We would like to welcome you all today. This session has been brought to you by Stockton Parent Carer Forum, Hartlepool Parent Carer Forum and Tees Valley CCG.

STOCKTON
PARENT CARER FORUM

NHS
Tees Valley
Clinical Commissioning Group

1 hart mind future
Hartlepool's Parent Carer Forum

Todays Agenda

Welcome, Housekeeping, Introductions and Co-Production

The Story so Far..........

Meet our children

Pathway Journey's

Current Pathway

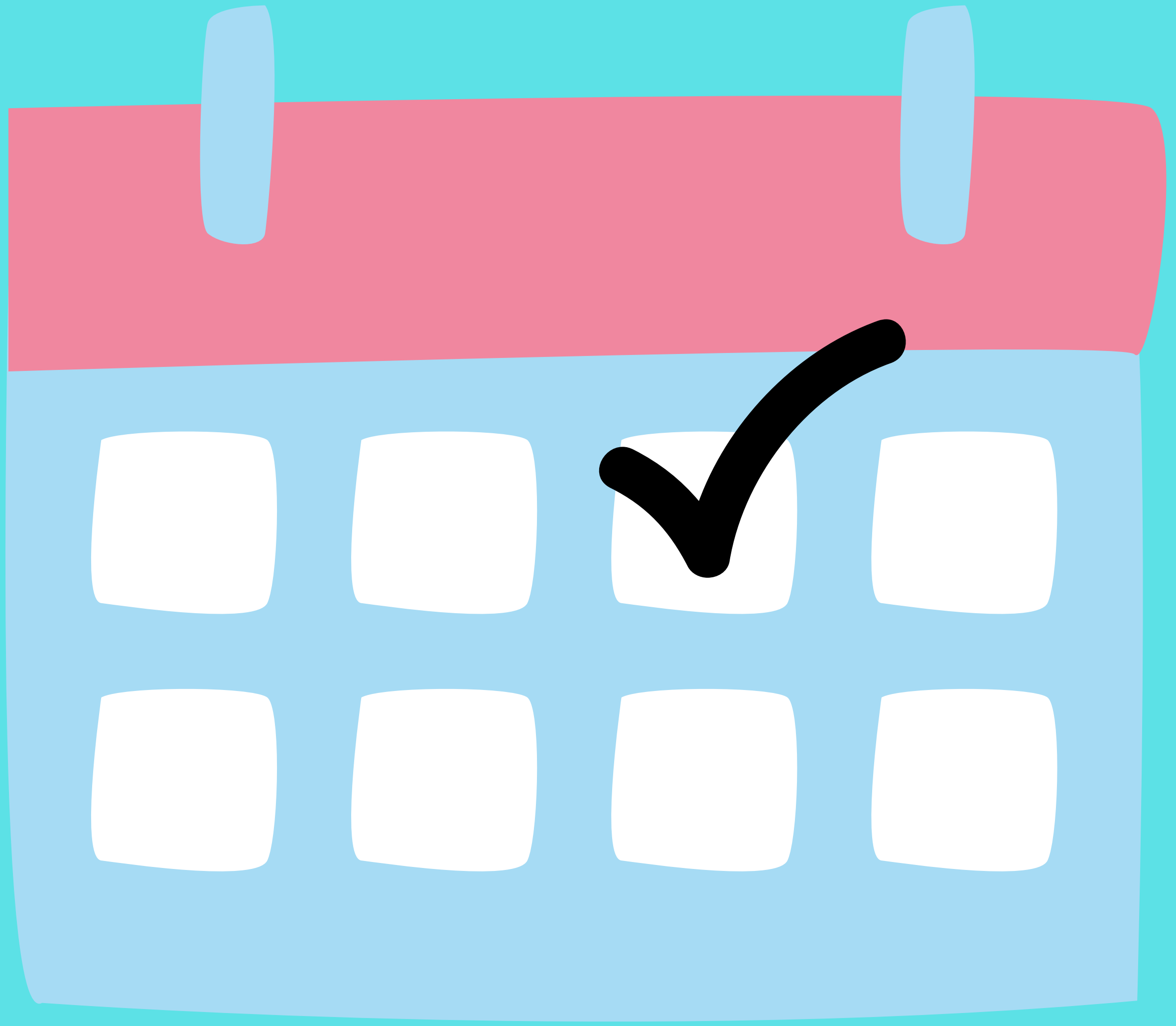
Gold Standard Pathway

Q&A Session

Policy & Key Agenda

Why are we doing this?

What happens next?



