

The Body Matters: Exploring disability and the body with disabled young people

“If you said “We can take that disability away from you say tomorrow”, then it would



feel a bit strange because one minute I have this disability, the next minute I’ve not and it’ll sort of make you look differently at the world. ‘Cos obviously I could just be normal, continuing my life but then I don’t think I would be the person I am.”

“Disability means you’re sort of different. But you’re a person as well, so you’re sort of a different person but you still have those feelings as a normal person would, it’s just slightly different to what you can do and what you are.”

Acknowledgments

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We are also very grateful to a variety of disabled young people who provided advice at different stages of the project, first the members of the Right Here, Right Now group supported by the Children’s Rights Team, Newcastle City Council and secondly the EXtreme group supported by Investing in Children in Durham. Thanks also to Heather Wilson who did the drawings for the website, we would like to thank her for doing such a great job!

The research team would also like to take this opportunity to thank all the members of our Advisory Group who offered invaluable feedback and ideas from beginning to end.

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Introduction

This booklet provides insight into the thoughts and ideas of a group of physically disabled young people who spoke to us about what they thought about their bodies as they were growing up and thinking about the future. What they said and shared with us is very important and we decided the best way to summarise that was to put together key things they said in their own words, alongside images they took or gathered. The aim is to get people to think about some of their own experiences of growing up, either with a body thought of as 'normal', or a body thought of as different in some way. That might be because of disability, or it could be something like skin colour, or body size. We hope people will read this and use it as a starting point to discuss and share their own experiences, or to reflect on what they think about the lives of people perhaps a little bit different from them.



**Attitudes
are the Real
Disability**



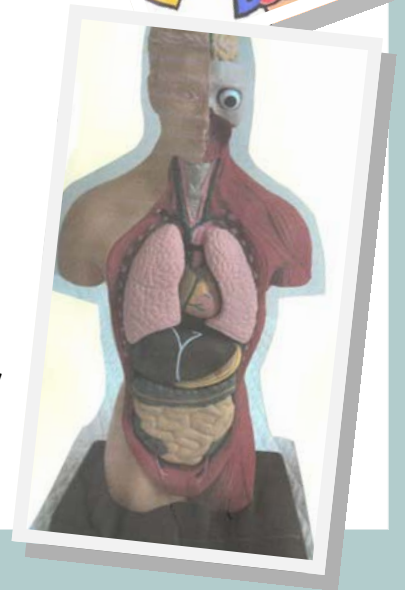
Background

What do disabled young people think about their bodies?

We wanted to find out what disabled young people think about having a body that might be seen as different by others, but which is normal to them. Our bodies change as we move from being children to young people, and we wanted to explore the ways in which disability changes that experience. We also were interested to know about young people's views on pain: what kind of sensations are thought of as pain; when does pain matter and what does it not; how is pain managed and what effect does pain have on life. Finally, we were also interested in young people's thoughts about the future and how that was influenced by being disabled.

What influences what they think?

We believe that what disabled young people think about their bodies is influenced by lots of things. This includes the range of things they can and cannot do compared to



others, the things done to the body to make it 'work', and the equipment they use to help them do stuff. Disability is not just about what a person can or cannot do though, it is also about the way people treat people with disabilities, and how the world around us is set up. We were interested in exploring how having a body that is different influences the stories people tell, both about their own bodies, but also about the world around them.



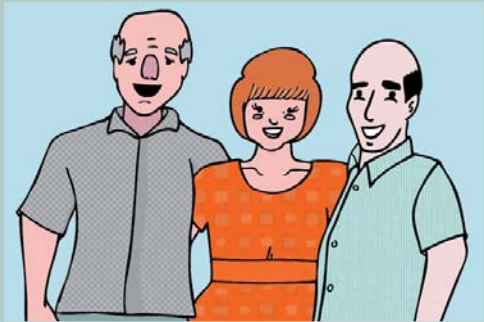
We did some work to find out

We asked 17 young people with cerebral palsy what they think about their bodies. We did this work in the North East of England. The young people were invited to take part because they had done research with us before or because they attended a local school set up for disabled young people. They received information about the study, and could ask any question they wanted. If they agreed to take part they gave their written okay. If they were under 16 their parents were also involved in the discussions and al-

so gave their okay. Here is some information about the young people who worked with us:

- 10 were young men and 7 were young women, and their ages were between 14 and 20.
- Their cerebral palsy ranged from affecting their arms and legs, to quite significant limitations to body function.
- Two participants spoke with a communication aide.
- Eight used wheelchairs to get about, whilst three more used sticks and frames or wheelchairs for longer distances.

We wanted to capture the different thoughts and feelings the young people had about the body, and the stories they tell about them. The study started with interviews that let us find out about disabled young people, their lives, and their thoughts on disability. Participants were then asked to put together a scrapbook of images that captured their thoughts on disability. We then asked more questions based on the scrapbooks. Finally we did some creative work, getting young people to think about how making jewellery can help explore what disability means. We went through all the things we were told, and have produced this booklet to share those things.



Given the work we did was with young people with cerebral palsy, issues associated with physical disabilities - for example having been in hospital and undergoing things like physiotherapy - were key things people shared with us. However, not all the things related to that and we think many of the things are also relevant to a range of disabilities that young people can experience - in particular the problems created by how people treat people differently because of the way they look, or speak or act.

The booklet

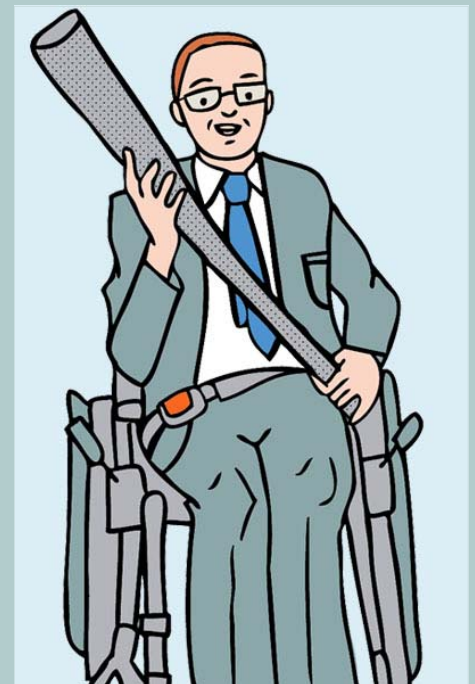
In this booklet we set out some of the things we found out - using the participants' words and images to highlight the things important to them. Some of the images people took have been turned into drawings. This is because images of people or particular things might identify them, so to ensure that is not possible we have used drawings instead. We also have changed people's

names and some details, so people can't be identified.

The booklet is set out simply so readers can get a sense of the various things people told us, and the different experiences that shape what disabled young people think about their bodies. Each page is separated into a distinct theme, and is set out with words and images so it will be interesting to look at. Most importantly though, we want to know what this makes people who read it think of, and what stories and pictures they might have to share. Therefore, there is a website linked to the project where anyone can submit ideas, stories, images. We will select some of those sent and add them to the website, so that conversations can continue around the thoughts shared by the research participants.

The web page for the project and to contribute is:

research.ncl.ac.uk/thebodymatters



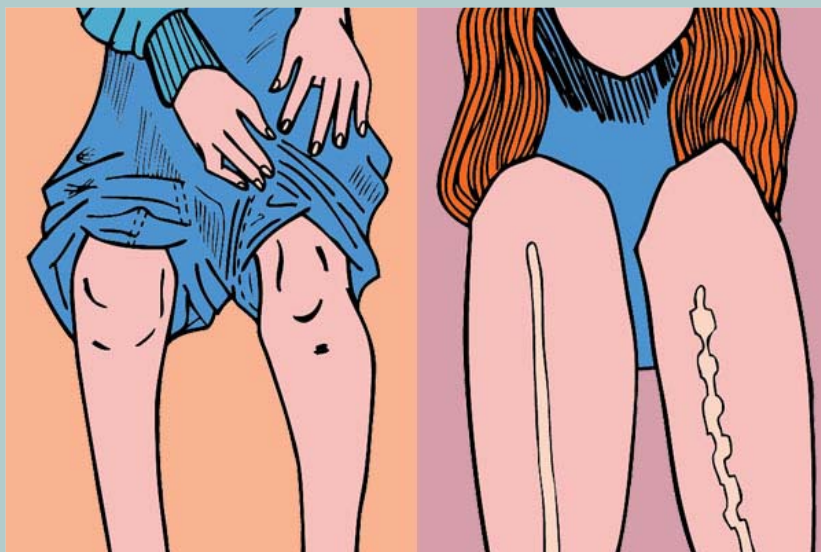
Stories and Images

Our participants in the project explored many things about the way their body looked, how they used it, what helped them do the things they wanted, things that got in the way – including the words and actions of others – and many other things. At the end are some thoughts we have on what we think is significant about what they said and the questions it raises for us.

The following pages speak to themes such as:

- Hospitals, surgery and the fixing of the body
- Finding ways and being able to do things
- Keeping active, happy and healthy
- Family, friends and support
- Feelings of pain
- Growing up and aging





Fixing the body

“I had four operations. The first was putting plates in my knees and putting cow bone into my foot, those sorts of things really. The second was putting wire into my foot, or taking the wire out, no taking the wire out. So I had wire put in my foot, and taken out, and the third one was having my tendons stretched from my hip to my foot. I’ve got a big scar at the back of my leg, that was quite sore, but yeah I got that over and done with. And then the fourth one was just taking

the plates they put in the first time out.”

Understanding disabled young people’s needs, and getting the right equipment

“I was twelve, thirteen, when I got diagnosed with visual problems. ‘Cos I wasn’t diagnosed, and my mum and dad kept saying at the school there’s something wrong with my reading. It was horrible, very poor. So they checked me again for dyslexia and they went ‘No she’s not got dyslexia, but she might have this other thing.’ And I got tested for that, and it turned out I had. Let me put it this way, if I was diagnosed earlier, when I was smaller, my grades and my levels could have been higher than they are now.”



