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Introduction: The tables contained in this document include information generated during a co-design process to develop resources to support transition from child to adult health services for young people with cerebral palsy.

The full report is published in Frontiers in Rehabilitation Science <https://www.frontiersin.org/articles/10.3389/frehab.2022.976580/full>

Summary of report

Introduction: Design thinking is a human-centred process that aims to identify the needs of end-users and iteratively develop solutions. Involving end-users in the development and design of solutions may enhance effectiveness by increasing focus on the needs of the target population. This paper describes the process of co-designing resources to support the transition from child-centred to adult-orientated health services using a design thinking approach.

Methods: Five co-design workshops were conducted remotely with a young person advisory group and parent advisory group. A design thinking process guided by the Stanford D.School approach was used to understand the transition needs of young people and their parents and iteratively develop solutions to improve end-user experience.

Results: Eight resource prototypes were generated: (1) designated transition coordinator, (2) digital stories of transition experience (3) written informational support (4) transition website, (5) transition checklists and worksheets (6) transition app, (7) transition programme or course and (8) educational programme for health professionals.

Conclusion: Design thinking is a feasible approach to identify, characterise and prioritise resources collaboratively with end-user partners.

Table 1 Description of 13 ideas for resources generated by young people and parents. We summarised each idea in a single sentence and described how the idea responded to the transition needs of people with cerebral palsy identified by young people and parents.

1	<p>Idea title: Map of available services</p> <p>Idea Summary: An interactive national map of services for people with cerebral palsy to improve knowledge of and ability to access services.</p> <p>How will this idea impact the challenge: We learned that finding out information about adult services or accessible facilities is challenging. Creating a map with a directory of services would help this.</p>
2	<p>Idea title: Directory of support persons</p> <p>Idea Summary: A directory of support persons/carers with profiles that list their interests, experience and hourly rate.</p> <p>How will this idea impact the challenge: We learned that PA support is important for young adults. However, finding support people with special skills to work with people with CP can be challenging. The importance of working with someone you have common interests with was also highlighted. Creating a directory of support persons/carers who list their interests and special skills would allow young people and parents to choose suitable people to work with.</p>
3	<p>Idea title: Transition website</p> <p>Idea Summary: A transition website that acts as a centralized source of trusted and reliable information about the transition process.</p> <p>How will this idea impact the challenge: We learned that information about the transition is difficult to find. A website would act as a centralized source of information that is easily accessible to a range of people.</p>
4	<p>Idea title: Written informational support</p> <p>Idea Summary: A written information source that can be given to young people and families to provide information about the transition process, for example, an information leaflet, transition packet or booklet.</p> <p>How will this idea impact the challenge: We learned that 1) people may not know where to look or might not be engaged enough to go looking for information, 2) some families prefer a physical handout they can refer back to 3) service providers lack information resources to hand out. Providing a core document/leaflet/package to everyone entering the transition period would be beneficial to ensure information provision</p>
5	<p>Idea title: Conference or webinar</p> <p>Idea Summary: A conference or webinar hosted in collaboration with young people and their families to provide information on the transition process.</p> <p>How will this idea impact the challenge: We learned that young people and parents lack knowledge about the transition process. An online conference or webinar is one way of sharing information. The conference or webinar should be hosted in collaboration with young people and parents and include personal stories of transition.</p>

6	<p>Idea title: Digital stories of transition experience</p> <p>Idea Summary: Digital stories that capture personal experiences of transition.</p> <p>How will this idea impact the challenge: We learned that young people and parents lack knowledge about the transition process and lack peers and role models to learn from. Creating videos of people's transition experiences would allow young people to learn from others who have gone through the process.</p>
7	<p>Idea title: Parent support network</p> <p>Idea Summary: A parent support group or network to connect parents with similar experiences.</p> <p>How will this idea impact the challenge: We learnt that parents have few opportunities to meet other parents with similar experiences. This is particularly true in adolescence and adulthood. Parents of young people who have gone through the transition could support and share information with parents who are just beginning the transition process.</p>
8	<p>Idea title: Peer support group for young people</p> <p>Idea Summary: A young person's peer support group or network to connect young people with similar experiences or connect young people with others who have gone through the transition process.</p> <p>How will this idea impact the challenge: We learned that young people would value the opportunities to meet with other people who have been through the experience to support each other, share experiences and help each other problem solve</p>
9	<p>Idea title: Transition checklists and worksheets</p> <p>Idea Summary: Checklists and worksheets for young people to document what they want to discuss at their next appointment</p> <p>How will this idea impact the challenge: We learned that young people may not know what to ask and that there is an assumption that young people who don't ask questions are on top of it when this isn't always the case. Having a checklist that is standard for everyone would help this. We also learned that young people may struggle to remember concerns between appointments and having a space to document this may assist.</p>
10	<p>Idea title: Transition App</p> <p>Idea Summary: An app to support young people during transition. The app may include information on the transition process, a profile with transition goals and a place to document notes, concerns and questions to discuss in the next appointment</p> <p>How will this idea impact the challenge: We learned that young people might need support with planning for the transition. Creating an app where they could record their goals and notes would be a user-friendly way to address this</p>
11	<p>Idea title: Health professional education</p> <p>Idea Summary: An educational programme for health care professionals to improve knowledge and awareness about CP and how to best support young</p>