Welcome, Housekeeping, Introductions & Co-Production

Start
Together
Stay
Together

Emma Zenaj
Stockton Parent carer Forum

Co-Production

Start
Together
Stay
Together

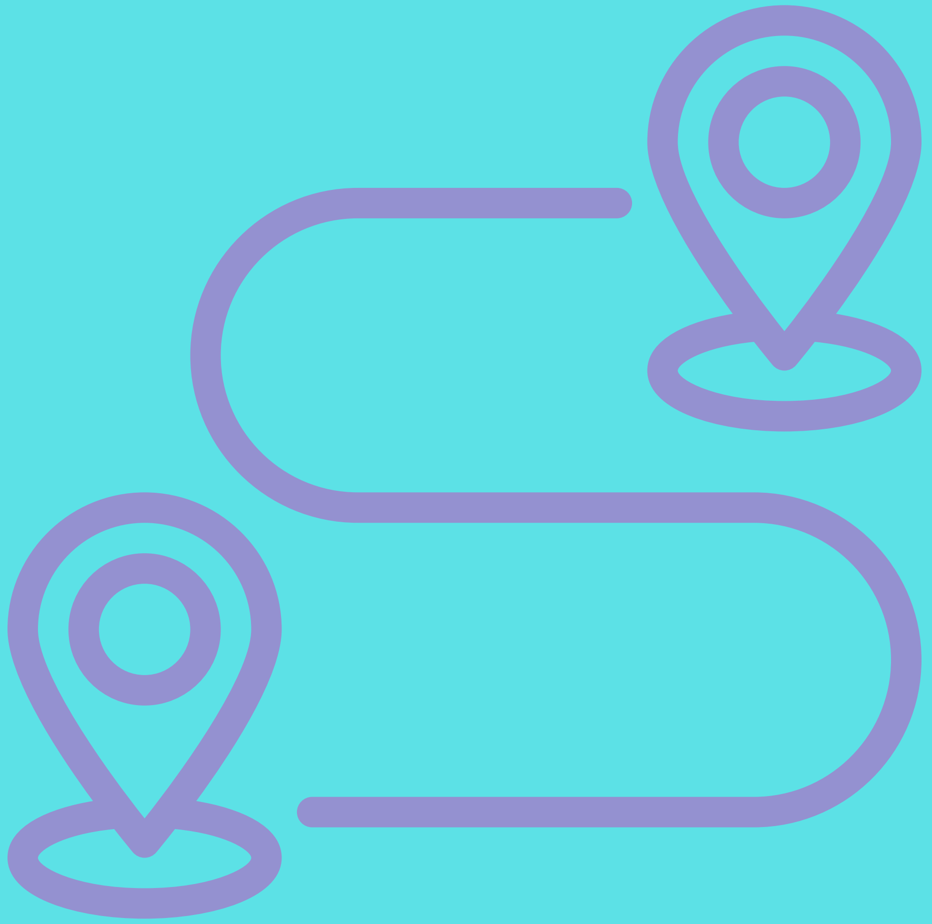
'Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered.'

The Story So Far……

Emma Zenaj

Stockton Parent carer Forum

Pathway Journeys



Leanne Baister - Hartlepool Parent carer forum

Rose Payne - Stockton Parent Carer Forum

WELCOME, EVERYONE!

We are children living in Hartlepool and Stockton that will journey through the.

