientations (Davis, 2008: 324; c.f. Wrigley, 1996).

The Resistance line

The Resistance line on the map takes us through a landscape of resistance to, among many things, misinformation, control, ignorance, science, discrimination, ascription, instruction and assumption. It runs through defiance, resilience, honesty, protest, patience, care, frustration and love, and it reminds me of my wish to find ways of constructing free spaces for the three families to contemplate and challenge dominant discourses, to re-visit and re-tell or perform their own versions of their lives. The resistance line is circular, and intersects every other line on the map.

The family narratives are, at their heart, resistance narratives, or counter-narratives (Andrews, 2002; 2004). Resistance is found not only within the stories themselves—within the telling—but also in the writing and the re-presentation. Resistance is present in the ways we made decisions, throughout, about the conversations we had, and how I, as a hearing researcher, worked with the narratives and the textual strategies I employed.

Lines of resistance lie alongside—across as well as in opposition to—other dominant lines or stories. Whereas it might be easy to understand counter-narrative as simply opposing a single, hegemonic script or discourse, the family narratives reveal shifting tensions. As Bamberg and Andrews (2004) explain, the question of what is dominant and what is resistant is not fixed, established and unchanging. Relationships between grand- and counter-narratives forever shift. While deafhearing family
narratives appear to resist what may be perceived as the single, dominant, medical grand-narrative of deafness, within, beneath, and between the stories exists a whole range of big and small, liminal resistances-in-motion. Hearing family members, in particular, while ‘grand-countering’ the medical-disabling script of deafness, also navigate the tricky path of allegiance with the deaf world (c.f. Preston, 1995) with wisdom, defiance and resignation, as well as with determination and joy. Deaf family members also embody the tensions of the ‘both worlds’ phenomenon by facing up to the reality, for example, of having no deaf peers, by running away from the town in which they were born and raised, and growing up in a culture full of its own tensions, contradictions, prejudices and shame brigades.

However, it is largely the resistance to medical, genetic, disablist discourses of an inconceivable life, that are at the heart of the family narratives—performative stories that re-script the visits of peripatetic teachers, the rules of oral grammar schools, or first-year undergraduates who can ignore a person living in the same house as them for weeks. Georgina recalls being told how to raise her deaf children; the moment when she was told after his first hearing test that Thomas was “fine” and she automatically thought that meant he was deaf. Brigit felt insulted by genetics advisors and by social peers who cannot see having two deaf children as anything other than undesirable or unlucky. Toni’s story of losing all her residual hearing, and Georgina’s angry retelling, reveals the way in which the school was unable to teach Toni once she became totally deaf—a school for deaf children that she had to leave, because she was too deaf.

Resistance narratives are angry, painful, full of frustration, tears, silences. Luke’s venting over the government’s HFEA amendments perhaps appears in text as measured, calm, objective, pragmatic. Yet, in the telling, in the underlying messages and the analysis, lies a deep hurt. As he sat next to Dora, whose reactions were visibly, audibly and linguistically charged with sadness and anger, Luke offered words and silences loaded with almost tangible rage and pain. Similarly, as Maisie and Harper, closer to home, talked again about their grandparents, we almost had to end the conversation, such was the intensity of feeling surrounding the different relationships the sisters have with their grandparents.

Resistance is, however, also manifest through humour, through witty observation, through mockery and through the sharing, remembering and re-performing of funny stories. Georgina, a skilled narrator, would tell serious stories in funny ways, through the use of particular signs, or facial
expressions. I am, as ever, frustrated at my inability to convey this in text. *Teaching or Fishing* is a perfect example of resistance through humour. The story itself is entirely located in history, and painful irony; deaf people were not allowed to teach deaf children *because* they were deaf (c.f. Ladd, 1991). Georgina took me back to her last year of school and showed me how she tried to challenge her teachers. She became 15-year-old Georgina in the telling—her body language, her facial expression, her childlike protestations—but there was an underlying stubborn, if sad, humour to her remembering.

Families tell resistance stories not only to speak out for the first time. They also construct their resistance narratives consciously to recall and retell acts of resistance. Once, when Georgina and Toni were given an appointment to see a genetics counsellor, rather than decline they decided it would be interesting to find out more about the family’s genes. Right at the end of their consultation, having gone along with plotting the family’s genetic heritage, Georgina remarked that this information would be useful for Toni when choosing a partner who would be likely to give her a deaf child (“… and the doctor’s face!”)

I also learnt, however, to see how telling stories itself is *resisted*. Thomas was keen to be involved in this work, yet struggled to find ways to tell his story. He wrote, “I don’t have any memories” and “I don’t want to tell that story”. As I think about Thomas, and my relationship with him, I find myself looking back over the years of working with him with deep respect and affection. His story, and the story of his story, is in many ways, the most profound, moving and difficult of all. Despite its randomness, poetry and chaos, I hope that readers can look into the gaps, the stilted minimalism of his narrative, and make their own sense of a strange, fragile and defiant life. I know if I were to read these sentences out to Thomas, he would smile, shrug his shoulders and say, “True enough.”

Communication lies at the heart of family life. For Dora and Luke, and for Brigit, the decision to bring sign language into their homes and their lives is about communication and bonding. Brigit told me that she had been told by the teacher of the deaf *not* to sign with Bella. Georgina’s family was already a signing family when Thomas was born. Her decision also to sign with her hearing baby illustrates the absolute desire and necessity for language, bonding and togetherness within the home: this in the face of years of interruptions, again from teachers of the deaf, who pressured her to make sure her very young deaf children wore their hearing aids at all times. Brigit was immediately, emotionally, physically and politically drawn towards sign language. *How could it be any other*
way? She had studied muted groups as a student, yet deaf people were absent from this category of groups without a voice. Dora knew early on that, in order for her family to stay together, they would have to become a signing family (“or there’ll be a crack in the family”). Thomas proudly told me that sign was his first language, with English second. Thorin, Brigit explained, is ‘bilingual boy’ as well as ‘deaf sandwich boy’. He signs, speaks, sings. Bella proudly listed the members of her family who sign (even if some of it is minimal, or ‘home’ signs). As Maisie said, it is not always a smooth ride, but if only other deafhearing families could be bilingual the same as her family, then there would be more hope for future generations of deaf children.

One of Brigit’s arguments against radical audiological intervention with deaf infants (aside from the risk of interfering with, or damaging the bond between parent and baby) is that sign language, like any other language, stimulates the language pathways and exploits the plasticity of the brain. In the same way that Georgina signed with all her children, so too did Brigit, Dora and Luke. Georgina, as a deaf mother, was able to raise her children in her own language, to socialise them, to explain that the world is hearing, to maintain and nurture that connection, through sign, through generations. This was passed on to her from her deaf mother and father, and from her mother’s deaf parents, down through the deaf generations. Dora, Luke, and Brigit, with first-generation deaf children, have seen the world in new ways and doors open to different dimensions because they have chosen to sign with their children. As Bella explained, sign is like French, “abroad language,” not a poor substitute for English, or a stop-gap. Desloges (1779: 45-46) wrote 230 years ago, “I cannot understand how a language like sign language … is still so neglected and that only the deaf speak it” (my emphasis).

It is not, Brigit believes, being deaf or using sign language that disables deaf children and deaf communities. It is the system in which they are automatically placed that disables them, or conspires with the idea of them as disabled. Georgina firmly believes that Thomas’s educational needs were overlooked because he was ‘Hearing-Mother-Father-Deaf’ (c.f. Bishop, 2008: xix) and that only private assessment, and then serious illness brought Thomas the long-overdue care and attention he needed. Brigit told me once that she had enquired at Bella’s school about provision for her as highly intelligent, gifted even, only to be told that, according to the Department for Children, Schools and Families (now the Department for Education), you can not be gifted and deaf. Bella sees how her hearing brother gets on and learns at school and wishes she had a dial on her chest so she could go to hearing, learning places, and fill her head up, then
switch back to being deaf again. She unwittingly echoes the post-Milan shift in the goals of deaf education (see Intertext III). Even though she attends a deaf, signing school, her curriculum is limited, narrow—"writingwritingwriting." It is hearing people, she often finds, who need interpreters, not her. As Brigit explains, her children, who have apparently got "communication problems", take far more steps towards hearing, non-signing people in order to communicate, only to be ignored. At the same time, Bella is proud that her mum signs, that she enjoys reading-through-signing as it helps to understand the story better; that in noisy places, it is easier to order drinks in sign. She also thinks that deaf people are more peaceful, and if I wanted to, I could turn the stereo up really loud so that I could also be deaf like her (at this point she grins widely and gives a big thumbs up). Yet, growing up in a deafhearing family, she concedes that, even with abroad language, deaf people are more like fish, and signing hearing people are like penguins. Despite this, she feels she was born at the right time, and—who knows—we may all get into space together one day.

