

Appendix 2

WARWICKSHIRE'S AUTISM STRATEGY CREATIVE CONSULTATION:

HEREWARD COLLEGE WELCOMBE HILLS SCHOOL BROOKE SCHOOL NORTH WARWICKSHIRE & HINCKLEY STRATFORD COLLEGE WARWICKSHIRE COLLEGE OAKWOOD SCHOOL EXHALL GRANGE SCHOOL RIDGEWAY SCHOOL WOODLANDS SCHOOL ROUND OAK SCHOOL

CREATIVE CONSULTANT: JANETKA PLATUN

Sessions took place between March 4th and June 14th, 2013. In total 147 young people participated in the consultation process. 114 boys and young men, 33 girls and young women. 'I am important, I am intelligent, I am the most perfect girl in the whole wide world.'

E, 6 years old.



BULLYING AND LACK OF AWARENESS OF AUTISM IN MAIN STREAM SCHOOLS

'I've experienced a lot of bullying. The support I've received from my family has been good. But local services could do more to understand how people with autism are often bullied.'

'I used to get bullied a lot when I went to mainstream school. That doesn't happen in special needs schools you're listened to more. I'd say to teachers at mainstream schools 'listen to people with disabilities' not just say 'get on with it'. They need to be more aware of who they're teaching. It's important to have one on one time if they want them to work properly and if they're concentration isn't good. Also they need to do more listening, you're asking for a limited amount, but they don't seem to want to give it to you.'

'In my old school there were lots of bullies. Teachers were a bit lazy and would say things like 'forget about it'. I used to get beaten up a lot and teased, that doesn't happen here. They need to employ special needs people who won't let that happen.'

'When my last school told me I had autism they said they could deal with it, but how is letting other children beat me up and call me this and that dealing with it?'

'This school is meant for children with autism, but I think every single school should have some type of training to deal with autism. There's no excuse.'

'I've been bullied throughout my education. Police and teachers need to take it more seriously. My picture shows how bullies blank you.'

'Lots of things aren't dealt with. I was verbally abused. People didn't know I was autistic since a lot more people have it more severe than me. You wouldn't think stuff like bullying takes place, but it does. I want to be treated like a normal human being.'

'We found out I had autism when I was three. I've had 13 years of verbal and physical bullying from the age of three. It only stopped when I came here. Teachers do nothing. I've had it pretty bad I'm surprised I'm still intact. They don't know much about autism, but they support me here. I've found a safe haven. The teachers need to actually do something. They need to talk to the kids before it gets worse. Nobody actually understands autism. Why we act in a certain way needs to be explained to other children and teachers. We'll be better off and won't get bullied. No way do I want somebody to go through what I have.'

'I started getting bullied during my secondary school life. I was mainly verbally abused but sometimes I was physically beaten up. Lots of people who bullied me didn't know of my condition. It feels good to get this all out.'

'My picture is of a green man on a golf course mowing the lawn. Green is one of my favourite colours. When I was younger there were a lot of mean students, it was the work, the stress, the whole thing. But here at college I've come out of myself, I've had a good time. It's the environment and nice students.'

'There was little or no hands on help during mainstream schooling. I was 'smart' so was left to do the work. Help was given to the less 'intelligent' students. I missed out on commendations for working hard. Depression doesn't help with things like this. I am different. Don't treat me like a leper, I'm not contagious. Just try and help me please.'