Down Syndrome Pathway

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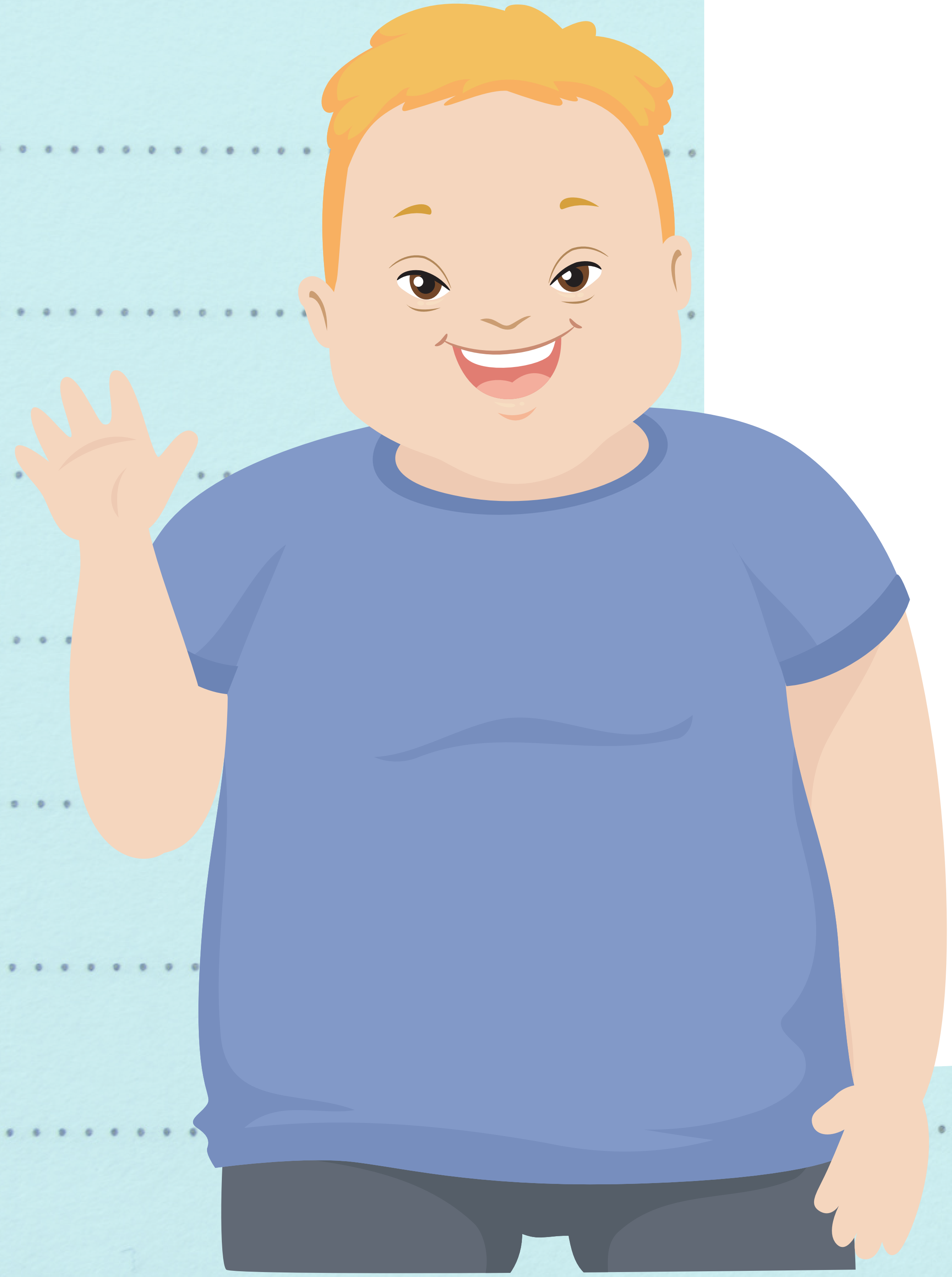

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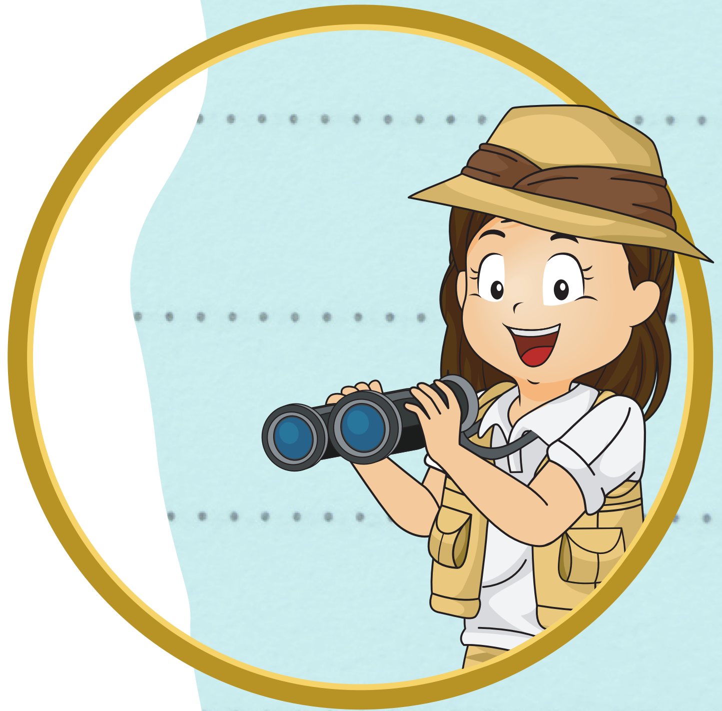

