

Staffordshire’s All Age Carers Strategy 2024 – 2029: Feedback from adult and young carers, families of young carers and social care professionals from the engagement process

Section 1: Results from survey of adult carers

Section 2: Feedback from adult carers’ focus groups

Section 3: Feedback from focus groups of adult social care professionals

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Section 5: Feedback from young carers’ focus groups

Section 6: Feedback from families of carers

1. Adult carers feedback obtained through the survey

Services and systems that work for carers	The majority of carers said	<ul style="list-style-type: none"> - Most respondents had not received support from social services in the last 12 months but most of those who had were happy with it. - It is difficult to find information about support, services and benefits and we need better signposting or making it easier to find. - I would not know how to access support or respite care if I needed it. - A GP or a social care professional who they had met in the previous 12 months had not identified them as a carer or offered support. - They had been involved or consulted to some extent in discussions about the support or services for the cared for person. -
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	A number of carers said	<ul style="list-style-type: none"> - Information quality needs to improve, and be timely e.g. from health and social care professionals at key points like times of crisis and diagnosis. - The system needs to improve (too complicated, too many blockages, fragmented and lacking continuity between services, carers have to repeat story, difficult to find the right person / department, feeling fobbed off, navigating benefits applications very difficult).
	A few carers said	<ul style="list-style-type: none"> - We need help to complete benefit forms. - Better website navigation.
Employment and financial wellbeing	The majority of carers said	<ul style="list-style-type: none"> - In the last 12 months caring has caused some or a lot of financial difficulties. - I'm not in paid employment for reasons unconnected with caring e.g. retired. - Flexible working arrangements and flexibility for medical appointments are most helpful to balance work and caring.
	A number of carers said	<ul style="list-style-type: none"> - I'm not in paid employment because of my caring role. - I am in paid employment and feel supported by my employer.
	A few carers said	
Supporting a carer friendly community	The majority of carers said	<ul style="list-style-type: none"> - I do some of the things I value or enjoy but not enough. - I have some control over my daily life but not enough. - I am neglecting myself or sometimes can't look after myself well enough. - My health has been made worse by my caring role. - I don't have as much social contact as I would like.
	A number of carers said	<ul style="list-style-type: none"> - I have no encouragement and support.
	A few carers said	<ul style="list-style-type: none"> - I am extremely worried about my personal safety. - I fear for the future when I can no longer care.

Using data and digital solutions to improve outcomes for carers	The majority of carers said	<ul style="list-style-type: none"> - They use a smartphone, mobile phone or tablet to support their caring role, including to set reminders for medication, appointments and share information with their caring circle e.g. What's App.
	A number of carers said	<ul style="list-style-type: none"> - They don't use any IT and aren't IT savvy. - They had no time or interest in it.
	A few carers said	<ul style="list-style-type: none"> - They use movement monitoring devices or cameras. - They would like more support to use it. - Too confusing, stressful, would prefer to speak to someone.
What would make the biggest difference to help you continue in your caring role?	The majority of carers said	<ul style="list-style-type: none"> - More support including more practical support e.g. gardener, handman, more flexible peer support groups and more local support.
	A number of carers said	<ul style="list-style-type: none"> - A break from caring including respite care - Discount card - Greater recognition of their role and professionals to have more understanding and empathy for them as a carer - Better and more accessible information - More financial support - Health and social care systems to improve including better communication
	A few carers said	<ul style="list-style-type: none"> - To be involved and consulted in decision making - More help with transport - Services they can take the cared for person to - Carer passport

