

'A Different Way of Engaging'

Transcription poems
by
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From the words of Katherine Araniello

In memory

Katherine Araniello
21st September 1965 – 25th February 2019

Foreword

Katherine died before seeing the finished version of this work; however, she had read an earlier draft and emailed a list of her concerns.

She asked for some reasonable specific changes, which have all been made. She had a more general concern about 'broken sentences, repetition etc' seeming clumsy and making her look stupid. But she also stated that 'I see this as a looser/natural form of language that isn't fluid and has lots of stopping and starting, and is honest...' and emphasised that 'I don't wish to mess up or sabotage the process'.

In happier circumstances this would have led to a productive discussion. I had sent Katherine a fairly early draft and many of her concerns would have been assuaged by the subsequent process of editing and fine-editing. (It is always tricky to know when to first send a draft for comments. One wants to pick up factual errors and mis-transcriptions as early as possible, but earlier drafts do tend to read quite awkwardly.)

Katherine expressed a desire for greater formality, with the particular example of 'want to' rather than 'wanna'. (It is surprising how difficult those two are to distinguish when transcribing.) I have borne that in mind more generally throughout the editing process.

I trust that this cycle of poems does justice to one of the most exciting artists to have come out of disability arts, who is greatly missed by her friends and admirers.

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Dream

When you talk about memory
I'll always remember
this particular dream, that I had
when I was about four and a half years of age.

Which was about being in a lorry
with no windows either side
and I was being carted off,
taken to a school for people with disabilities.

(Now, at that time,
I had never known anyone with a disability
or mixed with them.)

In my dream, in my head,
I was imagining being whisked away
in a truck full of freaks.
And that was my sentiment at that age.

And this was all because
I was going to be going
to a boarding school

because my father was in the forces
and there had to be somewhere
for me to go.

The local authority said don't worry,
we know where your daughter can go.
And so I started off as a weekly boarder,
I was there during the week,
went home at weekends.

So yes, I was absolutely petrified

of being deposited in this unknown place
at such a young age.

First Day

I also remember
being in the playground of the school
on the first day at primary school.

I was crying profusely
and I was in a manual wheelchair
because in those days you had to wait forever
to get an electric wheelchair,
and I could never physically manage,
I was never able to move in a manual wheelchair.

And so I was in the chair
and just sat there
because I'd been deposited
in the playground of the school.

And a girl came over to me,
she was a bit older than me, and said to me
you've got to pull yourself together
otherwise you'll sink and won't survive this.

Fatherhood

I think it was very hard for my father
to accept that I was disabled
even though their first child
had been born disabled
with the same disability as myself
and died at the age of
seventeen and a half months.

My physique then was very normal.
I looked completely able-bodied,
even though I was unable to crawl
or walk or weight bear or roll over,
but I still needed everything done,
(though I could do more then than I can do now).

My father just couldn't accept that fact
that I was unable to walk,
so I remember him sitting on the sofa
and then holding me standing up with my back to him,
and his belief was that
by letting go of me
I would naturally be able to just hold myself.
And I fell flat on the floor.

It's not something that I'm traumatised by,
I understand, I get it, but that was just something
that I very vividly remember.

And I sort of also understand that
because my father, I think that he,
I think that the particularity of my body
didn't match the level of what I couldn't do.

It made no sense to him.

So he had to go through this
quite rudimentary exercise
in order to just be certain.

Bedtime

I remember the summer of 1977.
(I was nearly eleven,
coming to the end of this school.)
We all had to be in bed
by seven in the evening.

With me, once I'm in bed
I can't roll over or sit up,
so I was literally bedded for the night
and it was excruciating.

There was no way
that I could sleep when it was so hot.
It was light outside and yet
they were still putting us to bed
by seven pm and that was it.

And there was nothing I could do,
nothing other than communicate
with the other people.
But they weren't great conversationalists.

So frustration was something
that I really was experiencing at the time.
Like complete frustration.

And maybe that's why now,
I don't even start to begin
to think about going to bed
till after one am.

I'm a late person.
I will not go to bed
until I'm ready to crash

because once again I cannot do anything.

Excursion

We went into the Sunshine Variety Bus.
And they took us to the pond,
so they had the ducks and the swans,
and they were too lazy to let us out.

We literally just sat
in the bus. Looked at the ducks
and the swans
till they took us back. That's all.

No wonder I turned out the way... My God!
I mean, you know, it's terrible isn't it?
You can tell what I think about this stuff.
It was awful.

These schools are absolutely disgusting.
Sort of psychological oppression,
they were restrictive.

We visited a shopping centre once,
we never went to the shops.
I was getting so desperate,
I signed up to go to Sunday school.

What kept me going was
I had very good parents.
But they were in Germany and I was in England,
and I'd only see them in the holidays.

Manual

I also remember that I was desperate
to have an electric wheelchair.
I've never ever been able to move an inch
in a manual wheelchair.

I wasn't one of those people
who was put in a manual wheelchair,
and if I tried a bit harder
I would somehow be able to move.
I wasn't able to move.

They had a rule that
the more able-bodied kids
weren't allowed to push the kids
that were in the wheelchairs.

So I wasn't actually able
to move around.
Until I was eight
I never experienced
freedom of movement.

Electric

At the age of eight it was decided
that I was old enough
to be put in an electric wheelchair.
And I was able to experience movement
for the first time in my life.