As Andrews (2004: 5) writes, family counter-narratives "challenge the constraints of the dominant stories which surround them." Largely, these dominant stories concern the birth and the raising of deaf children (usually by hearing parents). The three families tell stories and employ narrative strategies as acts of "defiance and resistance" (Andrews, 2004: 5) to hegemonic discourses of deafness, from railing against and mistrust of early 'medicalisation' following diagnosis of deafness and refusing to wear/fit hearing aids, to disruption or decentring of the disabled/normal binary (c.f. Gregory, 2004) and to absolute, fierce rejection of biotechnology and invasive, harmful practice on deaf bodies. Yet it is important to remember that each family, and each person in that family, constructs and articulates their own meanings, and offers their own resistances and resiliences, based on cultural, societal, personal, temporal and familial knowledge. The waters, as Luke put it, are constantly muddied; counter-narratives are not simply oppositional, but contingent, destabilising, fragile and varied. Individual narratives further disrupt, blur, overturn, even shock. The deafhearing, signing family is not an homogeneous, predictable, uni-oppositional force. Responses to the HFEA amendments are a case in point (see West, 2011).

For Dora, the HFEA became a mechanism for turning life on its head, to the extent that her response could barely be voiced until some kind of temporal and emotional distance was both achieved and held onto. Within the space of our conversation that day, the temporality of her motherhood, of future, present and past life, and of decisions and wisdom, imploded as
we attempted to make sense of the impact (hypothetical or otherwise) of the government’s proposals. Seated next to her, Luke searched for, and clung to rationality, in the face of attack. Maisie and Harper’s reactions were full of silences, of tip-toeing around what would remain unsaid, until they were able to find a way into a space of measured, controlled argument (that is, telling the Government to keep out, seeing history repeat itself, analysing the insidiousness of Science).

Brigit was clear: “It’s not about deaf. It’s all part of us trying to be creators. Interfering. It’s eugenics, of course it is. But who wouldn’t prefer to have a hearing child? Most couples wouldn’t say, I wanted to have a deaf child.” Toni and Georgina, whose culture, sensory being-in-the-world, language and family was under attack, offered another perspective, through a lens of cultural heritage. Toni would simply have to find another way: this is not about ‘designing’ a deaf baby, this is about being forced to take another route to arrive at the same place. Georgina, outraged by the immorality of the proposals, pointed out that, if choice is being brought into the equation, then choice is about being able to choose, and not about being given one choice (“You can’t offer choice, then take one away”).

Family stories invite the reader in. They also disturb, disquiet, shock. Brigit would love one of her friends to have a deaf child, and immediately feels bad. Maisie and Toni both liken parliamentary and health officials to Nazi eugenicists; Georgina’s mother cried when Thomas was diagnosed hearing. Intentionally shared, with an audience in mind, family resistance stories not only counter grand, familiar narratives, but also kaleidoscope through small stories, asides, insights and explanations. Sometimes they jar, and at other times, they almost slip by unnoticed. Yet certain phrases, vignettes, memories and metaphors stay with me more than others. Georgina brings Thomas into her story—she looks away from me, her gaze lowered slightly as she replays, relives, a conversation with her youngest son: “You are hearing world. Will give you back to hearing world.” There is something intensely moving, not only in what Georgina signs, but also how she signs it, and the meanings it holds. She becomes deaf mother of young hearing child, and talks to him once more, recreating that space, reliving the emotion. Preston (1995: 1461) reveals this moment as a common experience for CODAs (Children of Deaf Adults): “The time is coming. Soon you must go. That’s your world out there. The Hearing world. You belong there.” We know so little about deaf parents’ experiences, whether of deaf or hearing children (Najarian, 2006; Hoffmeister, 2008). Perhaps, for now, we should just sit with the image of a mother preparing to let her child go out into the world, to give them back to the place where they belong.
I am suddenly struck by the ways in which hegemonic, medical discourses almost force the hand of the families in the way that they speak/sign, reverting strategically to the binary when needed. Their narratives move, consciously or otherwise, in and out of various spaces, and perhaps it is when they enter Ladd’s (2003; 2008) spaces of colonisation that the discourse shifts, that specific oppositional terms are necessarily employed.

**Deafhood and Deaf Theory**

Within the landscapes of Deafhood and Deaf Theory, then, it is possible to see the ways in which deafhearing, signing/bilingual families tell resistance stories and construct political, oppositional, strategic and philosophical counter-narratives. Deafhood is constructed as critical praxis, aligning itself with postcolonial theory, and moving towards the authoring of a deaf epistemology and an ontological justification for the rights to a deaf existence (see Ladd, 2008). The family narratives open up intimate spaces for the consideration of grander Deafhood claims, in the ways that deaf lives are lived, unconditionally valued, embraced and celebrated. Stories lightly touch on the colonialism narrative by opening windows on to educational, medical and scientific thought and control (c.f. Lane, 1992; Wrigley, 1996; Ladd, 2003). The desire to tell stories of family life finds a small place within the Deafhood counter-hegemonic impulse.

In a similar way, it is possible to read, and think with, family stories through a Deaf Theory lens. Individual narratives reveal alternative, spiritual, sensory ontologies. Bella’s perceptions—as a tactile, visual, signing being—of the world and of her family, relate directly to the Deaf Theory imperative to confront audist (Humphries, 1975; Bauman, 2004) discourses of non-communicating, non-hearing, broken bodies, and to consider deaf-being in terms of phenomenology rather than audiology. She explains how sign, while simply convenient in many circumstances, also engenders ‘better’ ways to learn, to read, to understand, to know, through visual-spatial, kinaesthetic expression, processing and communication. Her hearing mother reads to her through sign. Together they learn stories through their eyes and their bodies. Brigit carried Bella on her back for months after she was born. Bella was able to take in the world through her eyes, her own body and the body of her mother. Brigit did not know at that time that her daughter was deaf. Looking back, however, she is grateful for that time, before the battles began. She believes Bella’s soul chose to be deaf, to set her mother on a particular path.
Toni negotiates the world as an eighth-generation deaf woman, who has left the family nest to embark on her own journey. Yet, as her mother observed, she always comes back. There is a powerful craving for sign; it is vital for Toni’s well-being. Once more, written English is incapable of recreating the way Toni told me, smiling, with tears in her eyes, of her absolute need for sign, and for prolonged, physical contact with other deaf people.

**Postdeafness?**

However, these deafhearing family narratives also demand a new, alternative forum, where hearing and deaf voices are listened to, within a postmodern, 21st-century space, perhaps unconstrained by constructions of Deafhood and Deaf Theory. Within academic inquiry, family stories of everyday life are at risk of being subsumed or obscured by complex, alien, distant, unrecognisable and irrelevant concepts. I feel a responsibility to draw attention to deafhearing voices within these academic domains, yet a greater one to care for them and to see that they do not get lost.

