

Speaking Out about Disability

Therapy Focus' Consultation with children and young people with disability

> Researcher: Celine Windsor Community Connect Coordinator

Aim of Presentation

Process of consultation

Findings from consultation



Why did Therapy Focus get involved ?

- WA's largest non-Government disability therapy provider
- Children and young people with a disability or learning disadvantage.
- Families, schools, carers and the community
- To improve quality of life. Helping them grow and reach their full potential.

Pre-grant Planning

- **Do we have the time and resources** to include our clients in a meaningful way?
 - -Explored suitable methods
 - -Budget
 - -Time
 - -Resources

Exploration

Investigated suitable methods for surveying children with disabilities:

- 1. How do we overcome barriers of comprehending the survey questions?
- 2. How do we support children with disabilities to communicate their ideas?



Photo aided communication

Photos used to express their ideas and / or supplement verbal and written language:

- Nind, 2008 National Centre for Research Methods University of Southampton
- Photovoice, Booth & Booth, 2003
- Swain, et al 1998
- * Can provide revealing and powerful data.

Survey preparation

1. Simplified all documents

Purpose and consent broken down

- simple language & visual symbols

2. Small steps

Process broken down into small steps with a tick box.



Survey preparation

2. Questions Modified

- Group of occupational and speech therapists review questions
- Looked at the essence / intent of question
- Simplified the language e.g what does community mean?
- No specific mention of disability.

Survey preparation

Scaffold to assist understanding:

1 question to a page

 Reward explicit: \$20 gift voucher.



Your chance to have a say

The Commissioner for Children and Young People Michelle Scott has an important job to help young people from all over Western Australia.

The Commissioner would like you to help her understand more about what it is like being a child with a disability.

She has some questions that she would like you to answer!

We understand that sometimes it is hard to put thoughts and feelings into words.

We will give you a camera so you can take photos to help you answer the questions.

You can then write and tell us in a sentence or two, the answer to the questions.

You will receive a small gift for helping the Commissioner.





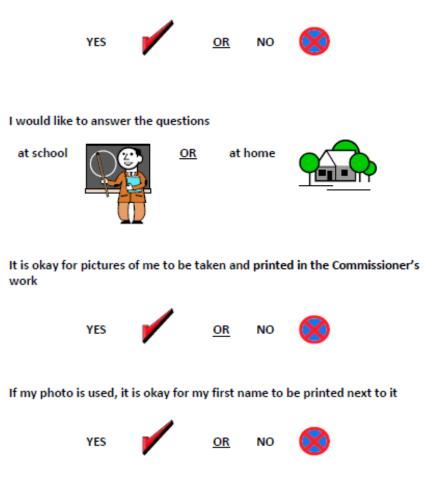






Please circle:

I would like to answer the questions and the Commissioner can use my answers for her work





Your parent/guardian will need to sign and return the next sheet of paper.

Scaffold

<u>Steps</u>	<u>Tick</u>
Read the questions in this book.	
Think about what you could take a photo of to answer each question.	
Use a pencil to write down your ideas in each photo box.	
Go and take the photos.	
Tick the camera box to remind you that you have taken this photo.	

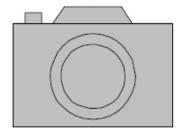


Use photos or pictures to help you tell the Commissioner.



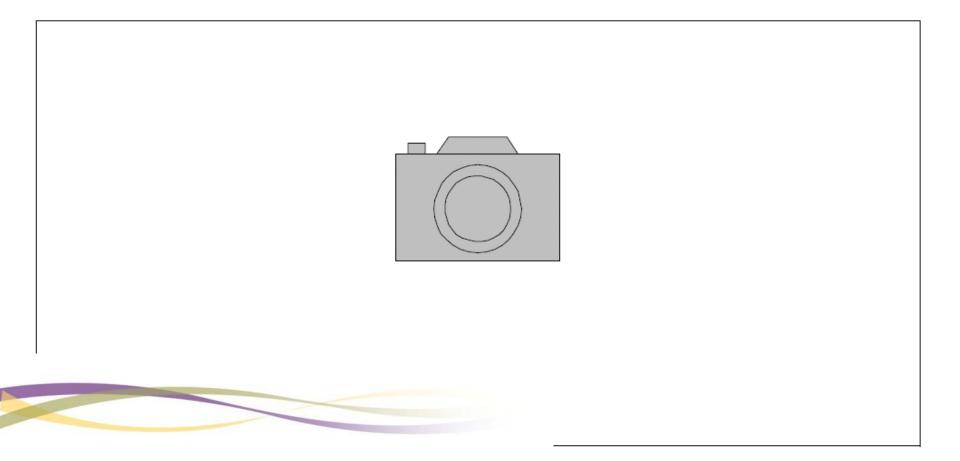
Everyone is different and special.