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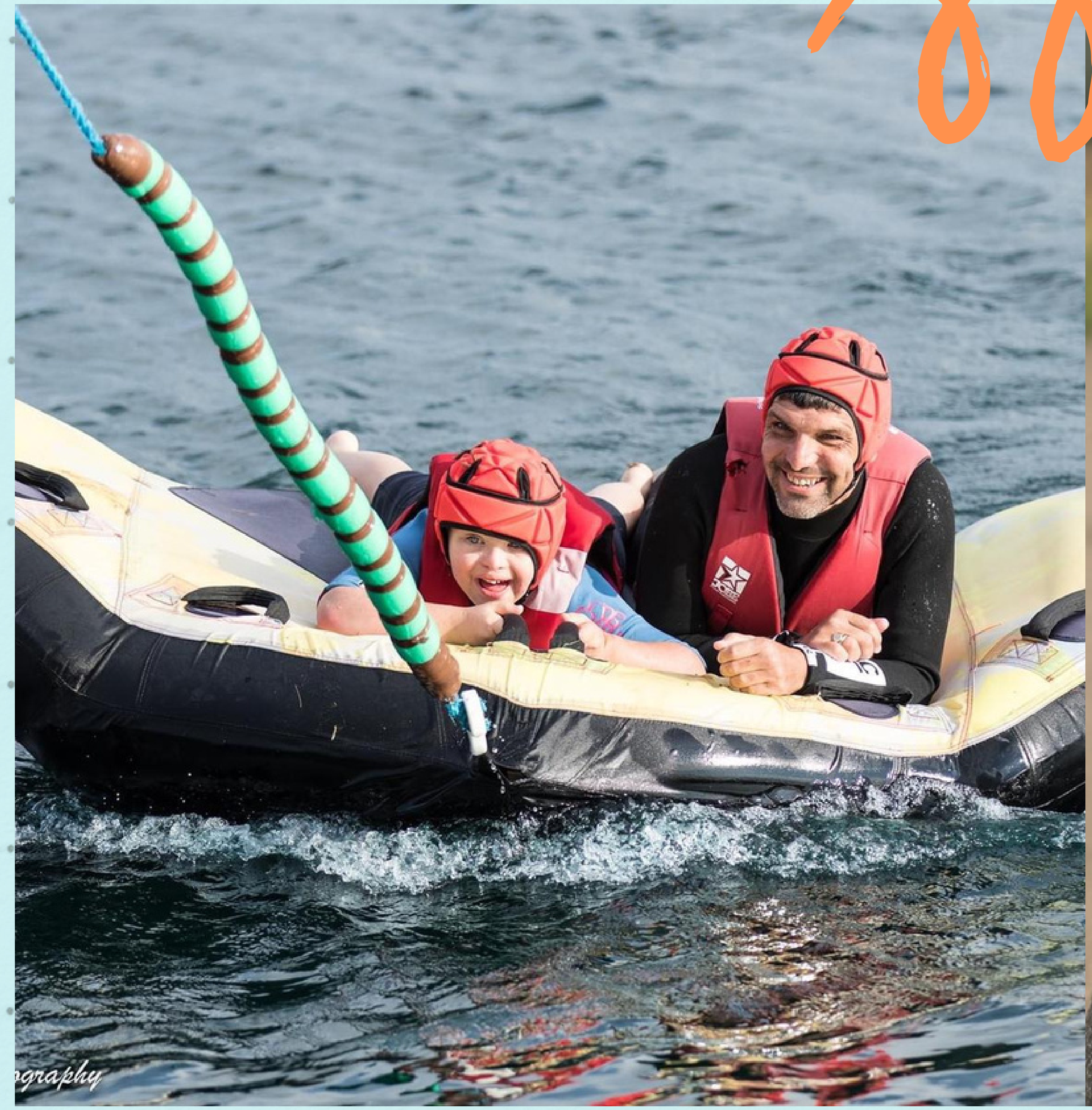

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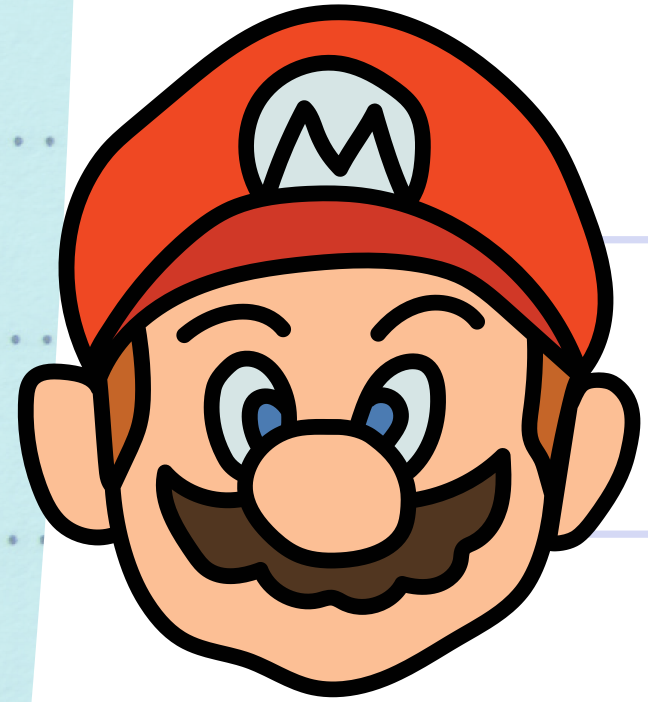
I like super Mario