I revisit the work of Davis (2008) and his critique of attempts to formulate political, non-medical, identity-based, linguistic models of deafness in order to counter the scientific hegemony that has done so much damage to deaf people over the last 200 years or so. Davis (ibid: 323) claims that we should discard the “firewalled” categories that serve only to perpetuate damaging, self-fulfilling binaries, and look instead at the category of *one generation*: groups of people who—already “defined in advance by an oppressor”—resist genetic, bodily categorisation, unify for new purposes, and rise like a postmodern phoenix from the ashes of identity politics. The idea of *one generation* allows fluidity, contradiction, heritage, languages, genetics and audiology to unite (deaf, hearing, 50/50, bilinguals, sandwiches, plants, fish, penguins, signers and singers) against assault from science, medicine, genetics and government. This ‘postdeafness’ concept acknowledges individual and collective heritage, but also recognises the impetus of the current generation, the deafhearing family, as having individual and collective, shifting, temporal, performative, yet united voices; written, spoken, signed. Brigit wants her family to inhabit one world. Harper and Maisie, with their parents, are a family unit; they are sisters, *that’s it*. As Napier (2008) writes on her HMFD identity, common metaphors and clichéd terms for deafhearing family life (loss, silence, outsider) are outdated. She claims her *ipseity*; her unique, personal and individual selfhood in relation to languages, cultures and experiences. These experiences just happen to be grounded in, and have sprung from,
her birth as a hearing child to deaf parents. I therefore suggest that this resistant expression of ipseity/selfhood be extended to all deafhearing families; but in particular here to Harper and Thorin as hearing siblings of deaf sisters and brothers (HSBD), to Georgina as deaf mother of hearing child (DMHC), to Maisie and Bella as deaf children with hearing parents (DMFH).

One generation perhaps best captures the storytellers here. They span several generations in a genealogical sense, yet, as a moment in time, as contemporary groups, they hold hands in resistance to the Deaf History line of oppression, harm, ignorance and fear and to scientific blindness to the diversity of humankind. One generation, as politically, physically, spiritually motivated, and driven not by academic Grand Narratives or models of ethnicity, culture or disability but by love, care and commitment, stands, or lies, alongside many other ways of paying attention to still muted voices—deaf hearing doesn’t matter.

What We Really Want to Say

Having lived with these stories for several years, and having travelled the lines and landscapes of this inquiry over and over, I am almost at the end of the line; or rather, back to the beginning again. I return once more to a close reading of the narratives as they have been crafted for the purposes of this book. Meanings, histories, interpretations, everyday relationships and negotiations, theory, praxis, ownership, sense, knowledge, recognition, transgression, resilience, stoicism, resistance: words and signs leap from the page like fireworks, illuminating, surprising, exciting, colourful, beautiful, brief. I pay attention once more to the words on paper, tune in to the voices, and replay the signs like films projected inside my head. These are not just resistance stories, recollections of events, but complex, profound navigation stories, laced with, or held together, by metaphor and poetics. Metaphors embrace ways to capture otherwise inexpressible complexity (Allison, Beggan & Midgley, 1996). Like glassblowing, metaphor breathes into stories, freeing (St Pierre, 1997) and expanding the meaning of “irreducible feelings and intuitions” (Etherington, 2006: 242) in new directions (Radman, 1997), bringing ideas, events or concepts together through particular words or signs, making links, seeking coexistence (Morgan, 1997; Luborsky, 1998).

I think with Brigit as she navigates the wasteland, and follow her into the clearing in the woods. Light shines through open doors, as her family-journey follows an elevating spiral path. I feel the discomfort, or disorientation, in the middle of the deaf sandwich, the bodily tension of a
sign-monster, the loud slam of a door, the release of the fluidity of movement between deaf and hearing worlds. Water: there is something about the cool, beautiful, weightlessness of swimming (c.f. Bourdieu, 1989), the calmness of being in water as well as the chaotic disturbance of the tsunami until the waters recede and the earth settles once more, that help us to make sense, to think differently about deafhearing family life. The negotiation of deaf and hearing worlds is made sense of through mechanical imagery: dials on the chest, petrol tanks, sound/vision channels, factory settings. The family, as a unit, as a nurturing place of love, care and protection, is a nest. Georgina’s poetic description of her fledgling children will never fully translate to the page: sitting with me she becomes a bird with gentle wings, who encourages her children to fly; if they go too soon, she lightly picks them up from the edge of the nest and brings them close again.

Metaphor can also reveal assertions of what may be understood as political postmodern identities (Koro-Ljundeberg, 2001) and helps me to make sense of all that I have been trying so hard to understand and to articulate. The resistance of, or challenge to, the deaf/hearing binary, the claiming of the value of deaf life, of sign languages, of alternative ontologies and orientations, and the claiming of individual and collective identities as multiple, contradictory and competing (Hole, 2008) is, as Thomas summed up, like looking carefully, sensitively and intensely at the way light reflects off plants. It is in understanding families as jigsaw puzzles, or as made up of agentic individuals, carefully, gently and sensitively threaded, woven, or held strongly together with glue, not sausages from a factory. This is, for now, What We Really Want to Say. For now.
Most of us would be horrified if a scientist offered to develop a test to diagnose skin colour prenatally so as to enable racially mixed people … to have light-skinned children. And if the scientist explained that because it is difficult to grow up black in America, he or she wanted to spare people suffering because of the colour of their skin, we would counter that it is irresponsible to use scientific means to reinforce racial prejudices (Hubbard, 1997: 187).

Reflecting then, on attitudes towards deafness over the centuries, similar themes recur. Lane (1992) links cochlear implants back to Itard’s medical experimentation 200 years previously. Mainstreaming finds echoes in the beginnings of oralism, with its goals of normalisation and integration. Eugenics casts its gaze back to evolutionism, and appears in various forms since Darwin. The term has reappeared recently, with the development of the Human Genome Initiative. The centuries-old dream of an end to deafness is set one day to become a reality. Geneticists claim to have identified the “so-called genetic error responsible for a common type of inherited deafness” (Lane, 2005: 303), signalling what many claim as the campaign ultimately to eliminate deaf births. Some conditions, such as deafness, run in families and the genetic team can give people information about these conditions; how they are inherited and how likely they are to recur in a family. If appropriate, they can also discuss the medical management of a disorder and what choices members of the family have in facing this situation. The underlying fear in many deaf people’s minds is the phrase, ‘medical management of a disorder’, and how it potentially represents the destruction of their culture, language and community. Arguments will arise that allow parents to be tested for the gene that causes deafness.

In 2007 the UK government proposed amendments to the 1990 Human Fertilisation and Embryology Act. One section of the amended act recommended that the deliberate choice of an embryo, or donor, known to carry an hereditary illness, condition or disability would not be permitted. As Baroness Deech stated in the Lords on 19th November 2007, “I hope
that your Lordships will be pleased that the deliberate choice of an embryo that is, for example, *likely to be deaf* will be prevented by Clause 14.”

For families with a known deaf gene who, for example, require assisted fertilisation, the amendments theoretically prevent deaf embryos being used. This has implications for the number of embryos selected as ‘viable’ for implantation. It also potentially affects deaf people who may wish to partake in assistance with fertilisation, such as egg/sperm donation.

In the UK, a deaf couple decided to speak out against the violation of their rights as culturally deaf parents, should Clause 14 in any way discriminate against them if they needed to use IVF technology to help them conceive. Their appearances on national radio—in itself a bizarre and ultimately disempowering experience—on television and in the newspapers exposed them to public attack and accusations of child abuse. The people who objected to Lichy and Garfield’s philosophical and human-rights arguments about choice, failed to see that the active prevention of deaf births might not be welcomed by the deaf community. They also failed to comprehend that:

> What we are talking about is an already existing potential person; the choice isn’t whether that embryo could be “made deaf” or not. The choice is whether to discard that already existing embryo for another one believed to be less at risk of turning out to be deaf (Lawson, 2008: online).

Furthermore, research suggests that very few deaf couples would actively seek genetic testing; being happy to bring a hearing or a deaf baby into the world (Middleton, Hewison, & Mueller, 1998; Stern, Arnos, Murrelle, Oelrich Welch, Nance, & Pandya, 2002). It is the ideology behind the legislation that has proved abhorrent and distressing to so many deaf (and hearing) people.

**I’m not ill**

The future of the Deaf community is in the hands of today’s medical and scientific researchers. Positing the signing Deaf community as a cultural community that has resisted the biomedical establishment’s attempts to eradicate it has opened people’s eyes to a different viewpoint on hearing variation (Burke, 2008: 73-74).

There is now a global biomedical agenda, constantly striving to eradicate deafness, which Burke (2008: 65) claims contravenes the “oldest command in medical healthcare”—*primum non nocere*; do no harm. From
the ‘normal’ centre, deaf people on the margins are seen as a broken set of
ears, needing to be fixed. The missing sense of hearing is the harm
suffered by deaf people; avoiding harm equals avoiding deafness. Yet, the
view from the margins sees the harm done to deaf people in the form of
institutionalisation, punishment for signing, Itard’s barbaric ear operations,
sterilisation, separation from one’s community, and the search for the gene
that results in people being born (or not being born) deaf.