What are 2 things that are special about you?





What do you like to do or see when you are not at home or school?



Choice / varied means of expression

Variety of techniques to make sure I understood their point of view:

- Written and / or
- Scribed by key person and / or
- Photo, picture or drawing and / or
- Spoken with additional probing questions.

How did we choose participants?

Expressions of interest:

- Emailed therapists: nominated children
- Emailed large Ed support schools
- Advertised on Therapy Focus Web page and Facebook page
- Approached previous participants of Therapy Focus programs
- Parent permission.

How did we consult?

- 20 survey packs provided to schools.
- 3 school 1 mainstream secondary,
- 1 secondary education support centre & 1 primary school satellite class.
- 20 individuals / families agreed to participate and each were provided with survey packs.

How did we carry out the consultation?

Dates:

• July / August / Sept 2013

Venues:

- Schools (Thornlie SHS, Mirrabooka Education Support Centre; Carson St Satellite class at Belmay Primary School)
- Family homes.

How did we carry out the consultation?

- 29 surveys returned
- 22 supplemented answers / photos with further discussion with researcher
- 7 returned survey books and declined further discussion
- 11 lost to follow- up: declined, withdrew or did not complete consent.

Demographics

Ages:

- < 10yrs 5
- 11yrs 5
- 12yrs 5
- 13yrs 2
- 14yrs 3
- 15yrs 2
- 16yrs 2
- 17yrs 4
- 17yrs> 1

Demographics

Diversity

- Gender: 17 male; 12 female
 - Metro WA
 - CALD: 5
 - Indig: 0

Demographics

- Intellectual Disability 14
 - Autism Spectrum Disorders 8
 - Cerebral palsy 4
 - » Osteogenesis 2
 - » Morquio syndrome 1



Summary of key points

- Family is a key for us having a good life
- Learning and mobility / access are most often most difficult
- Having a disability sometimes make us sad but with the help of family, school and friends, we focus on our abilities and strengths
- Recreation is a focus for our community

Summary of key points

- Crime and violence in the community is of great concern to us
- We look forward to having a good job, independence and adventures when we are older – just like other children and youth
- For us to stay happy and achieve our goals we need the ongoing support from our family, school staff and community service providers.

Hierarchy of common themes:

Family

- Doing things at home and the community
 - My pets

–School

»Friends

Family

- "Mum. She knows when something is wrong and knows how to fix it" G15
- "Mum and Dad support me" B12
- "My family are important to me because I love them" G16

"Mum and Dad help me when I have a bad day" Hannah 12



Family

- "I live in a house with my mum, Dad and older brother. I like going to the movies and swimming in the pool with my family. My 3 cousins live nearby as well" B11
- "My sister; my Gran" G14

"My family being there for me". Chelsea 12



Doing things at home

- "I like playing video games" B7
- "Watch my fish and ipad" B12
- "I really love building and collecting Lego" B11
- "Watch a DVD to chill out" B11

"Having a fort in my back yard". Axl 8





Nicholas, 17 indicates that his Ipod was a good thing in his life.

My pets

- "My dogs: Rosie and Toby" G11
- "Playing with my cat Gandalf" G12
- "Jake my dog. He has a certain comforting connection with me and knows when I need cheering up!" G15

"I love my dog Ralph" Ben 17



Doing things in the community

- "I like to do after school activities" B11
- "Therapy Focus Drama Group. Helen O'Grady Drama. I go with some of my friends at school. Going to Jujitsu" G12
- "I play cricket" B13

"I like that I watch AFL" Kevan 18



Doing things in the community

"I like to do after school activities but I haven't got transport" Dakota 11



Doing things in the community

- "The variety youth choir is special to me because I have lots of friends. I am also vocalist in a band with Music Rocks, 'Out of Sight'" G16
- "Going to coffee shops with my friends and bowling and going to Glee Club. Riding my bike and going to basketball and parks" G17

"Going on the ferry

and going to church" Alexia 11



School

"The school I go to is Christchurch and I think it is great because the teacher and boys are very friendly. There is so much to do and everyday is different".B11

