

Augmentative Alternative Communication and Leadership Research

Winston Churchill Travelling Fellowship 2012



Nadia Clarke

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BACKGROUND

I am 20 years old and I live in the United Kingdom with my large family. I am Deaf and disabled. I use an electric wheelchair to get around independently and an electric communication aid to talk.

I got my first communication aid when I was 5. It takes much practice and motivation to be an active Alternative Communication Aid (AAC) user. Over the years I have come to understand that communication was the key to my inclusion, education and self-worth. The United States of America has been ahead in the development of ideas and technology within the AAC world. I wished to learn from successful communities in the USA and bring this knowledge back to the UK to raise aspirations and expectations of young disabled people and professionals working with them. Not being able to speak is extremely isolating and yet experience has taught me that using alternative communication systems is uniquely challenging. The speaking world communicates and interacts at a speed and with language that is not easily accessible to non-speakers. The AAC community is small in the UK and many young users never have the chance to meet an adult with the same barriers. Many young people lack the motivation to use communication aids. It is both physically and emotionally draining. The primary benefit of this research is to bring new ideas and a wider range of experiences to these vulnerable communities. As a result of my own direct experiences, I am strongly driven to help raise the expectations, aspirations and integration of AAC users.

I have attended mainstream school. We lived in Northumberland and my family tried to get me a place in my local primary school. Unfortunately, at that time inclusion was only just beginning to emerge on the government agenda. They tried hard to find a local school that would integrate me and eventually we moved 100 miles to Halifax. Calderdale (the local authority) had signed The Salamanca Agreement as part of the United Nations Human Rights towards inclusive education. Tyne Tees and Yorkshire TV did a programme called "For the Love of Nadia" about us moving.

My mum and dad were very committed to my inclusion in all aspects of society and my being able to communicate within mainstream environments. I

remember going on a campaign march and demonstration in London when I was 5 years old and, together with an organisation called “The Alliance for Inclusive Education”, I delivered a letter, with my brother, to Tony Blair saying how important Inclusive Education was to me.

I went to the same primary and secondary schools as my 5 brothers and sisters. I then attended Calderdale College and completed Health and Social Care Level 2. I also studied English because British Sign Language (BSL) is my first language.

I understand the challenges around being disabled and using a communication aid. I have talked on the radio and also supported the campaign called “No Voice No Choice” with Scope the charity. I spoke at the Houses of Parliament, at the *Bercow* Review on Speech and Language Therapy, on the importance of having a voice.

I have done lots of interesting work experience over the years. This summer I had work experience at the Houses of Parliament and I shadowed Sharon Hodgson, MP, and Sarah Teather, MP; both are Health Ministers for Children and Disabilities.

I have spoken at many conferences around the country about inclusion, Direct Payments, Transition and Personalisation. I also talk to social work university students as a guest lecturer.

I have an interest in disability and civil rights and have marched against the recent budget cuts and also spoken in Calderdale at a rally together with our Member of Parliament.

I especially love to socialise and to communicate with people. This is why I am so interested in helping others. In the future I aim to Promote Leadership amongst disabled people especially those with communication impairments.

I planned my trip to America, thanks to receiving a bursary from the Winston Churchill Memorial Foundation. Their motto is ‘To Make a Difference’. For more information with regards to WCMF visit www.wcmt.org.uk. The areas I planned to visit were New York, Pittsburgh and New Orleans. I used research questionnaires and filmed interviews with other communication aid users.

AIMS

My aim was to analyse and understand the range of AAC use and experience in the USA – and possibly other countries - in order to inform and inspire AAC users within the UK. It is not simply about the technology or the therapy that users receive.

In this project my objective was to meet a number of individuals who use AAC and to listen to their stories and build-up my knowledge of how they overcome barriers to become highly effective communication aid users and communicators. I did this through face to face interviews with people from all over the world and also through questionnaires.



I am a Role Model for the national charity *1Voice - Communicating Together*. I come across many young people who, when they leave children's services, lack motivation to be active communicators. I wish to use the information and the stories from the US to train and work with young people in the UK. With due respect and permission, I will use film and other multi-media to showcase the American stories.