I had to basically reverse
and go forwards between beds
to prove that I was capable
of steering the chair.

And I think that also had an impact on me.
I have to always be able
to drive my own electric wheelchair.
And that has been increasingly more difficult

but the idea of being pushed around
like an ill person
is just not going to happen.
I don't want people moving me.

Assistance

It was survival,
it was like mental survival.
You had to be mentally strong
to survive at the school.

And I remember a report
that they wrote about me to my parents.
'Katherine excels in everything
but she does tend to take advantage
of the younger children.'

And what they meant by that was
I, because I was physically not able,
I needed things passed to me,
put closer to me, I'd already started
to orchestrate my own PAs, my little PAs.

The more physically able children
(not younger) assisted me.
And that was a survival strategy.
And they would do whatever
I asked them to do.

At teatime they'd give us sandwiches
and we'd have to eat everything,
even if we didn't want to.
I hated the crusts on the bread,

so I would eat the sandwich
and then pass the crust under the table
to the person that was my assistant,
and he would scoff them.

So I was really good at directing,

really good at directing.
It's like I was setting myself up
without realising it.

I'm not saying that every moment was bad

I'm not saying that every moment was bad,
it wasn't but it was just,
when I look back on it I just think
what a crazy, it was just
absolutely absurd
way of thinking.

And I am a product of that school.
And is that a good thing or..?
I'm not sure, it must have had
an impact on who I am now.

Maybe that's why my work is,
as an artist, very strong, very,
some might think it's forceful.
But I did, I did survive that primary school.

When you're restricted in that way
it just becomes what you're used to,
you don't necessarily challenge it
or believe that it is wrong.

There's a frustration building inside.
But you're with people of your own age,
so you make alliances,
that is part of a coping strategy.

So I, I became used to that existence
and felt safe. But it was a
completely distorted sense of safety.
It was very institutionalised.

Choice

You have a choice,
you either become a victim and oppressed,
actually no that's not true,
not everybody does have a choice.

I feel that I've managed
to maintain a strength, a mental strength,
I've always been strong mentally,

not always, that's not quite true,
but I think that it was a question of
it's not right to dwell on negativity,
it doesn't help me, it just,

it's like for me it's the opening of
starting to just think,
and not feeling that you're on top of things.

So the question is
to turn the negativity into something,
an alternative way of thinking,
an alternative perception.

Decisions

When I was three or four,
I decided what I wanted to wear,
how I wanted to wear it,
so I had complete control over,
she would have to dress me
but I would be in control.

And my mother, I remember her,
she would sit me in the kitchen on the surface
and she would pour all her problems out to me.

So I was very much able
to communicate with her.
I think that those two things
in parallel helped me to survive.

Burton Hill House School

It was huge, and looked beautiful
from the outside. Again,
another school that was hidden away,
nobody would know it was there,
unless you happened to take the wrong route.

And this school, I was there
from the age of eleven until sixteen
and that school was another,
I was there at that school for,
again that was a hideous.

Terrible, no matter how much..
Every day was all about survival. I
quickly realised that, again ..

I could physically move around,
I had an electric wheelchair.
I was quite frustrated that
all my peers had private wheelchairs
that their parents bought them,

but my father had always been
quite shrewd with money,
just wouldn't buy me my own electric chair,
so I made do with the one
that the state give you for free.

School Days

The last meal that we were fed
was at four o'clock,
and that'd be tea,
and after that there was nothing.

We used to raid the kitchen.
And there was nothing in the kitchen.
The actual way it was run was so bad that it,
it caused people to act badly,
not badly but rebellious. Frustration.

At the end of the day. I mean
we used to wander
up and down this huge manor house,
up and down the corridors,
going through the ballroom,
(it used to be the ballroom).

We used to wander round there aimlessly,
doing nothing because there was nothing to do.
We weren't allowed to go
outside into the grounds
without permission.
And that was it.

So we used to wander round,
up and down the corridors.
There was no encouragement to study,
and we were boarders, so we had no,
we didn't have our parents so we just,
so we just used to do whatever we wanted.

Staying alive

I think it's something that a lot of disabled people experience certainly then, and probably still now, is that life expectancy isn't going to be very good. So that was sort of stamped in an imprint on my brain at an early age. Also by the fact that because I went to special schools, disabled people with Duchenne's muscular dystrophy were dying all round me, so I didn't want to be sat there thinking, I wonder when it's going to be my turn, my time to die. I wasn't really given any information as to the difference between Duchenne's and spinal muscular atrophy.

They were weak and I was weak,
Plus I was told by the staff
live for today, you could be dead tomorrow.
And my parents were also told you'll be lucky
if she lives past the age of eight,
when the other fact was that
my mother's first child had the same disability as me
but only lived till he was
seventeen and a half months of age.

And then my parents were advised
by medical people,
wait five years and then try again.
And so they tried again,
they waited five years
and my brother came along,
who doesn't have SMA.
Eleven months later, I do have SMA.
It was slightly an improved version

of the brother that I never met that died.
I was slightly stronger than him.

There are different types of SMA that you are born with.

Expectations

Being told that I might die.
It gave me zero expectations.
The school that I went to,
which like I said was a special school,
there was no emphasis
on independent living or what we might become.
I don't know whether that was just of the time,
or whether that was because I was in a disabled,
segregated school for physically disabled children.

There was no encouragement for us
to be anything or achieve anything
because the mentality of the school wasn't about that,
it was just about looking after us,
giving us a basic education.

