

Time to Talk Next Steps Online Celebration

#TtTNSCelebration



Support for Parents and Carers

With Harriet Squirrell, Sharon Smith and Jo Palmer
Contact



Recording



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The session will be 1.5 hours long

- We will start with introductions
- Then we will share information about our work
- At the end we will answer questions

If we don't have time to answer your questions we will come back to you after the session with the answers.

This session will be recorded and shared with the public.

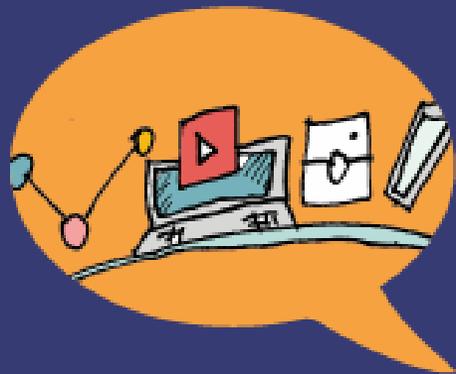
Just the presentations will be recorded.

The question time following the presentations will not be recorded however some questions may be noted down anonymously and added to the transcript for others to learn from.

The recording will be edited to our greatest ability so that there are no videos or names of participants shown when it is published to the public.

Please help us keep your personal information safe by staying on mute during the presentations.





Please put your name and your interest in this session in the chat



Put your questions in the chat or you can ask them at the end



You can keep your camera on, or have it turned off – we'd love it if you can give us a wave 😊



Please keep your microphone on mute while people are presenting

If you want to turn on automatic captioning, you can do this by:

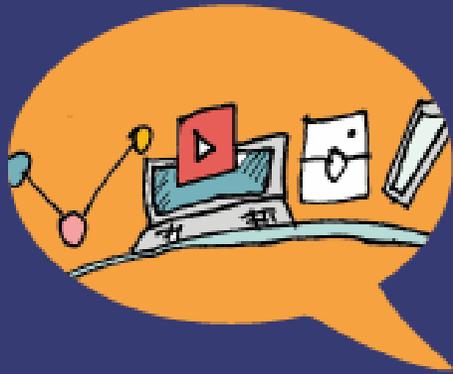
Zoom



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Time to Talk Next Steps



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Time to Talk Next Steps is a rights-based support programme for young people with additional needs aged 16 – 25 and their family/carers (in England)

NDTi has run this programme in partnership with Contact, a national organization which provides support, information and advice to parents and carers (www.contact.org.uk)



The programme has run for 3 years (2021-2024) and been funded by the National Lottery Community Fund.

Young people, family/carers staff and associates are running online sessions this week to celebrate, share learning and give examples of how Time to Talk Next Steps has enabled young people and their family/carers to

- Build confidence and learn new things
- Have their voices heard
- Meet other people facing similar challenges
- Move forward in their lives



National Development Team for Inclusion (NDTi)



www.ndti.org.uk

We are a not-for-profit organisation working to enable people at risk of exclusion, due to age or disability, to live the life they choose.

Our work aims to drive inclusion by:

- enabling people's voices to be heard
- coproducing programmes & resources which celebrate what's possible
- supporting changemakers & building self-determination

[Time to Talk Next Steps](#) has been run by the Children and Young Peoples Team at NDTi

Other work includes and [Preparation for Adulthood Internships Work \(Employment\)](#)



Preparation for Adulthood

Essential knowledge for parents and carers

Time to Talk Next Steps - Parent Support

'Everything, Everywhere, All At Once'

With Harriet Squirrell, Sharon Smith and Jo Palmer

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Picture of Everything
Everywhere All At Once
promotional material



Introductions

Welcome!

We would like to welcome you to this evening's presentation about the support offered to parents/carers through the Time to Talk Next Steps programme.

This support was delivered by Contact, with support from members of the NDTi team.



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Introductions

Harriet: Head of Family Support Programmes at Contact taking a strategic overview of the project. I'm passionate about supporting parents to find their way through their family's individual journey. Also, mum to Sam who is 16 and is starting to navigating the transition path as we speak!

Sharon: Mother to a 19yr old daughter who had been taking part in the Time to Talk/Time to Talk Next Steps programme. Currently navigating uncharted territories together, such as social care and direct payments. Thinking about how best to prepare Tanzie for her future adulthood – shaped by Tanzie's hopes and wishes.

Jo: Mum to Greg, aged 30. Together we have been navigating the support on offer for disabled adults, learning about our changing roles and sharing what we have learned. We hope that by sharing our journey we can make it less stressful for others.



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Contact

We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information. We provide advice, information and support to families of all disabled children and young people aged 0-25 years, with or without a diagnosis.

We bring families together to support each other. And we help families to campaign, volunteer and fundraise to improve life for themselves and others.



Picture of Father and Son



Picture of Mother and Son



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Contact Website

www.contact.org.uk

Our Helpline
Talk to us | Contact
0808 808 3555

[FAQs - Contact](#)



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Contact's [website](#) provides advice and information about any concern a parent might have about raising a child with additional needs – from diagnosis, entitlement to services and benefits, to childcare and support when their child is at school or college.