2. Adult carers feedback from carers focus groups

Are current priorities correct?	The majority of carers said	<ul style="list-style-type: none"> - Current priorities are broadly correct but need to be delivered - We need timely access to information, in a range of formats and to know where to find it or to be given it at key points e.g. diagnosis
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	A number of carers said	<ul style="list-style-type: none"> - Many people said they did not get any break from caring or only once a month. - Carers worry about what would happen when they can no longer care. - Carers gave a mixed response to digital solutions, some people quite savvy and use social media, Alexa, others had no access to PC, printers etc.
	A few carers said	<ul style="list-style-type: none"> - Need more support with financial management including information on website (financial contributions).
What is your experience of support or services	The majority of carers said	<ul style="list-style-type: none"> - Many people said GPs and hospitals know they are a carer but don't link or signpost to Social Care, provide adequate support or information re health condition, diagnosis. - Communication is poor.
	A number of carers said	<ul style="list-style-type: none"> - We don't know what support is available – this included statutory assessments, Staffordshire Together for Carers, and local community support or other peer groups. - Some people said they could not access peer groups due to lack of flexibility of time. - Carers assessments are a tick box exercise with no outcomes.
	A few carers said	<ul style="list-style-type: none"> - Social care professionals - lack empathy, no consistency and no key / allocated worker makes their role much harder including managing expectations downwards e.g. availability of respite. - Some carers said lack of services and respite for adults with learning disability in Leek / Moorlands. - Parent carers talked about poor experience of Children and Families Services and having to fight for their rights particularly with the Education Department.
What would make the biggest positive	The majority of carers said	<ul style="list-style-type: none"> - Better support from health and primary care, including information and signposting.

difference to help you keep caring?		- Many people said more peer support groups including specialist groups e.g. carers of people with mental health needs.
	A number of carers said	- Better access to respite so they could take a break from caring, enjoy outings. - Better communication, including named person to contact, direct phone line, someone to talk to face to face. - More information about services and support available, and more local services and support.
	A few carers said	- Consistent social worker / allocated worker, who understands them and the needs of the cared for person.
What are your top three priorities?	The majority of carers said	- More support, including face to face support, including social care professionals and access to groups. - Accessible and accurate information, advice and guidance, and signposting to this.
	A number of carers said	- More empathetic social care & health professionals who understand the carer's role. - Primary care surgeries to link or signpost carers to sources of support and information.
	A few carers said	- Primary care surgeries to share their carers register

3. Social care professionals' feedback from a focus group

Do you know where to signpost carers for an	Most people said	- There was good understanding of this within MPFT district teams and First Contact staff. Many attendees were carers assessors from First Contact Team.
	Some people said	

assessment of their needs	A few people said	
How would you prefer to source information when supporting or signposting a carer?	Most people said	<ul style="list-style-type: none"> - In email and printable format, and suitable for sending via text message. - Something simple and not too long. - Information on local services and where the gaps are.
	Some people said	<ul style="list-style-type: none"> - In hard copy as some carers don't have mobiles etc.
	A few people said	
What would be the most effective way to communicate changes to commissioned services or service pathways to you?	Most people said	<ul style="list-style-type: none"> - Service briefings e.g. PSW practice forum. - Social Work Learning Academy newsletter, leaflets, emails - but not on Fridays as these are the busiest for emails. -
	Some people said	
	A few people said	
From your interactions with carers, what are they telling you would make the biggest positive difference?	Most people said	<ul style="list-style-type: none"> - Respite and time for themselves, sitting services. - Easy access to respite as takes long time to access.
	Some people said	<ul style="list-style-type: none"> - Parent carer assessment: many don't feel they have an identity outside their caring role - would like an opportunity to meet other parent carers who can empathise. - Financial support due to cost of electricity and gas to heat home.
	A few people said	<ul style="list-style-type: none"> - More evening groups.

		<ul style="list-style-type: none"> - Priority access to mental health services for young carers and young adult carers as 6-month wait. - Ability to shape experience of coming into contact with services and social care professionals e.g. co-production, being involved in recruitment panel, access the website and choose how to get involved. - GP surgeries to be more empathetic and offer health appointments at appropriate times for the carer and the cared for person, as it can be impossible to get someone with dementia to an 8 a.m. appt.
Do you have any comments or suggestions you would like us to take into account?	Most people said	<ul style="list-style-type: none"> - There are service gaps (including local community groups and accessing benefits) as well as: <ul style="list-style-type: none"> - Availability of activities for young carers - predominantly delivered in 3 areas (Stafford, Lichfield and Burton) so people have to travel and lack of activities in school holidays. - Lack of face-to-face activities for 5 and 6 years olds - we are not meeting the need for them to get out of the home. - Information was shared about other activity providers. - Changes in age eligibility which meant a loss of provision for young carers aged 13+ years.
	Some people said	<ul style="list-style-type: none"> - Lack of provision for young adult carers 16 - 17 as activities usually take place at 4 - 5 p.m. and carers can't get to them. - Gap in Wombourne. - Struggle to get teenagers to engage - no peer support group for 13 + and in many of the areas. - Gap in age-appropriate support for young adult carers aged 18 - 30, e.g. contact with other adult carers and no online offer either.
	A few people said	