While there was this knowledge
that I could die at any time, so
I eliminated all plans.

Maybe get into another
Shaftesbury Society home,
where I can be with other people
with a similar disability to myself
and be able to watch TV and go out,
but that was it, that was my life's ambition.
It was really right down to hardly anything.

John Noakes Prize

I had no desire for education
because there was nobody really interesting me,
I just found it really boring,
although I did manage to, I liked art.

I did win a prize for the school,
John Noakes Prize where,
it was a national competition
where schools could enter,

and it was trying to get the kids
to clean their teeth,
so I did a really simple picture,
toothbrushes in a line,

queuing up to, at a Job Centre,
so literally a queue of toothbrushes,
and a door which said Job Centre
and then the slogan was,

'Is your toothbrush unemployed?'
And I won it!
So that was something good.

Powerful Lady

I do remember managing
to get into CB radio.
I called myself,
my name was 'Powerful Lady'.
This was amazing.

I don't remember what age I was,
probably about fifteen, and this was like my,
something that I was able to communicate
with people outside of the school environment.

And I found it the most liberating,
exciting thing, it was just amazing.
I was communicating outside of this,
you know oppressive environment.

I was absolutely addicted to it.
That's what kept me occupied,
just talking to all sorts of people and,
not about anything much but just,
I don't know, it was just something
to get access to another world.

But I think I was always very nervous
to meet the people
that I could communicate with
on the radio .

Matron

The Matron was an alcoholic.
That's a true thing,
she was an alcoholic.
Maisie, her name was.

Her background was that
she came from a shoe shop.
She became a Matron of a school
when she came with zero qualifications.
And she was an alcoholic.

I wasn't scared of her,
I was just impartial to her,
I could sense that she was ignorant.
But she managed to put the fear of,
fear to people being quite intimidated by her.

And I remember once putting
a Hitler moustache on her face.
On the photo. Of her.
On the notice board.

I couldn't physically do it,
but I instigated it
and it was publicly on display

and she went absolutely,
she was absolutely outraged by it.
And she could never prove it was me
because obviously I can't do it.

So that was one of those moments
where I was really very, very happy.
So that was one of my triumph moments.

She was absolutely determined
to find out who did it.
I never admitted it because..
why would I?

Good Times. Bad Times.

There were good times,
but the good times
were not made up by the school,
it was my own mental state
and being able to communicate.
They didn't do anything
to assist us to grow as individuals,
or encouragement.

The teachers did a bit.
I got on really well with the physio actually,
Mrs Butler, I liked her a lot.
I liked physio just because
she was an intelligent person
and communicated at a level that I appreciated.

There were staff there
that I did get on really well with.
One of them was called Mercedes.
She was Spanish, she was night staff.
And she was great.
She'd bring me in Pot Noodles, you know.
She was a great person,
I kept in touch with her for ever.

So I did have very strong connections with people,
I certainly wasn't a loner.
I was in control of my autonomy,
but when I'm thinking back on it now,
It just makes me really sort of angry
that such a place existed.

And the Shaftesbury Society
still carries on to this day

on this premise that
they are doing something positive.
I wasn't very interested
because it's absolutely not true.
It's real-life oppression,
certainly what they were doing then.
I've always been anti institutionalised environments,
I just don't believe in them,
I think they're dangerous places.

Detention

They had a gravel car park
and I dared to take my chair,
drive my chair across the gravel car park
which sat in front of the main entrance.
And I did drive my chair
across the gravel car park
down to the main gates. And again,
the gravel car park was there
to stop us being able to physically move.

And when they found out that I did it,
they confiscated my electric wheelchair from me,
put me back into a regular chair.
And I was a senior at this time,
they moved me to the junior dormitory
and they wouldn't give a time
as to how long I was going to be there.

I told my parents what had happened.
I just said I can't bear it, I can't move.
But anyway, that situation lasted a week.
Mum and Dad were really supportive.
It was difficult because they were in Germany.

Hatchford Park

I went to Hatchford Park School in Wokingham.
And it was just completely different.
The dormitory was beautiful, the food was fantastic.
Not private, it was just liberating
in comparison to the two previous schools.
I was only there for two terms
but I loved it. I felt, I dunno,
I was respected, treated differently
and treated as someone worth investing in,

whereas the Shaftesbury schools they, they
they didn't see us as ever becoming
productive, useful members of society.
So the whole ethos there was just keep you,
keep you safe, well that's a contradiction,
keep you warm and feed you, minimal.

They used to create this pathetic little
firework display on Guy Fawkes.
We had to sit inside the school
and watch it through the window.
It was just ridiculous.

Star Centre

Because I had zero expectations
in terms of thinking about the future,
I just didn't plan any sort of future.
And there I just learned to live.

I thoroughly enjoyed it.
I was ill, went into hospital
quite a lot with pneumonia
because I was completely
abusive to my own body,
because I just didn't care,
I was there to have fun.

We were allowed to go out,
going to Cheltenham town centre.

And that's where I had my first quote
'real' relationship,
with one of the members of staff.
It was same-sex, so this had to be kept
completely and utterly hidden.
And I was very proud of myself because,
despite being in an institution,
I managed to have a relationship with a woman
whilst being a student at the college.

I kept my, I was very discreet
about my relationship that I was,
that I found myself in.

So yeah, and college was all about
vomiting after getting too drunk,
smoking cigarettes and just using it
as a junior social experiment camp.