We support families, bring families together and help families take action for others

	Information & advice The best possible guidance for your family. Find out more >		Workshops & events Meet families like yours at our fun and informative events. Find out more >
	Listening Ear Our 1-1 emotional support telephone service. Find out more >		Parent carer participation We support parent carer forums in England shaping local services. Find out more >

Picture of Website support page

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Why was this work important?

- Young people were receiving support to plan and prepare for adulthood, but parents/carers were not
- Parents/carers play an important role in supporting their young person through the transition period (and probably beyond)
- The role of parents/carers will change during 'transition' too



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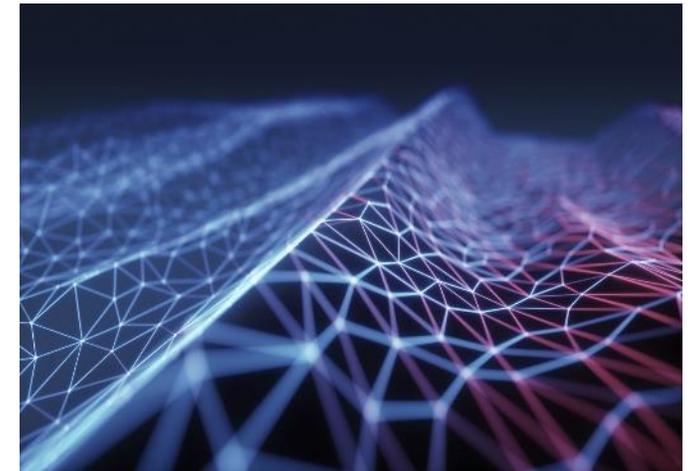
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Thinking about the future - why is it important?

- Planning will help put things in place to ensure that young people have the best adulthood possible
- Young people should be supported to shape their own future and be central to any planning
- A shifting role for parents – leader to cheerleader
- None of us ever know what is around the corner
- Peace of mind during a possibly challenging time

Helping a young person make plans for their future is one of the best gifts parents/carers can give



Picture of a network



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Difficult conversations?

- Parents/carers might not want to think about a time when they cannot care for their child
- They might think their child is not capable of making their own plans – but they still have the right to have a say in their own future
- They might think their child will get distressed about thinking about change or a future when they are not around to support them
- Planning can feel scary and overwhelming especially when their time is taken up giving support to their child/young person
- It is important that they should find time to sit down and think things through with their child/young person



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Parent carer wellbeing - why is this important?



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Carers often neglect their own health and wellbeing

BUT... parents/carers cannot pour from an empty cup! Carers need to take time for themselves and make sure they are getting help too, so that they can care effectively.

It is useful for parents/carers to spend time thinking about what help they might need in their caring role and in maintaining their own health and wellbeing – and what they want *their* own future to look like too!



Picture of a cup of coffee

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Essential knowledge for parents and carers

An Overview



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- The journey/changing role for parents/carers
- Planning for the future
- Support for parent/carers
- Thinking about outcomes
- Preparing for Adulthood topics (as a starting point)
- Further help and support available

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Essential knowledge for parents and carers

The Journey



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- Introducing 'The sea of transition'
- Our starting point in the training/support provided to parents/carers
- Based on Jo's lived experience and Sharon's questions