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- I love going to the park with my family, baking and making crafts
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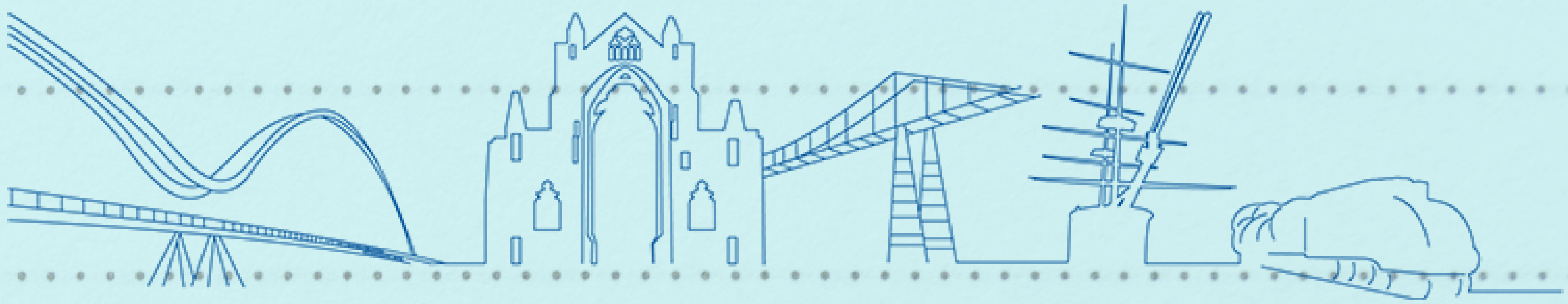

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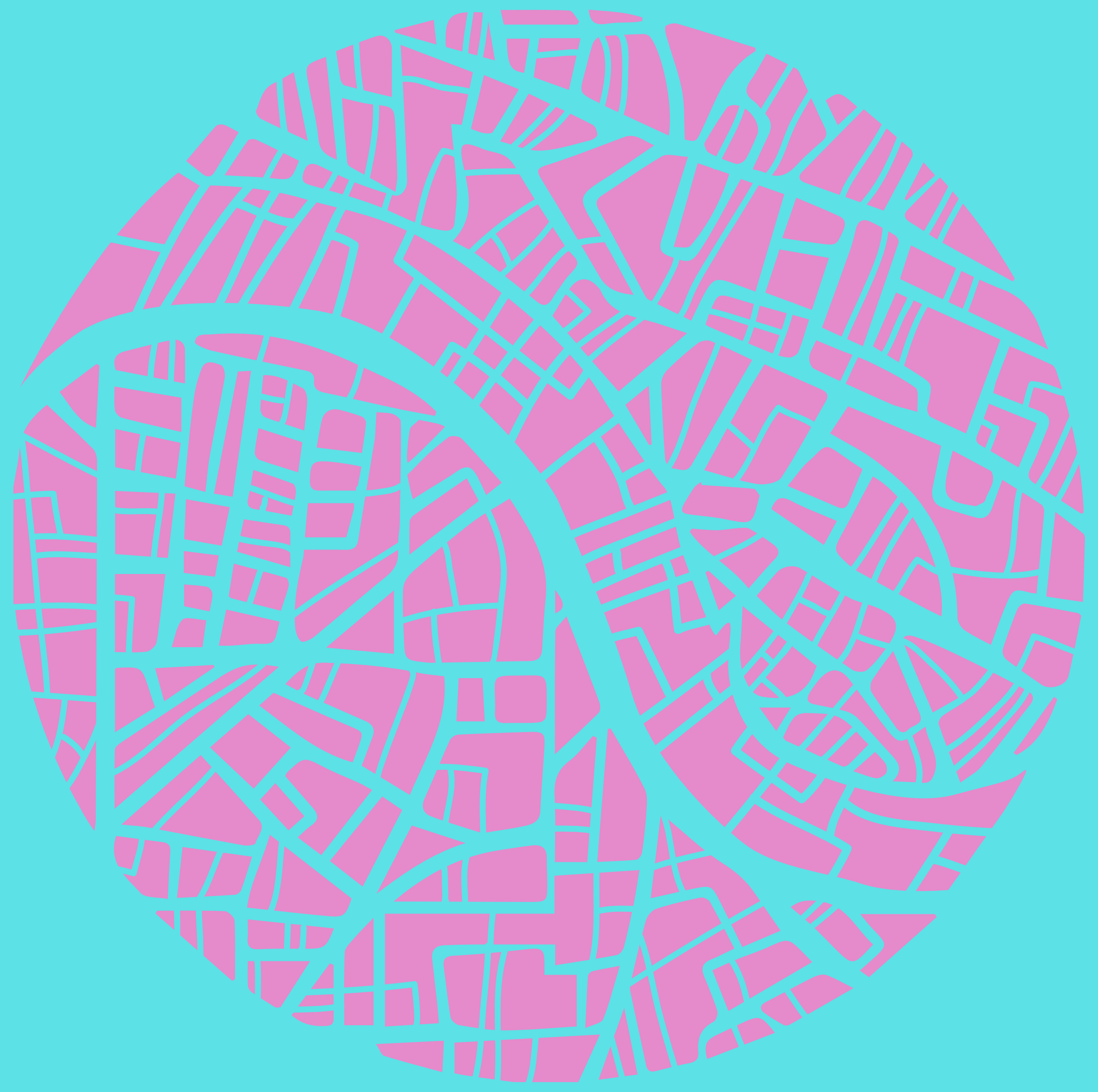
IT'S LOVELY TO MEET ALL OF YOU!

