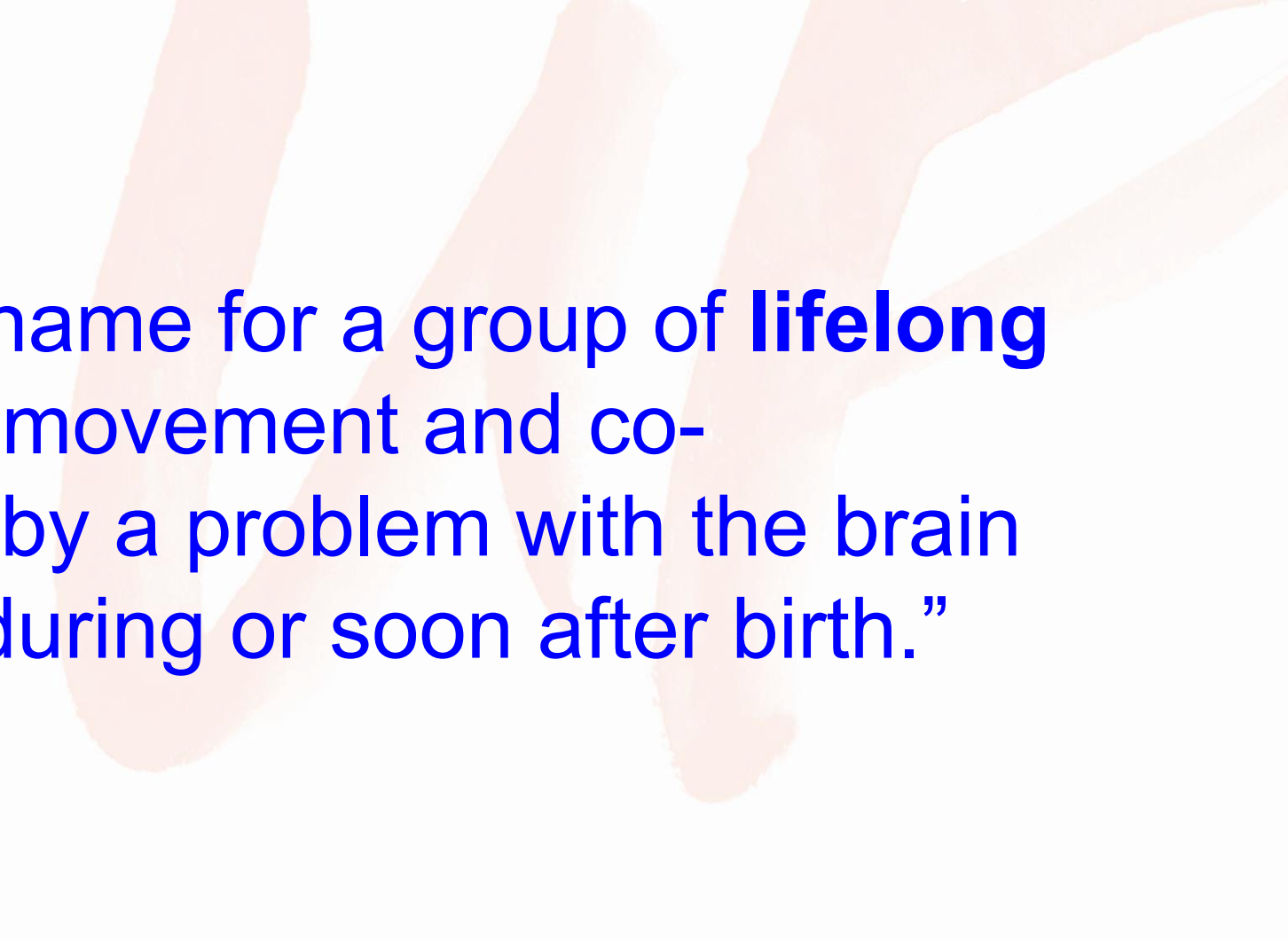


Taking a Lifelong Perspective on CP Challenges and Opportunities

Emma Livingstone, Co-Founder and CEO

Cerebral Palsy is lifelong



A faint, light-colored background image of a hand, possibly a child's, is visible behind the text. The hand is positioned with fingers slightly spread, and the palm is facing towards the viewer.

"Cerebral palsy is the name for a group of **lifelong conditions** that affect movement and co-ordination. It's caused by a problem with the brain that develops before, during or soon after birth."

Source: [nhs.uk/conditions/cerebral-palsy/](https://www.nhs.uk/conditions/cerebral-palsy/)

Challenges and Opportunities

- My Story
- Understanding Cerebral Palsy as a lifelong condition
- Preparing children for adulthood
- Living well with Cerebral Palsy in adulthood

My story

- Lack of accessible and coordinated care for adults with CP is a major barrier
- Misdiagnoses/diagnostic overshadowing and age-based restrictions highlighted systemic challenges
- Self-advocacy and exploring alternative options are crucial for managing your own health
- Importance of personalised and holistic approaches to CP care
- Adults with CP face unique challenges that require specialist knowledge and care.