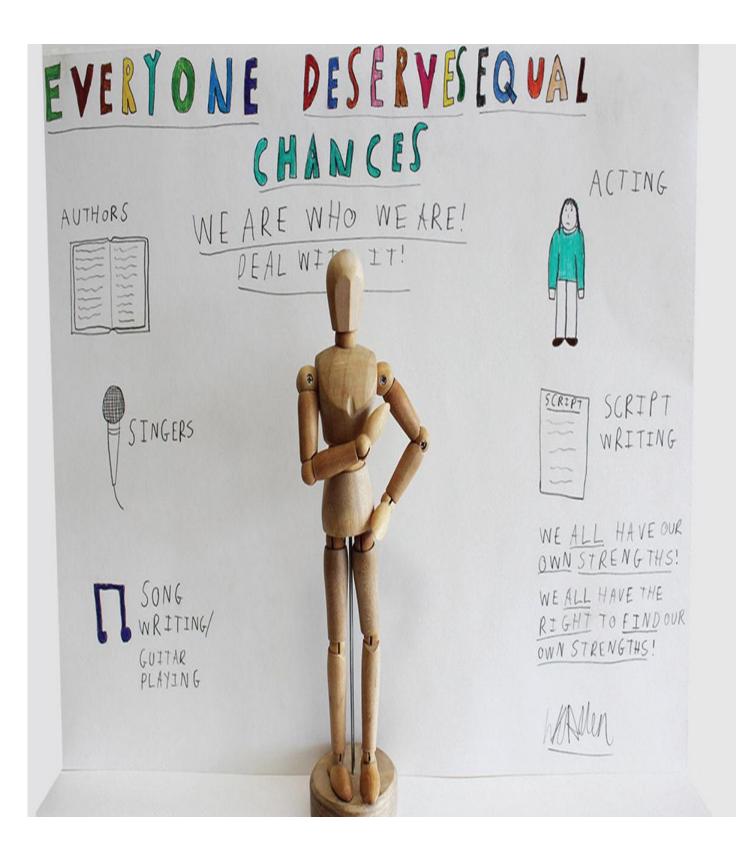
'The model I've made needs plastic surgery. I'm not happy with how I look, I used to get bullied a lot and had no confidence. Being at college has given me back my confidence. More needs to be done about bullying. The schools need to understand why they're bullying. They need to visit their family and find out what's causing them to behave like this.'

'My education was 50/50 of good and crap. When you tried to make friends there were always bullies who tried to make things hard. Something needs to be done.'

When my autism started I got bullied and beaten up. My ribs got cracked.

'When I was in my secondary school I used to get bullied a lot. Every day I used to get bullied. I have ADHD and sometimes blab out things that are not appropriate at that moment. I'm an easy target for bullies. I'm vulnerable. In my old school there was only one teacher who helped.'

'In my picture there is a black hole where I put all my worries in. I'd put bullies in the hole. I've been bullied a lot because of my autism. I get bullied outside school and at my old school. When I got hurt they just watched and laughed. It's horrible in the hole. I get angry and need help with my breathing. I covered the hole because it's scary.'



IMPORTANCE AND ADVANTAGES OF SPECIALIST SCHOOLS AND COLLEGES

'When working with people with autism you need to be calm and listen a lot. You need to be patient and not jump to conclusions. It's important that people understand that, which they do here.'

'My picture is a jigsaw puzzle that shows all the things I'm interested in. Each piece of the puzzle allows me to learn and provides new opportunities. People with autism need lots of opportunities to learn.'

'When I get older I want to buy a house and live independently. I could do with help with using the computer. At college I get to do things I haven't done before.'

'Normal mainstream schools are scary. They didn't understand me. It was better at a specialist school.'

'My picture says 'Stop, stopping me!' When I was at mainstream school the powers that be said they gave money to the school to support me. But I feel they prevented me from succeeding, that was a stop. I did a lot less core subjects than I should have. Instead of ignoring special needs children they need to cater for them. Even though they had a learning support system in the school it was barely used. In college it's different they ask 'what do you need help with?'

'Sometimes teachers treat people better than others and unfairly. I'd like teachers to talk in a calm way, otherwise it can make the situation worse. In my old school it was a bit weird, I felt I was treated a bit wrong and not understood. At this school it takes a shorter amount of time to be understood clearly. They're definitely more trained here.'

'My picture is about all the tension between my parents before they broke up. I'm stuck in a hole in the middle. My family do support me. In my old school they just didn't understand me. I'm worried about my little brother who is at that school because he's even more aggressive than I was. Your average teacher just doesn't know much about autism. They don't know what it's like and how to teach people like that. Here you actually get people trained to deal with people like us and it actually works. I'd like to train as an architect. It's easier to get into the swing of it here.'

'I liked my friends at my old school, but it wasn't a special school. In my old school there were 30 children in each class, here it's 10 children. I like it here because I want to have less noise.'