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The sea of transition

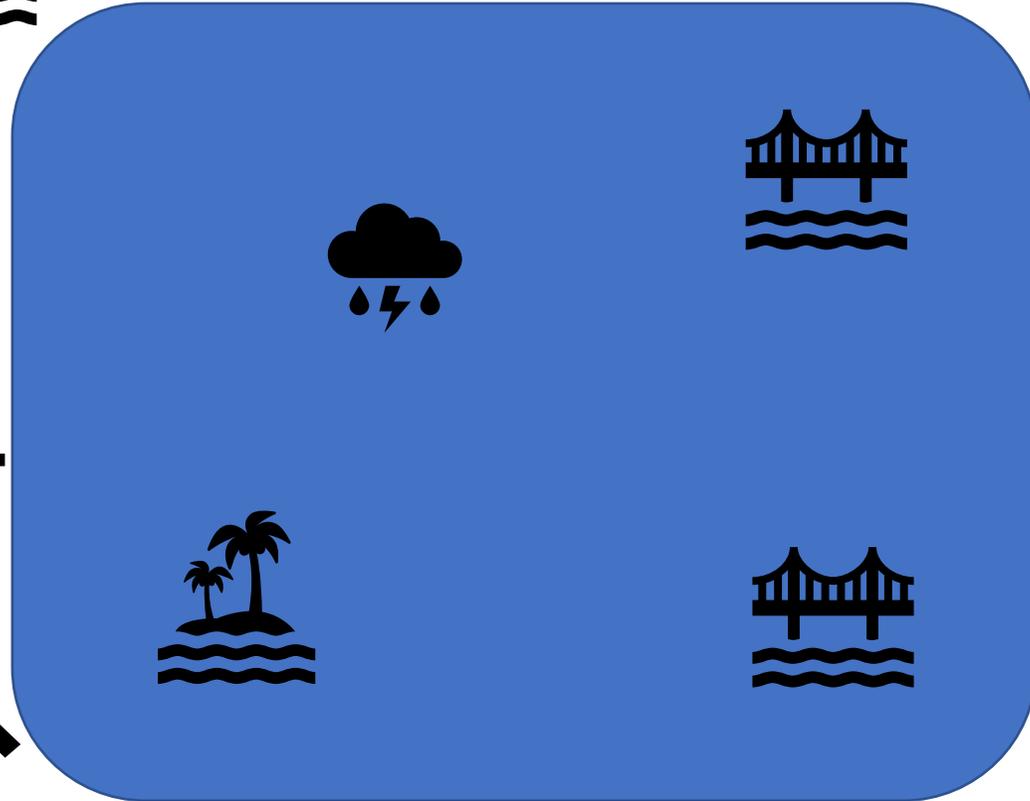
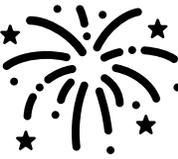
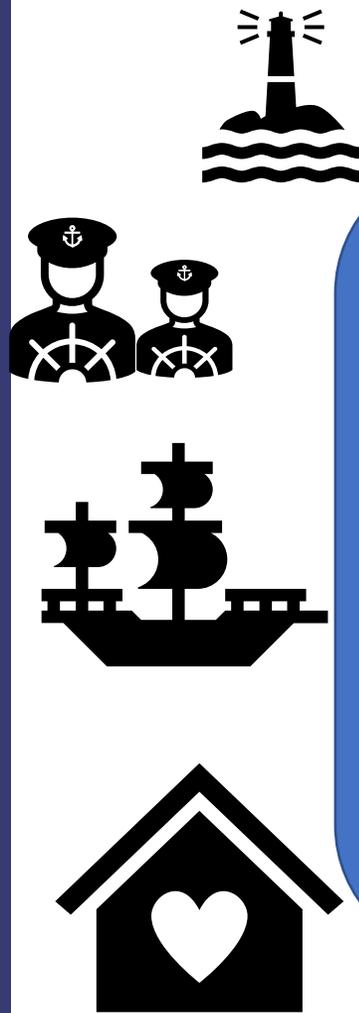


Image of the sea with storm, islands, bridges, boats and cities



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What happens when?



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Everything, Everywhere, All At Once (or so it can feel...)

From age 14

Education Health and Care Plan Transition Review, Learning Disability annual review

From age 16

Decision making, college applications, transfer to adult mental health services, option to claim adult benefits, education review focuses on Preparing for Adulthood outcomes

From age 18

Choices to move to college, employment or community support, health transition clinics, handover from paediatrician, Social Care adult assessment, Individual Budgets, Continuing Health Care funding and Personal Health Budgets

From age 21+

Secondary transition at the end of college, further social care assessments for community support and independent living

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Where did we start?

- Asked to produce a 1.5hr webinar (including a Q&A session) for parents/carers. This would be repeated 4 times a year (for different cohorts)
- The four 'Preparation for Adulthood' outcome areas felt like a useful starting point to build the content around



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*Additional
support also
available*



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- **Listening Ear:**

We offer 1-1 telephone appointments with a family support adviser for parent carers looking for a listening ear, reassurance and practical and emotional support.