4. What Staffordshire County Council and MPFT working carers told us (NB only 3 working carers took part in these groups)

Are current priorities correct?	Most people said	- Current priorities broadly correct
	Some people said	- Unaware of carers assessment, direct payments or commissioned carers support service
	A few people said	- Need to make schools aware of assessment. - Information needs to be available to community MH services so they can give paper copies of leaflets and newsletters to patients. - Information needs to be available at point of crisis, not discharge. - Information needs to be available at child in need assessment, Sendiass and Family Hub.
How does your caring role impact on your work life?	Most people said	- Caring role peaks and troughs and can have more impact on work at crisis point with greater need for flexibility to deal with practical issues like making appointments. - Impact of caring on mental wellbeing.
	Some people said	
	A few people said	- Work is good for people’s mental health and we need to recognise that we have to maintain a service.
How does SCC currently support you?	Most people said	- People feel very well supported by managers and flexible working policy for those in flexible roles. - People feel trusted to deliver the workload. -

	Some people said	- Lack of flexibility with some job roles can make certain roles unmanageable.
	A few people said	- Access to wellbeing support like ThinkWell is valued and supports with emotional wellbeing / resilience at the point of crisis.
Looking to the future, what else can Staffordshire do to improve the support that it offers to working carers?	Most people said	- Support to navigate the system and signpost to support, information etc. - Other organisations being carers aware.
	Some people said	
	A few people said	
Would a dedicated support network in Viva Engage be useful to talk to other carers in similar situations?	Most people said	- People were positive about this depending on how it would be used - e.g. as a chat / peer support group function, information sharing tool etc.
	Some people said	
	A few people said	

Carers also told us:

"I feel forgotten"

"I worry about what will happen when I die."

"I am happy to be a carer. I know that it won't be forever, but it has meant I have and will continue to neglect my own business, that is the struggle."

"I want to be listened to, be believed and be involved in decisions."

"I just feel that an afternoon off once in a while so that I could go shopping or arrange to visit a friend would be amazing."

5. What young carers told us through the feedback sessions:

1	Can you talk about the things you like doing?	The majority of children/young people listed activities they could do	Football, cricket, singing, arts and craft, listening to music, sport in general, being with friends, basketball, swimming, talking to friends, video games, archery, playdough, exercise
		Several children	Said they have people to talk to about the things they like doing
		One child/young people said	Cannot discuss things if they have had a bad day
2	Does the support you provide for your family member (change wording as necessary in terms of brother/sister/Mum/Dad etc) ever stop you from doing these things?	The majority of children/young people said	It does not stop them from doing the things they like to do
		2 children/young people said	Occasionally they cannot do the things they want to do due to their caring roles
		5 children/young people said	It does stop them doing the things they want to do Some example answers: <i>"Because I normally need to look after my 2 brothers as they are disabled"</i> <i>"I don't do much as I have to help my Dad and look after myself"</i>
3	How do you manage the support you give to your family member alongside of going to school?	2 children/young people said	<i>"I just do it"</i>
		2 children/young people said	<i>"I manage well"</i>
		2 children/young people said	<i>"It is easy to manage"</i>
		2 children/young people said	<i>"It is not hard and I manage"</i>
		5 children/young people said	I do not manage very well Answers: <i>"I need to check my Mum takes her meds",</i>

			<p><i>"In the holiday I care and help my Mum and family and on a school day I have to do both before and after school",</i></p> <p><i>"I struggle a bit as I try to look after my other and go to school and that stresses me",</i></p> <p><i>"I do not cope well, I get annoyed or stressed quickly if my sister does something I don't like and it doesn't help that I have had the stress of school already that day", "badly!"</i></p>
4	Does the support you give have an effect on how you look after yourself? (<i>sleep, exercise, food, social activities, etc</i>)	10 children/young people said	No, it does not affect how they look after themselves
		1 child/young people said	A little
		6 children said	Yes, it does affect how they look after themselves Some example answers: <i>"In my sleep my tummy hurts because of worries so I can't sleep", "I don't get enough sleep"</i>
		3 children/young people said	No and yes. <i>"have learn that in my religion if I help we get a reward from God, I sometimes feel sleepy as I need to get my brother to sleep for me to be able to sleep"</i>
5	Thinking about time with your friends, does the support you give affect this?	4 children/young people said	Yes and no
		2 children/young people said	It does not affect their time with their friends
		4 children said	Yes it does affect their time with their friends Some example answers: <i>"Kind of because I only have 1 friend", "only get to see friends at school as my Mum said no to going out after school"</i>