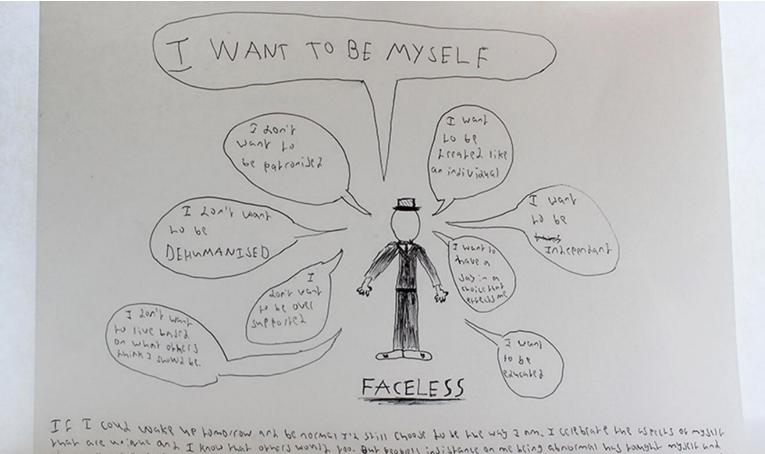
'I didn't like my old school. It was much too strict. Other children quite liked me and listened but not the teachers. They're better at keeping me happy here. They listen to me and that makes me feel important. I'd say to my old school 'die old school!'

'My picture is about my teacher at this school and how good he's teaching me. I've drawn my grades and my handwriting. He's taught me to do joined up writing, before it was rubbish. In my other school they didn't know what they were doing, at this school they know what they're doing.'

'My picture is of my new school. My mum tried to find me a school I love. At my old school teachers didn't let me play outside. They kept me inside. I tried to run back home.'

'I definitely feel more secure being in a specialist school. At my first school which wasn't a specialist school, I didn't get on well. They couldn't control me, they didn't know about autism. My mum told them I had autism and they didn't believe her. When I went to a school that could handle autism it was better for me. They used to lock me in cupboards because they didn't know what to do. But that was before my medication, it was just chaos.'

'I've drawn a picture of the bus that brings me to school. I like where it takes me.'



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TREATING PEOPLE WITH AUTISM WITH RESPECT AND GREATER AWARENESS OF ABILITIES AND POTENTIAL

'Everyone is focused on what I can't do. Why can't people focus on what I can do. I'm capable of more than you think.'

'I would like people who work with people with autism to stop underestimating our abilities. Don't judge me before you know me. You don't know what I can do.'

'My picture is about the way people sometimes judge me. I thought if I dressed like a normal person I would get treated like a normal person. School helped me with my disability and to fit in. It was a specialist school. I would like help paying bills and other practical support when I have my own place.'

'I have been intimidated and talked to like a child. People need to treat people with autism with more respect.'

'My mother had to go to all these meetings to get my transport money. It was going very badly. At one point they actually started referring to me by number rather than by name. So what she used to do is take portraits of my face to every meeting to remind everyone it's a human being we're talking about. I found that quite tragic in many ways, yet weirdly comedic. Ever since then I've been into the idea of faceless characters.'

'I don't want to be patronized. I don't want to be dehumanized. I don't want to be over supported. I want to be treated like an individual. I want to be independent. I want to have a say in the choices that affect me. I want to be educated. I don't want to live based on what others think I should be. I want to be myself.'

'I don't know whether people think I can or can't do something. I surprise myself, I'm an independent character.'

'If I could wake up tomorrow and be normal I'd still choose to be the way I am. I celebrate the aspects of myself that are unique and I know that others would too. But people's insistence on me being abnormal has taught myself and people like me to fear what others might think of me. It tempts me to be faceless, to hide something that others would object to. But I'm proud of my own uniqueness and so will instead strive to be myself.'

'I would like to be accepted more. People in society need to have more awareness of autism.'

'I feel people are fast to judge me. I always get bullied and don't feel people listen to my side of the story. It makes me feel really depressed. I have really bad depression.'

'My picture is about people being mean about their disabilities and about the way they look. We're all different and need to see people as they are. People stare at me and say 'what's wrong with you?' I want to be a doctor. It's annoying when people say you can't do things because you're disabled. My family help, they treat me like a real person.'

'In my picture the boy is cross, he is noisy, he presses switches, he says something irrelevant, he has a headache, he takes a deep breath. He's spitting, he has done something naughty. He is negative he needs to behave.'

'I feel so much power has been taken away from me. I don't think people listen to me.'

I decided to say something about people who have Asperger's and get bullied for it, like in my past experience. My picture says it doesn't matter whether you've got it or not everyone is different and you'll get through it.