This is basically what I did.

Getting Out

I never envisaged myself working in an office,
even though my mother was a top secretary.
That just wasn't of interest to me.
So what I learnt at the college was,
it was like just a freedom,
you could buy a packet of cigarettes and smoke them,
you could get onto a coach
and be dropped off in the town centre at weekends.
It was absolutely an amazing, empowering,
at last I had freedom to sort of move around,
a bit more like a normal person.

That's something that I'd never had before
in terms of when I went to the schools.
This was also a special college,
for disabled people only.
And that's where I learnt who I was,
against the fact that it was a very,
it was still an institution
and very shallow in its viewpoints.
I made, I was a part of, I had an elite group of friends
that I would just be with, a very small group of friends.
I was just able to come into myself there.
In terms of the right type of relationship.

Independence

My biggest, most important on my agenda
was always independent living. I had to,
I had to be in control,
I couldn't bear to be living with my parents
because although, you know,
they were very supportive,
If I'd gone to live with my parents
I'd just kill them.

My father, from the army,
quite controlling, very dictatorial,
likes to have things his own way,
I wouldn't want to live under that regime.

I moved into this area
because my Dad's last posting was in Woolwich.
I was in a relationship. She came with me.
That went wrong. I had to move.

GAD

I met Greenwich Association of Disabled People
I went to their offices and said,
they said oh hullo, how can we help you?
I said, no, how can I help you?
What do you want me to do?
So it wasn't like I was there
to receive their help. I was there
to see what I could do
to be practically involved
in something positive and progressive.

I'd already sorted out my money,
my dad bought a book on, more like a bible,
it was the biggest book, a big thick book about benefits.
I decided very quickly that I wasn't set up
to thinking about work.
So what I'd do was screw the system
as much as you can, not screw it
but just make sure that I got every entitlement I could,
but not through working.
And so my father bought a book
and told me what to do.

I had to get accommodation,
because my parents would have said
'Oh yeah, Katherine coming back home,
we don't mind'. I wouldn't have got presented anything.

So I had to have a, a sort of,
I had to make it look like
it was a very separated relationship
with my family. So that was my first priority.
Get into somewhere in this area.

Day Centre

I remember being made to see
how many social workers could visit me
and I said to her, not for me and
she said, well,
there's the local day centre that you could go to.

I said, I'm a similar age to you,
I said would you like to be deposited,
is that all that you can, is that it?
And I realised then that there was no point
in doing anything through social services
because their way of thinking is so limited.

So I went around the day centre, when I wanted,
and when I felt like it.
And I had to rely on these hideous turquoise buses
that would pick The Disabled up.

And I just remember wandering round this day centre,
about seventeen, eighteen,
no I must have been twenty,
thinking what the hell is this?
What the fuck? I couldn't understand
what for me at the time was
all these zombies walking around,
there were some people in wheelchairs
and some people just who were,
thinking that they were somewhere else.
And I didn't understand, I didn't get it,
I thought what the hell, what is this, what *is* this place?

I hadn't realised it was a mixture of people
with mental health and physical disabilities.
So that was my introduction to mental health

and I became fascinated by it. It includes me,
I find it interesting,
so it wasn't like I was scared,
I just was completely curious.
It was something I'd never, ever come across.
That was interesting.

But apart from all that I also started to,
you know analyse the whole thing,
realised that day centres were dumping grounds.
We used to do basket-weaving.
There were all sorts of things.
It isn't a day centre now,
it's occupied by Guardian residents.

Anyway, I went there for a bit,
learnt some basic computer skills
from a guy who used to come in.

Separation

That was a period of time,
my partner had become quite abusive,
she was in control of everything.
I wasn't allowed to see the bills.
I was literally just a cash machine
that she could benefit from
and do very little.
It was really hideous.

So I had to deal with that
in a way that again I controlled the situation,
found her a new partner.
It was quite a strategy.
At the time it was very important
that it wasn't made public.
The last thing I wanted
was the paparazzi,
'Victim of an Abusive Relationship'.
So that was dodgy.

I worked it out. Again,
I worked out a strategy to encourage her
to find someone else. And it sounds terrible,
but I had to do it. It was,
it took me a year and a half to get out.
When I first wanted to leave her
she threatened to commit suicide.
I was too young to handle this nonsense
but my Mum and Dad were very respectful,
just allowed me to deal with it in my way.

And I think that, for me,
I can deal with *any* situation,
as long as I'm just given the ability to do that.

When people start taking in,
or going over me,
I find that very, very intimidating.

Flit

There were really interesting people
at the Greenwich Association of Disabled People.
Like Rachel Hurst, Ann Rae.
Ann Rae was amazing,
she helped me stop this bloody awful relationship.
And it was through her wisdom and intellect
and supportive measures
that were about spreading right.
And I did a moonlight flit,
with Ann's support and assistance.
They found me a bedsit, a brand new bedsit.

My ex-partner was asleep upstairs,
because she never used to get up
until the middle of the afternoon.
I moved out and I think that's when
I started to take complete control of my life.
And start living.

But, you know, again I still had friends,
she'd been jealous of all my old friends.
But once I moved into that bedsit,
it was like starting from scratch.

Application

I became involved in GYPT,
which was Greenwich Young People's Theatre.
It was an accredited course
and I got distinctions and they applied for me
to go to university to do a BA in Theatre,
and I was turned down.