The *intertexts* that have interrupted this book are deliberately and
performatively presented here to illustrate some of the countless ways in
which non-deaf philosophers, educators, politicians, philanthropists,
witch-hunters, doctors, politicians and scientists have repeatedly failed to
consider that deaf life has equal worth, and that it is not their job to impose
their values or principles on to the bodies and minds of a *visual* variety of
the human race (Bahan, 2008). This is but one version of a complex set of
histories that in some and many ways touch the lives of deafhearing
families today.

*Image 22. Deaf like fish*
In the final reckoning the people who will advance the universal conversation will be … those able to bring hitherto untold stories, along with new ways of telling … And I believe that the curative power of stories can move the process forward (Achebe, 2000: 83).

A hero’s journey

One day, just as I was leaving Brigit’s house, she said, “Why don’t you interpret my children’s stories as a hero’s journey?” I had, somewhere, an old, worn copy of Campbell’s (1956) *Hero with a Thousand Faces*, so came home to re-read it. The monomyth, or Hero’s Journey, can be found in myth, folklore and religion around the world, according to Campbell, and largely consists of a journey in which:

A hero ventures forth from the world of common day into a region of supernatural wonder: fabulous forces are there encountered and a decisive victory is won: the hero comes back from this mysterious adventure with the power to bestow boons on his fellow man (Campbell, 1956: 30).

The journey begins with a call to adventure, and is marked, in Campbell’s model, by seventeen stages, trials or challenges. If successful, the hero returns with gifts, or boons, that will benefit or improve the world, or community. There exist other versions of the journey, many with fewer stages (see Leeming, 1981; Cousineau, 1990). The main criticisms of the construct focus on its implied ahistorical universality, Campbell’s own ethnocentrism, and its male bias (see Cosentino, 1998; Weigl, 1998). In particular, feminist criticism suggests that the inherently patriarchal monomyth can never apply positively to women (Duncan, 2004). Duncan (*ibid.*) however, is interested not so much in departing from or rejecting the monomyth entirely, but in indulging in what Goldenberg (1976: 448) calls “a rival search” for alternative constructions that “support feminist conclusions.” Taking Lady Augusta Gregory’s plays about women’s journeys, Duncan argues that women can be read as travelling a different,
middle road, as heroes who resist the universal, patriarchal male-hero construct. Cousineau’s (1990: xvi) version of the hero’s journey, for example, centering on “the courage to seek the depths, the image of creative rebirth, the eternal cycle of change with us, the uncanny discovery that the seeker is the mystery which the seeker seeks to know” is not, Duncan (2004) argues, exclusively male, but is open to a feminist interpretation. In Gregory’s plays, for example, the women characters all answer a particular call, are assisted by friends, experience real or figurative darkness on their journeys, and return with gifts for their communities, whether that is collective pride, self-empowerment or reconciliation and peace (Duncan, 2004). Phillips (1998: iii) likewise acknowledges in women’s writing commonalities with the male monomyth, such as the notion of a quest, a ‘magical’ guide, the offer of a boon, and a return; yet she also identifies elements that contain or embrace female emphases, such as being caught in a patriarchal system, naming of one’s own reality, and the creation of a new community. What Duncan, Goldberg and Phillips ultimately propose, therefore, is not for women’s plotlines to be shaped or read through a male lens, but for stories to be told and read from a female point of view. Gregory’s female heroes become transformed through their journeys, and, as Duncan (2004) points out, in doing so challenge and transform the notion, or archetype, of hero.

We can read the deafhearing family narratives as heroes’ journeys. Brigit suggested the idea for her children, but with a different point of view, each narrator can be seen to be on such a journey. One could write the birth of a child, deaf or hearing, as the call to adventure, whether for the child, or for her parents/siblings. The journeys, as revealed in the family narratives, consist of treading different paths, opening new doors, swimming in rivers, walking across wastelands, often into and out of symbolic darkness, in between worlds. The reader might see the way that some heroes spend time withdrawn or apart from their families or communities (see Leeming, 1981) and face difficult choices and trials. These families constantly negotiate what Preston (1994: 198) refers to as “hyphenated lives”: remembering and forgetting roles and responsibilities, allowing oneself to get cross, to become unreasonable, to shout at the world, to slam a door or to throw tomatoes. They come up against brick walls, lose themselves in mazes, happen upon bridges. They receive support and guidance—mostly from unexpected sources—gaining courage and knowledge on their way. There are many mysteries encountered and solved, as layers are peeled away and as heroes’ trajectories spiral and circle. Each bring gifts, new ways of seeing, being and communicating, to their families, friends and communities. Having committed to re-telling
their stories, I see Brigit, Bella, Thorin, Georgina, Toni, Thomas, Dora, Luke, Harper and Maisie, not as “helpless victims of fate” (McDiarmid & Waters, 1995), as objects of pity or derision, as sufferers, but as agentic beings who offer wisdom and sense-making on the mysteries of deafhearing life to others. Readers may simply need to “readjust their vision” (Duncan, 2004) to these stories in order to receive the boons contained therein.

Re-visions

This work, the experience of doing it, being it, writing about it and revisiting it, has taken place at a complicated and shifting intersection of cultures, languages, politics, worldviews and voices. My autoethnographic sketch, as an account of my participant observation and observation of my participation, in deaf and hearing spaces (and the uncomfortable clashes of the two), was written in order to begin a process of understanding myself as a legitimate—albeit uncomfortable—researcher. Looking back and re-reading my story I am tempted, like Harper, to get out my pencils and paints, and to start colouring in the sketch, erasing, tearing off, discarding, adding new layers. I have decided, however, to leave it be, as a reminder, an artefact, however troubling. Like Brigit, I recognise a younger, angrier, less articulate self in those pages. The anger resolves itself in a biased reporting of events, selectively highlighting the extremes of joy and sorrow I experienced as I began a journey into a deaf world, as a hearing person, as a teacher who found herself bewilderingly and inexplicably drawn to sign and to teaching deaf children. My former boss becomes the target of my frustration, actual and symbolic, embodying as he did so much of what I have eventually found the words to counter here through listening to the stories of others as a longed-for sense-making process. If I were to add to my sketch, leaving the original sous rature (Ronai, 1999)—still just visible yet layered over with new colours, lines, images—I would re-vision it (Ellis, 2009) through the eyes, mind and hands of someone who re-reads a story and identifies therein the tangible silences, the available resources, the inherent, almost unforgiving binaries, and troubles them further. The tension lies in my need at that time to get a story out, to type the words into my computer, to do something with my emotions, and in the fact that, like the three families, I gave myself permission to script, light, direct and cast it as a performative, therapeutic, resistance narrative. I wrote that it was a true story. It is a true story; temporally and historically situated, and written from my heart in 2007. It would look very different if I were to write it now from scratch. I now see myself, and
my place in ‘all this’ differently. I feel braver, more knowledgeable, still vulnerable. I have learnt about tolerance, patience and honesty from my family narrators. Working with them and writing about our work has taught me that there is not only a place for shouting at the world, but also a place for quiet reflection, for empathy, for generosity, exploration and mutual understanding. My boss was not an evil person. My trainers were not conspirators. The system was not utterly corrupt, hopeless and cruel. We each construct our own sense based on the social and historical discourses and resources available to us. Prevailing discourses of deafness when my boss trained as a teacher leaned strongly towards integration and normalization of deaf children. He found himself, however, in the midst of a rapidly shifting philosophy of deaf education in the late 1990s and an influx of signing deaf children with whom he struggled to communicate. Suddenly, he was the one who needed an interpreter. I also know parents of deaf children who have decided to raise and educate their child(ren) orally, to send them to mainstream school, to have them fitted with cochlear implants. Their desire to give their children the best possible start in life is equally valid to that of parents who learn to sign; their resistances will be different. Wittgenstein’s (1958) family resemblances should therefore be extended across the postmodern, poststructural landscape to embrace the further extremities of sense-making, beyond, or obscured by my original visioning. I offer these thoughts now as windows on to the messy, conflicted, unresolved and unspoken story that lies behind, beneath or within the gaps of the account I deliberately constructed.