'I like to protect my autistic friends from bullies, I like to help them and console them and treat them like equals.'

'I have a tendency to be independent, which means I do things by myself. People think I can't do things when I can.'



IMPORTANCE OF SUITABLE WORK EXPERIENCE, CREATIVE OPPORTUNITIES AND INDEPENDENCE

'I think they need to make jobs for people with autism, an autistic group or company in Warwickshire where we can go and work and socialize together. What I'd love the council to do is fund a project where people with autism can work in specialist shops with experienced people helping us and teaching us. It might be a charity shop run by autistic people. I would worry less working with other autistic people.'

'I like taking my dog out on walks. He's cute. When he wants to go I take him out on the hills. Having a dog gives me independence. I started taking him out when I was 14. In the future I'd like to go to sixth form and then college. I'd like to then work in a shop. I've done work experience in a co-op. I'd like more opportunities to see what jobs I could do in the future. I want to live independently when I'm older.'

'Independence to go anywhere and transport is important to me. It's expensive and there is a lack of public transport. There needs to be more buses where I live.'

'I would like to do work where my special needs are understood. I would like it if there were more work experience for people with autism. It's really good. I would like to do canteen work in an elderly home.'

'The expectation on an academic level is too high for me. I struggle with English. I would like more hands on courses like metalwork, woodwork, plumbing. I'm a very practical person but my language is holding me back.'

'Being independent makes me more confident. My bus pass and railcard are very important to me. They give me freedom. I like travelling to familiar places at a variety of times.'

'I want to go to college. My picture is about a really good work experience that helped me to realize what I want to do. Relevant work experiences are very important for people like me.'

'When I grow up I want to work in a jewelry shop. I would like run my own shop. But I don't know how to be supported to make it happen.'

'I did try work experience in a charity shop once but it didn't work out. I could only work on the till if someone was with me. They didn't have enough staff to stand over the till with me. I was told there was no point in me coming back. It's too stressful if they don't have staff to support you.'

'My picture is of someone in an art gallery and the gallery is called 'Splat'. I go to the art club every day. If I didn't have art I would be bored and sad. I love art, it makes me happy. I write lists and they're important to me as well.'

'Computers let me socialize. I don't really have much freedom. I think I'm old enough to go out and do things by myself. I'd like more freedom, it would make me feel grown up. Right now I feel like a five year old.'

'In the future I'd like to be a photographer and travel a lot. I've got a simple digital camera. I like taking photographs of buildings and landscapes. I don't often get to see or do much photography.'

'I like gardening. I've drawn the National Trust logo because I want to be a National Trust gardener when I'm older. I'd like to do an apprenticeship with them. It's a bit different with me because people might not know I have autism. I think people should have opportunities to do work experience.'

'Art is very useful, because it helps me to express myself, other people and my feelings.'

'I'm ambitious and want to succeed. I need drive and support from people to help me be successful. I know what I want in life, but don't know how to get it. I feel trapped in a stagnant scene.'

'I can get a place in college, but if I don't have the money to pay I can't afford to go. With autism there needs to be more financial support.'

'I'm going to start residential college, I want to learn housekeeping and socialize with new people but I'm a bit shy. I know I'm going to be scared. My mum wants me to come back at weekends because she is worried about me. I want to go and do it, but I don't know what support I'll need. I want to make friends but I'm very nervous. I've got fears inside me so I'd like to be able to go to someone I can talk to like a mentor. It's going to be really hard for me to go away from home. I'm scared.'

'I went to Charlecote Park to do a week's work experience, I got a lot out of it. I want to be a farmer and it gave me lots of tips. I think there are lots of good benefits for young people to get these opportunities.'

'I love art my way.'



BENEFITS OF EARLY DIAGNOSIS

'I wasn't told I had autism until I was in year 4. I think I should have been told earlier. Being told later causes a lot of hurt.'

'I was told I was autistic three years after being diagnosed. My advice for young people who are diagnosed is to tell them straight away. I knew I was different and knowing why helped. Because I have high functioning Asperger's lots of people don't realise I'm autistic. I sometimes feel I have too many commitments and feel under pressure. I need people to understand that I can easily feel overwhelmed and need support to help me balance my life.'