All of them were saying the same,
sharing the same sentiments that
while they felt I would very much
be able to cope with the theory side,
I don't have the physical ability.

They suggested Graeae, I felt no,
I'm not going to be involved in Graeae,
because I want to make it academic.
So I wasn't interested in joining Graeae
just to be in the theatre,
I wanted to go to university.

And that's what changed my course.
I decided art, fine art.
They weren't giving these restrictions
that the theatre was at the time.
And so that's how I became an artist.

Guildhall University

I loved the foundation
because it opened up
the whole concept of art.
I mean it wasn't just this thing
about drawing something, drawing what you see.
I created a visual diary, visual reference scrapbook,
things I was thinking around
that I'd never considered before,
we'd certainly never been taught that
at any of the previous schools or colleges.

The course for me was about creating a portfolio,
so that you could then present that
to get onto a BA course.
Mainstream, no special facilities,
what I had was my P.A.
When I needed to, I would just direct her
if I wanted anything, get that stand,
get that bit of paper, stick it there,
so I was doing it but not physically doing it, drawing,
I could still just about move enough to draw a bit,
I used to go to the life drawing but I'd feel
that all my people used to look
like they were disabled.
When I tried to draw able-bodied bodies,
they always looked a bit disabled.

I could draw, I was able to draw, I love drawing.
I took that course very seriously
and got it, got the portfolio.

Construction

When I went to the university
and they accepted me
and I started my three year B.A.,
fine art and this progression.

I remember making a construction.
I wanted to make a cube,
a space in which someone,
a transparent space which somebody could go into
and I wanted the breathing machine.
I wanted it to be like a sculpture/sound installation,
so somebody could go into it
and hear the sound of the breathing machine.
So you didn't see it, it'd be just a sound piece.

So I made this thing with the P.A.
I had no skills whatsoever in construction
and neither did the P.A.
so at first attempt it collapsed!
That meant I needed a hand
to deliver my concept,
because I was just hopeless,
I just get that piece of wood there,
does that look like the same width as that piece.
I wasn't doing it in theory, in a theoretical way,
I was just looking at it and trying to work out
how to, how to put it up.

'Slapping'

That video was all about presenting an image,
if I think about it now,
it was looking at inequality,
the concept of inequality conflicting with equality.

It was about presenting
a black and white image where neither were..
they were equal,
neither was more equal than the other,
and slapping because we were somehow,
there was a physical, a physical interjection,
running on a loop.

I was looking at the idea of,
this is disabled people.
Representation of disability,
certainly then,
always seemed to see people as The Victim.
I was trying to create a sense of there was no victim.

There was no victim, there was no hero,
it was a sense of equality in a minimalist state,
it was saying something
and I think at the time it was really important not to,
it's not about verbalising it, it could be,
as I was more of a visual artist,
about trying to, you know,
present equality between two people,
one who's obviously physically disabled
and the other person who isn't
and presenting that image, trying to,
the concept behind it was to create an equality
even though the initial reading would be inequality.

So I was trying another way of representation
that wasn't sort of politically charged
or making it, you know
I'm not coming from a political standpoint
but more within the aesthetics of art, I think.

And by not putting big statements on it
or charging it as a political piece or,
or turning it, trying to, you had to think,
you had to engage with it.

Representation of disability
is often so charged
in a way that one is told how to see disability.
When you're not told,
it's just there, that is interesting.

And it throws people into a whole disarray,
like, oh, this isn't a documentary
about disabled person's struggles.
It provided, it purposely negated
medical, social models.

It's something like the urinal,
you know Duchamp,
he took it out of its familiar surroundings,
what's its purpose?
You put it in a gallery
and people are mystified by it.

Suddenly they're looking at it
from a whole different perspective.
I think that's what I was doing,
taking disability out of its normal surroundings
and television and political and tragic documentaries,

and just removing it to a place
where it's in an entirely different space.

And I won a prize,
I won the end of year prize,
so that was a proud moment.

Out of the Ghetto

I think the M.A. gave me,
opened up my mind in terms of I went,
I'd already in between my art at college, doing my B.A.,
I'd become very involved in disability art.
And I was aware that my work
was effective in that environment.
But I wanted, I needed more. I
needed it to be really critiqued.

It would always sit with disabled people,
because how could it not, that's my life,
the background that I have,
my work will always sit
in a disability context.
But I wanted it to be scrutinised more.
I needed harsher critique.

I wanted to make it somehow,
get it out of a cliché.
I wanted to lift it out of the ghetto
and do it so that it was aimed
to be seen for a wider audience.

It was important for me
that the work didn't become part of a ghetto,
that was very important.
It needed to get out there.
And I wanted to push my mind harder.

It's all very nice to go,
'oh, I'm a bit different',
but it's not really helpful.
I wanted to be critiqued.
That's why I went to Goldsmith's.

You ask me about my work

You ask me about my work
and what can I make work,
I think that my sort of way of thinking
about all of that is not all about
'oh I'm a disabled person'.
I don't think that.
It's not what I think,
it's not what I have.
I just make work that I think is absolutely vital
and it isn't about preaching or trying to,
trying to tell people this is what you must,
this is how you should think
and this is what it's all about.

My work is about presenting a piece of work
and then putting it out there
and people can think what the hell they want to think.
It isn't prescriptive. So I'm not saying, like,
somebody for example like Mat Fraser
who in the past his work was very much
about trying to educate people about thalidomide.
I don't do that,
I'm not trying to educate people in *anything*.