6	Do you feel supported to be a carer, if so by who?	Majority of children/young people said	Yes
		2 children/young people said	No <i>"Not really, as being a young carer is not well known"</i> <i>"I have not been given support because my case is very serious"</i>
		People or services which supported them:	By everybody By friends and family Counsellor Teacher
		Majority said young carers service supports them	Young carer service
7	How long were you supporting someone before you knew you were a Young Carer and had some help/assessment?	Variety of answers	6 years x 3 7 years x 3 8 years x 2 5 years x 3 4 years x 2 3 years x 2 <i>"All my life"</i> Don't know x 5
8	Thinking about the support you offer your family member, what worries you the most?	Several children/young people said	Nothing
		One child/young people said	Don't know
		Several children said	Yes Some example answers: <i>"Arguments and crying",</i> <i>"school",</i> <i>"everything",</i> <i>"school and homework",</i>

			<p><i>"Mum getting worse",</i> <i>"falling behind in school",</i> <i>"him getting hurt",</i> <i>"if my family was unhappy",</i> <i>"something wrong happening to my brother which makes him go into hospital",</i> <i>"my Mum being alone",</i> <i>"I feel my family will suffer when I am in school",</i> <i>"my Mum being upset or if something happens"</i></p>
9	What help has made the most difference to you?	3 children/young people said	<p>Nothing <i>"Nothing as I am always worried and afraid"</i></p>
		2 children/young people said	Not sure
		Variety of answers	<p><i>"Friends",</i> <i>"counsellor",</i> <i>"help from my family",</i> <i>"school and other charity help",</i> <i>"getting an extension on the house by the Council"</i> <i>"my family has always been on my side when I have suicidal thought and my mental health is bad"</i> <i>"socialising with friends"</i></p>
10	What do you think the Council should consider most important to support Young Carers? (Discuss what the Council is etc)	Variety of answers	<p><i>"more money for young carer staff"</i> <i>"discounts towards basic needs"</i> <i>"making sure we are happy"</i> <i>"extra payments for those who help us"</i> <i>"more sport and friendship groups"</i> <i>"more people to help us"</i> <i>"more fun things to do"</i></p>

			"bringing friends on trips as well as family" "time to talk" "make young carers more known"
		3 children/young people said	Don't know
Additional questions for older young carers			
11	Does the support you give have an impact on what you will do after you finish school? (16/18+, future working, education, life?)	7 children/young people said	No One child said: "no as I will be successful"
		4 children/young people said	Not really/not sure "my Dad can function without me, I think"
		5 children/young people said	Yes Some example answers: "Yes, as I cannot move away", "yes, it will have an impact on me"
12	What do you think the Council should consider most important to support Young Carers?	Several young people said	Don't know
		2 young people said	Help make young carers be more known
		Several young people said	Help more young carers join the groups

6. What families of young carers told us

Completed via Microsoft form sent out by the commissioned service for young carers

1	Can you talk to us about the things your child/young person likes doing?	Variety of answers	Art and walking, going to different places and making new friends, swimming, reading, playing, cooking, bowling, Spending quality time with Mum and Dad. Watching movies, gymnastics, mountain biking, animals and outdoor activities "monthly get togethers have been his life saver"
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			Holidays, drama, visiting places, listening to music, horse riding <i>"she loves going to the group each month and doing the fun activities on offer with her friends"</i>
2	Does the support they provide for their family member ever stop them from doing these things?	1 person said	No
		1 person said	<i>"Try not to let it"</i> <i>"we try for it not too but we have to make reasonable adjustments which means sometimes it does stop or make it less enjoyable owing to worrying about doing things with conditions"</i>
		10 people said	Yes Some example answers: <i>"we are unable to go to a lot of places due to the disability/behavioural problems of her twin brother who struggles in busy/different environments"</i> <i>"yes all the time they don't get time to these activities until I am upstairs in bed"</i> <i>"he does worry about going to any activities that mean him going away overnight from his family member – this is something he won't do"</i> <i>"yes, they do not get to have any recreational or socialisation time as due to my disability I cannot take him anywhere"</i> <i>"yes, our son just trashes anything she is working on"</i> <i>"yes, as she has a younger brother she also has PICA syndrome so will eat anything from beads to pebbles"</i>