I will also present my findings to the national charities working in the field of AAC, in order to offer a users perspective to the professional community.

THE PROJECT

New York 20th to 25th July 2012

Interviews

<p>22nd July 2012 11am Waldorf Astoria, New York</p> 	<p>I met Marlena Katene in Waldorf Astoria Lobby. Marlena lives in Australia and she has own business. She has used AAC for many years, and is a friend I met in London's Hyde Park 2010, at a festival. Marlena agreed to meet me in New York, whilst she was travelling through America, to discuss Leadership and so that she could participate in my questionnaire.</p>
<p>23rd July 2012 11am Waldorf Astoria, New York</p> 	<p>I met Laurence Byrne in ISAAC Barcelona 2010. Laurence is a fellow AAC user and a very inspirational man, he writes and publishes E-books in Australia where he lives. I was lucky to meet with Laurence in New York prior to the International AAC conference in Pittsburgh. Laurence has so many views about Leadership. It was fantastic to interview him, especially when he had organised to meet in the Waldorf Astoria Ballroom!</p>

Pittsburgh 25th July – 03rd August

ISAAC conference 28th – 03rd August 2012

Interviews

26th July 2012

Half 12 pm

DynaVox Mayer Johnson



I met, Todd Tyler, Vice President and Heather Koontz, Marketing Coordinator at the DynaVox facility. I had a tour of the facility which took me through different areas, for example, the laboratory where Dynavoxs' are created, the marketing suite and the business suite. I finished the day by meeting all the staff, and I was lucky to have a meeting with the Vice President to discuss Dynavox solutions, marketing and general information.

My visit to DynaVox Headquarters, Pittsburgh



I was keen to visit the headquarters of Dynavox since, having been a communication aid user for the last 15years, I felt it was important to meet the people who market and sell the product and for me to have the opportunity as one of their successful consumers to have a voice in their product delivery.

Over the years I have had regular contact with the suppliers in Britain and have spent many hours with their technical support team. We have had a lot of input and training over the years. More recently we have had contact with the Pittsburgh team over the telephone when things have gone wrong with the technology. As I was already in Pittsburgh at the Conference I thought it was a good idea to meet their US team.

In 1983 an undergraduate student called Gary Killiany, a volunteer at the rehabilitation institute of Pittsburgh met a young woman with cerebral palsy. He was inspired to create a device which would allow the young woman a voice.

Today, that creative thought has turned into a device which helps thousands of people worldwide to have a voice, this device, a communication aid is called a DynaVox.

In 2001 Medicare joined DynaVox in a joint effort, to allow third party funding for individuals instead of people paying for their own devices. Still to this day DynaVox acquire third party funding so that people can have a voice.

I think it is fantastic opportunity to use a communication aid because disabled people need a voice. A communication aid has lots of words and folders in a DynaVox.



PITTSBURGH • WOW



PITTSBURGH • WOW



ISAAC and AAC Camp

One of my reasons for visiting America was to attend the 15th International Seminar for Augmentative Alternative Communication in Pittsburgh. This was a perfect opportunity for me to interview and research my Leadership project.



About ISAAC.....

ISAAC – the International Society for Augmentative and Alternative Communication – is a membership organization working to improve the lives of children and adults with complex communication needs.

ISAAC's goal is to create worldwide awareness about how AAC can help individuals without speech. ISAAC accomplishes this by sharing information and promoting innovative approaches to research, technology and literacy through AAC. Activities include hosting the ISAAC biennial conference, sponsoring projects, and offering awards and scholarships.

- ISAAC was formed in 1983.
- ISAAC has Chapters in 15 countries and more than 3,600 members in 62 different countries.
- ISAAC members include people who use AAC, their families, therapists, teachers, students, doctors, researchers, organizations and companies that make communication aids.
- The ISAAC International office is located in Toronto, Canada.

International Society of Augmentative Alternative Communication (ISAAC)'s mission that people anywhere in the world who communicate with little or no speech deserve to achieve the most effective communication possible in order to achieve their maximum potential.