Becoming Hearing

I wrote in my story, How Did I Get Here? about being confronted by the History of Hearing People’s Oppression of Deaf People and about facing up to my position in a long line of Research On Deaf People. I accept and bear my ascribed and socially constructed Hearing identity (member of an ‘oppressive majority’), as well as my biological hearing identity (I can hear). Yet very little has been written about the tricky epistemological and ontological ground navigated by hearing people who work with deaf people—in or around Deaf Studies; with, on and about sign language—in transparent, reflexive ways. Sutton-Spence and West’s (2011) recent exploration of minority/majority, powerful/disempowered spaces of identities within the context of Deaf Studies offers a radical (if cautious) naming and claiming of self: accepting the challenge of being born hearing and becoming consciously Hearing; embracing what is good about Deaf Studies while explicitly valuing the contributions hearing
people can make to the field. Finding myself situated between/across university departments, between/across languages and cultures, between/in-the-middle-of academia and narratives of everyday life, I recognise more clearly the process of becoming. I used to think I consciously ‘became’ Hearing the moment I met Sam. I now realise this is ongoing, and can be named as such.

As a hearing researcher, my agenda is shaped very much by the people I know and care for, and by the stories they tell me, which trigger a response on a deep, human-rights level. I do not necessarily—cannot even—share their experiences, but I feel and appreciate them, and wish, even, to take advantage of my status as a hearing academic in order to have others listen to them, think about—or with—them and maybe even act on them.

Bainton (2007) writes about adopting an indigenous perspective as a non-indigenous researcher, and being on the side of indigenous practitioners without claiming to speak for them. Being on the side of the families I worked with, as a hearing woman without children, is, as Bainton (2007: 197) terms it, an “uncertain encounter”. I duly note, however, that—with these families—it is only I who flags up, or hides behind, my audiological condition. There have been times when we have shared jokes about hearing people, where my own (deliberate?) self-effacement or ignorance then becomes a source of exploration, mutual understanding and enlightenment. I have shared my (edited) family story with the three families, and never did anyone say, “Well of course, you don’t have children so …” or “Well, the problem is, because you’re hearing, that means …” Perhaps that never arose because we already knew each other. Perhaps I would never have been able, or willing, to do this work if these relationships were not already in place and if they were not (or were not to become) the kind of friendships that will continue for a very long time after we have put the camera away and I have stopped typing. Perhaps I can find comfort in Davis’s (2008) concept of one generation that unifies for new purposes. Perhaps I can claim and assert my hearing identity with something other than discomfort and almost crippling self-consciousness. Perhaps I can draw strength from the fact that all three families said “Yes” to working with me, with enthusiasm, generosity and faith. I am hearing, and I can never—would never—attempt to ingratiate myself fully in the one generation of deaf, mother-father-deaf, brother-sister-deaf, son-daughter-deaf; but the idea of a unified, postdeafness coming-together under a banner that rails against hegemonic assumptions and harmful practices, to categorisation, to reductive essentialism, carelessness and paternalism, somehow represents
a space I can imagine myself entering, temporarily, if invited. As Bainton (2007: 199; see also Benham, 2007) explains, the question is not who speaks, but what they speak, and from what position they speak; to which I would add, how and why they speak, to whom, and for how long.

**On narrative and the ‘v-word’**

The work from which this book has grown is loosely framed as a narrative inquiry, and as I compose this last chapter, I reflect once more on how it has grown, expanded, taken flight; how it has faltered, shifted, found its feet and its form. Narrative inquiry has often been criticised for its lack of rigour, analysis, generalisability and validity (Connelly & Clandinin, 1990; Atkinson 1997; Strawson, 2004). This book has never been about the generalisable or the representative. Stories of family life are not told, written and re-presented for their ‘applicability’ and ‘usefulness’, but to convey and communicate meanings, feelings and experiences to deaf and hearing audiences, to create spaces for dialogue, debate and critique; to evoke emotion (Jones, 2005b: 773), to prompt introspection and to ignite the possibility of action and change (Sparkes, 2001). However, the validity requirement is one I wish to trouble. An inquiry such as this deliberately problematises and disrupts what Pinnegar and Daynes (2007: 30) refer to as a “positivistic conception of validity” that is based largely on reliable control, manipulation and measurement of data. Yet creative research practices, which include narrative inquiry, autoethnography, creative non-fiction, magical realism, performative social science (*inter alia* Richardson, 1997; Sparkes, 2001; Spry, 2001; Clough, 2002; Jones 2006; Speedy, 2007) are regularly and inevitably subjected to validity questions, and in terms such as truth, accuracy and evidence (Richardson, 1997; Walford, 2004). The response has been, in many cases, either to dismiss validity as a concept altogether (Mishler, 1990; Wolcott, 1994) or to draw up new criteria that lift validity from the positivist domain and transport it to a more useful and relevant space. These criteria range from verisimilitude (Van Maanen, 1988), aesthetic finality, conviction, adequacy, plausibility (Spence, 1982; Connelly & Clandinin, 1990; Clough, 2002), integrity and honesty (Dillard 1982: 56), to evocation (Ellis, 1995) and fidelity (Blumenfeld-Jones, 1995). Others choose to hyphenate the v-word: Sparkes (2001: 542-543) identifies the following ‘-validities’: negotiated, ecological, catalytic, communicative, pragmatic, reflexive, rhizomic, voluptuous, consensual, interrogated (from Altheide & Johnson, 1994; Belgrave & Smith, 1995; Kvale, 1995; Lather, 1986; 1993; 1995).
While I acknowledge, and enjoy even, the ways in which these authors have, as Smith (1984) urges, attempted to enlarge the validity conversation, I find myself aligned with Mishler (1990), walking away from validity in its methodological or logical sense, with its vocabulary of truth and accuracy. Dora, Luke and I reflected on their story, discussing how in the midst of dry academic theory, it is stories that reach people: “You remember them, don’t you? They’re more powerful. They stay with you.” Whether it is the words and how they are spoken, or the signs and how they are written, whether it is the creative, aesthetic production of an artefact, whether it is the gaps, silences, or the messages therein, whether it is the telling of a good tale, or the invitation to interpretation:

The proof for you is in the things I have made, how they look to your mind’s eye, whether they satisfy your sense of style and craftsmanship, whether you believe them and whether they appeal to your heart (Sandelowski, 1994: 61).

Our hope is that these stories will be read and heard; that we have appealed, satisfied, persuaded, moved and convinced; that these stories and this work are adequate, truthful; that they linger in the mind (Bochner, 1997). For readers with ‘validity’ questions, or ‘reliability’ questions, our hope is that they are reassured by the story of the stories. This book is, after all, an attempt to encourage readers away from positivist safety, standardised outcomes, predictions and causality, away from “Yes, but …” and “So what?” It is a call to imagination (c.f. Coles, 1989): the creation of an open space to think and experience differently, with stories of identity, sensory experience, language, communication and the body, with stories of misunderstanding, of dismissal, of ignorance, with stories of love and celebration.

**Dear World …**

Within these imaginative spaces, however, lie clear messages to certain people, groups, organisations and decision-makers. Our inquiry is driven by a desire to tell stories to particular readers, with positive change in mind. In asking, “What’s the story of your family?” I anticipated stories about education, about audiology, about science. The families all had Teacher Stories, Doctor Stories, Radio Four Stories, Hearing Neighbour Stories, Deaf Community Stories, Extended Family Stories, City Council Stories. I later asked, “Who do you want to hear your stories?” and the answers came in floods. Other families. Anyone with a deaf child. Anyone who has contact with deaf people at all. Doctors, Audiologists, Teachers,
Headteachers, Teacher Trainers. Students, Family Services, Local Authorities, Councillors. MPs, The Government, Charities, Policy-makers. Luke joked, “The WORLD! We want the world to hear our stories!” In many ways, it is an obvious list, yet it is also a sobering list. The three families whose stories you find here feel that, to date, the people on their list do not yet understand what it is like to be deaf, to have deaf children, to have deaf parents, grandparents, siblings. The people on their list are professionals in positions of power, trained to provide services, to administer, to legislate, to support, but they are stuck; struggling beneath the weight of their own bureaucracy, and suffocated by their own rhetoric.