	<p>people with CP during the transition.</p> <p>How will this idea impact the challenge: We learned that service providers lack knowledge about CP, may have assumptions about CP and may not know how best to support young people with CP during the transition. Creating an educational resource for HCPs would help this.</p>
12	<p>Idea title: Designated transition coordinator</p> <p>Idea Summary: A health professional in a dedicated transition coordination role to support young people with their goals, advise on and facilitate the transition process.</p> <p>How will this idea impact the challenge: We learned that young people and families don't know what to expect about the transition or how to navigate to adulthood. A designated transition worker with knowledge of the process could help young people plan their goals, advocate on behalf of the young person, act as an information source and provide reassurance.</p>
13	<p>Idea title: A transition training programme for young people and parents</p> <p>Idea Summary: A transition programme or course to empower young people with the knowledge and skills required to transition to adulthood. It may include modules about the transition process, emotional well-being and living options</p> <p>How will this idea impact the challenge: We learned that young people and families feel unprepared for transition and that having a training programme that would cover life skills would be helpful</p>

Table 2. Detailed description of 8 resources that were prioritised by young people with cerebral palsy and parents. All information was obtained from young people and parents. Text in italics indicates additional comments obtained from a health professional advisory group

Written informational support	Format	Content	
<p>Purpose:</p> <ul style="list-style-type: none"> • Reduce chance element of information sharing • Prompt families to think about the transition process • Act as a communication tool to begin transition conversation <p>Users</p> <ul style="list-style-type: none"> • Young people • Parents 	<ul style="list-style-type: none"> • Leaflet/booklet • Hosted on website • Includes alternative accessible formats e.g. Easy Read 	<p>Information about transition</p> <ul style="list-style-type: none"> • What is transition • When does transition happen • How will it affect me • What will happen going forward • What services need to transition • Where do young people transition to <p>Information about adult services</p> <ul style="list-style-type: none"> • How adult services work • Differences between children’s and adult services • Introduction to new responsibilities in adult services • What you should be prepared for in adult services • How to access help and assistance in adulthood • <i>Include caveat that service users check with local provider for further</i> 	<p>Directories</p> <ul style="list-style-type: none"> • Directory of further education options • Directory of accessible facilities, and changing places. • Directory of mental health supports • Directory of personal assistant supports • Directory of adult services with service details including <ul style="list-style-type: none"> ○ Location of service ○ Age range catered for ○ Disability types catered for ○ Activities offered ○ Staffing offered ○ Respite attached ○ Transport included ○ Hours available ○ <i>Level that programme is pitched at</i> ○ <i>Care needs catered for to</i>

		<p><i>details as individual situations will vary</i></p> <p>Cerebral palsy</p> <ul style="list-style-type: none"> Information about cerebral palsy Information on aging with cerebral palsy <p>Glossary of terms related to transition</p> <ul style="list-style-type: none"> What is a hub What is a catchment area What is a multi-disciplinary team What is a profiling meeting What is an activity based centre What is New Directions What is a personal assistant and how can they support me List of relevant disability legislation and brief explanation of each Act 	<p><i>enable participation</i></p> <p>Rights and entitlements</p> <ul style="list-style-type: none"> Information on entitlements Signposting to relevant sources of information and services e.g. citizens advise, revenue <p>Funding information</p> <ul style="list-style-type: none"> Information on the system of funding and how funding negotiations work
Transition checklists and worksheets	Format	Content	
<p>Description</p> <p>A suite of documents that includes:</p> <ul style="list-style-type: none"> A space where young people can document questions and concerns A space to set transition goals, 	<ul style="list-style-type: none"> PDF hosted on website Printed paper materials Part of an app 	<p>Checklists</p> <p>List of considerations for the transition process</p> <ul style="list-style-type: none"> I have a contact point in adult services I know who my adult community team will be I know what equipment I need in adult services I am aware what equipment will transfer from child to adult 	