3	How do they manage the support they give to their family member alongside the demands of going to school?	Variety of answers – all had an element of difficulty	<p><i>"find it hard not to worry"</i></p> <p><i>"we have to try and get school homework done when her brother has left for school in the taxi in the mornings, but time is limited"</i></p> <p><i>"we try to balance this as much as possible"</i></p> <p><i>"with great difficulty and often by self"</i></p> <p><i>"not too bad at the moment, but as she gets older and has more to do, I think this will get harder"</i></p> <p><i>"they have to share duties: hoovering, washing up, cooking and other household chores"</i></p> <p><i>"he mainly supports his family member before school evenings and weekends"</i></p> <p><i>"they are struggling and very tired"</i></p> <p><i>"she copes quite well but can appear sad and withdrawn at times"</i></p> <p><i>"very difficult but we manage"</i></p> <p><i>"struggle sometimes to balance it all. School don't seem to register that being a young carer affects schoolwork and focus. Lots of funding and extras given for pupil premium children or LAC or SEN but no extra support given to young carer and they don't affect data. PPG and LAC and even SEND get free school meals , exam help, access to support, trips etc but young carers are never factored into this, yet they are often the ones who need it most"</i></p> <p><i>"they are quite settled at school and get no with their schoolwork and homework, but it is sometimes hard when I cannot help them due to my severe sight impairment"</i></p>
4	Does the support they	1 person said	No

	give have an effect on how they look after themselves? (<i>sleep, exercise, food, social activities, etc</i>)	2 people said 10 people said	A little/sometimes Yes Some example answers: <i>"her sleep gets disturbed every night which impacts on our daughter's tiredness the following day"</i> <i>"they stay up later to spend time with parents, food not always healthy as convenient for time, not able to get out and socialise, so not as confident"</i> <i>"struggles to remember to put herself first"</i> <i>"he will worry at times more and his nan has to step in and get him to go and spend time at her house to relax, and have time to destress and have time for himself"</i>
5	Thinking about time with their friends, does the support they give affect this?	1 person said	No
		3 people said	Sometimes
		8 people said	Yes Some example answers: <i>"yes, as the little time we have respite using the PA hours, we like to make this time special with our daughter, so this leaves little time for activities with friends out of school"</i> <i>"going to monthly group has helped him socialise and gain more friends"</i> <i>"can cause meltdowns in the home, because they want to be out but can't always do this"</i> <i>"she is more mature than some of her friends, owing to the responsibility she has, and it can affect her relationships with friends, as some of the things that "normal" kids do, just seems immature to her. Old head on young shoulders"</i>

			<p><i>"yes, we keep away from people as our son can be aggressive which impacts upon her"</i></p> <p><i>"it is difficult for them to socialise with their friends outside of school due to the fact that most of them either invite them to the park or birthday parties and as I cannot get them there, they miss out"</i></p>
6	Do you feel they are supported as a carer, if so by who?	1 person said	<p>School</p> <p><i>"school are very supportive; Staffordshire Together for Carers have had a real positive impact on social interaction and confidence"</i></p>
		2 people said	<p>Family</p> <p><i>"he is supported by other family members when he allows them to support him. He is a very private person and will isolate himself if he becomes too stressed"</i></p> <p><i>"us as a family and then Staffs young carers group, that is it. Doesn't seem to be support elsewhere for hr"</i></p>
		10 people said	<p>Young Carers/Staffordshire Together for Carers Service</p> <p>Some example answers:</p> <p><i>"by STfC but not much by anyone else"</i></p> <p><i>"young carers have been amazing"</i></p> <p><i>"STfC gives them respite and time away from myself and go beyond and gave them a few days away from me"</i></p> <p><i>"Young carers service is the only support she gets"</i></p>
7	How long were they supporting a family member before	Variety of answers	<p>Since they were at school</p> <p>7 years</p> <p>Assessed when they were 7 years old</p>