We could make a list of recommendations for educational, medical, scientific, audiological and social policy, but it would either be too long, too overwhelming, too reductive, or too general, too specific. Government reports, with their measured, objective rhetoric, frame deafness in familiar terms, within an insidiously normalising discourse. The National Deaf Children’s Society Early Support Programme Information for Parents (2007) offers comprehensive, clear advice and information to parents of deaf children, covering a vast range of issues, from causes of deafness, to cochlear implants, to communication; from the ear, to equipment, to education. Full of reassuring and informative quotes from other parents, lists of organisations and explanations of terms, it is difficult to pin down exactly why and how the sentiment or concern is lost in translation from text to daily life, from policy to home visit, from informed choice to isolation. Whether policy documents, or information publications, whether national legislation, or local encounters with service providers, no matter how sensitive, politically correct, helpful or well-meaning, a fundamental blindness to being deaf (Thoutenhoofd, 2000) is still evident and illuminated in many of the real-life stories deafhearing families tell.

The extent to which these family stories are resistance narratives is open to debate. I would suggest that as a one-generation, multiplicitous, messy, conflicted and intersecting set of performances, they are. As postmodern, postdeaf tellings, they are not homogeneous and two-dimensional, but situated, temporal and informed. Mathews (2010) voices concerns over the differences between resistance and transgression among parents of deaf children; the latter more common, more private, more simply based on common sense than any political motivation to overthrow the hegemony. Resistance, she feels, is more akin to subversion and protest than is throwing your infant’s hearing aids in a drawer, choosing to sign with your hearing child, or walking away from a conversation about the shame of deafness. Resistance therefore is an intentional response to
power, while transgression lies outside the domain of ideological struggle (Rose, 2002).

Again, where does one draw the line? Within, beneath and between each story here—deaf, hearing, adult, child—exist examples, some ongoing, some forgotten, of transgressive behaviour; an infringement of standard accepted audiological practice here, the non-acceptance of received wisdom on communication in the deafhearing home there. I concur with Rose on the nature of transgression. I also believe that this inquiry, this project of ours that uncovers stories and that weaves the political, personal, cultural, social and sensory threads of a small number of deaf and hearing lives in such a way, is driven by the spirit of resistance. Perhaps this is a failing on my part to incorporate, or draw your attention to, everything I have learned and experienced and think is important in one book. What have not made it to the page are all the backstories, the inbetweens: the protests marched, the conferences attended, the letters written, the working groups participated in, the poems performed, the songs written, the lessons taught, the pictures painted, the hot coals walked, the deaf and hearing lives lived. For that I am sorry.

What we really want to say, therefore, is, in Luke’s words, “Hear our stories.” Take a deep breath, put your prejudices or beliefs to one side, allow yourself to think differently, and see where it takes you. It is difficult if you have never met a deaf person, never had a deaf child, a deaf parent. It is often difficult if you have.

Brigit summed it up: “It’s about thinking outside the box. It’s about perspective, about the system of training people. I don’t think doctors and teachers are evil people plotting. The same as pharmaceutical people—I don’t think they are plotting in whatever they’re doing. They genuinely believe they are doing the right thing. But part of me wishes that people could see the world in a more anthropological way, through a different lens. We need to build bridges towards mutual understanding. That is the way forward.”

Signs of hope

This book does not offer what Crapanzano (2004) refers to as closure. After all this time, it feels like a very small step in a very big world. I think that we (the families and I) have all, at some time, wondered, “What is the point?” We have all worked very hard together on this project of ours, and that time together perhaps has more personal, individual, local value than a grander ‘outcome.’ Our day-to-day contact, our collaboration, has been about the telling, sharing, remembering, teaching and learning, to and
from each other, in small, intimate spaces; but there are other real and imagined audiences out there that we secretly or explicitly want to reach. Our hope lies in the stories these stories will generate in others, and our faith in narrative as more effective than graphs, or abstract explanations (Ellis, 2009).

Having navigated thus far the tricky ground, I might ask “Where next?” I am strangely relieved that my critical, mindful and reflexive discomfort has not diminished.
I am writing this chapter towards the end of 2011. I met Toni last week for coffee and one of the things we talked about was the strange process of remembering, telling, recording, writing, sharing, interpreting, re-writing and now, committing to ink and paper. This book is already out of date. It is an artefact; a fixing of a series of encounters—some planned, some serendipitous, some formal, some random, some wonderful, some upsetting—and a framing of all this human interaction as a research inquiry, bound within covers and set in print. The stories, and the story of the stories, have gone through many stages to reach here. Some have been passed down through families, through signs and words, held in the memories of deaf and hearing people. Others have been constructed in silence, waiting for someone to ask the right kind of question. Some have come together particularly and deliberately for this work, others have been teased out. Some have slipped out, and others have been worked and re-worked on the page, in an e-mail, over a drink. In the act of telling, stories become, as Brigit observed, “out there, released, left behind.” Life moves on. To set them in stone somehow goes against the spirit and intention of storytelling as an ‘oral’ performance. However, this text is not designed to sit, unread, on a shelf. It has been created with readers in mind. The stories take on a new life as you think about, with, against and through them. At least, that is what we always hoped.

**Strong together**

This book began with Dora, Luke Harper and Maisie. It ends with them: how our work together has changed things for them; how memories, anecdotes, rants and jokes that emerged in the telling infuse family life; how telling their stories has encouraged them to confront, or challenge, that which has previously been left to fester, the elephant in the room, the itch that can’t be scratched; how sitting down together with me, narrating their lives, has reminded them how much they love each other; how having their stories written down has given them something to treasure always; how very much they would like others to know their story.
ALL THE THINGS I CAN’T SAY TO YOU: Dora

I asked Harper this question
when she was here this morning
Who would she show this to?
And I was thinking about it
on a much more personal level
People
Actual People
that we know
Whereas she was saying
I think
I’d like to think
it was seen by families
I’d like to think
it was seen by doctors
I’d like to think
it was in audiology clinics
She was thinking much more broadly
much more like
How can we make it more effective?
Whereas I was thinking
“Right!
I want you to read this
cos I want you to know
all the things I can’t say to you”

OUR FAMILY STORIES: Dora and Luke

I hadn’t looked at it
interestingly
for a while
And I got it down
looked through it again
and it was soooo lovely to read
Like Luke
I haven’t read all the clever stuff
but I have looked through it
and read some bits of it
and really enjoyed what I’ve read
(but some of it’s a bit beyond me!)
But just reading the stories
the family stories
was just lovely
It was really really lovely
and I said at the time
It’s a lovely thing to keep
and I’m thrilled that we’ve got it
I did try to show it to my aunt
I think she got frightened <THICK BOOK>
I was trying to say to her
  just read the bits in the middle
But I think maybe
it should be shown to more people
and I don’t know why we haven’t
And of course
the people I would really like to show it to
  I can’t show it to
    That it would be very difficult to
to show it to them
I think they’re lovely stories
I really like them
  I like the touching ones
and the funny ones
    And they’re such
  they are such-
they make the subject accessible
And you know
  Human stories
Narratives

It’s a way in
It’s accessible
and it’s the sort of stuff that
if I’m reading something
I always look for that part of it

Cos it’s real people

HEAR OUR STORIES: Maisie and Harper

So
who do we want to hear our stories?

Who do we want?
Hearing parents who have deaf babies
and they’re trying to work out what to do
and the answer’s easy
  Sign!

And anyone who uses that word
Shame
I want them to read it all!
She’s right!
So the boy whose room is opposite mine
I’ll give it to him to read!
    Oh! So you think it’s a shame do you?
    Well read this! (smiles)
I think in the end
we came up with a plan
to sneak into audiology clinics
and replace all the leaflets
with family stories

Or get a DVD
so in the audiology information
take out all the stuff about speech
and replace it with a signed DVD!
    Ha!
    That could be interesting!
For me
it’s the Shame Brigade
definitely
Smile sweetly
and hand it over
Just read this first, OK?

Yes
Every
Single
Person
who’s ever said
It’s A Shame
Hand it out to all of them
    That would be quite a long list of people!
    Yes
    As soon as you see the word
shame on their lips
that’s it
    whip out the book
    and make them read it!