ISAAC Camp

ISAAC Camp 2012 is a weekend camp experience for non-speaking or severely speech impaired children from the ages of 5 -21 who functionally use augmentative communication (AAC) strategies and tools to communicate. Children get the opportunity to interact with other children using AAC systems while increasing their ability to communicate and enhancing their language and literacy skills through functional activities. The Camp is conducted in English.



The Mission of the AAC camp was to help the children to become more

competent users of their AAC system, provide opportunities to develop relationships with other AAC users and provide a fun environment for campers and families to interact and learn. For me it was a fantastic opportunity to meet with children who use communication devices. For three days I became a Role Model to the youngsters, I supported them to create different activities. I was very lucky to be asked if I would tell the children a story, my story is called *Diva Goes to London* (I have a copy of the presentation on a film for you to see). I think all the children were so interested it was fantastic! All the children had never been to London before. After I had finished the story the children talked about how inspired they were to start writing stories of their lives and achievements.



Diva goes to London

By Nadia Clarke






ISAAC provided me with my best experience. I gave AAC users and professionals a presentation called Deafness and AAC. It gave an insight into my world of Deafness, and how my life changed and those around me had to adapt to a new life experience. The presentation had

fantastic reviews from all who came to watch and for the rest of the day I felt so happy and proud.



Further interviews

<p>29th July 2012</p>  <p>1pm Hampton Inn and Suites Board Room, Pittsburgh</p>	<p>The first time I met Isabelle Duncanwood , was by passing each other in my hotel reception area. This was a great opportunity because she has written a story book and has married another AAC user. Isabelle hasn't always used an AAC device, she has only used AAC for the last 7 years, due to an illness which has disabled her body and speech.</p>
<p>30th July 2012 Half 8am Hampton Inn and Suites Board Room, Pittsburgh</p> 	<p>I met Snoopi Botten in Pittsburgh. Snoopi lives in America and has used a communication aid for 26 years. Snoopi produces CD's, he programmes music. Before he became a producer he was a Comedian. His favourite music is Gospel music. He has won awards for his music.</p>
<p>1st August 2012 3pm ISAAC Westin Conference Centre in Pittsburgh – The Courtyard</p> 	<p>Rick is the Senior Consumer Executive at Dynavox. Rick has used a communication device for 20 years. In 1965 he became depressed as he could not communicate with others, but now he has changed his life around, he found God and is now a Pastor at his local church. Rick says "He believes in blessing others instead of expecting to be blessed".</p>

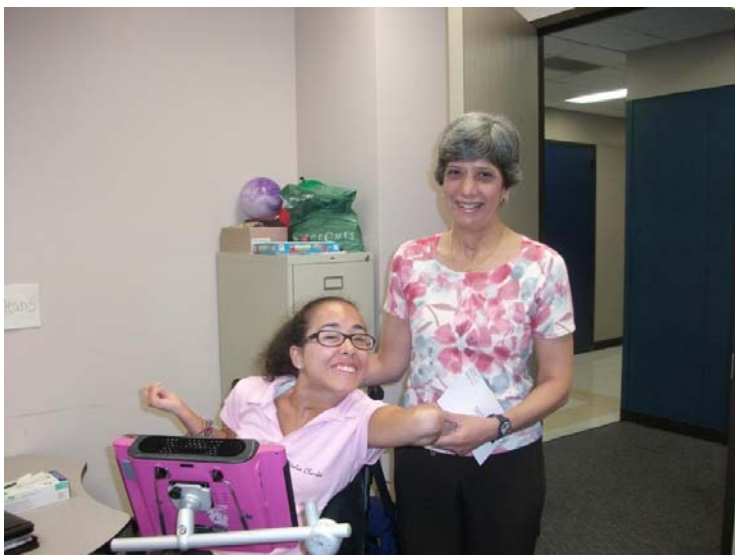
New Orleans

3rd - 9th August 2012

Interview with Professor Meher Banajee Ph-D, CCC-SLP

Professor Banajee is an Assistant Professor who works at the school of Allied Professionals, New Orleans.

Her job is to understand and research language development and AAC devices.



I was lucky to receive an invitation to visit Professor Banajee by email, after contacting the School of Allied Health Professions Department whilst researching what AAC and communication facilities

New Orleans had.