<p>aspirations and monitor progress</p> <ul style="list-style-type: none"> • A checklist of areas and actions to consider during the transition process <p>Purpose</p> <ul style="list-style-type: none"> • Aid transition preparation • Act as communication tool. Health professionals can view questions, concerns and goals and provide information and support • Prompt young people and parents to think about the transition process • Create accountability for the transition process by setting goals and monitoring progress <p>Users</p> <ul style="list-style-type: none"> • Young people • Parents 		<p>services</p> <ul style="list-style-type: none"> • I know how to maintain my equipment • I know what a key worker is and how they can support me • I know what a personal assistant is and how they can support me • I am aware of my rights and entitlements • <i>I have received an individual family service plan</i> • <i>I have discussed my family service plan</i> <p>Checklist of considerations if applying for funding package</p> <ul style="list-style-type: none"> • Transport • Respite <p>Checklist of required documents for transition</p> <ul style="list-style-type: none"> • Medical reports • Proof of catchment area <p>Worksheet to document</p> <ul style="list-style-type: none"> • Notes • Worries about healthcare needs • Questions or concerns for health care appointment <p>Goal worksheet</p> <ul style="list-style-type: none"> • Space to document young person's transition goals and aspirations <p>Space to track and review goals</p>
Digital stories of transition experience	Format	Content
<p>Purpose</p> <ul style="list-style-type: none"> • Share learnings from 	<p>Participants</p> <ul style="list-style-type: none"> • Real people talking about 	<p>About transition</p> <ul style="list-style-type: none"> • Information about transition

<p>people who have gone through transition</p> <ul style="list-style-type: none"> • Showcase peers and role models who are further ahead in the transition journey • Provide information in an accessible bite sized format • Prompt young people and parents to think about the transition process <p>Users</p> <ul style="list-style-type: none"> • Parents • Young people • Family, siblings, grandparents • Health professionals 	<p>their experience is preferred to animated stories</p> <ul style="list-style-type: none"> • Young people may share their experiences • Parents may share their young person’s story on their behalf or share their own experience <p>For education on cerebral palsy, a mixture of people with cerebral palsy and health professionals is acceptable</p> <ul style="list-style-type: none"> • Participants should be 16-25 years (Parent advisory group) • Participants should include a wider age range to include adults with cerebral palsy at different life stages (Young person advisory group) • <i>Including different ages and stages will offer a variety of perspectives. Including people who have just transitioned and people who are in their 30’s will offer different insights (Health professional advisory group)</i> • Include different representations of disability • <i>Include people from different</i> 	<ul style="list-style-type: none"> • Successes and challenges of transition • Emotions around transition (nervousness, letting go and associated emotions) • Benefits of growing up • Hopes and goals for the future • <i>Consider questions like “What does transition mean to you”</i> <p>About adult services</p> <ul style="list-style-type: none"> • What adult services is like • What getting a new adult health professional is like • Responsibilities in adult services • Experience of first visit to adult services • Differences between adult and children’s services • Video induction/introduction to adult services • <i>Consider questions like “What was the main difference between child and adult services that you experienced?”</i> <p>How to get ready</p> <ul style="list-style-type: none"> • Tips for talking with the adult health professionals • Gaining your own voice/becoming more independent • How you can prepare, anything that helped you on your journey • Advice for other parents: <ul style="list-style-type: none"> ○ what helped ○ how to ask for help ○ how to find an advocate ○ how to reach out for support ○ avoiding burn out ○ pursuing respite ○ self-care • <i>Consider topics like “what helped me was”</i> • <i>Consider potential topics like “preparing my child for turning 18, what I wish I had known ”</i>
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	<p><i>geographical regions. Transition experience will differ depending on where people are in the country</i></p> <p>Length:</p> <ul style="list-style-type: none"> • Mixture of short and long digital stories • Vary length by the depth of the topic. Shorter length for emotive or intense topics. • <i>Consider short individual digital story clips in TikTok style</i> <p>Accessibility</p> <ul style="list-style-type: none"> • Must be accessible to all. • <i>Consider accessible formats for example closed captioning, sign language interpreter</i> • Include option to filter digital story collection by topic so young people and parents can select the most relevant stories • Digital story should contain all information content. Displaying links for information relevant to digital story after the video is 	<p>CP education</p> <ul style="list-style-type: none"> • What is CP <p>Becoming an adult/broader transition</p> <ul style="list-style-type: none"> • Living options • Relationship, LGBTQA, Sexual health • Mental health, emotional well-being and self-care • Working life with CP for example preparing a CV, disclosing a disability to an employer
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	<p>acceptable</p> <ul style="list-style-type: none"> • Include option to contact people in the digital story with questions <p>Structure</p> <ul style="list-style-type: none"> • Blog style • Each digital story should follow a format • <i>Display the question asked and then the video of participants response</i> • One person speaking for the duration of digital story • Or multiple participants speaking on a topic, edited together to form a digital story • Consider format of young adult talking to a younger adult • <i>Consider template like</i> • <i>“telling my story to my younger self”</i> 	
Transition Website	Format	Content
<p>Purpose</p> <ul style="list-style-type: none"> • Provide an accessible, centralised source of transition information • Provide centralised 	<ul style="list-style-type: none"> • Optimised for searching through simple Google search terms • Linked on key disability sites • Simple and accessible • Engaging design 	<p>About transition</p> <ul style="list-style-type: none"> • What does transition mean/What does transition entail • Roadmap to transition: Who do I need to talk to, what do I need to do, how does transition work • Preparing for adult services: Differences between child and adult