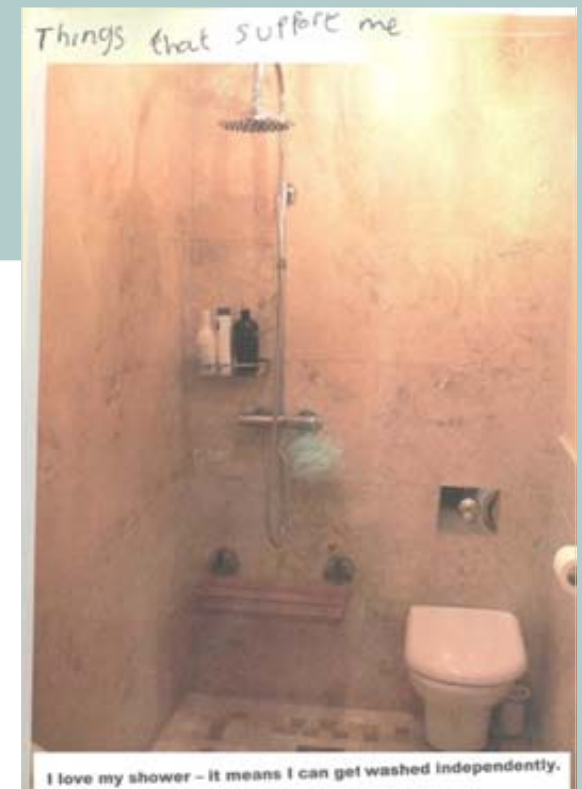


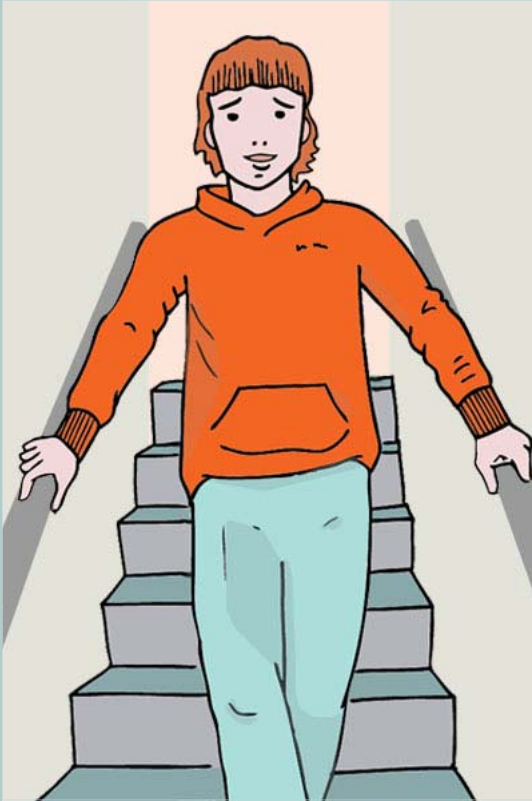
Facing challenges, and finding your own way to do things

“Disability doesn’t stop you from doing stuff. If you really want to do something you can do it. It does mean that it’s harder for you, and you have to work more at it, but it doesn’t mean that you can’t do it. You still can do things. It might take you a bit longer to do it, or it might be a bit harder. Doesn’t stop you from doing anything, just means you have to either work longer or work harder or find different ways of doing things.”

Building the right spaces

“They made a wet room for me so I can shower for myself. There’s a tiny little step to keep water from flowing out of the bathroom. The floor is better, it’s less slippery, and the seat pulls down so I can sit, ‘cos I can’t stand up and wash myself, ‘cos I lose balance. It’s very good for me, ‘cos I’m independent. I can do it by myself, and go in to the shower. I don’t really need help now. I need the odd help if I’m really, really wobbly, but apart from that I’m alright.”





Getting around

“This is how I get down stairs. I lift myself up on the banister rails and just fly down. Sometimes I lose a bit of grip, so I stand back, get my grip back and slide back down. I don’t even know why I started doing that. Due to going to the gym and rugby I’ve got a lot stronger and just one day, well like I say I used to go to scouts and we had done a lot of walking, so I probably did walk a mile for one day, and I was really tired and my legs and my knees were really hurting, I could barely walk and I just done it, you know, something easier to do.”

Asking for Help

“If I can’t do things my grandma will want to do it for me, but I’ll say to her ‘No, I want to try and do it myself.’ I tell her so I can do it myself and adapt it to the way that I can do it. Just so I can get that independence. Like if I’m cutting up a piece of meat and she sees I’m struggling she’ll look at us as if to say ‘Oh you know do you want me to do it for you’, and I’ll be like ‘No I’ll, I’ll try it myself.’ If I can’t do it then I’ll ask her to do it. It’s very rare she needs to step in, ‘cos I’ve adapted a way to do it. It’s just certain times I need that bit of extra help.”





Being active, enjoying life, forgetting disability

“I’ve played with the team for about a year now. I joined last season, and it’s one of the things I love doing. We’re like a big family, and even though we lose more often than we win, it’s good banter and a load of fun. I’ve always played for able bodied teams, and I’ve never had any trouble with my disability playing for them. It’s nice to be doing something where they’re not checking up on us all the time, they let us get on with it, and wait for me to tell them

rather than them asking me things. I’ve got lots more freedom when I’m there, it’s pushed to one side and you’re just there, having a good time.”