The LSU Health New Orleans is a facility has a Speech and Language department and a Communications Disorder Department, amongst others. Professor Banajee is one of the Speech and Language consultants, at present she is working with the following three projects. An 18 month old child who cannot speak is learning how to use a communication aid. The child appears to enjoy developing new words from pictures.

1. Asking existing AAC users to show new AAC users how to operate their devices.
2. Working with children who have autism and how the communication aids help their development. Prof Banajee has developed a classroom programme with visual support, low tech communication systems. This programme has been tested and they have found great success.




I thought
Professor

Banajee was very inspirational. She taught students how to programme their communication aids and she also helps disabled people to understand their communication aid. In some schools a Speech Therapist can be accessed however this varies according to where you live. It is a 'postcode' lottery. There are some good examples of support in both America and England. Some children however are still without communication aids due to lack of expertise within their local area. And lost aspirations from staff and parents around what can be achieved. If no support is provided students can feel isolated, depressed and have low self esteem.

Contact information for Professor Meher Banajee. [Meher Banajee, Ph.D., CCC-SLP. Assistant Professor, LSUHSC, Communication Disorders Dept., School of Allied Health Professions, 1900 Gravier, Rm. 9C1, New Orleans, LA 70112.](#)

Further Interviews

<p>7th August 2012 10am</p> <p>No Photo</p>	<p>Margeret Labelle has use communication aid for 3 years. She lives in New Orleans with her husband. She worked has a teacher with children in school for 10 years, but she had to retire because she was ill. The illness made Margeret's body disabled and three years ago she lost her voice, this is why she now uses AAC.</p>
<p>7th August 2012 Half 12pm</p> 	<p>Mr Ambrose lives in New Orleans with his family. He has use communication aid for 6 years. His Role Model is Steven Hawkins. His biggest influence is Professor Meher Banajee for teaching him how to use the communication aid.</p>

Results and Information received from AAC users.

I obtained my information from other AAC users by means of interviews, general conversation, questionnaires and email.

I have provided 'spider diagrams' to show five questions asked to AAC users and their responses are highlighted around the question in black writing.

The five questions asked are as follows;-

- 1) Think of some of the challenges you have faced from early on in your life until now?**
- 2) What solutions did you find to overcome some of the challenges?**
- 3) What are some of your biggest influences that have made a difference in your life?**
- 4) What are some of your successes and achievements that you feel really proud of?**
- 5) If you could say three things that you would like to do to make a difference in your own community what would they be?**

"It's hard to go out without a communication device".

Julie Burns, US

"Before, I had no communication and no friends".

Krista Howard, US

"People believing in me and my method of communication".

Maressa Mackeith, UK

"Because I have a communication aid I don't need to go to a special school".

Katie Caryer, UK

I asked.....Think of some challenges you have faced from early on in your life until now?

"Finding the right technology that would give me a voice".

Bob Segalman, US

"Professionals not giving me enough time to complete my sentences".

Greg Gilmour, UK

"When people talk to my assistant and not me".

Beth Moulam, UK

"People thinking that because I am a disabled person I have no brain".

Isabelle Duncanwood, US

“Trying to make learning about my communication aid fun. “

Julie Burns, US

“I have found no solutions. “

Snoopi Botten, US

“Patience!”

Margaret LaBelle, US

“Improved my communication aid. “

Rick Hohn, US

“Finding good support.”

Nadia Clarke, UK

“Having a strong disability identity. “

Katie Caryer, UK

I asked.....*What solutions did you find to overcome some of the Challenges?*

“Having a strong personality and good social skills.”

Simon Stevens, UK

“I became a ‘Smart Alec’!”

Isabelle Duncanwood, US

“A willingness to challenge the “norm”.

Simon Stevens, UK

“Finding the courage to ask for help.”

Maressa Mckeith, UK

“ Fantastic
teachers”.

Julie Burns, US

“Going to a school
that met my needs”.

Julie Burns, US

“European youth
conference”.

Simon Stevens, UK

“My family”.

Jennifer Lowe, US

I askedWhat are
some of your
biggest influences
that have made a
difference in your
life?

“My 1 voice
friends”.

Jemima Hughes, UK

“My religion”.

Rick Hohn, US

“Meeting other
AAC users”.