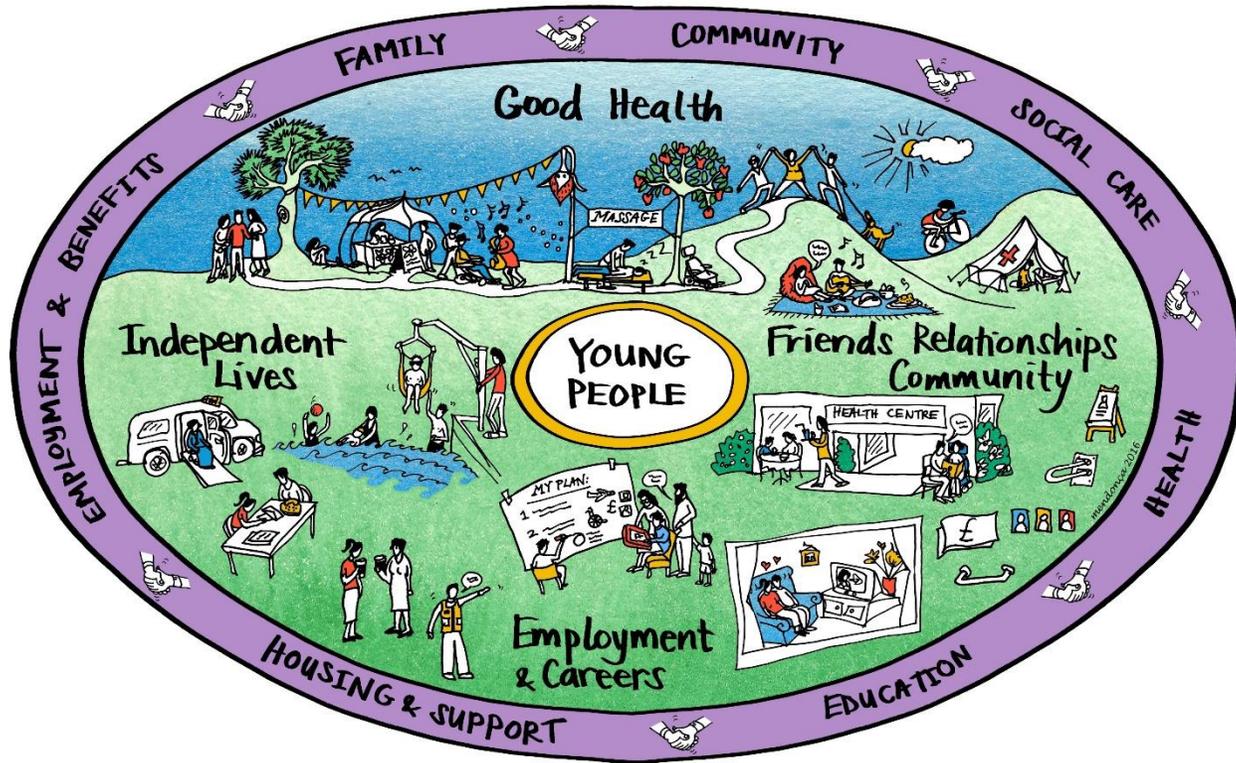
- **Contact Helpline:**

Our helpline is for parents and carers in any part of the UK with a disabled child aged from birth to 25. Your child can have any kind of disability or additional need, and you do not need to have a diagnosis.

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Preparing for
Adulthood



Planning for
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However...



- After an initial brainstorm and collation of content, we soon realised that it would be impossible to cover everything needed in one webinar session
- We suggested that we run four different sessions across the year instead.
- The idea was that parents would sign up to the 'course' and attend all four sessions, building knowledge and also peer support with the others attending



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Preparing for Adulthood – wider topics