	they/you knew they were a Young Carer and had some help/assessment?		<p>6 years 5 years 2/3 years When they were 7 and 8 Long time 3 years x 2 2 years <i>"he has been a young carer since he was 8, and Young Carers Service were involved when he was 10, his older brother mentioned to his 6th form teach how ill their parent was and the caring they were all doing outside of school. She stepped in and referred them both, but her elder brother wasn't helped but the youngest was"</i> <i>"they took on their caring role at quite an early age and I didn't realise support was available for them until a couple of years ago"</i> <i>"since they were able to understand that their brother was different"</i></p>
8	Thinking about the support they offer their family member, what do you think worries them the most?	Variety of answers	<p><i>"not being there for me"</i> <i>"she wants her brother to stop banging his head because he hurts himself. He also targets other people especially our daughter, he pulls her hair out, scratches ad pinches so she is constantly worried about getting hurt by him an always on guard in her own home"</i> <i>"she is worried about lots of things"</i> <i>"the aggression from sibling who needs care, rejection from sibling, what things will be like when she grows up"</i></p>

			<p><i>"me having falls and them not being here"</i></p> <p><i>"that the young carer will say he isn't coping and involve Social Workers who will remove him from home" (this is a fear due to neighbours being foster carers)</i></p> <p><i>"the unpredictability of everything and mortality sometimes"</i></p> <p><i>"I think my safety and the fact I can't see much is what worries them the most"</i></p> <p><i>"how angry he gets"</i></p>
9	What help do you think has made the most difference to them?	Variety of answers	<p><i>"time away from caring"</i></p> <p><i>"having PA hours so we get to do normal things twice a month as a family"</i></p> <p><i>"having and talking to people in the same situation, time away to be a child"</i></p> <p><i>"breathing space away from being a carer"</i></p> <p><i>"we are still figuring out what help is available, nice to meet people with shared experiences"</i></p> <p><i>"he gets to go monthly to be with other young carers be a child, have fun at Xmas. They take him and a family member which he absolutely loves to a pantomime as he says he gets to spend just a couple of hours laughing and relaxing not worrying and seeing his family member smile because of their pain daily it doesn't happen much"</i></p>
		Several people said	Young Carers group

			<p>Young Carers support Young Carers weekends away Young Carers trips Confidence and socialisation opportunities from young carer support/groups</p>
		1 person said	Counselling
10	What do you think the Council should consider most important to support Young Carers?	Several people said	<p>Young Carers group More activities available for young carers More support early on in their caring life Schools to support more More respite for young carers Counselling Listen to their needs</p> <p>Some example answers: <i>"they need the support very early so they won't miss opportunities to socialise and learn"</i> <i>"that the young carers are needed. A lot of children out there living a life trying to be the grown up worrying about an adult in their household and this organisation (young carers service) steps in and lets them be a child again, if only for a few hours. They get to leave their worries at the door and also talk to others who know how it feels.</i> <i>This is a really important thing for a child as they get forgotten so many times as their voice is only heard when it's too late so please keep it going"</i> <i>"their voice, their concerns, their opinions. Getting schools to know who these young carers are and having them on the radar for support"</i></p>

			<p><i>"I think Staffordshire County Council should consider more respite breaks for young carers and also activity sessions to let children just be themselves and enjoy being children with no responsibilities for a short period of time"</i></p> <p><i>"That time with others like themselves, so they don't feel alone and like they are the only one with a family member with an illness or disability"</i></p>
11	Do you think the support/care they give will have an impact on what they will do when they finish school? (16/18+, future working, education, life?)	7 people said	<p>Yes</p> <p>Some example answers:</p> <p><i>"yes massively, we worry so much about how she will be able to study in peace in the future as her brothers behaviours and noise levels are too distracting. This is going to have a huge impact on her studies and results. We do think she would be amazing working with children and adults with additional needs"</i></p> <p><i>"yes because they constantly worry about things"</i></p> <p><i>"yes I think it is very important that children have an opportunity to live their childhood and enjoy themselves which will in turn impact their decisions on what they want to do after they leave school"</i></p>
		2 people said	Maybe
		2 people said	Not sure