My story

- Need for an MDT that has an understanding of cerebral palsy
- Need for extended rehabilitation after surgical procedures/ or life event/fall for someone with neurological condition
- Consider impact of intervention on the rest of the body e.g. skin integrity, leg pain, long term crutch use
- Knowledge about cerebral palsy and how aging impacts disability
- Not everything is because of cerebral palsy, but CP may be having an impact on its presentation



The consequences

Requiring life-impacting surgery

No support or understanding from the medical community

Needing to come terms with functional change in ability

Questioning life choices

Dealing with guilt



Low self-esteem and anxiety

Disempowered

No positive association with exercise or knowledge of how to help myself

Isolated from the community and having never met anyone else with CP before

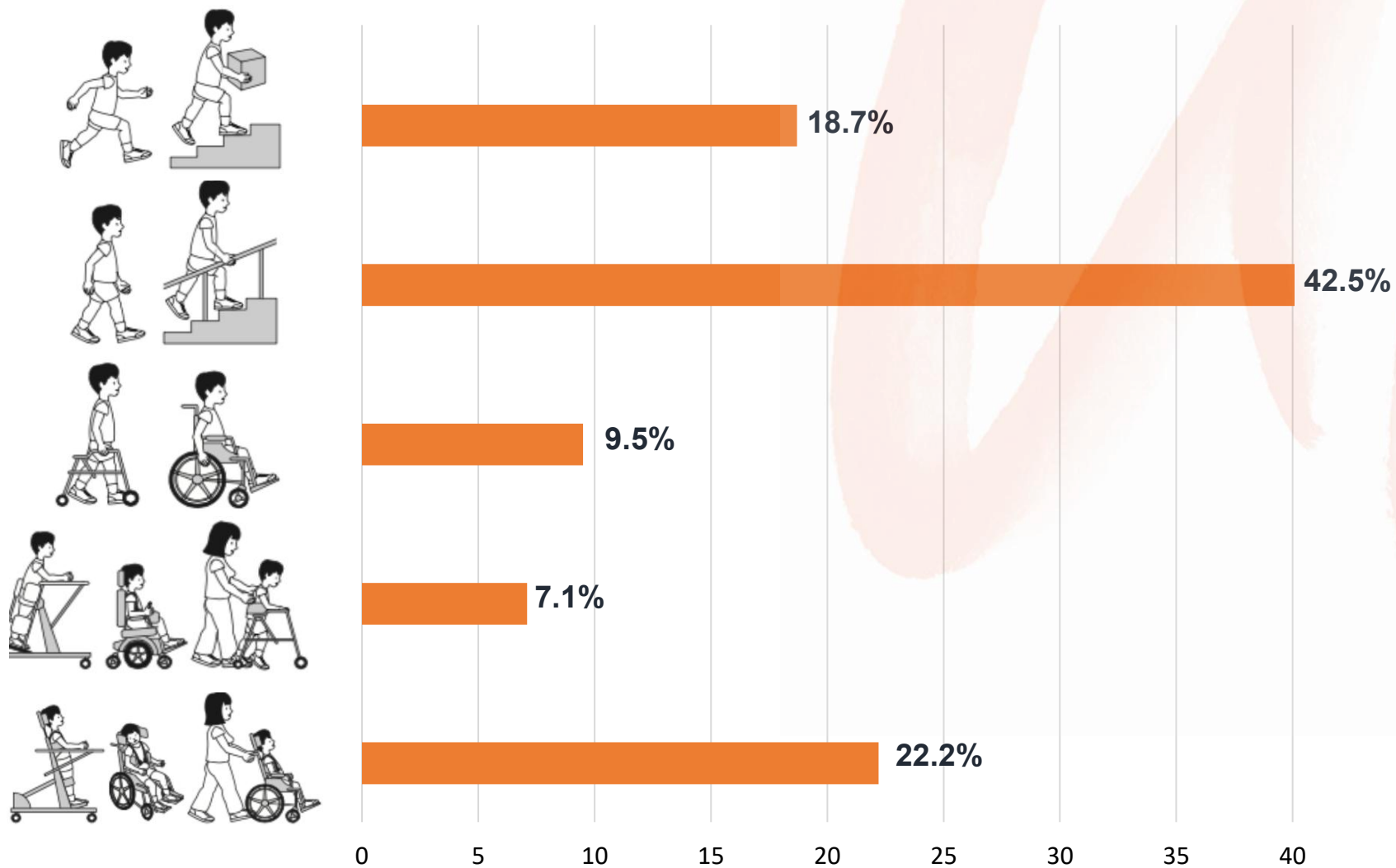
Adults with Cerebral Palsy

A community of 130,000 adults living with CP, the largest group in the UK living with a lifelong condition.

Comparable in size to those with Multiple Sclerosis and Parkinson's Disease, yet without the same resources.

No coordinated, specialist medical care and services fall short of NICE guidelines.

Impact is unnecessary pain, reduced quality of life, avoidable medical problems and increased mental health issues.



The community tell us...