Maresa McKeith, UK

“ Discovering the
disability rights
movement”.

*Simon Stevens, UK (when
he was 8 years)*

“Becoming an executive director of a large organisation, called Dynavox”.

Rick Hohn, US

“Talking at conferences and schools”.

Nadia Clarke, UK

“My book”.

Isabelle Duncanwood, US

“Having a positive attitude”.

Mr Ambrose, US

“Going to college to study becoming a speech therapist”.

Krista Howard, US

“Making films to inspire other AAC users”.

Jemima Hughes, UK

I asked.....What are some of your successes and achievements that you feel really proud of?

“English degree”

Maressa Mackeith, UK

“Completing a PHD”.

Bob Segalman, US

“ Confidence to help others who have a disability”.

Margaret La Belle, US

“ Passing my GCSE and A Levels and level 2 Business studies”.

Gregor Gilmour, UK

“Becoming a Role Model”.

Maressa Mackeith, UK

“Develop new ways of communicating with disabled people”.

Snoopi Botten, US

“Promote inclusion”.

Marlena May Katene, AU

“Educate non disabled people about people with disabilities”.

John m, Pfab, US

I asked....If you could say three things that you would like to do to make a difference in your own community what would they be?

“Ensuring people who need a communication aid get the right strategies given to them”.

Beth Moulam, UK

“Eliminate hate crime”.

Jennifer Lowe, US

“Developing software that meets the needs of those with communication challenges”.

Bob Segalman, US

“Support people to be positive about their situation”.

Simon Stevens, UK

Main Themes Which Emerged and Lessons Learned.

A number of disabled people - particularly those from the United States - said that they looked up to Jesus and their religion to find help.

Before people received their Communication Device they felt Isolation and Exclusion.

Before they had reliable AAC systems they felt ignored and had no voice.

Now people have a communication aid they have a voice, many have a job, have a family. Most importantly, they have a reason to live!

During my research project I met people who use communication aids from America, Australia, South Africa, Canada, Holland and from my home country the United Kingdom. One commonality that stood out from all the people I interviewed was that they had good support. This came from a number of sectors: Speech and Language therapy, Professionals, friends, family, carers and personal assistants. Without good support people are saying that it would be very difficult to have aspirations and achieve goals..

Good support allows people with communication impairments to feel empowered and motivated to use a communication aid, even at the early stages in their lives.

Being a confident communication aid user takes years of practice and hard work. It also requires a holistic approach and needs team work from a range of people. It doesn't just happen. Words need to be programmed, taught, practiced and, due to the physical access being limited, there also needs to be motivation and encouragement. There is no doubt and in my own personal experience that using an aid is hard work. Growing up I personally found times that I just did not want to use my communication aid and sometimes I felt like giving up. It was thanks to my family and those around me that I realised how important it was to have a voice.

Motivation can come from the family but often there is a range of professionals involved with the necessary skills and experience when using a Communication aid. From all involved there needs to be a degree of high expectations and knowledge. There needs to be a belief of the person's ability and their true worth.

The majority of the people I interviewed as part of the research - and also those I met at the conference in Pittsburgh - were very confident individuals. Disabled people who use communication aids need to be resilient and feel strong and positive about themselves and how they fit into the world that disables them.

Throughout the interviews I found out that many of the adults had experienced feelings of despondency and sometimes severe depression. A few people had thought about suicide.

My Conclusion and Future

It is hard to believe many children grow up without a voice or speech!

There are a number of people in the world who use Augmentative Alternative Communication and I personally think this is wonderful. However, there are many challenges to using AAC as there is often little funding available. Many people do not understand how important it is to use a communication aid or do not understand rights to communicate.

Whilst in America I met lots of AAC users and it became apparent that around 70% of them felt isolated as they were growing up because they didn't know about communication aids. Another common barrier was that, once they did receive their communication aid, they then didn't know how to communicate with another person. Receiving the aid is really only the first step. They then have to overcome language barriers. Some people had to learn how to use English – or their own country's language - and learn about how the communication aid works. Some of the communication aid users didn't want to go out; they felt isolated due to lack of confidence.