<p>repository of information specific to cerebral palsy</p> <p>Users</p> <ul style="list-style-type: none"> • YPAG: Parents or young adult/late adolescence. Early to mid-adolescence may not engage • PAG: Young adults and parents 	<ul style="list-style-type: none"> • Information mainly contained in digital stories rather than downloading documents 	<p>services, what to expect in adult services; what a day in adult services is like</p> <ul style="list-style-type: none"> • Tips on how to talk to professionals in adult services • Glossary- what is a hub, catchment area, MDT, activity based Centre <p>Managing my healthcare</p> <ul style="list-style-type: none"> • How I can manage my healthcare • Information on being healthy • CP specific information and advice about mental health <p>Ageing and CP</p> <ul style="list-style-type: none"> • What could I develop • What am I trying to prevent <p>Downloadable resources</p> <ul style="list-style-type: none"> • Transition checklists • Goal worksheets • Question and notes worksheets <p>Non-healthcare transition Resources & support (signposting)</p> <ul style="list-style-type: none"> • Travel training • Housing/Living options • Personal assistants • Respite information • Employment/Work experience • Independent living skills • Further education options/schemes • Advocacy <ul style="list-style-type: none"> ○ How I can become an advocate ○ Advocacy training ○ Advocacy organisation • Entitlements and allowances
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		<ul style="list-style-type: none"> • Directory of adult services options with service details • Links to other organisations supporting exercise Disability rights • Links to relevant Citizen's information and Revenue • Directory of mental health supports • Links to disability organisations and what they can provide
Transition App	Format	Content
<p>Purpose</p> <p>Communication tool</p> <ul style="list-style-type: none"> • Promote communication between health professional and young person through discussion of concerns, questions and goals documented in app • Promote communication between parent and young person about the transition • Assist with relaying information and medical history by recording summary information in app • Reduce reliance on parents to answer questions by facilitating access to key medical summary for the young 	<ul style="list-style-type: none"> • Accessible, young person should be able to use App independently • Easy to use, refined to most important points • Headings to indicate different sections • Colour coding of different sections • Consider security- avoid overly sensitive medical information • Flexible to allow basic interaction or more in depth interaction depending on user's need • More fun, less informative. May contain link to website 	<p>My profile</p> <ul style="list-style-type: none"> • My goals/wants/wish list for transition. <ul style="list-style-type: none"> ◦ Include a list of goal headings for example leisure, education • Reason for visit today • Concerns or questions I want to discuss at my appointment • My notes • Transition discussion and decision log <p>Health record/summary</p> <ul style="list-style-type: none"> • Statement of need • Practical things I need for adult services, for example equipment • Digital health passport • Key points summary • Snapshot/overall picture of who I am • List of medications and calculations • Clinical contacts, in case of emergency contacts <p>Information</p> <ul style="list-style-type: none"> • Digital stories to provide information • Skills on managing emotions • Transition checklists