- Fatigue
- Pain
- Sleep
- Declining mobility
- Managing functional decline
- Poor mental health and anxiety

Which lead to issues with wider participation e.g. social relationships, in the workplace, travel, hobbies etc

The experiences of the community is backed up by the research

- 65% of adults have pain
- 40% of adults have limited knee mobility
- 33% of adults have limited hip mobility
- Among ambulatory adults, 56% reported to perceive a decline in walking function or capacity over time
- Proportion of adults in remunerative employment is 39%; it's 56% in samples of adults without ID



van Gorp et al. *Epidemiology of cerebral palsy in adulthood: a systematic review and meta-analysis of the most frequently studied outcomes*. Arch Phys Med Rehabil. 2020;101(6):1041-1052.

Ryan et al. *Prevalence and incidence of chronic conditions among adults with cerebral palsy: a systematic review and meta-analysis*. Dev Med Child Neurol. 2023;doi:10.1111/dmcn.15526

We also know that

- Many women from the community find it difficult to access appropriate support for their Mammograms and Cervical smears
- Morphology, composition of muscle/ fat ratio is different in Adults with CP
- BMI monitoring may not be reliable for this population due the higher levels of visceral fat
- Adults with CP have higher rates of metabolic syndrome, cardiovascular disease and stroke and this could be related to excess body fat but also linked to lower levels of fitness and activity

Full life participation means talking taboos

- Menstruation
- Contraceptives
- Sex
- Relationships
- Pregnancy
- Alcohol and Cannabis

*The American College of Obstetricians and Gynaecologists Menstrual Manipulation for Adolescents with Physical and Developmental Disabilities.. College Publications. 2016.
Wiegerink et al. Social, Intimate & Sexual Relationships of adolescents with Cerebral Palsy Compared With Able Bodied Age-Mates J Rehabil Med 2008 Feb*

Full life participation means recognising the Social and economic impact of disability

Four in ten living in poverty

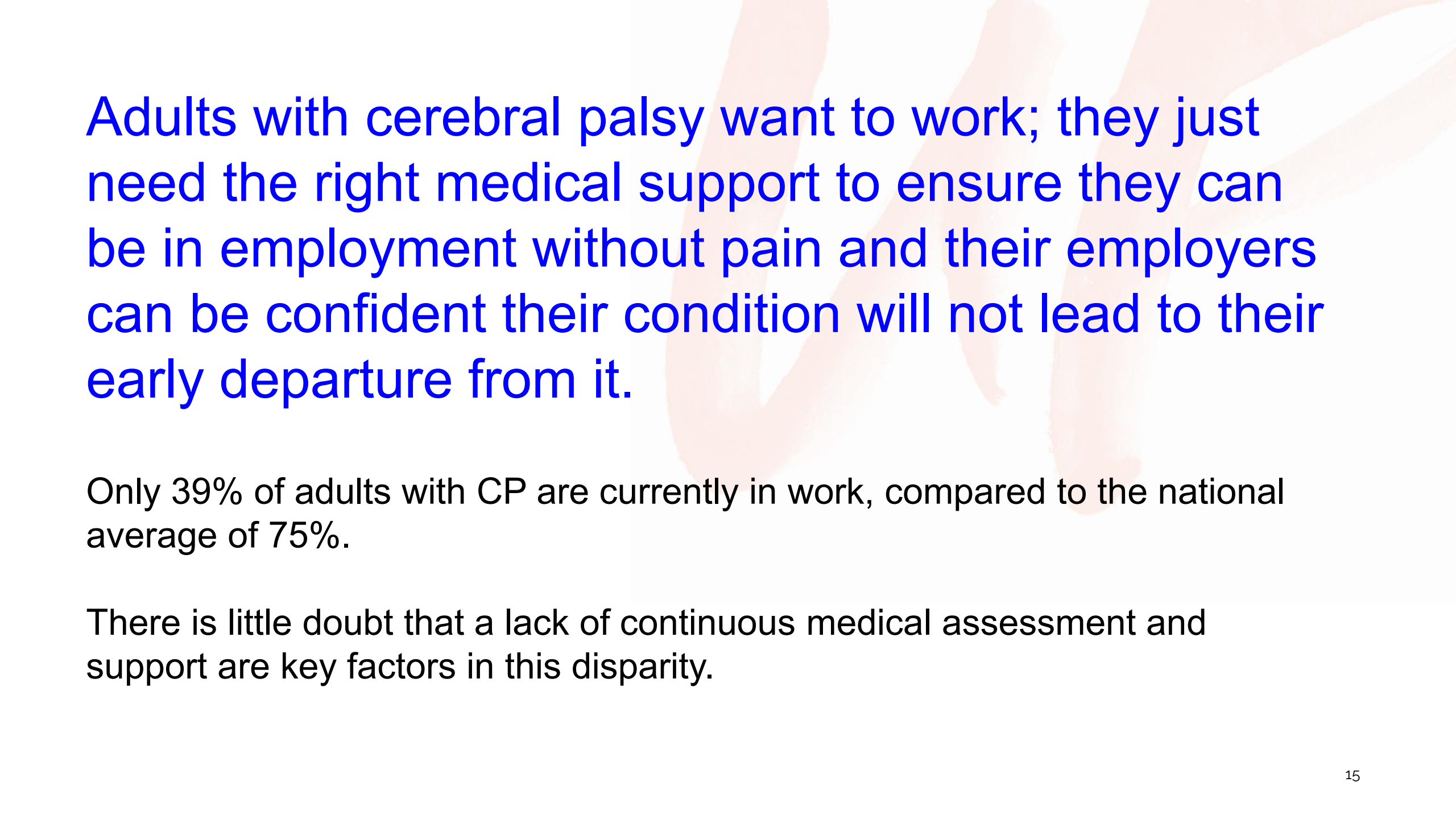
32% feel not accepted by their local communities