TOGETHER WE ARE THE CHANGE

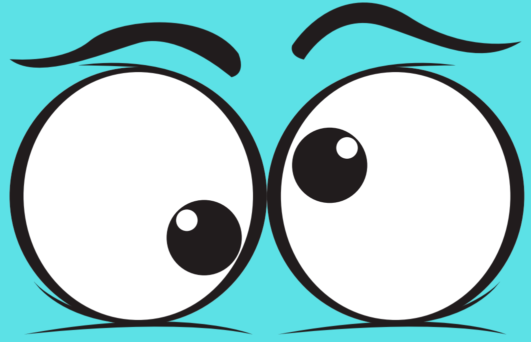
The Current Pathway



Caroline Turner - Stockton Parent Carer forum

Lack of provision

Reports



Inconsistancies

Chasing Appointments

Navigating the system

Poor Communication

Pre-natal diagnosis

Educating Professionals

Language

Pre - Birth

General expectation that 'mum' will have all screening, no real consideration that not all families want to go complete this part of the pathway

During pregnancy felt like the pre-birth diagnosis was 'the elephant in the room' – it was ignored by Midwife – NT last 4 years

Results of screening/testing 'I'm "so sorry" your child has Down Syndrome' NT

Range of families
2 diagnosed at 1st scan
7 babies diagnosed at birth
1 is S Tees + missed at birth (diagnosis 9mth)

Terminology – should be 'choice' not 'risk' "Sorry"

NIPT Test?? Is this the same as the quadruple test?

Professionals expect termination as outcome (high rate of ToP)

Screening: **10 weeks:**
Bloods – Sickle cell, Thalassaemia

18-12 Weeks:
Bloods – HIV, HepC, Syphilis
If diabetic: eye screening

10-14 Weeks:
Triple Test:
Down Syndrome
Edwards Syndrome
Patau's Syndrome
Or Quadruple Test – Down Syndrome only (up to 20 weeks)

18-21 Weeks: Ultrasound
11 conditions bones/heart

Routine: HV home visit between 28 + 35 weeks

Leaflet provided in last 4 years (NT) : "Handicapped" Children

Systemic - terms used during nursing training @ Teesside Uni

Down Syndrome 'overshadows' everything else medical V. high pain threshold

What happens if Down Syndrome is identified? How do families experience this
14 weeks?
21 weeks?

RVI for scans –
Weekly scan wk 8 – 16 due to RVI oversight – each time asked if she wanted a termination

Language - usually 'weeded out' (?NT)

Tell it right campaign should be promoted antenatally

Birth

Need to clearly tell patients what is going on behind the scenes

Should share peer support details

Lacked community support groups – once born

MD + Karyotyping meeting not always taking place in hospital (following dx) **H**

Heart scan should be at birth and not within 6 weeks (in guidance)

Babies don't always cry for food – had to wake baby to feed. Tire easily whilst feeding if heart issues - Reflux issues – lack of advice/support

Need to reinforce that Down Syndrome babies can breast feed. Can help with speech etc as strengthens jaw

Training for tube feeding needs to be improved.

Importance of language used + approach of Paed + Midwives – own room. Not always positive experiences

Told on ward with other patients

Diagnosis at point of delivery :

- Karyotyping + chromosome tests whilst in hospital ✓
- Multi disciplinary meeting with Family – Consultant, neonatologist + midwife ✗
- Written information pack, advice & guidance ✗
- Opportunity for ongoing contact with paed ✗
- 'Essential medical surveillance' ?
- Printed personal child health record for inclusion in Red book – includes weight + growth charts, information about oral health
- 2-4 weeks neonatologist ✗
- Within 6 weeks – echo – ECG (heart lesions – additional information about oral health ✗
- Notification to GP, Midwife, HV, Community paed ✓
- If issues with suckling/swallowing then referral to SLT ✓
- Haematology ?
- Guthrie (thyroid) ✓

Gastro info not provided @ birth and should be

Kent have comm nurses and co-ordinated support

Routine:
Baby check
NIPE
Hearing
NBS

Info pack Birth needs to be positive – past experience is that its negative in nearly all cases