Education and Employment

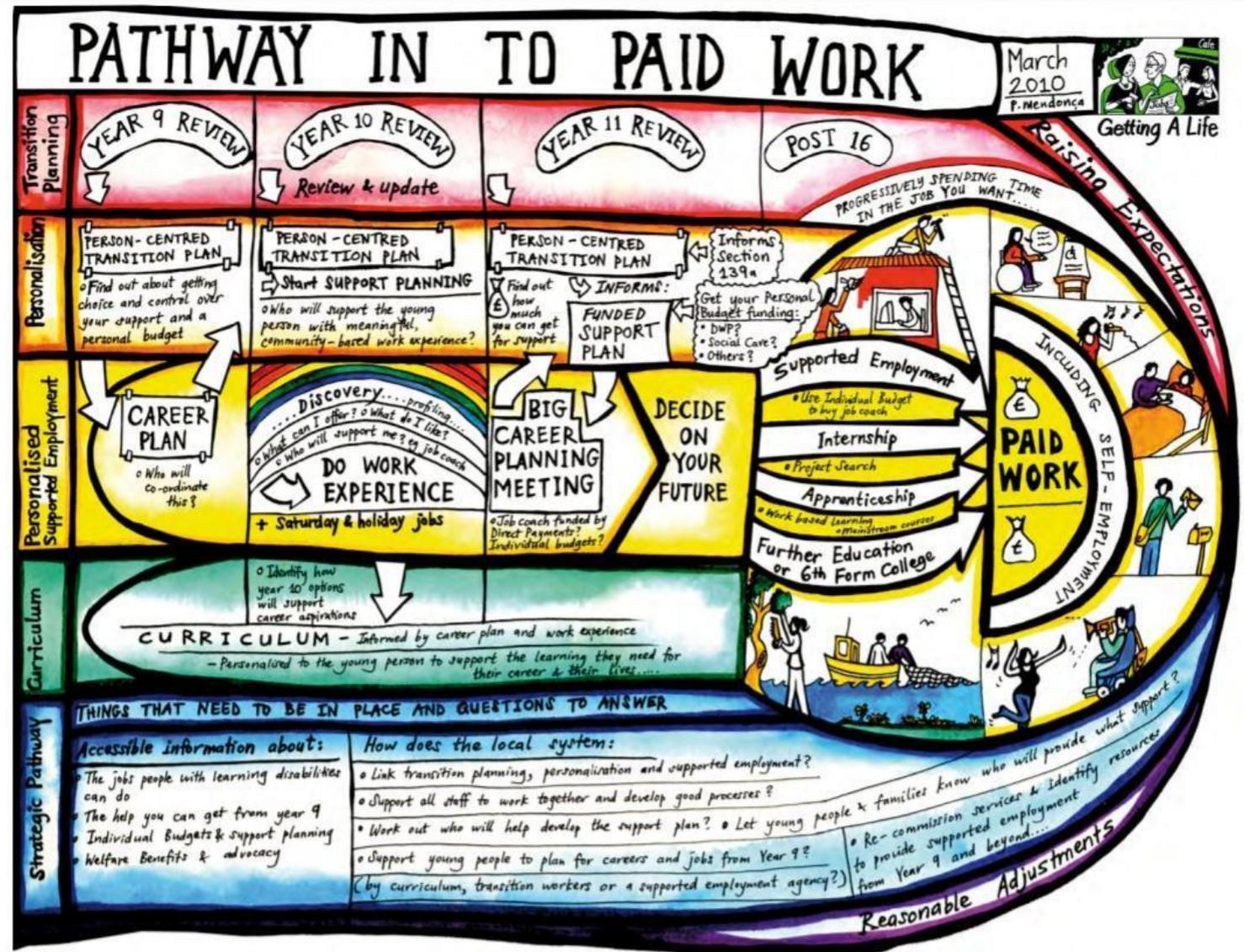


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- Education, Health and Care plans
- Support for young people with EHC plans
- SEN Support
- Further and Higher Education
- Other education and training options
- Routes to employment

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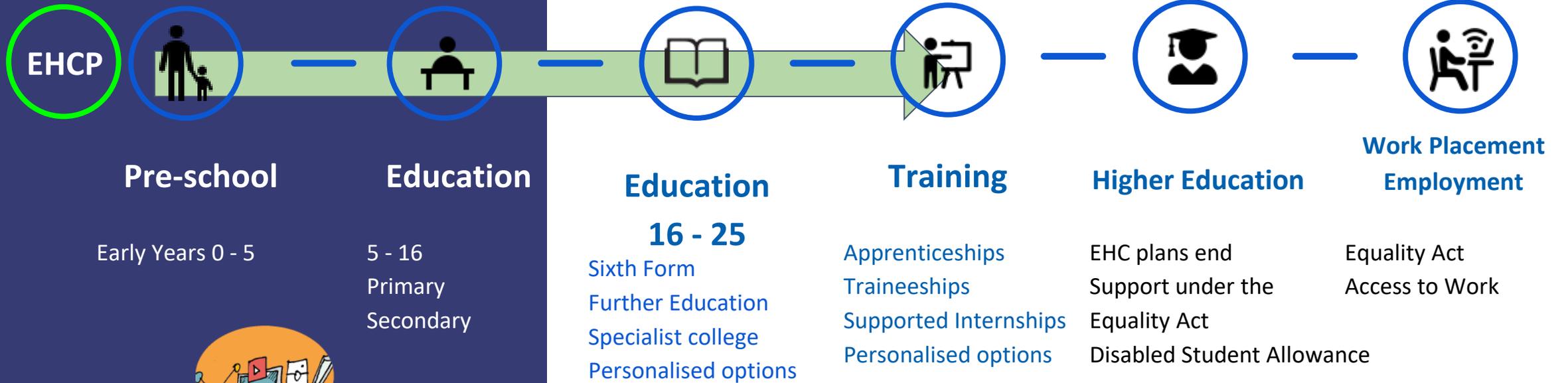
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Support with and without EHC plans

**NO
EHC
Plan**

SEN Support, Healthcare plans, Personal Health Budgets, Reasonable adjustments, Disabled Students Allowance, Access to Work



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Picture of pathway to adulthood chart