52% have experienced discrimination at work

25% who need adapted accommodation don't have it

58% victims of crime

One in three has been refused service or turned away from pubs, leisure centres, restaurants or other public places

A faint, stylized background image showing two hands, one light-skinned and one dark-skinned, gently cupping a heart shape. The hands are positioned behind the text, with the fingers pointing towards the center where the heart is located.

Adults with cerebral palsy want to work; they just need the right medical support to ensure they can be in employment without pain and their employers can be confident their condition will not lead to their early departure from it.

Only 39% of adults with CP are currently in work, compared to the national average of 75%.

There is little doubt that a lack of continuous medical assessment and support are key factors in this disparity.

Overlapping needs

Individuals with Cerebral Palsy have needs that overlap the following areas:

Health Care – Social care – Vocational – Social participation

Physical health issues can exacerbate social and mental health for adults with CP. Issues such as loneliness, social isolation, social exclusion and mental illness are all commonly reported in this population.

These complex physical, social, and mental health issues point to the need for specialised support. In childhood people with CP are often supported by specialist teams. However, once people reach adulthood they are often discharged from these services and transitioned to non-specialised care that many people with CP describe as *falling off a cliff*.

At this point, it is a GP rather than a specialist clinician who becomes their main point of contact and healthcare support. As such, there is a need to look to innovative ways to support this population within the community.






“Inadequate health provision for adults with CP leads to great **physical pain** and **constrained lives.**”

*Barriers for adults with Cerebral Palsy on achieving full life participation:
access to healthcare services and progressing at work*

All-Party Parliamentary Group Report, March 2022



"90% of children with Cerebral Palsy reach adulthood and find themselves at a **cliff-edge**, without the support they had relied upon for their first 18 years of life."

*Barriers for adults with Cerebral Palsy on achieving full life participation:
access to healthcare services and progressing at work*

All-Party Parliamentary Group Report, March 2022



“Poor transition from child- to adult-oriented healthcare may lead to **negative outcomes** and **dissatisfaction** with services in adulthood”.

Transition from child to adult health services for young people with cerebral palsy in Ireland; implications from a mixed-methods study

Jennifer M. Ryan

What does good transition look like?

1. Tailoring parent involvement requires intentional actions to enable parents and young people to adapt to changing roles.
2. A standardised transition pathway is required for all young people with CP across organisations, developed in collaboration with young people and parents.
3. Provision of information to all young people, families and health professionals should be provided in a collaborative and phased approach that starts well before transfer.
4. A common understanding of self-management is needed between young people, health professionals and parents.
5. In the absence of health services for adults with CP that take a lifespan approach, there is a need for joint working between child services, adult services, and GP's to optimise transition.



If we agree that we want full life participation for our children – then what happens in childhood matters.

From Passenger to Pilot

1



2



3



Preparing our children for adulthood

1. Information is Key
2. Building Skills
3. Healthy Habits
4. Success is Participation
5. Signposting
6. Role models





TRANSITIONS

Healthcare for adults with physical disability

TRANSITION STAGES TO THE ADULT HEALTHCARE SYSTEM

Introduction stage (12-14 years) Checklist

This stage is about working out what you need to know before you leave children's services

Tick ✓ as you complete

Planning for transfer

visit [Transition and transfer](#) for more information

Find out what the terms transition and transfer mean

Start to learn about privacy, confidentiality and consent such as who can access your health information

My disability and health

visit [My health and function](#) for information

Explore how much you know and understand about your disability

Start thinking about how you look after your physical and mental health. Start trying new ways to look after your health that might help you in the future.

Speaking up for myself

visit [Speaking up for myself](#) for information

Talk to your parents/guardians about how you might take responsibility for your healthcare as you get older

Start answering or asking questions during appointments with health professionals. If you're unclear about anything ask them to explain or give you more information

Parents/Guardians: Give your child opportunities to ask and answer questions in appointments and in other situations not related to healthcare

Managing my healthcare

visit [The new health service](#) for information

Learn the names of doctors and other health professionals you see and the reasons you see them

Start to develop a relationship with your GP

TRANSITIONS

Healthcare for adults with physical disability

TRANSITION STAGES TO THE ADULT HEALTHCARE SYSTEM

Preparation stage (14-16 years) Checklist

This stage is about learning the skills you need to look after your healthcare. During this stage, responsibility for your healthcare slowly shifts from your parents/guardians to you. Your parents or guardians will still support you as you need them.