What I'm doing is something different

What I'm doing is something different,
it's a different approach,
an approach that I'm playing with people,
I'm taking them on emotional sort of roller coasters.
Because I think it's far too generous
to be explaining to people.

You will never hear me say
I have spinal muscular atrophy
and this is what it is to live with it.
But it does enter into the work
in a way that can't be so,
it isn't going to relate to anything
that they may have read
or not read about you know, the situation,
be it disability or not.

I think it's more open to interpretation
if you don't stereotype your own work.
That's not how I want to make work.
I'm trying to make it more about
psychology of what's unbelievable.
And also a basis from a .. a fun perspective.

In saying that,
it's not about eliminating anything.
So it's not about eliminating disability,
but it isn't about
only people with some connection to disability
will understand the work,
because I think once that happens
the work is restricted
by who can or cannot relate to it.

So this is why
the work that I make at present is about,
I'm trying to think of instances,
it's about illuminating stuff out there,
but looking at it from a fresh,
from a fresh perspective with a,
in a way that is, is completely different.
While it has me in it,
it isn't creating sort of, a set of scenarios
that are easily palatable by an audience.

So for example 'Miracle of Life',
I've literally picked up all the worst sentiments
that come hand in hand with somebody
who's weak and needing full-time assistance,
can't eat very well or swallow.

I've completely turned it to myself,
presenting myself as a victim
as opposed to a heroic paralympian
or this heroic woman with a disability
who is so self-assured that she or he is
telling people how we need to think
and how discrimination is out there
and it's really, it's all wrong.

I don't do that. I actually
sort of immerse myself into that fucked-up position
that society has on disability.
And then intentionally ridicule myself to the audience
and then they are not able to do it, I guess,
or are thinking what the fuck is going on here,
there's something not quite right
but I can't put my finger on it.

Artist's Talk

I was asked to lecture, an artist's talk.
I didn't want to do a straight talk,
I refuse to do straight talks.
So I went there as a victim
and presented everything from a victim's perspective.
And that was the talk I gave to the students.
They really didn't know how to..
to respond or to relate.
And a lot of them felt really baffled
by what I was doing.
And some of them got it.
I don't make things easy for people.

I'm sort of setting it up to make it
as if you were watching paint dry.
So it's all contrived.
Everything I do is contrived.
So for example, I would say oh hi everyone,
thanks for being here today,
it was a really quite a sort of
horrendous journey getting here
and I'm really grateful to you
for being able to come here today
because I don't get out much.
So what I do is I'm filling them
with utterly regurgitated
all the sort of negativity that people have on disability,
either consciously or subconsciously,
spewing all over them.
And that's how I would do that talk.

What I do

I'm quite inventive in terms of
I might have a piece of work for one thing,
but I re-invent it in the workshop.
So for example I had a film which is animated,
got animation, it's still animation.
It's about a stick person
who's doing all sorts of things
that you wouldn't expect a disabled person to do.
It's very crudely drawn in Photoshop,
under my direction. And it's of a person in a wheelchair
doing things like they're shooting babies,
running over ducklings and they're,
they're all part of a charity,
which is a charity run by Together for Short Lives.
And we have this image of
a stick person in a wheelchair
with pillows on their lap
and a sort of connection there is
they're about to put the pillows
over the babies' faces to kill them.
So, you know, I try to make it as sick as I can.

I'm presenting it as an artist's talk.
I will sort of say, you know,
as an artist I do a lot of painting,
I stick the brush in my mouth
or wherever it will go and, you know,
I really get a lot out of..
so what I do is I create
an inspirational profile
for why I'm making work.
And so actually what you're doing
is you're juxtaposing
the complete opposite of why you're doing it

to what the visuals are.

I present myself as this really sort of earnest artist
who's making work as a,
as a hobby rather than as creative process.
And that's really the essence to my work.
It's that completely, just twisting everything around.
Because to me
that's interesting and exciting
about playing to those models
that are inspirational and motivational
when actually I don't see myself
as any of that stuff. I don't gravitate towards
disabled people that see themselves as role models.
I've done quite a lot of research
on disabled people that do this
and it's just so hideous, so horrendous.

I used to get my stimulus from the disability Workhouse Cabaret
now I've gone on to the internet
and seeing really what I consider to be
very sort of misleading representations of disabled people.
I find it all so nauseating.
But that has also helped me to redevelop work
that challenges those, it turns this notion
that disabled people are iconic,
in any sense of the phrase, on its head.

Because nobody will see my work
as major art, it's just so good.
'Oh that's just really lovely,
'Katherine's really trying to say something here,
'cause she's said it really well.'
If they wanna do that,
the work will never do that.
Just can't do that, sorry.

I'm sick and tired
of those strong powerful messages,
so I, I create a different formula, a different,
just a different way of engaging.
So I guess the viewer is forced
to engage in a way
that can't be so stereotyping.
Does that make sense?

Working with Aaron

I met him for the first time at Sadler's Wells,
at an opportunity for disabled artists to pitch an idea.

He was there with 15mm Films
and I was there completely independently
doing my thing, but we were both
coming from film perspectives.
He really liked what he saw,
that I was doing, and so he,
this other person introduced us.
And then I became the editor.
He just liked my concepts
and he could see what I was doing.