'I've only just been told I have autism. My primary school thought I had autism. Why couldn't my old school tell me? Why wasn't I told until now? I looked on my phone to find out what autism is. I think I have it. I want people to help me as much as they can. Like in lessons, when I struggle with work I get ignored.'

'My picture is not exactly what our garden looks like. The garden is filthy, I've tried to make it look better than it is. I got diagnosed with Asperger's half way through year 4. I try and make things better. I'd like to work with animals.'

'It was horrible when I was diagnosed. My sister was really crying. It's better knowing than not knowing.'

'In my picture I've drawn things I like and things I don't like. I sometimes feel different to the rest of my family. But if I didn't have CF (Cystic fibrosis) and autism I wouldn't be the person I am today. I know that most people don't actually think about autism and some people in this school don't want to think about it. They need to be thinking about it at my kind of age, if they don't think about it they won't know why they're so different. I know what it's like to live with autism.

I think the council needs to do something about it. They need to do more than just putting people in schools. They need to show people with autism life outside schools. Then they will know what life is like outside, and how they can confront it when they're older. I'm picturing opportunities to go out and make friends with people with and without autism. I don't have any friends without autism. I think people shouldn't be afraid to be friends with disabled people. It would make both their lives good.'

'My mum's two brothers were autistic, so she's had the experience of having brothers who were autistic. I was three when I was diagnosed. I don't come across as that autistic to some people. I was raised to know what autism is, and that I had it. She encouraged us to ask questions about it and so I've been raised in a different way. I think a lot of people don't tell their children they have autism and therefore don't know they have autism. But then the children wonder why they're different, why they can't talk to people. They should tell them they're autistic so they can understand it and ask questions. I've been able to overcome the way it affects me because I've been helped to understand it. People should raise their children telling them.'

'It's better to be told you have autism earlier on because then you learn to cope.'

1 think if I had been supported more by teachers they would have picked up there was more than just dyspraxia. 'A' levels is when it fell apart. I would suggest that when teachers are doing their training they do a module on special needs. Just because they're not going to teach in a special needs school doesn't mean they don't need training because about 10% of the population will have some form of difficulty. So they should still help those three or four in the class.'

'When I was two years old I went to my first party. After the party they realised I had autism because I was freaking out about the party lights. It's good to find out these things when you're young. My mum tried to do something about me freaking out about the lights so we went to my doctor and they put me in a room with my favourite songs and the disco lights on. It worked.'

I shut off and don't people how in feeling. I also can't tell why in sad and when i'm squt. talk to anyone. Trying I find it hard to to make me talk to you will make me worse talk to new people and make new Friends because I don't know what to I don't like people say and when I can say something. touching me because of my autism. I get very upset and angry but sometimes I hide it. It's because it feels weird and it irritates Sometimes I can't me. If you touch me on tell when people are joking one side, you have to touch or being surclustic. me on the other side because it's in-even. I don't always understand what people are asking me to Repte don't always do. Reople have to say things understand what I'm trying to say, but my older sister in a different way so that and is also autisic, understands

me straight away.

I understand.

I find it hard to tell

If i'm upset, angry etc,

GREATER UNDERSTANDING OF THE COMPLEXITIES OF AUTISM

'Having autism is unpredictable. I think employers need to think about the working environment and change the format. For example lighting and noise would be an issue. I wouldn't want to work in retail.'

'My picture is all to do with how I feel and how to be more understanding about me. I like to sometimes work with other people and yet sometimes I want to work on my own. I like it at home when it's the right level of sound. I don't like it when it's noisy in class with music playing. I always like it when things are the right temperature. I don't like when it's cold or freezing.'

'I need help with my listening skills. I struggle at times and need help to improve. People without special needs, need to do more listening.'

'In the past I used to live in the country. I found it hard to move to a new school. I need help to deal with changes and make the right choices. My family do help me a lot but I could do with help in the future.'

'I don't like it when there are lots of noises. For example there is a red light that comes on and makes a loud noise.'

'With autism, there can be anger issues, which need to be understood.'

'My picture is of a person stuck on an island. They're holding a message in a bottle with 'Help me' inside. He hopes he'll get off the island. I feel like I'm stuck on an island sometimes.'

'Autism is complicated to live with, I don't think people realise how complicated. It's quite difficult to understand if you don't have it. Autism makes me clumsy, and I struggle with concentration.'