Tick ✓ as you complete

Planning for transfer

visit [Transition and transfer](#) for information

Explore how you can take part in planning for the transfer to adults' services with your parents/guardians and your health professionals

Parents/Guardians: Encourage your child to attend and participate in all meetings with you, where their future plans are discussed

Talk to your parents/guardians and health professionals about how adult health services might be different to children's health services

Talk to your parents and health professionals about changes that will happen to confidentiality and consent when you turn 18. Discuss how these changes will affect you and your parents

Get information about any services you may be eligible to attend as an adult and how you can access them

Talk to your health professionals about how you get referred to different health professionals as an adult

My disability and health

visit [My health and function](#) for information

Ask about your disability, therapies you receive (like physiotherapy, occupational therapy, speech and language therapy), medications you've used or are using, surgeries you've had, and equipment or assistive technology you use or have tried in the past

Learn more about how your disability affects you and how it might change as you get older

Learn more about how you can look after your physical and mental health as you get older

TRANSITIONS

Healthcare for adults with physical disability

TRANSITION STAGES TO THE ADULT HEALTHCARE SYSTEM

Transfer stage (16-18 years) Checklist

At this stage of transition, you may start to feel confident about managing your healthcare on your own and take over the practical aspects of managing your health, where appropriate. Your parents or guardians will still support you as you need them.

Tick ✓ as you complete

Planning for transfer

visit [Transition and transfer](#) for information

Explore opportunities to connect with other young people transitioning to adult healthcare. Stay connected to friends, family, and community organisations.

Find out when you are leaving children's services and where you will be moving to, if relevant

Find out if referrals have been sent to any relevant specialist services

Explore opportunities to meet the health professionals you will children's services

Request a copy of any letters or reports that your children's services and/or your GP

Find out if a copy of your medical records will be sent to your new service or if you can request a copy of your full medical history

If you are awaiting surgery and require intervention after it, ask the necessary referrals have been made

Talk to your health professionals about how to handle any urgent issues between the time you are discharged from children's services and with an adult service

If you or your parents think you may require assistance to make decisions, talk to health professionals and others who support you about options

My disability and health

visit [My health and function](#) for information

Be able to share information with health professionals about your history of receiving therapy, surgery or other services

Create a list of community services, supports and trusted online resources for your physical and mental health

Checklists you can fill out

- ✓ Checklist for people with CP: Introduction stage (12-14 years)
- ✓ Checklist for people with disabilities: Introduction stage (12-14 years)
- ✓ Checklist for people with CP: Preparation stage (14-16 years)
- ✓ Checklist for people with disabilities: Preparation stage (14-16 years)
- ✓ Checklist for people with CP: Transfer stage (16-18 years)
- ✓ Checklist for people with disabilities: Transfer stage (16-18 years)
- ✓ Checklist: Adult day services and rehabilitative training
- ✓ Checklist: Understanding my options for education, part-time work, or employment

TRANSITIONS

Healthcare for adults with physical disability

ADULT DAY SERVICES AND REHABILITATIVE TRAINING

Checklist

If you are considering post-school options such as rehabilitative training or tailored adult day services, you may find the following checklist helpful for preparing

Tick ✓ as you complete

Talk about how and when to apply for adult day services and rehabilitative training with health professionals or others involved in your care

Find out if an application has been made to the HSE Day Opportunities Officer.

When discussing options with the officer, consider asking about the following topics:

- Whether transport is included
- Whether therapy services are provided
- Whether respite options are included
- Whether the building is accessible
- Whether the toilet and/or changing facilities are appropriate
- Whether meals are included

If you are attending a special educational needs (SEN) school, discuss when you will graduate with your health professionals and others involved in your care

Gather the necessary paperwork to apply for funding, such as medical reports, letters, assessments, and proof of catchment area, and ensure they are given to your new service

Check that all reports are current and up-to-date, including psychology assessments, Feeding Eating Drinking and Swallowing Difficulties (FEDS) reports, communication passports and sling/equipment assessments

Find out if you can visit the day service or rehabilitative training service and meet the new professionals before you leave children's services

Ask staff in the new service if they can complete specific tasks you need such as manual handling, feeding, providing behavioural supports, and supporting your medical needs

CP-Life Research Centre

Healthcare for adults with physical disability

CHECKLIST

Understanding my options for education, part-time work, or employment



This list contains various factors to consider when searching for education or job opportunities.

How does it apply to you?

This list can help you think about what will go well for you and for which things you might need to find a solution or where you might need help. Fill this in with your parent. It might be helpful to bring it to your health professional, doctor or guidance counsellor.