> *"I like school. I like camps"* Danny 10



School

 "Coming to Cyril Jackson ESC was the best thing that has happened to me" B17

"My high school is awesome. I had a great time at the school ball with my friends" Ben 17

1. What are some of the good things in your life?

Friends

- "My friend Hannah. She is very kind and caring" G15
- "Family, nice people. At school with my friends" B7

"My friends" Isaac 12



2. What are some of the things you find difficult in your life? Hierarchy of common themes:

- Learning
 - -Mobility / Access
 - Doing things

 Communicating & »Relationships
 "Talking to people" Sophie 13



2. What are some of the things you find difficult in your life?

Learning

- "Sometimes the bus as I know I am going to school" B8
- "Maths is hard" G13
- "Home work and school work. Lunch times nowhere quiet to go" B12
- "English is too tough" B18
- "Trying new stuff- Business Skills" G16

2. What are some of the things you find difficult in your life?

Braeden, 12 says:

Homework and school

>Lunch times

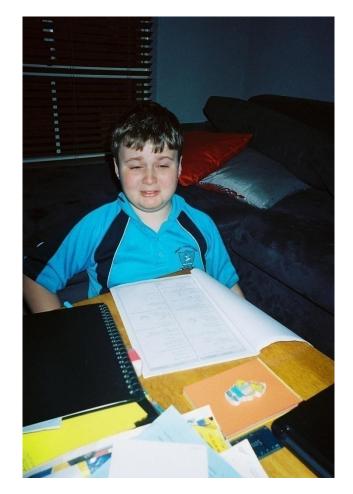
nowhere quiet to go

Making friends

➤ Sports

➤ Coordination

Ball skills and fitness.



2. What are some of the things you find difficult in your life? Mobility / Access

- "Being in a wheelchair" G14
- "I want to play sports but no one can take me" B11
- "Sport is hard" B10

Some play equipment is hard for me to play on. Hannah 11





2. What are some of the things you find difficult in your life? Mobility / Access

• "The accessibility to our patio. It is up a level so that I cant access it in my wheelchair. Friends houses are also difficult to access so if they have a party I can't go and have to stay home. At Burwood Dome I went to the Taylor Swift concert and the disabled seating was next to a concrete pillar so I could not see. Kalamunda markets has also go crowds and thick grass. There were no disabled toilets at the Truffle Festival in Mundaring." Indiannah 15

2. What are some of the things you find difficult in your life? Doing things

- "Sports coordination, ball skills, fitness" B12
- "Playing Mario Kart is hard" B17
- "I find hip pop hard" B14

"Playing Connect 4" Nicholas 17



2. What are some of the things you find difficult in your life? Doing things

- "I like riding a bike but I need a special bike" G11
- "Dressing myself can be a little tricky especially socks. It is also hard for me to use some of the equipment at the park like the flying fox" B 11

"Playing Sport" Dylan 10



2. What are some of the things you find difficult in your life?

Communicating and Relationships

- "Talking to people" G13
- "How I feel, sometimes people don't understand me" B10
- "Sometimes I find it hard to say how I feel" B11
- "When people do not understand what I am saying" G11



2. What are some of the things you find difficult in your life?

Communicating and Relationships

- "Making friends" B12
- "Being bullied" G12
- "Shy / nervous" B12

"I am happy and I use my PODD book to help me talk" G11



- We are all different and have talents and abilities that make us unique.
- Living with a disabilities sometimes make us sad – life is sometimes hard.
 - Change worries us

"My teacher says that I am a great worker and listener" Julian 11



3. What would you like to tell the Commissioner about children and young people with disability? We are all different and have talents and abilities that make us unique.

- "My knowledge of trains, solar system, Titanic, dinosaurs etc remembering facts. I'm organised, punctual, good manners, can follow rules" B12
- "My sense of humour and good public speaking. I am a good singer and have a good memory for other languages e.g. Italian" G16

3. What would you like to tell the Commissioner about children and young people with disability?We are all different and have talents and abilities that make us unique.

- "My wheelchair is especially made for me" G15
- "I like my routine with pictures I like to see what I have to do" B7

"My elbows are different but don't affect my life".

Indiannah 15



We are all different and have talents and abilities that make us unique.

N pointed to his hat to indicate this is special about him – He has his hearing aid in his hat." Nick 17



We are all different and have talents and abilities that make us unique.