<p>person</p> <p>Transition readiness</p> <ul style="list-style-type: none"> • Provide information to support transition process • Stimulate young person's interest in transition • Prompt young people and parents to think about considerations for transition <p>Transition planning</p> <ul style="list-style-type: none"> • Prompt young people and parents to begin planning what they want from the transition through recording transition goals • Create accountability by recording transition goals and aspirations • Promote young person involvement and partnership in their transition process 	<p>for further information</p> <ul style="list-style-type: none"> • <i>App should be filled with live, and interactive content. If it's just a series of documents it won't have any longevity</i> 	<p>Experience sharing</p> <ul style="list-style-type: none"> • Social hub that allows young people to communicate with their peers • Digital stories to share experiences • <i>If there is a social aspect it would need to be moderated and managed</i> <p>Expert consulting</p> <ul style="list-style-type: none"> • Frequently asked questions section • Include feature to allow young person to digitally share content in the app with health professional
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<p>Users</p> <ul style="list-style-type: none"> • Young people from early adolescence • Parent can view app to discuss content as a family, with young person's permission • Parent can use app on young person's behalf if they are not able to, with young person's permission • Health professional can view concerns, questions, goals and medical summary with young person's permission 		
<p>Educational programme for health professionals</p>	<p>Format</p>	<p>Content</p>
<p>Purpose</p> <ul style="list-style-type: none"> • To assist health professional to support young people and families during the transition • To improve knowledge and awareness about cerebral palsy in adult services • To correct assumptions 	<ul style="list-style-type: none"> • Training module in undergraduate training • Rotation/placement in cerebral palsy in undergraduate training • Training module for qualified health professionals • Conference for health professionals • Educational video for health professionals 	<p>Education on cerebral palsy in general</p> <ul style="list-style-type: none"> • Education on impairments, severities and complex need • Adjustments and support to make adult appointments accessible <p>Ageing and cerebral palsy</p> <ul style="list-style-type: none"> • Physical changes associated with ageing • Additional health checks required for example bone scans • <i>Education on cerebral palsy is very broad. Aging with cerebral palsy and the issues that arise would be more useful</i>

<p>about cerebral palsy</p> <ul style="list-style-type: none"> To improve accessibility of appointments in general medical settings by increasing awareness of cerebral palsy <p>Users</p> <ul style="list-style-type: none"> GPs Support people/personal assistants/Carers Adult healthcare providers who work in hospital setting Mental health professionals Employers Dental care professionals Educational professionals 	<ul style="list-style-type: none"> People with cerebral palsy should present part of training <i>More disability education and awareness is being incorporated at undergraduate level</i> <i>Training module is likely to have a limited uptake among health professionals with a limited caseload of people with cerebral palsy. Online information on area specific supports, that can be accessed quickly is more likely to be helpful</i> <i>Include an educational video about what cerebral palsy is as a starting point</i> <i>Consider an E-learning module or multi-disciplinary course</i> 	<p>Communication skills</p> <ul style="list-style-type: none"> How to communicate with young people at different stages of transition How to communicate in an age appropriate way and not talk down to young people How to talk to people with different impairments Learning to give young people time, space and understanding in appointments so they feel confident to speak up How to use inclusive language How to provide family-centred care where appropriate in adult services How to support autonomy Improve understanding of level of support needed at each stage of transition Improve understanding of expectations for independence and provide appropriate levels of support to promote independence How to provide choices to young person Improve understanding of how to support mental health and emotional well-being <i>How to support self-efficacy for all young people</i> <i>Consider training on communication skills e.g. How do we talk to young people when we talk about transition?</i>
<p>Designated transition coordinator</p>	<p>Format</p>	<p>Content</p>
<p>Purpose</p> <ul style="list-style-type: none"> Improve understanding of transition process for young people and parents Support young people and 	<p>Dedicated role</p> <ul style="list-style-type: none"> Dedicated role focused on transition Single person in the role. Multiple people may lead to 	<p>Advocate</p> <ul style="list-style-type: none"> Act as an objective advocate to act on the young person or family's behalf Support families when they feel they aren't being listened to Contact point