Preparing for Adulthood – wider topics

Independent Living

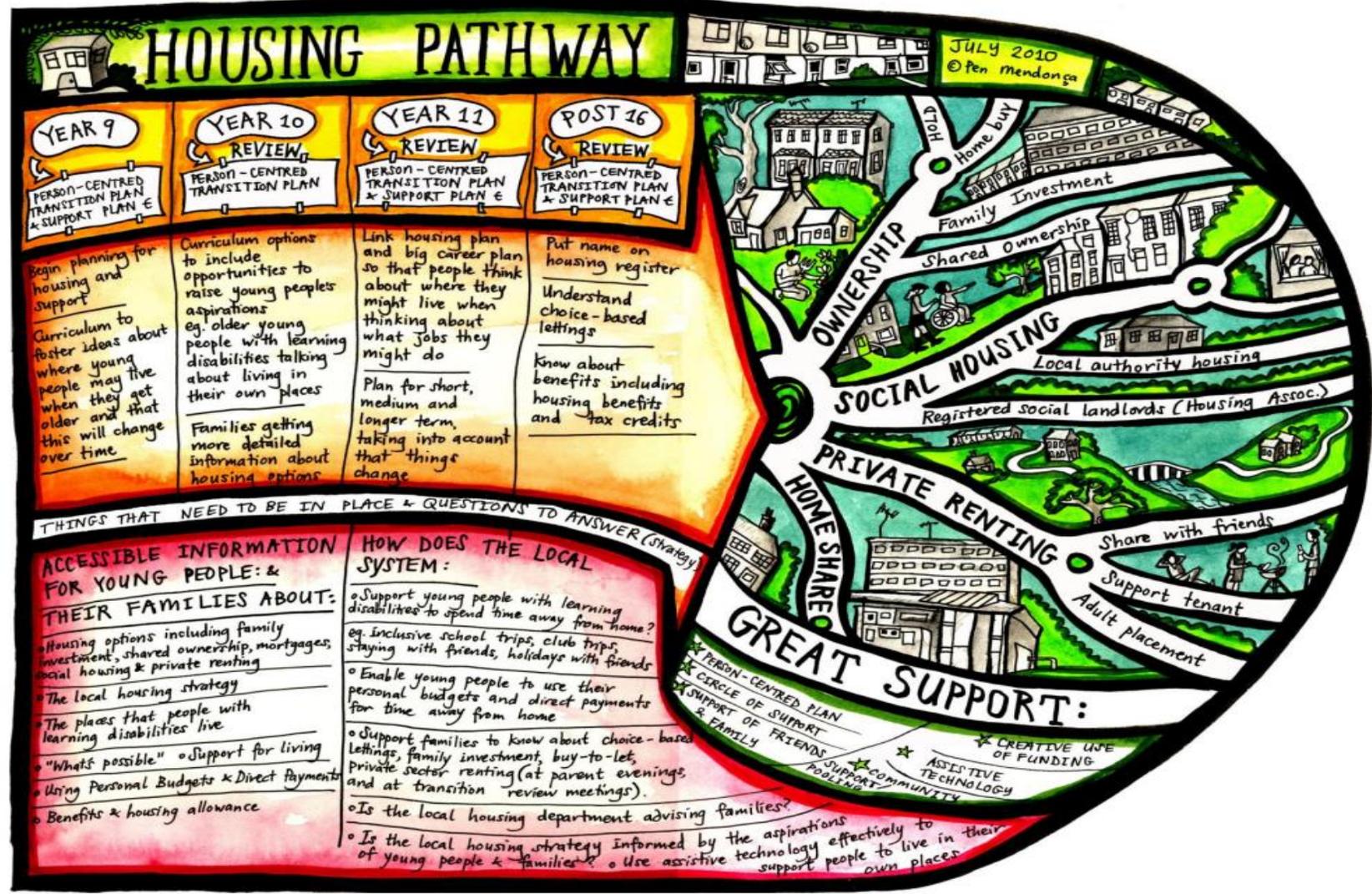


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- Adult benefits
- Benefits for young people in education
- Supported money management
- Choosing where to live
- Housing adaptations

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Preparing for Adulthood – wider topics

Community Inclusion



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- Friendships and relationships
- Sex and relationships
- Building a meaningful life
- Being active
- Self-advocacy

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DEVELOPING FRIENDS, RELATIONSHIPS & COMMUNITY

YEAR 9	YEAR 10	YEAR 11
Person-centred transition plan	Person-centred transition plan + support plan	Person-centred transition plan + support plan
Set up a Circle of Friends: include best friend & other people from the neighbourhood or school	What is important to me about friends and having a social life now? In the future? Is the Circle meeting?	Do a PATH with your Circle of Friends Find P.A.s Have a support group? Connect Circle of Friends with Circle of Support
Support me to keep and develop friendships Include family support	How do we make sure friendships are maintained after school ends? How best to stay in touch?	How do we make sure friendships are maintained after school ends? How best to stay in touch?
Take part in extended school & out of school activities	Use Direct Payments/ Personal Budgets	Move on to new things with friends
Take part in the same things as other young people Go out with friends	Am I going out often enough? Am I part of my community? (Use Inclusion Web)	
CURRICULUM: Personalised to you so you get the learning you need for your life How will your Year 10 options help you work towards your hopes & dreams?		
THINGS THAT NEED TO BE IN PLACE & QUESTIONS TO ANSWER (STRATEGY):		
<ul style="list-style-type: none"> Do youth parliaments/councils include young people with learning disabilities? What reasonable adjustments do the youth service in order to include young people with learning disabilities? Are extended/after school activities inclusive? Are special/mainstream schools working together to provide inclusion? How does the local system support Circles of Friends/Support & peer mentoring? 	<ul style="list-style-type: none"> How does the local system develop an ethos that enables welcoming, accessible, inclusive environments & the development of positive social relationships? Do anti-bullying policies include specific behaviour that indicates positive attitudes to learning disabled young people? How are friendships monitored? Do they go out? 	<ul style="list-style-type: none"> Tools: Community Mapping / Capacity Building / Inclusion Web

POST 16

I have some close friends * I know lots of people * I am part of a social group

I know how to stay in touch with people * People stay in touch with me *

I meet friends regularly * Direct Payments/ Personal Budgets support this *

I get out and have a good time!

- My PA helps me use public transport
- I travel with friends or on my own
- or my PA can drive my mobility car could I learn to drive?