Portage has a Down Syndrome folder with specific milestones - much better – not available at all in Hartlepool

Down Syndrome growth + development charts not in red book. Provided by Neonates / HV
Most families do not have at all

Neo-nates were v. good
H'pool & Neonates were brill. Ward not good. If don't hit neonates then rely on MD to pick up

'Generic' milestones in Red book – Reinforces negative messages

HV didn't know Down Syndrome height + weight chart

'Bright Starts' book provided at point of delivery archaic - DSA leaflets generalised no stories **H**

Letter rec'd if miss an appt saying they are being discharged – parents are stressed + coping with a lot – one missed appt should not result in that

First 12 months

Mum reported son did not have ¼ checks - seen once – many

ENT at James Cook.
Guidance indicated that Sleep studies before age of 3 are good practice as babies with Down Syndrome are predisposed to sleep apnoea – not always offered

Quarterly medical review by Paed
to include: ✗
- Sleep apnoea, gastro intestinal, growth/weight, dental reviews, heart, cranial vertebral instability, assess developmental milestones as per red book – referral to PT, SLT, Portage, ED psych as required at any point

6 – 10 month assessment full audiology assessment ✓

Annual thyroid (finger prick) test ✗ **Annually until transition →**

Feel HV need more knowledge. Parents end up knowing more

Ophthalmology is brilliant at James Cook
NT – Hit + Miss

Audiology ok

Specialist teachers should come out + advise parents on best ways to teach, best visuals etc.

Not all had sleep tests

Portage gap ? Email to L Allen **H**

Should always see a senior clinician as juniors don't always know how to interact with child

COVID **H**
Not always seen ¼ ly rearranged appointments

Don't feel onward referrals are happening

Routine:
10 day check
6 week check
6 week ophthalmology
3 – 4 MM 9 – 12MM

Comms from assessment back to Paeds re outcome

Variable – 12/18 or 24 months – sometimes a full blood test not pin prick – thyroid not always checked

12 months – 4 years

Neck instability not checked
* Some were in Hartlepool

Links to social care + EHCP processes

ASQ is ‘universal’ **H**
nothing for SEN specifically or Down Syndrome specifically
-> flags up the negative

12 months – 4 years **H**
Orthotics referral

- Footwear + equipment
-> variable

Annual medical review by Paed ✗ Annually until transition →

Annual audiology check ✓
– referral to paed ENT/SI/HI service + SI teachers

18 – 24 month ophthalmology check ✓

4 year ophthalmology check ✓ Bi-annually until transition →

Annual thyroid (finger prick) test ? Annually until transition →

McClaren **H**
pushchair / wheel chair accessories
(linked to their weight) – appropriate access to equipment (safety and access to community) is limited

Routine: HV 2 – 5 year integrated review ASQ

No one has a named Paed due to Dr Joshi moving to ST

Skills Gap **H**
0 – 19
HV to School nurse – transition needs better planning
Training/experience needed

Incontinence **H**
-> PADS group
-> Toileting Programmes
-> **Needs** / Down Syndrome eligibility?

5 - 11 years

Annual medical review by Paed ✗ Annually until transition →

Bi-Annual audiology check ✓

4 year ophthalmology check ✓ Bi-annually until transition →

Annual thyroid (finger prick) test ? Annually until transition →

Routine:
HV 2 – 5 year integrated review ASQ,
Access to health child programmes through School Nursing
Imms and other national/mandated programmes

11 plus years

Annual medical review by Paed ✗	Annually until transition →
Bi-Annual audiology check ✓	Bi-annually until transition →
4 year ophthalmology check ✓	Bi-annually until transition →
Annual thyroid (finger prick) test ?	Annually until transition →

Routine:
Access to health child programmes through School Nursing
Imms and other national/mandated programmes

14 plus years

Hospital passport
-> Durham is good
Traffic light
CYP version
DSNE to use

Annual medical review by Paed ✗ Annually until transition →

Bi-Annual audiology check ✓ Bi-annually until transition →

4 year ophthalmology check ✓ Bi-annually until transition →

Annual thyroid (finger prick) test ? Annually until transition →

Routine:
AHC
Flu vac
HAP
Hospital Passports

} ? Lifelong Annual / Ongoing →

All Parents who have contributed to these conversations have younger children

Current Pathway
What is working?