<p>families to navigate to adult services</p> <p>Users</p> <ul style="list-style-type: none"> • Young people • Parents • Allow flexibility for health professional in dedicated transition role to work with young person individually or with young person and parents 	<p>inaction or mixed messages</p> <ul style="list-style-type: none"> • Dedicated role allows for cumulative building of transition knowledge • Person in the dedicated role should be transparently identified to young person and parents • <i>Value in having one person with more knowledge and responsibility to help other professionals and act as single point of contact, however no one person will have the answer to everything</i> <i>Where single person is responsible, delivery of transition can be ad hoc. Role of designated transition coordinator could be to ensure oversight of process, ensure transition goals are met and all information and options are provided</i> <p>Ideal professional</p> <ul style="list-style-type: none"> • Social worker • Psychologist • With appropriate experience and training other health professionals would be suitable 	<ul style="list-style-type: none"> • Act as identified point of contact • Someone you can call when you have questions <p>Liaison/coordinator</p> <ul style="list-style-type: none"> • Bring you on the journey • Ensure things are put in place • Ensure you know who your health professionals are • Identify additional supports required e.g. psychological support • Provide introduction to adult services • Liaise with adult services on family's behalf • Identify contact point(s) for family in adult services • Put young people and families in contact with services • Assist coordination with adult hospitals • Assist with coordination of holistic services e.g. employment, social activities • Ensure information/files transfer to adult services • Ensure equipment transfers to adult services • Pass on requirements to adult services <p>Aid transition preparation</p> <ul style="list-style-type: none"> • Help young person prepare for transition • Inform young person on what to expect during transition • Provide oversight of the transition process • Guide young person and family through transition process <p>Information source</p> <ul style="list-style-type: none"> • Give you the information and tools that you need • Signpost to information sources • Answer questions • Highlight areas that families should be aware of and consider • Provide information on wider transition options (e.g. employment, housing)
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	<ul style="list-style-type: none"> • Transition worker can link with other professionals for advice and information • <i>Progressing Disability Services is moving away from discipline specific roles.</i> • <i>The key worker from health and social care professions may be the most appropriate person for this role.</i> • <i>Access to social worker to fulfil dedicated transition role might be difficult in different geographical regions</i> <p>Stage of transition they assist with</p> <ul style="list-style-type: none"> • Role should cover both paediatric and adult • Consider two equivalent roles. Paediatric transition worker transfers person to adult equivalent • <i>Ideally the role should move back and forward across the divide to work with the person who is transitioning until their early 20's, however young people currently transition at 18 years</i> <i>Working with young people until they are in their 20's</i> 	<ul style="list-style-type: none"> • Provide comprehensive information • Provide basic information (e.g. will therapy continue, where will therapy be located, where to go for equipment) • Provide direction on what to do for transition • Provide an honest picture of what the transition options are and what they include (e.g. transport) • Provide information on what is available and not available <p>Establish goals</p> <ul style="list-style-type: none"> • Develop individual transition plan • Develop transition goals • Support aspirations for adult services and the future • Ensure young person's views/needs/hopes are considered as part of transition process
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	<p><i>provides flexibility to address topics they weren't ready to discuss at 18</i></p> <p>Relationship and rapport</p> <ul style="list-style-type: none"> • A known health professional would be beneficial due to an established relationship and rapport • A new health professional in this role may be beneficial as they haven't known the young person from childhood and may treat you in a more age appropriate way • If the person is unknown offering 1:1 support initially to build relationship and trust important • <i>There is merit in professional knowing the young person, their family needs, complexities and circumstances.</i> • <i>If role is based in an organization and young person transitions to another organization need to consider if person in dedicated role can follow up when they leave paediatrics</i> <p>Communication approach</p>	
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	<ul style="list-style-type: none"> • Flexible communication based on need, continuous input may not be required • Different communication options e.g. in person, email, phone, virtual depending on each person's needs/wants and available resources 	
Transition programme or course	Format	Content
<p>Purpose</p> <ul style="list-style-type: none"> • To prepare young people and parents for transition • To empower young people and parents with the knowledge and skills needed to transition to adulthood • To prepare young people emotionally for the transition <p>Users</p> <ul style="list-style-type: none"> • Young people • Parents • Targeting both young people and parents will ensure transition is talked about and 	<p>Programme should incorporate group format</p> <ul style="list-style-type: none"> • Group format includes social element and allows young people to work with peers • Include separate groups for young people and parents to allow young people to have their say and ask questions • Joint parent and young person group may be appropriate where parent is communication partner for the young person, however Individual communication styles (e.g. non-verbal, assistive and augmentative communication users) should be facilitated • Parent and young person group could run at the same time with each group in a 	<p>Module on the programme may include</p> <ul style="list-style-type: none"> • Knowledge about CP • Increasing transition readiness <ul style="list-style-type: none"> ◦ What is transition ◦ Differences in adult services ◦ Establishing goals and hopes for the future • Developing autonomy and independence • Building self-advocacy skills • Developing confidence • Managing emotional well being • Managing physical health • How to maintain/develop social networks as you transition • Developing self-research skills • Ageing and CP • Vocation, employment, work experience options • Individualized budget options • Living options • Community inclusion • Relationships