I never told him anything,
he just, he really liked it
and so he approached me,
I didn't know who the hell he was.
And, we just, I liked his sensibility, he was,
you know, intelligent, bright, charismatic person,
but was really just completely
clued in on disability stuff.

And for me he didn't form part of the ghetto,
he wasn't confined to just disability arts,
he was able to go outside of it and in it.
And he's funny. I found his humour funny.

And we weren't sat there for hours
trying to educate each other,
we already had that education that one needs
when it comes to disability politics,
enough to be able to make art that we,
that fucks around with people.

And I think that's how, you know.
we formed the Disabled Avant-Garde
and we got commissions.
None of the critics wanted
to write about the work
because they didn't know
how to communicate about it.
They could only see it
through the eyes of sentimentality.
They weren't able to see it
for the art it is.

And so it was very difficult to get reviews.
That was the struggle.

Commissions

To get work as disability art
it's not always easy, because to try to,
our ideas are so forward-thinking.
It doesn't fit in
to the sort of medical rules that people,
(whether they know that or not) are used to.

I know someone recently who got a,
really lot of money to make a piece of work.
And basically it was about her pain and suffering.
And that's what they like to commission.

What the Disabled Avant-Garde wants to do,
what I like to do, is make work
that really doesn't embrace disability
in the sort of way of saying
aren't we fantastic
and aren't we great
and by showing this work
more and more of us
are all going to become empowered,
you know and just by watching it
you're going to understand our lives better
and really that we'll become equal.
It's just bullshit, absolute bullshit.

But it seems that commissions aren't,
even with Unlimited,
they're not interested in work
that's going to create controversy.
That's why they love someone like Sue Austin,
who swims around underwater
in a wheelchair.

I'm not saying their work is bad

I'm not saying their work is bad,
but it isn't doing what,
what the work that I would do,
which would be actual completely different sensibility.

And it wouldn't be work
that could be seen as beautiful or celebratory,
it's another type of work, but it is,
it is saying something.
But as many people can't read,
they won't be able to engage.

That's why I think the live art scene
is where I've sort of found my niche.
I feel comfortable within that scene,
knowing that they, that they get it,
irrespective of disability.

Disabled Avant-Garde

I think my work as the Disabled Avant-Garde
is different from my solo work.

I really like working with Aaron,
it's just easy. He comes up with an idea
and we both do brainstorming,
and often he comes up, you know,
with strong ideas and because they're so good,
I don't really, I'm not into sort of saying,
oh no, why don't we change,
why don't we turn it into.,
it's just a waste of time.
If the idea's good,
then just leave it and get on with it.
And so, he's very easy to work with
and a hundred percent reliable.

He can source anything, he can do anything
and so for me working with him is a real pleasure.
And, you know because we are ultimately
taking the piss, but Aaron's very good at
intellectualising anything that we do in a superb way.
And I think that the work I do with him
is slightly different,
but it still has that same thing going through it,
which is very much, you know,
against the grain,
going against how society,
the expectations that society holds
in everything, not just disability,

DAG Spa

We had such a good idea for the Unlimited round this year
and they just didn't even invite us to have a talk.
We wanted to open up a spa in Spitalfield Market
and have like a stall, like an area
where people could come and be pampered
by the Disabled Avant-Garde.
It was such a good idea,
people would come in
and we'd puff up their ego and,
it was structured,
and they won't work like that
because it doesn't follow the strands
that Unlimited are wanting to achieve.
We weren't even invited for an interview.

We were thinking about actually having
our own Spastics Shop,
but we wouldn't call it Spastics Shop,
we'd call it something good.
And we would come into this space
and it would be where it all went on workwise,
we'd have like little badges
that were promoting the Disabled Avant-Garde.
So we're talking about using that sort of,
that aesthetic to recreate a shop where you went into and it was all like..
But it was like experiencing I don't know,
like brain-curling disability,
the sort of garbage that's out there
and the trash that people can buy.
But we've created that trash inside a sort of shop,
like a DAG Spastics' Shop or something.
I mean I worked with Aaron very well.
It was, at the time, it would
it would have just been hilarious

we were going to film it a bit like
The Only Way is Essex,
turn it into like a live sort of,
and we were saying things deliberately to the public
that were provoking towards disabled people.
And again, Unlimited won't run that type of stuff.
They don't want it because it's too,
it doesn't fit within the very small alcove
of what they like to commission.

So I think when I do things with Aaron
it's sort of, you know it's exciting and we think,
if we're actually getting funding,
we throw up very good ideas.

'Miracle of Life'

But often, when you haven't got the funding
your ideas are smaller because
if there are loads of restrictions,
you have to think in terms of DIY aesthetics.

For example, the 'Miracle of Life',
which I've turned into a karaoke song,
which I've used in my live art performances to date.
The idea was eventually
to turn it into a video,
so that it would sit amongst
the most awful disabled songs.
The background behind that was,
everything on YouTube or the internet,
everything to do with my disability,
or disability per se
always has this sentimental music.

And there's all this stuff, all these role models
or this guy that's got no arms and legs but does this song.
And it was really terrible,
and he's a preacher, he's a pastor as well.
And so my idea was to create,
to do a song called 'Miracle of Life',
which, I was, the words are just horrendous,
I even paid a composer I'd worked for in the past
and he had loads of research material
to make me this really trashy,
this really nauseating original soundtrack.