Challenging assumptions

“If people had never seen me walk they might think how’s he gonna do that, but people who know me know that I can do it. I’ve got really good hands. But if someone just walked in and didn’t know me they might wonder how I’m gonna do things like play wheelchair football and things like that. I’m a great advert for people with cerebral palsy, ‘cos I show that all cerebral palsy kids can do things, get out the house and do stuff. It shows that people with cerebral palsy can play a sport or do something.”





Family care

“My mum’s been there for us all the time, all what I’ve been through, and since I was little. She always takes us places and drops us off, and when I was getting my operations she would always be there, she’d stay in the hospital, like, straight afterwards, like, she would have her own bed and that. She would stay over to make sure I was okay... If I was upset or anything like that, she would make us feel better and when I came home from the hospital, when I had my leg in the cast she did stuff for us.”

Support from friends and partners

“My boyfriend helps me a lot. When I went in to hospital he came in to see me every day, and when I came out of hospital he kept texting me saying ‘How are you doing, how was everything’, and he helps me, ‘cos I couldn’t put weight on my legs for a while, till my ankle got strong enough and he used to carry me places. He picks me up like a doll, he thinks I’m a doll I’m sure of it! But he used to help me get up stairs, he helps me walk and got my chair for me, and he got things for me and he supports me quite a lot. Took me out places like on buses and things, shouted at people when they used to call me horrible names.”





Being Left Out

“When we went to sixth form, with the change of routine, my friends have forgotten there are things I can’t access. I let it lie, we were just getting into the routine, but when it went on I thought I have to make them aware. So I said “You’re leaving me out.” In the sixth form canteen there are high stools they’ve been sitting on. Not that I can’t get up, just that it would be a bit chaotic in a busy dining room, with me making my way through, because they’re in the corner of the room, and it’s difficult for me to get through.

That led me to think I need to say something to them. But you can’t expect people to remember all of the time about what you can and can’t do.”

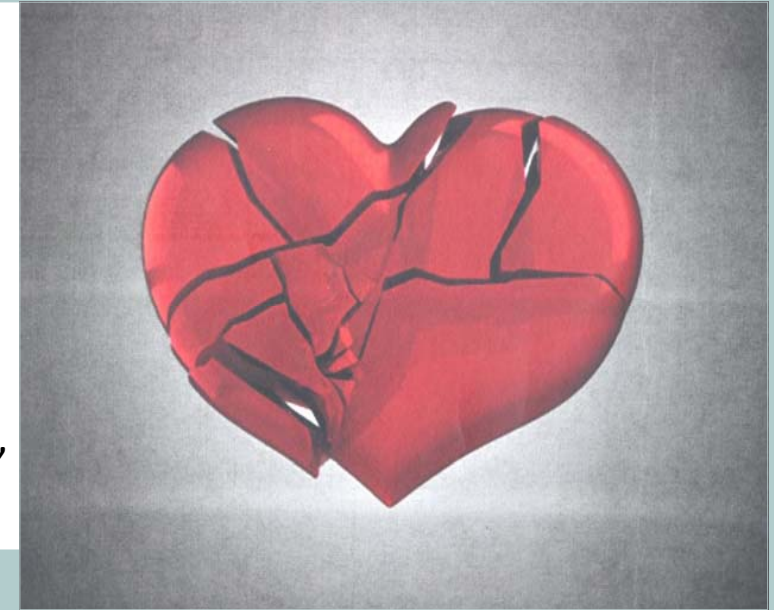
Being called names

“I’ve been called that quite a lot. I’ve been called that when I’m out with canes. I was walking down the stairs at college and my leg jerked, and these kids called me. It makes me feel very angry and upset, and I think why call people that? That’s just a horrible name. I think it’s rude, impolite. I actually burst out in tears when I got home. I got very angry and then cried ‘cos I hate, I can’t bear that word, hate it. Just don’t think it’s, nice.”



Pain

“Pain’s not just physical, it’s emotional as well, ‘cos obviously you get pains in your joints and stuff like that which is the physical side of pain, whereas in the emotional side of pain’s, say when something happens, like you get an illness, you’ve got the emotional pain of dealing with that. Pain is not just the physical side it’s the emotional side and how it affects you emotionally as well.”