<p>reinforced at home</p> <ul style="list-style-type: none"> • <i>Targeting both young person and parent will lead to a stronger output</i> 	<p>different room. This would allow autonomy but parental support is close by if needed</p> <ul style="list-style-type: none"> • Where support is required a young person could attend with a sibling close to their own age <p>Programme should be professionally led</p> <ul style="list-style-type: none"> • Different professions may lead each session based on their knowledge/expertise/subject area • In person format preferred to online format. It is easier to share your worries and concerns in person. • However, online may suit those not confident enough to attend in person • <i>Virtual could be easier rollout. Virtual route would allow more opportunities to run past the age of transition and do further follow up.</i> <p>When programme should be delivered</p> <ul style="list-style-type: none"> • Programme could be delivered in the evening, 	
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	<p>over a number of weeks.</p> <ul style="list-style-type: none"> • Parent programme could be delivered through evening weekend course/conference • Programme could be included as part of a transition year, be covered in school or as a QQI module with support from educational professionals • <i>Having an adolescent strand could target young people that are in their local school in the community but who still need to understand the path forward and build advocacy skills</i> <p>Information delivery</p> <ul style="list-style-type: none"> • Introducing all information at once may overwhelm. Topics should be split into different sessions • Programme should include core transition modules that are covered by all participants • Other optional modules should be available based on need • Some modules might be • more appropriate when you 	
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	<p>have transitioned (e.g. housing). Include option to revisit this information.</p> <ul style="list-style-type: none">• <i>A lot of the topics like living options might only be for people who are aged 18 years and older</i>	
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Table 3 Additional recommendations to improve transition made by young people with cerebral palsy and parents. Recommendations are categorised under “health system”, “adult services”, “transition services”. Column entitled Design Stage indicates stage of the Design Thinking Approach process at which the recommendation was made.

Recommendation	Learnings	Design stage
Health systems recommendations		
Adequate staffing needed for transition	<ul style="list-style-type: none"> • There is a lack of staff on the ground • Redeployment due to COVID worsened staff availability • Staffing affects transition 	Workshop 1 & 2 “Story share and capture”
Adequate funding needed for transition	<ul style="list-style-type: none"> • Funding/resources must be adequate for successful transition 	Workshop 3 “Brainstorm”
Adequate funding needed to support adults’ aspirations	<ul style="list-style-type: none"> • Sufficient funding needs to be in place to support adult aspirations 	Workshop 1 & 2 “Story share and capture”
More transparency needed around funding options and allocation	<ul style="list-style-type: none"> • Parents report limited transparency about available funding and where funding is allocated 	Workshop 3 “Brainstorm”
Care staff should be valued	<ul style="list-style-type: none"> • Need to recognise the value of the work care staff do • Need to fund care staff adequately and provide training 	Workshop 1 & 2 “Story share and capture”
Better interagency working is needed	<ul style="list-style-type: none"> • Lack of joined up thinking • No one takes responsibility for transition • Lack of communication between professionals • Health service and education department should liaise about transition earlier 	Workshop 1 & 2 “Story share and capture”
Database of people with CP to highlight and track need	<ul style="list-style-type: none"> • Need process & platform to collect data on who is transitioning, who requires disability services and collect data about upcoming need • Need accurate data/ registers to show gaps in service delivery so they can be addressed 	Workshop 3 “Brainstorm”

Better provision of living options	<ul style="list-style-type: none"> • Independent living should be termed living options to reflect need for different models e.g. single occupancy, shared housing • Counting young people on the housing list should be prioritised • Living outside family home needs to be resourced sufficiently 	Workshop 3 “Brainstorm”
Recommendations for adult services		
Reassessment and reviews should be accessible and timely in adult services	<ul style="list-style-type: none"> • Cerebral palsy may change as you get older. You may not get access to services when leaving children’s services because of your level at transfer • Need reassessment in adulthood so you are not on your own • Check in and reassessment needed, as things may change as you age 	Workshop 1 & 2 “Story share and capture”
	<ul style="list-style-type: none"> • Annual review in adulthood to ensure needs are being met 	Workshop 3 “Brainstorm”
Healthcare in adulthood should be centralised	<ul style="list-style-type: none"> • Need to reduce fragmentation of services • Everything should be in one place • You should be able to see two or three professionals, on the same day, under the same roof 	Workshop 1 & 2 “Story share and capture”
Healthcare in adulthood should be community centred	<ul style="list-style-type: none"> • Adults services should be community centred, in primary care 	Workshop 1 & 2 “Story share and capture”
Healthcare should follow a life needs model	<ul style="list-style-type: none"> • Kids with CP become adults - need a lifespan model • Need to look to the future from an early age • Equipment should follow you rather than having to reapply in adulthood • CP is for life, therapy access should be too. People shouldn’t be expected to use private healthcare 	Workshop 1 & 2 “Story share and capture”