One of the things I have personally found from being confident with my communication aid is that it can open up so many new opportunities and experiences. I love to get out, to travel and to go on holiday with my family and personal assistants. Without my communication device I don't believe that I would have the confidence to enjoy these experiences in the way that I do.

I feel very lucky about my life and I feel that in the future I am going to change how people and families feel around communication, especially communication aids.

I aim to offer training to families around communication aids and offer support how to promote inclusion not isolation.

In the future I would love to travel the world to offer training to disabled and non-disabled people – and particularly to parents - about Augmentative Alternative Communication. I would like visit schools to help with Support Staff, teachers and children to understand how to use communication aids.

In the future I plan to write a story about my life, but first I want to go to University to study Disability Studies. Beyond that I plan to continue my research; work in the Houses of Parliament to support the government around the issues of Disability rights; get married and have children of my own. I am not sure which order I will do this in!



To the Winston Churchill Memorial Foundation for giving me the opportunity to carry out my research. I would recommend to anyone who believes that they can make a difference to apply to become a fellow.

Thank you to all the team at the Winston Churchill Memorial Foundation, especially **Julia Weston** who has provided me with full support throughout, from start to finish.

Thank you to **Dynavox** for welcoming me to Pittsburgh and for helping me when things went wrong with my communication aid in Pittsburgh and for your continuous support.

To my **family** thank you so much for supporting me and always being there for me, especially **Nikki**, my little sister who helped with my filming and interview preparation in New Orleans.

Thanks to **Sean** my big brother who has put his degree in Media to the test by creating my film for all to view of my trip and interviews.

A huge thanks to my Personal Assistants **Alanna Bentley** and **Cheryl Wickson** for providing support and encouragement while I was in America. Cheryl, thank you for all your help with the organising of the trip plus thank you for your patience whilst creating my Winston Churchill masterpiece. 🙌

To my BSL Interpreter, **Tracey Cade**, who supported me with my BSL interpretation at the ISAAC conference, Pittsburgh. There are no BSL interpreters in America, so thank you for your time.

Thank you to **Will Case** for inspiring me to partake in the Winston Churchill experience, by sharing his ideas, wisdom and positivity with me. Without you Will, I would have not taken the challenge.

I would like to thank all the AAC users and their families that took time and effort to help me with my research, without you all this would have not been possible;-

Marlena May Katene

Lawrence Byrne

Gregor Gilmour

Maresa MacKeith

John M.Pfab

Jemima Hughes

Katie Caryer

Simon Stevens

Rick Hohn

Snoopi Botten

Bob Segalman

Isabelle Duncanwood

Beth Moulam

Jennifer Lowe

Julie Burns

Margaret LaBelle

Krista Howard

Faye Warren

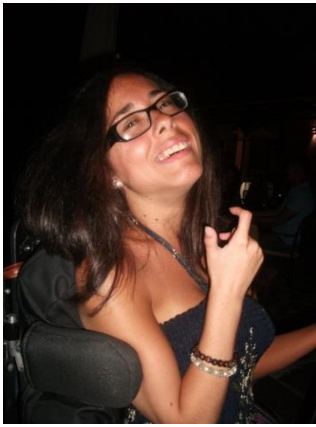
Mr Ambrose

Christine Quayla and her son Brian



Appendix – Itinerary

New York	Confirmed meet with Marlena May Katene and Lawrence Byrne at the Waldorf Astoria
<p>Pittsburgh and the ISAAC Conference</p> <p>Dynavox Pittsburgh</p> <p>Interview sessions at the Hampton Inn and Suites Pittsburgh</p>	<p>15th Biennial ISAAC Conference to be held in Pittsburgh</p> <p>Workshop to interact with other AAC users about issues related to my project, with the intent to record interviews for reflective learning A great opportunity to talk at the conference and attend various AAC workshops.</p> <p>Todd Tyler, Vice President and Heather Koontz Marketing Coordinator - confirmed meeting.</p> <p>Interview Candidates confirmed:- Snoopi Bottan, Rick Hohn, Isabelle Duncanwood, Julie Burns, Krista Howard, Beth Moulam, Jennifer Lowe and Simon Stevens.</p>
<p>New Orleans</p> <p>Private Interview Sessions</p>	<p>Meet Professor Banajee at the Allied of Professionals</p> <p>Mr Ambrose and Margaret LaBelle – confirmed home visit and interview.</p>



NADIA CLARKE

Nadia_rocks@hotmail.co.uk

ALTERNATIVE, AUGMENTATIVE COMMUNICATION (AAC) AND LEADERSHIP

WINSTON CHURCHILL PROJECT 2012

OVERALL AIMS:

To create positivity through sharing skills and experiences in order to determine and demonstrate Leadership in the wider community for those using Augmentative Alternative Communication.