Bus stop * NIGHTCLUB



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Preparing for Adulthood – wider topics

Health and Social Care



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- Adult Social Care – rights and eligibility
- Social Care needs assessments
- Paying for Social Care
- Supported decision making
- Adult Health – rights and eligibility
- Adult Health care
- Adult Continuing Health Care (CHC)

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TRANSITION PLANNING FOR GOOD HEALTH

JUNE 2010
Pen Mendonca

YEAR 9	YEAR 10	YEAR 11	POST 16
PERSON-CENTRED TRANSITION PLAN	REVIEW: PERSON-CENTRED TRANSITION PLAN	REVIEW: PERSON-CENTRED TRANSITION PLAN	<p>I AM IN CONTROL OF THE SUPPORT I NEED TO BE HEALTHY £</p> <p>I GET A HEALTH CHECK EVERY YEAR (this builds on my health plan)</p> <p>I KNOW HOW TO KEEP HEALTHY</p> <p>PROFESSIONALS WHO SUPPORT ME TALK TO EACH OTHER ACROSS SERVICES</p> <p>PEOPLE KNOW HOW TO COMMUNICATE WITH ME</p>
Health PLAN	Health PLAN	Health PLAN	
<ul style="list-style-type: none"> Who will co-ordinate this? Does this plan bring all my health needs together in one place? 	<ul style="list-style-type: none"> Is in place It includes information from paediatrician, CAMHS, community nurse, therapists, hospital..... 	<ul style="list-style-type: none"> Is reviewed Me and my family and all my health professionals are clear about when I will be discharged from each service. We will have the names of people who will take over responsibility. I know how my health needs will be met. 	
<ul style="list-style-type: none"> Begin engaging with mainstream services Develop a communication passport to help new people who meet me Arrange for me to have all the equipment I need when I leave school Will my current staff transfer with me? 	<ul style="list-style-type: none"> My GP has my plan The practice nurse and community nurse share information about my health It is clear how my health needs will be met I know about Personal Health Budgets 	<ul style="list-style-type: none"> Me and my family and all my health professionals are clear about when I will be discharged from each service. We will have the names of people who will take over responsibility. I know how my health needs will be met. 	
<p>ACCESSIBLE INFORMATION ABOUT:</p> <ul style="list-style-type: none"> Who will work with me when I'm discharged from children's services? Who is responsible for funding my equipment & aids? Who will make sure that things are in place in good time? Free prescriptions • Dental services OT & other therapies • Diet & exercise Opticians • Relationships & sexual health 	<p>HOW DOES THE LOCAL SYSTEM:</p> <ul style="list-style-type: none"> Support partnership working between specialist children's health services & mainstream services? Make sure that health professionals understand person-centred planning & contribute to transition & health plans? Connect data about the needs of disabled children & young people so that strategy & commissioning can tackle poor practice & inefficiency. 	<p>STRATEGY:</p> <ul style="list-style-type: none"> How will specialist community paediatricians make sure that GPs learn about young people and are ready to take responsibility for their healthcare? How are GPs able to get to know young people before they are discharged so that there is shared care for a period of time? How are children's therapy services working with adult service colleagues to ensure that young people have a communication passport, communication aids, wheelchairs, postural care...? 	<ul style="list-style-type: none"> How are CAMHS working with adult mental health services to ensure consistent, high quality support? Is the SHA asking PCTs to connect data on disabled children's health outcomes? Does the PCT collect data on disabled children's health outcomes eg. premature death Does the PCT provide GPs with a training & development programme & information about common conditions? Does the local health service enable people to develop person-centred health plans & profiles with clear outcomes?



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What we learnt...



- We still could not cover everything in depth
- The gaps between the sessions were too long
- Peer relationships did not emerge – too much presenting, not enough time for discussion
- Parents/carers joined the programme during the year would have to wait or join part way through, missing previous content
- The content we presented did not align with the issues parents/carers were facing in the ‘here and now’



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A change in plan for Year Two



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- Content from the four original sessions was broken into smaller presentations
- Each short presentation was recorded and uploaded to YouTube on a Private link.
- Every academic term, four drop in/informal Q&A sessions would run, one per month aligned to one of the PfA themes.
- Prior to the session, attendees would be sent the YouTube links to watch the ones relevant to them
- Attendees were invited to bring questions to the session

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Intended outcomes:

- Parents/carers could join the next term's cohort (ie after their young person signed up) so not having long to wait
- Sessions once a month, so less waiting in between sessions and more opportunities to build peer relationships
- Drop-in sessions dedicated to discussion, support and Q&As as the videos provided the key information in advance
- No need to watch any of the videos that they already knew about (ie not timewasting)



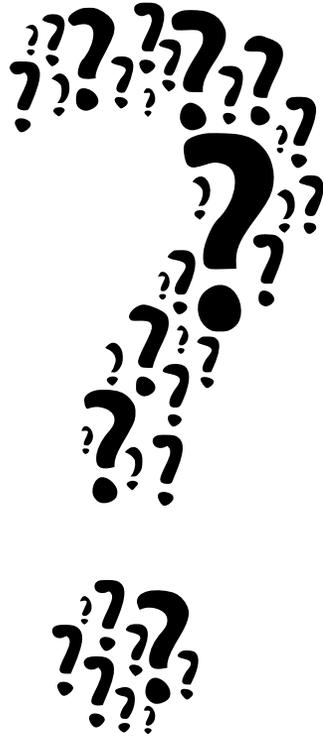
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How it went...

- Although each session was themed, parents came along with questions for other areas or that covered multiple areas of content (nothing is ever standalone)
- Parents did not watch the videos in advance (many said they did not receive them)
- Different parents attended each session (though a few were consistent across a term) so no consistent 'group' formed



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How it went...