- "I am good at Math. I got an A. A good student" B18
- "My teachers say that I am a great worker and listener. I am good at remembering messages" B 11
- "Caring, creative" B12
- "I have fashion sense" G12

"My creativity/ artwork"

Chelsea 12



3. What would you like to tell the Commissioner about children and young people with disability? Sometimes we get sad:

- "I am different from anybody else. I am fragile" B11
- "Going to PMH all the time" G14
- "People looking at me "funny" when I go out" G17
- "(put my) Splint on" G10

"I am sad when I am on my own" Hannah 11



Sometimes we get sad:

"People teasing me. People stop playing with me. I want to play sport but no one can take me."

Dakota, 11



Sometimes we get sad:

- "Having no friends. When people leave me out" G 12
- "My scars. I think they are ugly so I try to cover them up :(Breaking bones" G15
- "Having surgery" B11

"Botox. Going to PMH"

Heidi 10



Sometimes we get sad:

"Having to do school work every day of the week just to keep up and therapy" B12

" Go to birthday parties with other kids at school". B17

> "It makes me sad to hear and see people bullying others."

> > Julian 11



Change worries us

- "Not knowing what employment I will have when I finish school" B17
- "Graduation what happens" B17
- "Starting High School" G12
 "About next year Year 11. Lots of exams"

Jessie 15



- Recreation: Place to go
 - Venues
 - -Shopping Centres and movies

parks

- Parks
- Sport and active
- Recreation

Axl 8, loves the new

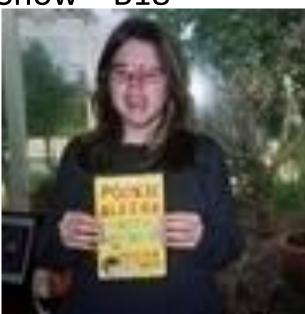


Recreation: Place to go

Venues

- "Movies, Bell tower, the Perth Mint" G16
- "Play games at Time Zone and Royal Show" B18
- "The beach" G10

Reading books and going to the Bayswater Library" make Taylor 16 ,happy.



Recreation: Place to go

 "The museum and eat lunch. Patterson stadium to watch football" B17

"Julian, 11, likes to go shopping, to the movies, swimming at Lords and eating at Sizzler. He likes that he has parks with cycle paths and new equipment near where he lives.



Recreation: Place to go

Shopping Centres and Movies

"I like to go to the movies with my friends.

We saw Reck It Ralph. I like to go

shopping to get the newspaper

for myself and Starburst Iollies"

Ben 17



Recreation: Place to go

Shopping Centres and Movies

- "I like to go to the movies its always wheelchair accessible" G15
- "I like to go to the markets" B10
- "I like to go shopping. I like to go to the pet shop" G12

Julian 11, likes living close to the

cinema and shopping Centre



Recreation: Place to go

Parks

- "Ride my bike in the park. Play tennis in the park"
 G12
- "I like walking to Nanny's house. I like

the playground" B7

Elizabeth 17, likes to go to coffee

shops, bowling, basketball, parks,

Glee Club, riding her bike and

catching buses



Recreation: Place to go

Parks

"Ride my bike in the park. Play tennis in the park" Charlotte, 12



Sport and Active Recreation

- "Go to the Roller dome or go to AMF bowling. Go to the football – watch the Eagles" G15
- "Go-Kart riding" B10
- "Playing sport. Go to the skate park and ride my scooter" B11

"Local skate park" Dylan 10



Sport and Active Recreation

- "I play cricket" B13
- "I also like swimming at Lords" B11
- "Riding the Quad bike especially at Grandpa's" G15

Colin 16, likes Swimming with Special Olympics.



Crime and violence

- Better access and facilities
- -More / better facilities
- More community action and initiatives
 - Social Justice
 - Initiatives

Crime and violence

- "Fighting " G11
- "Graffiti" G10
- "Noisy cars" G11
- "Noisy parties" G12
- "Littering" G12
- "I don't like seeing people drunk and falling all over the place" B17



"I don't like the cars driving fast" Ryan 7

Crime and violence

- "I hate seeing crime of any sort! It makes me so mad! I don't like to see people smoke. I figure why make yourself sick when there are children that are sick and don't choose to be and then someone gets sick from smoking and blames the whole world. It's a choice and some people don't get a choice" G15
- "People being cruel to animals" G12
- "I would like better law enforcement in the suburbs" B17

5. What would you like to change about your town or community?Better access and facilities

- "Some play equipment is hard for me to play on" G11
- "Have more Makaton signs for me to read when I go into the community" G11

"There are not many footpaths and cycle paths near where I live. When I ride my bike on the road I need to be careful and watch our

for the potholes" Indiannah, 15



Better access and facilities

"I would put lifts in every building in Perth and put in more footpaths sot that I could wheel around my suburb." G 15

Elizabeth 17, with support from her mum discussed being isolated, not enough support from community, the need for mentoring, transport and socialisation assistance. She would like to do photography".