Hello, my name is Nadia Clarke; I am 20 years old and I live in the United Kingdom with my large and often quite manic family. I am Deaf but still manage to hear my sisters arguing. I am also disabled, and therefore use an electric wheelchair to get around independently and an electric communication aid to talk.

I am fun, enthusiastic and have a great sense of humour. I see things in a positive way to overcome any challenges. Similar to many people of my age, I have many interests and hobbies such as watching films-especially the ones with Zac Efron. I also love listening to music, and going to festivals in the summer with friends and family. The sunshine puts a huge smile on my face, and holidays abroad are the best. Finally, I love to read-recently I have been reading 'Ghost Boy' by Martin Pistorius, an inspirational and interesting story.

I thrive off socialising, spending much of my time at the cinema, going out for meals or visiting the pub with friends. Socialising and communicating with people is so important and this is why I am so interested in helping others. In the future I aim to Promote Leadership amongst disabled people especially those with communication impairments.

World news is definitely something that intrigues me, spending time on the BBC news website and watching the news on the television. The news also allows me to learn more about the Government and I can keep up to date with whether things are changing in terms of disability rights- the status of disability within society and any changes in policy.

I have been through mainstream school and now I am at college studying Health and Social Care Level 2. This will help me in my future as I would like to study Disability Studies and Inclusion at University. I also study English because British Sign Language (BSL) is my first language.

I have done lots of adventurous and interesting work experience over the years. This summer I will be doing work experience at the Houses of Parliament and I will shadow

Sharon Hodgson MP and Sarah Teather MP, both are Health Ministers for Children and Disabilities.

In July, I will be going to America after winning a bursary from Winston Churchill Memorial Foundation. Their motto is 'To Make a Difference'. I will be acting as an ambassador for the Trust, for Sir Winston Churchill and the United Kingdom. For more information with regards to WCMF visit www.wcmt.org.uk. Whilst I am there I will be researching Leadership and Alternative Communication (AAC). The areas I will be visiting are New York, Pittsburgh and New Orleans, where I will be researching, using questionnaires and filming interviews with other communication aid users. My aim is to be an Advocate and also help change policy and people's attitudes around Disability to reduce barriers.

I will be around at the conference to pick up the questionnaires, and my team of PA's will be available if you need extra support to fill out the questionnaires. I will also be filming and using video equipment as well as using the questionnaire. If you are happy to be filmed whilst you are at the conference please get in touch with me. There will also be a chance to have a face to face discussion instead of completing the form.

Nadia Clarke's Questionnaire: The Challenges and Opportunities of being an AAC user

Your Name: _____

Your Address:

Email address: _____

For how many years have you used AAC? _____

I am interested in developing my understanding of some of the barriers and difficulties which people face who use AAC. Think of some of the challenges you (as a communication aid user) have had to face from early on in your life until now. Can you tell me about some of the main challenges:-

.....

What solutions did you find to overcome some of these barriers?

.....

I am especially interested in role models and people who are important to you in the world of AAC. Which people who have played an important part in your life and why are they important to you?

.....

What are some of the biggest influences that have made a difference in your life?

.....

I am also interested in leadership. What do you think makes a good leader in the world of AAC? What personal skills and qualities do you have that makes you a good leader?

.....

What are some of your successes and achievements that you feel really proud of?

.....

If you could say three things that you would like to do to make a difference in your own community what would they be?

1.
2.
3.

Thank you so much for taking the time to fill this questionnaire in which will help me with my research. Do send back via email or send by post to Nadia Clarke, 15 Savile Park Gardens, Halifax, Yorkshire, England. HX1 2XL