Pain and Hospitals

“They scare me, hospital brings back bad memories. ‘Cos I think hospitals, pain; doctors, operations, doctors, pain. So basically they hurt me because that’s what it’s been like with my surgery, being in pain after and being very worried and things. It’s physical pain but it’s mental pain, memories of me being in pain, like the mental pain, me getting needles, or being in pain. I remember when I was younger I used to get these Botox injections in my leg when I was awake and I can still feel the pain, I can feel the pain from this day of the needle going in, like tattooed on my brain.”



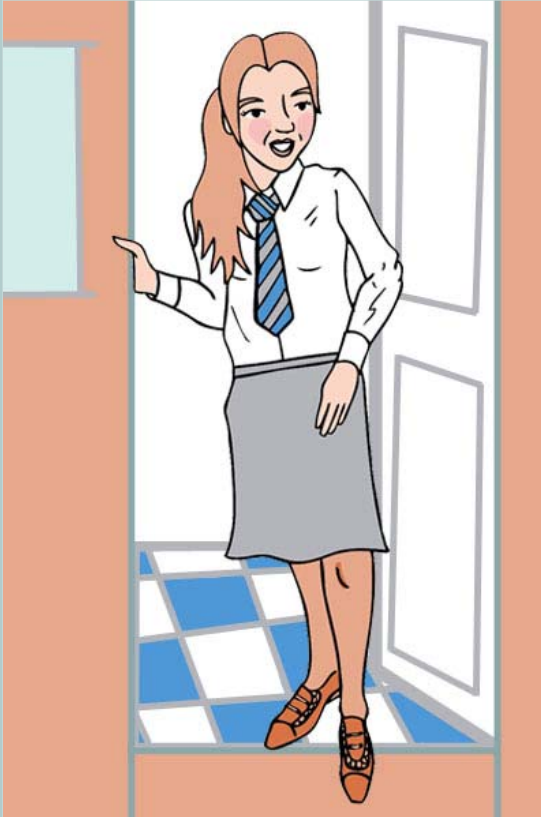
Managing pain

“My dad goes diving a lot, so I wanted to do it. I love it, surrounded by lovely warm water, lovely plants, gorgeous fish and the sun beating down on the water. It’s pretty really, and relaxing. I feel happy ‘cos I’m with my dad and I’m doing something me and my dad love. Being in the water makes me feel free ‘cos I’m not in pain. The water is holding my body weight, so I can do anything basically. My muscle’s not fighting with each other. It’s lovely.”

Staying connected, relaxed and organized

“Every appointment I have, I put in my phone, ‘cos I’ve not got a very good memory. It’s with us constantly, there’s music on there when I’m travelling and it’s my log so I can keep up to date with things, and make sure I’m at hospital appointments, appointments at college, and social events. I keep in contact with family if I’m on my own somewhere. If it was an emergency, say I did miss the bus or something happened and somebody had to come and get us. I’ve got numbers in there ready.”





Growing up, becoming independent

“I hope that I’ll be able to learn to drive. It looks from what my friends got that an abled bodied person would be able to drive it, she’s got a lever for a brake and then she’s got her accelerator which is like another metal wheel behind the wheel of the car, so she just like pulls it towards the wheel and then it kind of just accelerates from there. I’d like to drive, it would make me feel more grown up. Obviously I’d like to drive in the future for when I get my own job and have my own children. I won’t be able to ask my mum if she can give them lift to school, so I’ll need to learn to drive eventually .”

Aging Bodies

“I know when I’m gonna get older, I know this is gonna get worse, well when I say older, I’m on about in my fifties, sixties... I know how cerebral palsy is, I’ve seen people... but I’m not thinking about that. That stage for me is years away. But at the moment I know when I get older, I’ll probably be in a wheelchair just because I know how my muscles will be, but to be honest I’m not really that bothered... I take things when they come... That’s all I can do.”