And tape up their mouths
so they can’t say ‘shame’ again!  (laughs)
MESSENGERS: Dora and Luke

It’s very
It’s very hard
to
try and take …
the
new world view you have
by something big happening to you
like having a deaf child
and having a broader outlook
And
passing that on second hand
to someone who’s not experienced it
But you’re hoping that
they will end up
with the same world view
as you have now

So we can be messengers
But imagine you’re trying
to get doctors
and
audiologists
you know

There might be a five-minute slot
in the four-year course
So it’s very difficult to say
here’s a <THICK BOOK> story!
It almost needs
to be part of mainstream culture
A storyline
in a TV soap

I was thinking about
who would be most likely
to misunderstand
or ignore our stories?

And I thought
probably the same people
who misunderstand
and ignore everything
and whose minds you’re not gonna change
whose views you’re not gonna affect

So they wouldn’t believe it
even if you gave it to them
DEAR WORLD: Dora and Luke

In terms of the power of these stories it actually comes back to Harper’s point. For other families potentially going through a similar experience and just being able to read someone else’s story and go ha! you know We’re not alone in this and this is how it worked out and these are the things that happened

So it’s not Deaf Like Me
It’s Hearing Person/
Parent Of A Deaf Child
Like Me

The last question Who d’we want to hear it? The answer’s The Unwilling or Those who are unwilling to want to hear it should hear it And I use the word hear and that’s the trouble isn’t it? You go back to where we started The Government Those in influential positions in the Department of Health Those who write policy Those who implement policy Those in senior positions in organisations Anybody in equality bodies People in HR departments We’re coming up really with the world The world! That’s all! (laughs)

And what you what you’ve put out there I think I said in one of my e-mails It’s important
Epilogue

It’s important to keep going with this
We can’t just go
W e l l  i t’s a l l b e e n s a i d
I think we’ve gotta keep saying it
and some people might hear it
and some people will never hear it

But hopefully
some of those who do hear it will listen
and some of those who listen will think
and some of those who think will remember
and some of those who remember will try and change
and some of those who try and change will
succeed in
changing their world view

And
the more this happens
the more the world can change
Dear world …

WHAT WE *REALLY* WANT TO SAY IS: Maisie and Harper

I want to say
I can’t have a better sister than you
There
That’s what I wanted to say (smiles)

And you’re the best sister
in the world!
You’re the best
She is the best

If families can’t communicate with each other
how do families work?
How can they be together?
They have to be able to communicate

I feel it’s impossible
to analyse specifically
how my sister has influenced my life
but it’s given me a little bit of a leap
into a different world
and that has definitely been
a positive in my life
most definitely!
And I wouldn’t be without that
No

Imagine if you were in a hearing family
That would be *completely* different!
I think I’d get bored

Right!

It would be very boring

(both burst out laughing)

September 2011

The work you have done and the record of our discussions are a wonderful thing to have. Knowing it’s there to look back on makes me smile. It means I can and will be able to take myself back to a particular point of the family’s growing-up. I am reminded of how our family life is full of love and we were brave facing up to a world that was complicated and sometimes uncaring of us. I don’t know how you will feel about me saying this but with you observing, recording and examining our words I feel this validates what we did and do in some way. Harper x

It doesn’t seem very long ago that we had the chance to reflect on our family through your hard work. But it was. So much has changed and yet stayed the same. Harper and Maisie are now adults, independent and living their own lives and I couldn’t be more proud of them. So much that I was scared about is no longer scary and things that I could not foresee have taken us by surprise. We have a precious snapshot of that time and the love and humour that was there then is there still. I feel very lucky that we have such a good friend who, through her remarkable skill, has held up a mirror to allow us to see ourselves more clearly. Dora x
NOTES

i  It has since, however, changed back to British Deaf News.

ii Martha’s Vineyard during this period had a “strikingly high incidence of hereditary deafness” (approximately one deaf person to every 55 hearing) (Groce, 1985: 3). What made the island such a source of interest was the hearing islanders’ willingness to use sign and speech: As the title of Groce’s book illustrates: Everyone here spoke sign language.

iii Sultan Suleiman at the court in Constantinople (circa 1525) is reported to have employed several ‘deaf-mute’ slaves. “Suleiman observed two brothers, who, as they could not speak in his presence, made signs to one another. The sultan enquired of each of them in private what they had meant to express by their gestures; and they frankly acknowledged, that they had asked each other how they were going to be disposed of, by means of a conventional language which consisted only in signs” (Castellan, 2001:209-210). The sultan is reported to have introduced signing—being so respectful, inventive and resourceful a way of communicating—to the seraglio and to have ordered its use among his staff (Necipoglu, 1991).

iv Cited in Réé (1999).

v According to Winzer (1997), while Hippocrates straddled physiology and the ‘supernatural’, Galen’s practices were purely based on physiological understanding and methods.

vi Huber and Clandinin (2002) write about the complexities and dis-ease of working ethically with children as co-researchers. Bella was curious, not only about me and my family, but also about the process of interviewing, of filming, of asking questions, and of reciprocation and dialogue during a research conversation. On one level, this turning of tables felt like a methodologically valid, sensitive and respectful choice. In reality, however, it was confusing, somewhat false, and ultimately required greater levels of ‘control’ than any of our other research conversations. While I maintained an equitable relationship with Bella as a participant, my clumsy attempts to recognise her curiosity and critical awareness of our work risked putting a greater distance between us.

vii With sign language in particular, which has no written form, the recording (by a hearing person) of sign-language stories told by (or about, even) deaf people whose history is largely one of discrimination, marginalisation and muted voices, is a methodological, epistemological and political minefield. Not only does it concern the ability of the translator to ‘find the right words’; but also there are issues of power, representation, cultural translation and conceptual equivalence (Simon, 1996) together with the potential effect of rendering the source language invisible (Temple & Young, 2004). For many deaf people, this is what has been
happening to their language since the mid-19th century (Lane 1984a; Baynton, 1996).

viii In the past, and at the request of the deaf children I was working with at the time, I have rendered BSL into less standard English, as a way not only to represent the different structures of sign, but also to remain recognisable and familiar to those children who signed to me. The danger in such re-presentation is that it risks creating or perpetuating misunderstanding in the reader who perceives deaf children—on the basis of such representation—as illiterate, inarticulate or unintelligent. Remaining closer to the original telling also runs the risk that fewer people will read or appreciate the stories. As Shope (2006) writes, the decisions we make concerning how to write and re-present others’ stories may mute, rather than amplify voices.

ix This however is a resistance strategy. Some readers will know what this may mean, and others will not. We know what it means. In a postcolonial context, the language of the ‘majority’ (English) is being used in an unfamiliar, disruptive, even subversive way.

x The point I most wished to emphasise with Bella was the idea of how she might feel about her ten-year-old stories when she was 15, say. This turned into a complex discussion, where she interrogated me on several ethical points. She asked, “Well, how can I possibly know how I will feel when I am 15?”

xi It is worth noting here that, while Greek philosophers such as Aristotle saw deaf people as intellectually impaired, deafness—unlike blindness—was not regarded as a physical disability (Winzer, 1997). As Edwards (1997: 36) points out, deaf people were the objects of philosophical, rather than cultural, or societal discrimination: “more people in the Greek world were interested in farming than rhetoric.” This hints at a key difference in the lives of deaf people in Ancient Greece; deafness was more likely to become an issue within philosophy circles than in everyday working life.

xii Nelson and Berens (1997) note that, in spite of groundbreaking theories of visuality, much of the work of the Royal Society failed to go beyond reading English spoken on the lips, or reading English text. If only they had made a leap into the visuality of sign language and had seen signs as text and sign language as more than mere substitute, the gap between their thinking and that of French poststructuralists of the 20th century such as Derrida and Cixous might have been much smaller, and more smoothly synthesised. It is worth noting that in France, Saboureuex de Fontenay, a deaf man, described fingerspelling as language—the hand as the pen (see Lane, 1984b), and Epée, educating deaf children in Paris, perceived sign language as writing in the air (Mirzoeff, 1992: 581).

xiii Cited in Réé (1999).

xiv Cited in Réé (1999).