Recommendations for transition services		
Age of transition	<ul style="list-style-type: none"> • Planning for adulthood should have a set age. • It should start when you go into the senior end of school • It should start before you transfer • When domiciliary payment ends transition planning could begin 	Workshop 1 & 2 “Story share and capture”
	<ul style="list-style-type: none"> • Need defined age to begin transition process 	Workshop 3 “Brainstorm”
Transition planning meeting with health professionals, parents and young person	<ul style="list-style-type: none"> • Include young people in planning meetings • Consider combining educational and clinical transition plans • Review meeting needed before discharge to assess needs and make referrals • Series of meetings needed so families have time to plan 	Workshop 3 “Brainstorm”
Handover process between child and adult health professionals	<ul style="list-style-type: none"> • Handover needed between staff to share knowledge/experience • Handover meeting with both teams • Period of co-working between teams would help ease transition • Joint consultation to share information about young person between paediatric and adult health professionals 	Workshop 3 “Brainstorm”
Provide opportunities to meet with adult team before transfer	<ul style="list-style-type: none"> • Establish adult service in advance of young person leaving paediatric services • Facilitate visits/introductory meeting before transfer • Facilitate induction to the new service (e.g., parking, timetable, staff, access, toilets) 	Workshop 3 “Brainstorm”
Provide opportunities and skills to support emotional wellbeing	<ul style="list-style-type: none"> • Provide opportunities for young people to speak to others about how their CP makes them feel • Provide access to professionals to discuss emotions and address skills to manage emotional well-being • Provide skills on managing emotions 	Workshop 3 “Brainstorm”

	<ul style="list-style-type: none"> • Provide links/contact details to helplines with people trained around supporting emotional wellbeing • Supporting emotional wellbeing should begin early and should be • checked during transition because it's a vulnerable phase 	
Work experience provision	<ul style="list-style-type: none"> • Limited work experience opportunities • Accessing work experience is challenging • Transport barriers in community create barriers to employment • Training needed on managing fatigue, employment discrimination and disclosing a disability to employers 	Workshop 3 "Brainstorm"
Holistic/ Person centred transition process	<ul style="list-style-type: none"> • Use inclusive language • Discussion currently focused on needs rather than wants • Views, wants and hopes should be considered along with needs • Addressing and planning for all holistic needs of young person should be considered during transition 	Workshop 3 "Brainstorm"
Additional time in appointments to allow young people space to make decisions and ask questions	<ul style="list-style-type: none"> • When young people are rushed, parents jump in to make sure nothing is missed • Giving young people more time in appointments will facilitate them asking questions and being more independent 	Workshop 3 "Brainstorm"
Health professional should encourage autonomy by directing focus to young people	<ul style="list-style-type: none"> • Health care professionals sometimes speak more to parents than young people • Including young people in the conversations and directing questions to them will help develop their independence • Ask young person at every appointment do you want to answer the questions • Start from a young age, don't just wait until transition 	Workshop 3 "Brainstorm"

<p>Parents need to step back to let young people try things themselves and build independence</p>	<ul style="list-style-type: none"> • Parents need to let young people develop independence rather than doing everything for them • Allowing young people to try things out and make mistakes is important • Parents can create space for young person to give their opinions during appointments 	<p>Workshop 3 “Brainstorm”</p>
<p>Copy of all correspondence provided to young person and parent</p>	<ul style="list-style-type: none"> • Address correspondence to young people • CC family into correspondence, referrals and handovers • Provide copy of letters from paediatric healthcare service to adult healthcare service to young person and parent 	<p>Workshop 3 “Brainstorm”</p>
<p>Develop confidence and self-advocacy skills</p>	<ul style="list-style-type: none"> • Professionals need to be understanding that becoming confident is a process and requires time. • Support should be removed gradually to grow confidence • Self-advocacy is key to ensure health professionals listen to individual needs • Improving condition specific knowledge needed to develop confidence and advocacy • Training needed to build independence and autonomy including how to relay information to health professionals in school or groups 	<p>Workshop 3 “Brainstorm”</p>
<p>Introduce and practice responsibilities for adult services before transfer</p>	<ul style="list-style-type: none"> • Need awareness and training on responsibilities before you leave children’s services • Need information and preparation for the differences and expectations in adult services 	<p>Workshop 3 “Brainstorm”</p>