Name

Date



This resource was developed with funding from the HSE and CRC



Additional resources and guides are available on our website www.cahabioresources.ie or scan the code

TRANSITIONS

Healthcare for adults with cerebral palsy

Health Summary

This health summary belongs to

Before you start:

- Read the whole summary to understand the questions under each section
- Complete the summary over time and in stages
- You might find it helpful to gather the information you need before filling in the summary
- Ask for support to complete the summary, for example from parents and health professionals
- Keep the summary in a safe place
- Consider bringing the summary with you to appointments with new health professionals
- Add to the summary over time so it remains up-to-date.
- It may be helpful to update at key times in your life such as being discharged from a health service, attending a new health service, attending a new education setting or starting a new job

About me	2	Pain	12
About my cerebral palsy	4	Other medical conditions	13
Gross Motor Function Classification System (GMFCS)	5	Allergies	15
Manual Ability Classification System (MACS)	7	Vaccines - Teenager / Adult	15
Eating and Drinking Ability Classification System (EDACS)	8	Vaccines - Baby / Child	16
International Dysphagia Diet Standardisation Initiative (IDDSI)	9	Equipment	17
Communication Function Classification System (CFCS)	10	History of orthopaedic surgery	19
Scoliosis	11	History of other surgery	20
Epilepsy	11	History of other hospitalisations	21
Fatigue	11	History of spasticity management	23
		Other medications	25
		Any other medical history	26
		Contact details	27

Emergency contact





Name	Name
<input type="text"/>	<input type="text"/>
Relationship	Relationship
<input type="text"/>	<input type="text"/>
Telephone Number	Telephone Number
<input type="text"/>	<input type="text"/>

www.cphealthcaretransition.eu

TRANSITIONS

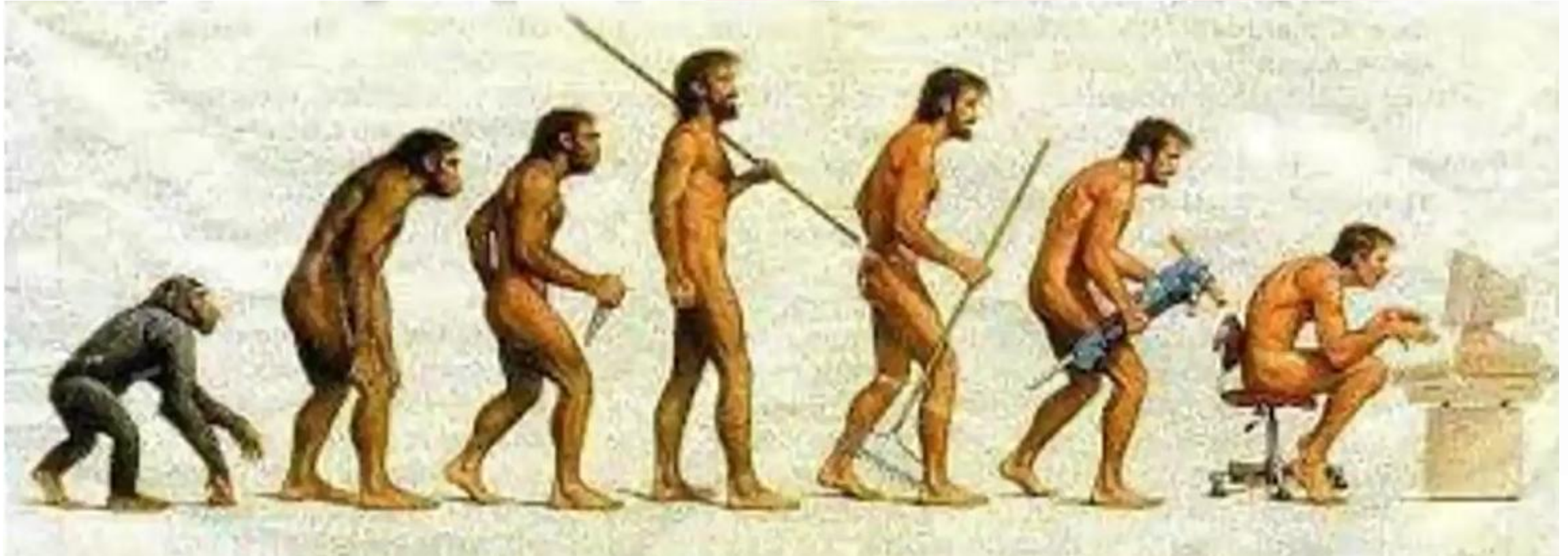
Healthcare for adults with physical disability

DIFFERENCES BETWEEN CHILD AND ADULT HEALTH SERVICES

	CHILDREN'S HEALTH SERVICES (Where you are now)	ADULT HEALTH SERVICES (Where you will be)	SOME TIPS
Where you go for appointments	You probably know your way around children's health services. You will mainly have other children and young people around you.	Adult health services will be new to you and it will take time to find your way around. With time, you'll become more used to them. You may find there are people of different ages, often older than you, in the waiting rooms and clinics.	Try to visit and get to know your new adult health service before you leave children's services if you can. 
How long the appointments are	Appointments may be longer. You may spend more time with the health professional at your appointment.	Appointments may be shorter. You may spend less time with the health professional at your appointment.	Ask your adult health professionals or GP if you can make a longer appointment if necessary when you first go to adult services. 
How often you have appointments	You may have regular appointments with health professionals.	You may not get regular appointments with health professionals.	If you notice any changes in your condition or any problems such as pain between appointments, you should seek advice from your health professional or GP 
How you see different health professionals	Often, the different health professionals you see are in the one place. You may see a number of health professionals at one appointment.	In adult health services, your health professionals may be in different locations. You may see one health professional at an appointment and not a team of health professionals. You may be referred to health professionals in different services or hospitals. It may take more effort to coordinate the different services you need.	Find out what health professionals you might be able to see as an adult with help from your parents and health professionals. Get their help to link you up with new services. 