'Life with autism is good, bad, surprising and it can also be a bit hard at times. What makes it good depends on what I like doing. What makes it bad is my mood swings. I don't get them all the time, but when I don't agree with something I sometimes get them. I am mostly couped up in my room. I do go on trips but some days I have off days and want to stay in my room. Having things to do helps me with my mood swings. Between the ages of 2 to 5, I was quite a trouble maker and caused quite a bit of havoc. Between 8 to 10 I used to hurt myself on purpose. As I got older I was able to control my anger a bit more.'

'I feel safe at home, that's why I've drawn my house. I don't feel safe with strangers. I don't like feeling unsafe and need help when I'm surrounded by strangers'

'My OCD stops me doing stuff. I think people need to be more aware of how hard it is. I feel like I'm in a minority, I'm not in this section or that section. I wish my mind could process things normally, but my brain is different because I have autism. For example if I get told off I get very worried and upset and end up saying sorry numerous times. I know my symptoms and my habits, most autistic children have them but might not notice they have them.'

'I don't like people touching me because of my autism.

'It helps to talk to my cousin who also has the same autism as me. With my typical autism I have anger so I could do with having as much support and understanding as possible from my family. My life is like a circle with autism in the middle.'

'My idea is I wanted to keep it all simple, because my version of autism is to keep it simple. When someone says something I don't always understand it first time, I have to ask them to keep it simple and explain it. That way I get a better understanding.



EMOTIONAL AND PRACTICAL SUPPORT

'I've had a social worker for three or four years. He helps me to get out and do fun things. I've made two pictures. One of my life with him and one of what it would be like without him. My picture is about going out with my social worker and all the activities we do together. I do badminton, golf, I go out for meals and I also make meals. We meet every two weeks and he's become a friend, it's good that I've got someone to trust.'

'I get supported in school but there's not much support out of school.'

'My family don't get enough support. There are different types of autism but all families with autism need special support.

'I didn't tell my boyfriend I had autism for ages. It didn't bother him. I was depressed, I had counselling. I went through three counsellors the third one was brilliant. If you have the right person who understands autism then I think it's a good idea.'

'It's hard for me to manage my emotions. I've just come out of an abusive relationship. I need help in handling these things. I've found activities and doing physical exercise helps.'

'It helps to talk to my cousin who also has the same autism as me. With my typical autism I have anger so I could do with having as much support and understanding as possible from my family.

'I need support to keep calm and deal with bad news. I'm hoping to get a counsellor soon to sit with me and help keep me calm. My autism doesn't let me sleep much and I when I do I scream in my sleep.'

'Services tend to be child like, there needs to be more adult based services. Mencap have supported me. I now live on my own. Support workers come in and help with day to day tasks.'

'My mum and aunty support me the most. They've got their own problems and don't get much support. I don't feel confident in myself to get a job. I need more help to enter the workplace.'

'I trust my two best friends but they live in Ireland. I feel ugly and unwanted. People don't know what it's like to have autism, no one really does unless they've got it. They need to speak to more people who have autism and under- stand different kinds of versions of it.

'When I feel sad or down I need to find ways to relax. I have lots of support workers who are there for me.'

'I feel fragile and get stressed and feel not wanted. I don't want to feel rejected. I would like more people I can talk to help me getting my feelings out.'

'My picture shows all the things I really am. I have a lot of fear, but I can be brave at times. My college and family support me mostly.'

'In my picture the sun is shining and it's a hot day and there are seagulls, a magnum and the beach. It's a picture of where my Nana lives in Wales. She's lovely and she understands me.'

'My picture is about protection, I lacked that when I was younger. The eye is blood shot because it's tired. We're all fighting this battle together. I'm not on my own now, I'm with someone. It means a lot to me and what other people can see as well. At this school if you don't understand they'll explain it in a different way it's not just 'do it' like in my old school.'

This picture is about a new house with the words 'handle with care'. The outside is on one side and the inside on the other. I feel happiest and safe at home. I'm about to move house.

Nanny and Granddad are really important to me, they come to my house and they love me.

My sister, mum and dad have helped me to control my emotions. I'm adopted, my mum was too young and didn't know how to look after me.'

'I've got five siblings who are all autistic. I understand them and they understand me. My dad was autistic. I plan to go to college, I'm nervous about making new friends and going somewhere different.