xv Epée is variously—erroneously—held up as the ‘creator’ or ‘inventor’ of signs (see Desloges, 1779, in response to Deschamps, 1779). While his recognition that deaf children could be taught through sign language (Lane, 1984a) marks a significant turning point in the education of deaf children, it should be remembered that, in the words of Desloges, Epée learned sign language, and then “rectified that which he found defective in this language; he developed it, and gave it
methodological rules” (Desloges, 1779: 39, 7). Desloges, author of the only book written by a deaf person in the entire 18th century (Bézag-Deluy, 1993), both admired and criticised the work of Epée, for bringing signs into education, but at the same time, imposing an imperialist French language system on to an existing, fully fledged sign language (Lane, 1984a).

xvi Foucault’s (1977) discussion of the concept of the ‘author’ and its ascribed meanings of authority and acceptability raises all sorts of questions concerning who should rightly sign their name to this kind of work. As Bella pointed out, since she has contributed her stories, should she not also have earned a PhD.

xvii Herman and Vervaeck (2005) also comment on the necessarily unclear distinction between author and narrator; the implied author being the person whose responsibility lies in the ideology of the text. Largely concerning fiction and concepts of reliability, this does however highlight critical issues concerning voice, responsibility and visibility when narrators’ stories are entrusted to another person. My aim is to describe, transparently and reflexively, how I worked collaboratively with my family narrators in order not only to re-present their stories, as their stories, but also to problematise terms such as author and narrator, particularly in the context of a collaborative inquiry.

xviii For example, the Nueva Coronica (New Chronical) of the Andean Felipe Guaman Poma de Ayala (1613) written as a 1200-page letter, addressed to King Phillip III Spain. The writing of a ‘chronicle’ can be seen as a direct, strategic, ‘mirroring-back’ appropriation of one of the main writing apparatuses of the Spanish at the time of the invasion and colonisation of Peru (Pratt, 1994).

xix Even the term silence is ambiguous. I have deliberately used Mehrez’s (1992) phrase as a direct challenge to the mainstream conception that deaf people live in a world of silence, thus reflecting back this erroneous assumption, while maintaining the original intent; that silence refers to the state of marginalisation through hegemony.

xx Several poetic texts have not been included. My decisions as to what to set aside were influenced by a complex range of factors. Some have been taken out or edited at the request of the families. I have tried to balance layered stories that both complement and contradict, which disrupt and shock, across the three families. There are stories that have considerable personal and intimate meaning that may not reach the unknown reader in a way that matches the original intention. There are stories that raise too many issues concerning vulnerability and exposure. In the end, I thought of each narrator and our mutual ethic of care, and re-visited conversations about What We Really Want to Say, and allowed myself to be guided by that.

xxi This finds echoes in 18th-century deaf-education philosophies of visuality. In 1706, for example, Leibniz wrote a letter to the Dowager Duchess of Orléans (cited in Réé, 1999), wherein he remarked on the fortunate sensory condition of deaf people, in that, unencumbered by a fifth sense, they were better able to exploit their visuality and rise to the highest ranks of society through their understanding of written systems (for example the symbols of alchemy and algebra that are largely independent of language).

Branson and Miller (2002: 38) attribute the ideology of normality to Comte, and state that normal does not appear in the Oxford English Dictionary until 1828, with normalise following in 1868.

‘Oralism’, as Karacostas (1993) observes, is often confused, or used interchangeably, with ‘oral education’. The latter simply defines a teaching method that has the attainment of spoken language and maximum use of residual hearing as its primary goals, whereas the former describes a politically infused ideology.

The picture is, however, far from simple. As Winzer (1997) reminds us, even when signs were being used widely in 17th-century deaf education, there were always particular individuals who persisted in oral experimentation, guided by the belief that the voice was the very spirit of God. In Europe, for example, John Conrad Amman, a Swiss doctor who moved to Holland, firmly believed in the superiority of spoken language and worked towards the “artificial restoration and use of the voice” (Mathison, 1906: 420). Very little is known of his pedagogy: his publications reveal only his methods of teaching articulation (Amman, 1972; 1873). In Paris, the role of signing was being queried at least fifty years before the 1880 Milan congress (Mottez, 1993).

Baynton (1997) notes that in the US, deaf education reveals far more about underlying concerns on national identity and individualism than about pedagogy and educational theory.

One of the key strategies was known as the ‘rotation’ system, where teachers would follow their class year by year up through the school: “Since speech and lip-reading had become a mandatory part of the curriculum, Deaf professors who were not able to teach orally would necessarily be downgraded to teachers’ aids working under the hearing professor” (Karacostas, 1993: 138). Signs were also to become increasingly used as a stop-gap, until articulation in spoken French was achieved. Signs could then be viewed as hindering progress in learning speech, and ultimately eliminated from the timetable altogether.

The Nazi proposals for a bill for the “avoidance of inherited diseases in posterity” were approved in England by a 1933 issue of the journal, Nature (see Davis, 1997: 19).

Lexington School and Centre for the Deaf and Jewish Heritage Project (2003: 7).

The persecution of disabled people by the Nazis was not recognised after the second world war: “In 1964, a Jewish person who was deaf and who had been sterilised by the Nazis was recognised by the court as having been persecuted as a Jew, but the court ruled that his sterilisation as a deaf person did not constitute Nazi persecution” (Friedlander, 1999: 11-12).

The 1938 Eicholz committee, which reported on “Children with Hearing Defects” viewed children with a hearing loss greater than 40dB as beyond their terms of reference, and therefore ineducable.


Although the stories are creative reconstructions of experiences, told at a particular point in time (Etherington, 2006: 234), many are now different, and will continue to shift, expand, relocate, emphasise, alter, or diminish as lived life goes
on. There is a curious phenomenon at work: I have entextualised the families’ narratives at a point in time, thus marking the time at which they were told. The tension lies in the fixing of ink on paper, the creation of an historical artefact. Years have passed; it is no longer The Story of the Family, but a recorded memory of a past story, at times nostalgically familiar, and at others, unrecognisable.

xxxv On 18th March, 2003, the UK government recognised BSL as one of the UK’s official languages. This represents progress, yet falls some way short of the full legal recognition (c.f. the Welsh language Act) that campaigners have been demanding (Wheatley, 2009).

xxxvi Thomas’s changed audiological status may be seen as a coming-together of audiology and deaf-inside. It may also be seen as highlighting his hearing-world-ness, as his audiological status shifts towards hearing-deafened (despite being culturally deaf-inside).

xxxvii Anderson’s (1991) concept of imagined (political) communities is helpful in terms of thinking about global and national deaf communities as connected and affiliated through languages, sensory orientation and histories, rather than through geographical proximity, or nationhood. Deaf people around the world may never encounter each other yet “in the minds of each lives the image of their communion” (Anderson, 1991: 6).

xxxviii From The Songlines: “Richard Lee calculated that a Bushman child will be carried a distance of 4,900 miles before he begins to walk on his own. Since, during this rhythmic phase, he will be forever naming the contents of his territory, it is impossible he will not become a poet” (Chatwin, 1987: 303).


child no pain, but achieves its goal. The child will now be permanently deaf. Is this a case of child abuse? I suggest that it is. What the parents have done ensures that their child will never be able to hear Beethoven, or a babbling brook, or listen to lectures and debates delivered in spoken languages, except in translation. The child will also be at a disadvantage in countless other ways in getting through life. Admittedly, we must also take into account the benefits that the child will get from being part of the Deaf community, especially when being a part of the Deaf community means that the child grows up in the community to which her parents already belong. But that does not justify what they have done. If you respond to this example in the way I do, and accept the principle I stated above, it follows that it must at least be permissible, other things being equal, for parents to take steps to ensure that their child will not be deaf” http://www.utilitarian.net/singer/by/2003---.htm#3 (accessed 17th October, 2008).
xliv Emery, 2008.
xlv Bainton (2007) sees the uncertainty of cultures and languages as fragile, but also sees this fragility as a gift, rather than a failing or a weakness.
xlvii Borrowed and adapted from Bloom’s (1998) *Under the Sign of Hope*.


Signs of Hope: Deafhearing Family Life


Speedy, J. (2001). *Singing over the Bones: A Narrative Inquiry into the Construction of Research and Practice Cultures and Professional Identities by Counsellor Educators at the University of Bristol and within the UK*. PhD thesis, University of Bristol.


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