More / better facilities:

- "More shopping Centres, Free events community forums, guided tours. More parks" G16
- "The toilets at the park near my house are disgusting. They are really smelly and dirty most of the time" B 11

"I'd love a local public swimming pool with a giant slide " Dylan 10"



"Unlimited broadband. More Indoor play centres for over 12's to hang out – playing electronics" Braeden12



5. What would you like to change about your town or community?

More / better facilities:

- "Have a fenced area in a park, so I can ride my bike with my family" G 11
- "More wildlife parks; water playground, indoor play centres for over 12 – that have electronics. Unlimited broadband" B 12
- "I would make Perth host the Youth Olympics in the further future. More sports arena and upgrading the WACA " B 18

"Theme parks" B 11

5. What would you like to change about your town or community?

More community action and initiative –

Social Justice

- "Bullying" B 11
- "I feel sad when I go to the city and see Homeless people lying on the pavement. I wish that everyone had homes to go to" B 11
- "I don't like to see people who are hurt" G 12
- "People looking at me "funny" when I go out" G 17

5. What would you like to change about your town or community?

More community action and initiatives

- "I would have a special Green Thumb Day. I would ask everyone in Perth to help clean up" G12
- "Find all animals a good home by having a special day" G12

"A lot more awareness about Asperger's" Braeden 12



A family member

- Mum G 11
- My Dad B 10

"My step dad Paul and my mum" Elizabeth, 17



A family member

- My sister B 8
- My big tall cousin Angus. He is handsome and funny and taller than Dad! G 12

"My Dad" Dylan, 10



"My mum" Chelsea, 12



My teacher or Education Assistant EA

- "Denise Demetri Variety Choir Director" G 16
- "Mrs Goodley my Yr 7 EA she went through bone cancer and breast cancer" G 15
- "Mahlia Mher" (Education Assistant EA) B 14
- "Mrs Vane der Spay (teacher). She helps me when I get stuck" G 10

"Mrs Travers (EA)" Danny 10



Good friends

- "Kiam is my friend he is awesome and funny" B17
- "My friend jasper, because he is nice person who is my friend and stuck up for me when I was bullied at school" B14

"Codi (a class mate in my SOSE class). She like me and we help each other". Kevan 18



"When I met Danny Green is a good thing in my life. When Danny Green gave me a T-shirt, and a hat and boxing gloves." My hero(es) are Craig Lowndes and Jamie Whincup, V8 Supercar drivers and Danny Green." Colin 16



Inspirational People, Idols and Superheroes

- "Batman is my hero because he protects Gotham City from evil. He is smart, kind and very strong. People can rely on Batman to always help" B 11
- "Lady Gaga, Katy Perry, Courtney in Total Drama she's so amazing – she is an A type temperament and has a personal digital assistant"G15
- "Christian from Dance Academy" B14

Ryan 7, loves superheroes



7.What are the most important things you need to have a happy and healthy life?

- Relaxing Chill out time
- Emotional support from family, and friends
- School, community supports and service providers

Isaac 12, loves to spend time playing with his pet dogs Wally and Daisy



7. What are the most important things you need to have a happy and healthy life?

Relaxing – Chill out time

- "Playing (computer) games especially mine craft" B10
- "Lay on my bed with Ralph my dog". B 17
- "Wait til I get home from school and go on Youtube and find something funny –takes

Braeden 12, with his

electronics – computer games



7. What are the most important things you need to have a happy and healthy life? Relaxing – Chill out time

- "Walking for a time. Being able to relax on holiday after being stressed" B 17
- "Reading my favourite book" G 14

"My PS2 and the computer" Colin 16





7. What are the most important things you need to have a happy and healthy life?

Emotional support from family and friends

- "My parents. Thinking good thoughts" G 16
- "When I am in hospital or bed ridden, I love it when I see my brother. He always makes me laugh" G 15
- "When I have a bad day I like to talk about it with my mum, dad or brother" B 11