I made a crowd-funding live
and I created this terrible profile
about me trying desperately to get funding
because I hadn't got long to live

and I wanted to write my last..
And I got over four grand.
Which I haven't even spent.
It's still there waiting to be used.
So what I say is I've set things up that were
messing around with people's heads.
I've put myself in a crowd-funding thing as a victim.
And I wrote it from a third person.
I got someone, I wrote it of course,
but this friend of mine who's like me.
I create these sort of fake scenarios.
Again, playing with the whole
perception that people have.
You know I can't say
I don't use disability, but I just use it
in a very contemporary way,
as do most artists.

And that is a piece that I use
during my performance
but I will be turning into a video
at some point
and the idea *is* to put it out there.
I want more people to see it
- and believe in it.

Working Practices

When I'm dealing with somebody else
there's always a difference there.
And I think that we are,
I think the Disabled Avant-Garde, we are,
we're generally making the work
where we have a commission
as opposed to me just churning it out.

I think the concepts
are always strong with Aaron.
I think that we, for me the good thing
about dealing with Aaron
is that he's just another person
to go through the process with.
And that's really energising.
I think we egg each other on.
And that's really helpful.

Whereas if I'm doing a piece independently,
it is more of a case of,
you know you have to be more confident
because you haven't got somebody else to...

And as far as what I'm saying in the work,
do the Disabled Avant-Garde say anything different,
I don't think it is. I think we're putting it out there,
but in different, in just a different way,
depending on the commission
and what we've been asked to respond to.
I think it's still, based on where obviously he comes
from a different school of thought,
he's a very practised art performance worker,
he's very disciplined and he's absolutely,
if it involves a dog he will bark like a dog.

And he really will,
we're not talking about an actor mimicking a dog,
we're talking about Aaron completely
immersing his entire self into the dog,
oh my God, despite the fact
that he cannot hear any more everything.
And also he, it's unbelievable.
Unbelievable what he does.
And I admire the amount of discipline that he has.
And I also recognise that it is easier for him to do that
because he doesn't have fucking PAs.
Or carers, whatever you want to call them.
So I think that working with him is really brilliant,
but it's also, I mean I totally,
yeah I love that, that he doesn't,
it's not about acting,
and I think there's a very clear distinction
between what is acting and what isn't.
So if he had to, what ever it took to get into the role,
he would do without any sort of inhibition.

And that's the sort of person that you,
that I want to work with.
And I really think,
I think that I've learnt a lot from him.
But at earlier stages, so that now I'm able
to just do something without.. you know
I don't want to be thinking about
is this okay for the audience,
it's nothing to do with that,
that isn't the process.
The process of thinking about a piece
and get it, presenting it to where you want to,
how you want to present it.
And not actually taking into consideration
the viewer whatsoever other than

'If I do this, will it kill them?'

I think absolutely that
Aaron and I have never ever
had a conversation in which we are talking
about how can we change the way
in which society sees disability
or whatever, it's all about,
sometimes we do touch on subject matters
where we have to at some point
cut the reins as to whether we could be offensive.

With a commission, if we have a theme,
like a brief, then we can very much sort of
bounce off of each other,
come up with some very good ideas.
It's like brainstorming,
it's very quick, DIY's about speed,
it's about doing it very quickly.
As opposed to, you know,
think about it forever and then making it,
it's a very quick thing to do.

Collaborations (1)

I'm not totally embarrassed
that I tend to have artists approaching me
and wanting to collaborate with me.
Artists with their own art, established artists.
So that's very nice.

I did a Battersea Arts Centre residency recently
and I had Ursula Martinez as my mentor.
And she's done work, I really liked her, actually.
But she comes more from a theatre,
she has done performance, she does do performance where
she did a piece called 'Hanky-Panky',
where she completely strips down to nothing,
she also had work shown at the Soho Theatre.

I really liked DIY,
whereas she's, everything's sort of,
she knows where everything is,
and it's all very much more organised,
and structured, and so it's interesting
where I think as a mentor as well as Kim Noble
is an artist whose kind of mental health,
depression for years, and his stuff
was really amazing as well
and it was really good to have them
understanding my expertise
as being encouraging to me to what I do
and saying things like, you know,
people like you need to do what you do.
And I think at any age
it's good to get that feedback,
particularly from people that wouldn't,
they wouldn't know anything about the disability art movement.
So yeah, that was good.

And so that made me think about
maybe applying for some funding
to take the show to the Soho Theatre,
you know is it something I could actually do,
because, but I think I could,
I think I would love to do that.
The Lights On and stuff, shows there.

I would never fit into that mainstream theatre
but could potentially fit in to Soho Theatre.
Or Battersea maybe, Rich Mix,
somewhere like that, just do a piece of work
that was really demanding
for the audience to watch,
you know plays around and at the same time
does have subversive humour in it
like 'Miracle of Life'.

Collaborations (2)

I think a lot of people
don't necessarily understand my work or get it,
because they come from a theatre background.
And so they don't really understand me
and they start critiquing it
and look on it as a piece of theatre.
It isn't a piece of theatre
I just don't say anything,
I just hear what they say
and then realise that they don't really understand.

Because I have people in the art world,
in the live art scene approaching me,
but I don't really have anybody
in the disability arts scene
approaching me to make work.

To me,
making a piece of work that's good
involves a conversation
in which you can connect to the person.

If you don't connect,
you can't make a piece of work.
Because you're seeing things
with a completely different logic.
Even though you think the person believes
they're on the same wavelength,
you can't make work with them.