www.cphealthcaretransition.eu

Dangers of Sedentary Behaviour



Skills identified

1. Independence
2. Self advocacy
3. Decision making





Building healthy habits

- Positive experience of exercise
- Finding an activity that is fun and sociable
- Family pursuit- integrated into everyday life
- Exercise is for “me too” – cardiovascular and strength training
- Mental Health impacting physical health and visa versa



Mobility aids increase
participation and support
inclusion

Digital stories

Eight young people came together to share their experience of moving from child to adult health services and growing up with cerebral palsy.



Getting to know your cerebral palsy



Moving to adult services



Navigating adult services



Talking to health professionals



Speaking up for yourself



Living with people's perceptions



Finding your support network



Asking for support



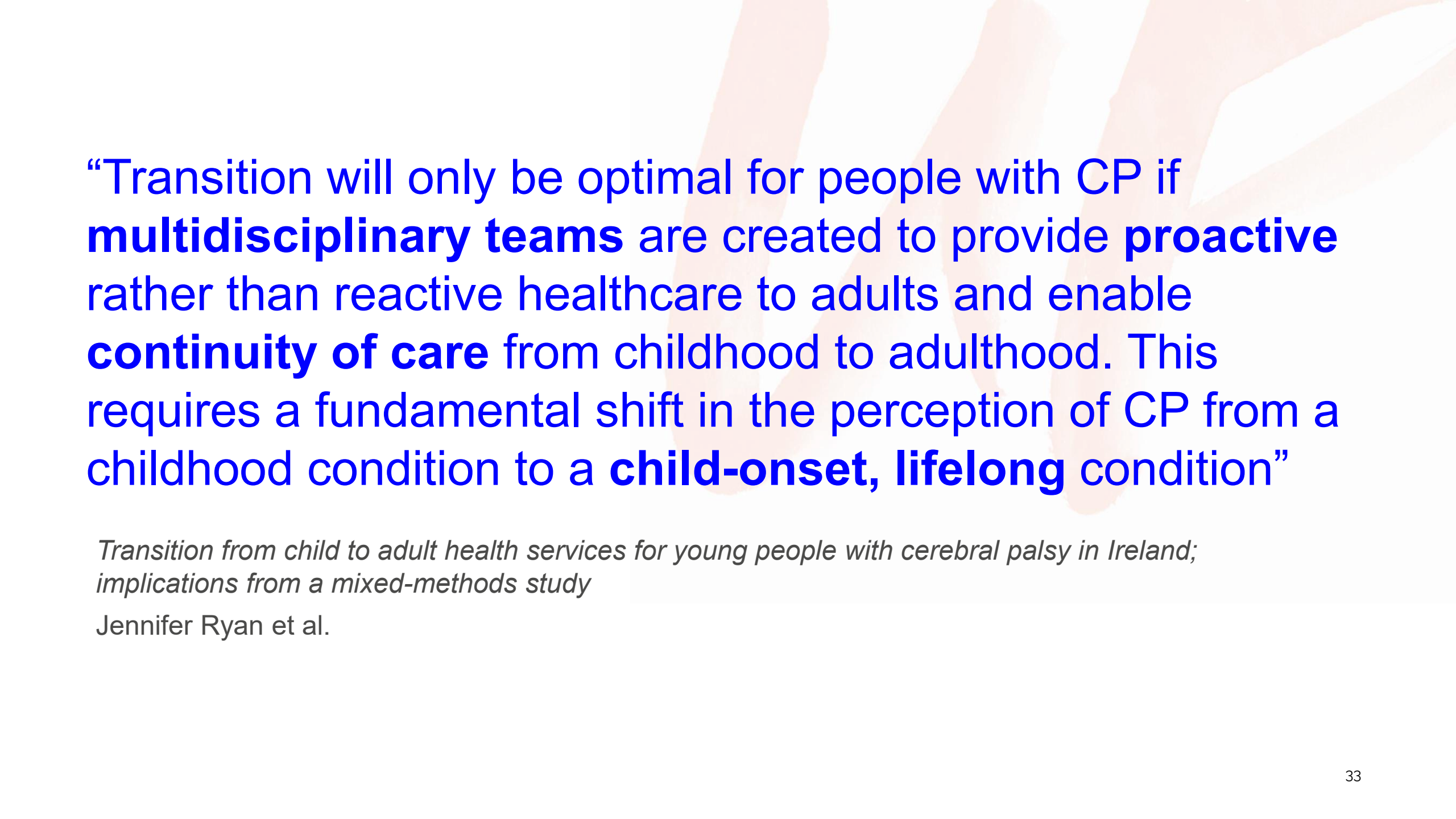
Working with a personal assistant



Growing up



Thinking about the future



“Transition will only be optimal for people with CP if **multidisciplinary teams** are created to provide **proactive** rather than reactive healthcare to adults and enable **continuity of care** from childhood to adulthood. This requires a fundamental shift in the perception of CP from a childhood condition to a **child-onset, lifelong** condition”

Transition from child to adult health services for young people with cerebral palsy in Ireland; implications from a mixed-methods study

Jennifer Ryan et al.