"Hugging my parents"

Hannah 12



7. What are the most important things you need to have a happy and healthy life?

Emotional support from family and friends

 "Being with my friends Talk to my friends and ask them to play with me" B11

> "My sister; my Gran" Chelsea 14



7. What are the most important things you need to have a happy and healthy life? Community supports and service providers

- "My teachers: Ms Marnic and Ms Richards. Mrs Fitzgerald my aide" G 12
- "Mummy" B 12

"My loving family. Extra things that make me feel good: Willie and the horses (RDA Hills div); drums and band (Dean Music Rocks Aust), Evan and Ollie

- they care for me (Therapy Focus)

Isaac 12



8. Is there anything you need to help you share your views and ideas with others?

- "My mum helps me" B7
- "Codi (a class mate in my SOSE class). She like me and we help each other" B18
- "I sometimes need help understanding my school work and I have a great teacher in the classroom that explains things carefully to me" B 11

"I use my PODD book to help me talk"

Hannah 11



- Having a job that I like.
- To do things just like everyone else
 - I dream of adventures
 - Being independent
 - Global Change

Hannah, 12, doesn't like seeing people hurt, graffiti or loud parties. She would like her suburb to be clean and to have a ute



9. What are your dreams or hopes for the future? Having a job that I like.

- "Having my own inside job with computers or doing animal research (biology)" B12
- "I dream of joining the army or any armed forces" B17



Sophie, 13

would like to work at Coles.

Having a job that I like.

- "Drive a bus. Drive a truck" B 10
- "Having a good job after studying Uni. I would like to study web design" B 18
- "I would like to be a singer in musical theatre"
 G 10

"Work at the RSPCA or at Mattel" Holly 12





Chelsea 14, would like a career in broadcasting / television or as a Radio Presenter



To do things just like everyone else

- "Have an Iphone" G 15
- "Trampoline at Hillary's but I cant because of my problem" B 11
- "Go to birthday parties with other kids at school"
 B 17
- "Soccer being part of a good team its is not about who wins of loses" B 11

To do things just like everyone else

Mareg 14, hero is Christian from Dance Academy. Although it is Hard, he likes to likes to do Hip Pop and back flips. He would like to play NBA to Level 13, soccer and sing like Chris Brown.



He wishes his brother was Nic Natinui.

To do things just like everyone else

- I want to get married B 14
- "Being a Dad" B 11

"I want to drive", "I want to become a mechanic"

Colin , 16



To do things just like everyone else

- "To play NBA to Level 13 and play soccer, basketball and dance like Chris Brown" B14
- " It would be so amazing if I could keep up with the other boys at sport and I wish that school work could be easier for me" B 11
- "I'd love to be in a cricket club. I'd love to go and watch the football and cricket" B17

Dakota, 11 would love to have a club to go

to near his house



I dream of Adventures

- "Go on a holiday overseas eg Bali or Asia. Plane travel – no disabled toilet on a plane" G 16
- "Travelling overseas" B 17
- "I would like to do parachuting. I would like to be able to ride a motor scooter" B 17
- "Skydiving" B1 1

"Scuba diving" Alexia 11



I dream of Adventures

- "Go to Lego land / fantastic places" B 12
- "Host a TV talk show like the Circle or the Living Room" G 6
- "Boating and knee boarding. Jet skiing" B 11
- I would like to go parachuting. I would like to be able to ride a motor scooter B 17



Being independent

- "Having my own apartment" B12
- "Going on a plane all by myself to the UK" B12
- I could build myself a house in our backyard... I would live there by myself" G12

"Living independently somewhere in the City of Gosnells by myself" Kevan 18



Being independent

- "If our backyard was bigger. I could build myself a house ... I would live there by myself" G 12
- "Buy my own car" G 12

Making tea and breakfast, and driving. Alexia 11



Global change

- "World peace. My mum out of debt" B17
- "Bullying should never exist" G15
- "Finding a cure for osteogenesis imperfecta" G15

Isaac, 12 dreams of helping people in need



10. Is there anything else you would like to tell the Commissioner?

"I think a Kids Club would help me and other children who have a disability. A club after school where I could meet other kids with special needs and make new friends and we can talk to each other and then join other clubs together – like athletics" Heidi 10



What did we learn?

- Our consultation could be broader than our parent reference group
- We should all include and ask young people in decisions that effect their lives
- Regardless of abilities and skill levels, all participants hade valuable opinions and insights

Questions