Our reflections on what disabled young people shared with us

Our aim was to explore what it is like to grow up with a body seen as disabled and different. Some of the things shared with us are, of course, not just about bodies, but about the everyday lives of ordinary disabled young people, such as their relationships with their friends and family, their pleasures and pursuits, and their concerns around growing up.

Nonetheless, we think the body is part of those things, as something that has an influence on the lives of disabled young people. The stories and images captured:

- The ways the body works and doesn't, and how that effects the things disabled young people can do and their thoughts on what they might do in the future.
- How disabled young people can take a lot of pride in the things they can do with their bodies, including how they do things differently from other people.
- The significance of both the social environment and the responses of others to how much having a disabled body matters.
- Thoughts on all the ways their bodies have been changed by physiotherapy or surgery and their own 'body work' since childhood and into the present and future.
- Ways in which hospital and treatments get in the way of doing other things such as being at school, or with friends or family.

- How pain can be many things, including the pain of being treated differently by others because their bodies are different.

Sometimes it frustrates disabled young people, even angers them, that other people just see what they cannot do or think it funny how they do things differently and use that to call them names or not let them join in.

Being part of things is as important to disabled young people as it is to others, and often they just want to have a chance to give things a go, and not have people make assumptions that they will not be able to do something, or that they will not be any fun to be around. The young people we spoke with were very creative in how they used their bodies, and technologies, to get around, to communicate and to say something about who they are.

What they think is important is that people around them—friends, teachers, family, strangers—take the time to recognise that.

At the centre of all this is how people draw meaning from disabled bodies. Our project has sought to give disabled young people the opportunity to talk about the body, and to not be uncomfortable with doing that.

Questions to think about

Having read what people shared with us, here are questions people could use to discuss what they have read with others.

- What does disability mean to you?
- If you are disabled, how has it shaped your life, and the things that you have experienced?
- Do you think disability is about the body, or do you think it is more than that, such as how people treat disabled people, what they say, and how they look at people different from themselves?
- Are there different ways bodies can be different that people use as an opportunity to make fun or treat people badly?
- How can we challenge the prejudice people can experience because their bodies are different?
- What is exciting about doing things differently?
- How can we celebrate doing things differently and being different?



We'd be interested to hear back from you. If you want to share some thoughts go here :

research.ncl.ac.uk/thebodymatters/

Information and Resources

Action for Kids (Youth Participation)

- Mobility aids, work-related learning and family support services.
- <http://www.actionforkids.org/>

Beat Bullying

- Helpline and support to help children deal with bullying.
- <http://www.beatbullying.org/>

Making Ourselves Heard – newsletters

- Promotes the active participation of disabled children and young people.
- <http://www.councilfordisabledchildren.org.uk>

Volunteering: V Inspired

- Connects young people with volunteering opportunities.
- <http://www.vinspired.com/>

Youth Net

- Advice, information and support to young people aged 16 to 25.
- <http://www.youthnet.org/>

Whizz Kidz

- Community events for young people in wheel chairs.
- <http://www.kidz-unlimited.org.uk/>



Research Team

We are all researchers who work at Newcastle University and in different ways we explore various things about the social world and the people in it. The main members are:

Janice McLaughlin (PEALS, Newcastle University)

Email: Janice.mclaughlin@ncl.ac.uk

Telephone: +(0)1912227511

Edmund Coleman-Fountain (PEALS, Newcastle University)

Email: Edmund.coleman-fountain@ncl.ac.uk

Telephone: +(0)1912227511

Allan Colver (Institute of Health and Society, Newcastle University)

Patrick Olivier (Digital Interaction, Newcastle University)

Website: <http://di.ncl.ac.uk/>

Additional Support: Abi Durrant (Digital Interaction, Newcastle University); Jonathan Hook (Digital Interaction, Newcastle University); Roisin McNaney (Digital Interaction, Newcastle University); Jayne Wallace (Art & Design, Dundee University <http://www.digitaljewellery.com/>)