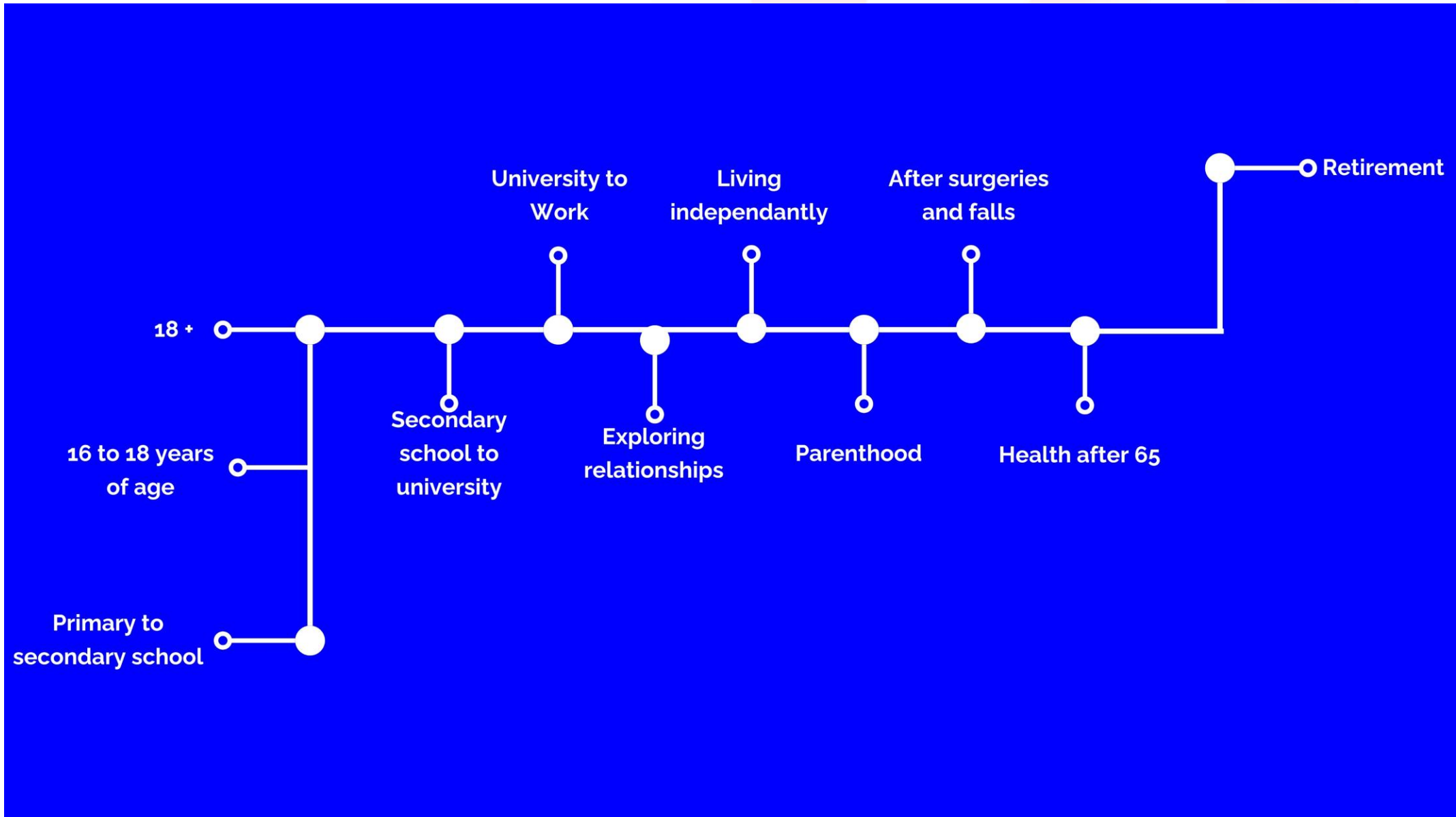
Therapy Goals

1. Saving energy
2. Increasing function
3. Supporting participation
4. Pain management



...supported by knowledgeable clinicians
who work in partnership

Transitions across the lifespan



- Knowledge and skills
- Support
- Signposting
- Services



We are changing the way people think about Cerebral Palsy
Better health and social care leads to happier lives



Thank you.

 @upmovement_cp

 @upmovement_cp

 @upmovementcp

 @upmovementcp