- We found many of the parents were already well informed but struggling to secure their rights
- Some were professionals/trained and were still failing to get the right support for their young person
- Many of the issues presented were incredibly complex and really needed in-depth 1-2-1 case support



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What we learnt...

- This is definitely a time when parents can feel very isolated and may not know where to get help/support from
- Even the most knowledgeable and connected parents can find the transition to adult services/support challenging
- Many of the issues are complex and not related to discrete areas
- Linear presentations of topics are not necessarily helpful to those in the thick of it/at crisis point



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What we learnt...

- Some families joined from NDTI's advertising and some from Contact's – we felt like we were repeating information each time to some attendees, because of new attendees just joining
- These sessions did not reach the large number of parents who need this valuable information and support



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What we learnt: as trainers

- The trainers delivering this training had to be knowledgeable about an incredibly wide range of topics – *everything, everywhere, all at once!*
- There is no ‘one’ source of information available to refer to or to signpost to
- These sessions can be emotionally draining and can take their toll. You come away unsure if you have been able to help



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What we learnt: The numbers

Attendance at group sessions 2022-2023

36

Webinar views 2022-2023

153

Attendance at group sessions 2023-2024

77

Webinar views 2023-2024

176



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What we learnt: Parent feedback

Something you've learned:

- That I need to start talking about transition to adulthood at my sons next annual (when he is 15yrs old)
- Person centred planning tools
- Lot more support out there than i thought
- There are different avenues for after 16
- Individual support available from Contact via a family support adviser
- The coping strategies tool looks very useful.
- Thinking out the box - how to utilise technology in a positive way with my son. Brilliant discussions.
- that I am not alone, others also struggle



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Something that was missing - what could we offer in the future that would be most helpful to you:

- More on the sort of support that the DSA could offer an autistic student
- More Tips for starting out from parents further on in the process
- PB, DP , access to SEN /CIN funding is still a nightmare and grey area
- Size of slides
- More time for questions

Something you will do as a result of the information received:

- Go to Contact and NDTi websites to start building a social village for my son
- Take appropriate action early as possible
- Use NDTi and Contact tools and share with parents/carers
- Follow up all the resources mentioned, to gather more information on the available support
- look out for more Contact sessions. Look more into Internships. Take on board the suggestions and ideas that came up in discussion.
- Next EHCP AR- visual board , 1 page profile

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What we learnt: The difference the support made to you or your family

- A big support for me and it's installed a positive change in the way I feel
- Gives me confidence to keep plugging away at social services
- Signposting to listening ear service very welcome. It felt a very friendly and welcoming session, thank you.
- Truly, extremely helpful feeling you are not alone. Hearing the positive outcome stories, helps to believe the YP can leave as normal & enjoyable life as possible
- Thank you, it's nice to know I am not on my own
- given me hope that Alex can signpost me to possible solutions
- felt a bit exposed at first because it's a small group and I wasn't expecting to be seen but I felt supported and listened to
- Brilliant team with so much knowledge, skill and empathy



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What we think is needed – 14yrs+

- The videos should be revisited with minor tweaks made and re-recorded OR delivered live for families at the start of the journey (ie Y9 families)
- As it is 'in advance' content, it can be presented in a linear format, topic by topic
- NDTi's very helpful tools and resources can be shared for families to use in Y9 Annual reviews and beyond



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What we think is needed – 18yrs+



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- The videos should be revisited/edited and re-recorded to be placed online with a permanent home eg on Contact or NDTi's website
- The content should be written up and added to Contact's website, ie to add to the existing resources and information available
- 1-2-1 case management across a few weeks for parents/carers in the same way that young people were offered direct support
- Access to legal advice re: benefits, mental capacity, securing entitlements to support

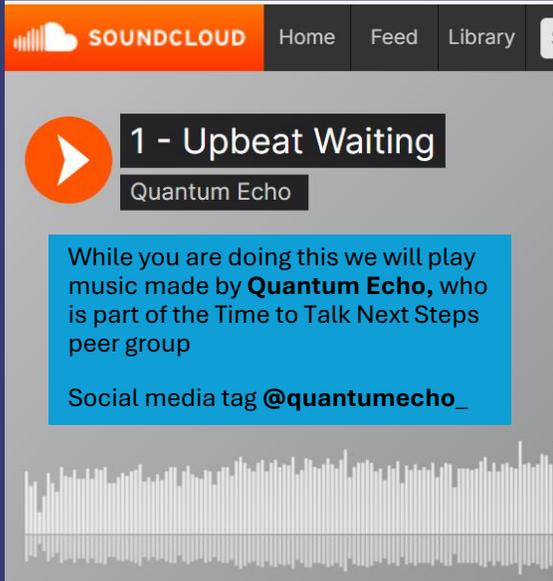


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Feedback Form



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Please take a moment to fill in our feedback form by

- Scanning the QR code or
- Following this link: <https://forms.office.com/e/xyMcrVeXUX>

You can submit the form multiple times but please:
only rate each session you attend once.

Our plans after this event....

Through a new project called Partners Make Time to Talk we plan to run training and mentoring for other organizations.

For more information see our plans [here](#)

If you'd like to work with us let us know on the feedback form.