audiology & ophthalmology provision

SALT

neonatal community nurses

Hospital Passports

early physiotherapy involvement

Paediatric Consultant support

neonatal consultant care

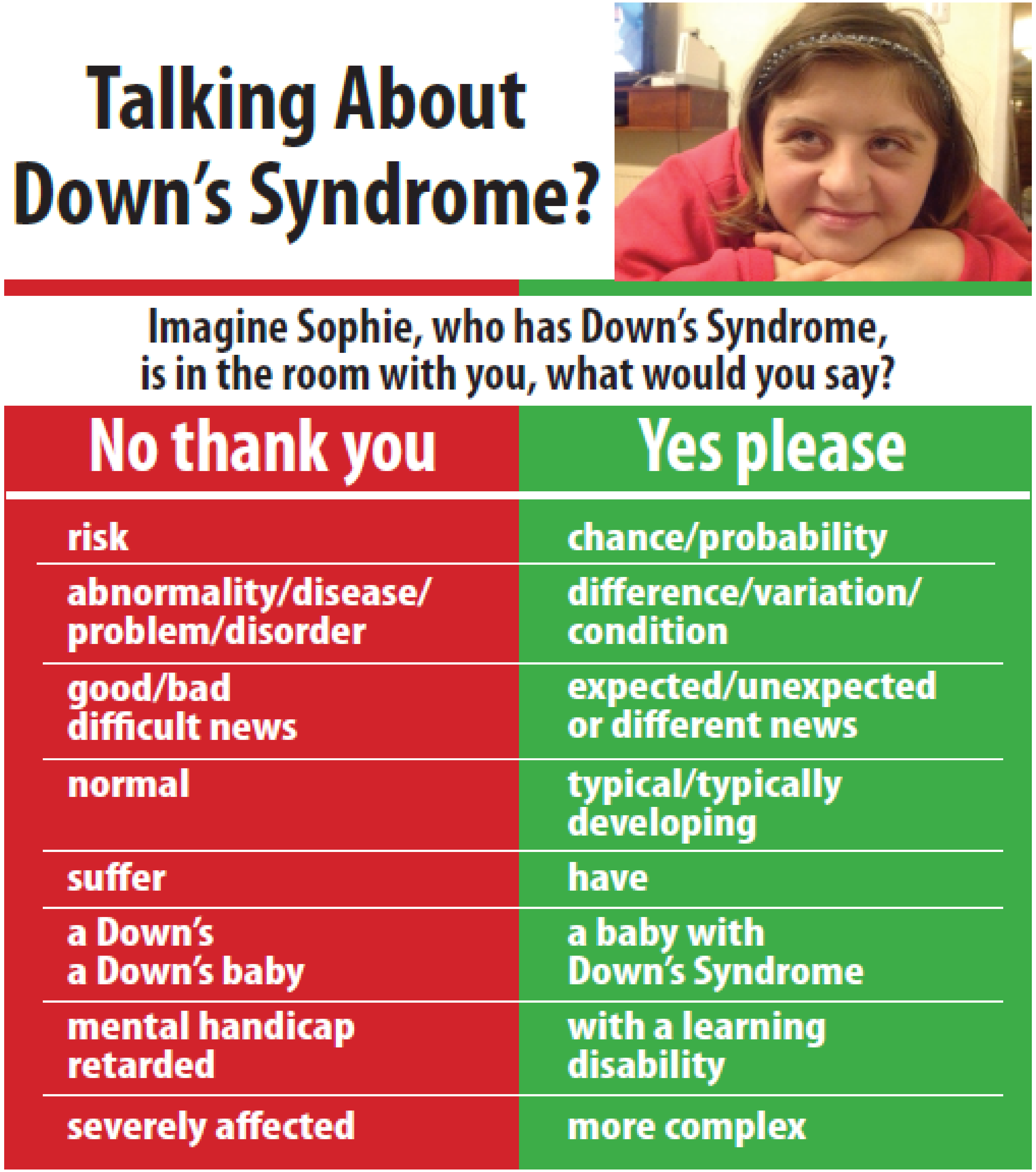
Gold Standard Pathway

Leanne Baister - Hartlepool Parent Carer Forum

Gold Standard Pathway DOES NOT imply this is something remarkable or additional. It simply is a summary of expected provisions and services that are being consistently provided and needs met. It is not a fragmented pathway but a seamless pathway.

Hull Gold Standard Pathway Key points:

*Clear and concise pathway that is easy to follow.
*Key information provided that explains roles of professionals.
*Key areas of DS highlighted with explanation of what support is required and by who.
*Appropriate forms in red book that are DS specific such as centile charts and checks.
*Language used is appropriate 'chance' used not 'risk'. Importance of the use of language.
*Links to additional support that can be referred to 'Down Right Special Charity' provides support prior to birth in areas such as play sessions to meet other parents, closely work with key professionals, offer new born baby packs and information, early years support, neonatal support, support in health, education, social and information.
*DS health visitor champion introduced from birth
*Referral to portage
*Referral to Down Syndrome Medical Interest Group
*Referrals done to all appropriate services and professionals from birth
*Early intervention
*Reference to Disability Living Allowance
*SEN strategy implemented
*From age 14 health checks with GP, health booklets given, health action plan
*Access to a DS Dementia Clinic with relevant professionals.
*Down Syndrome Champions

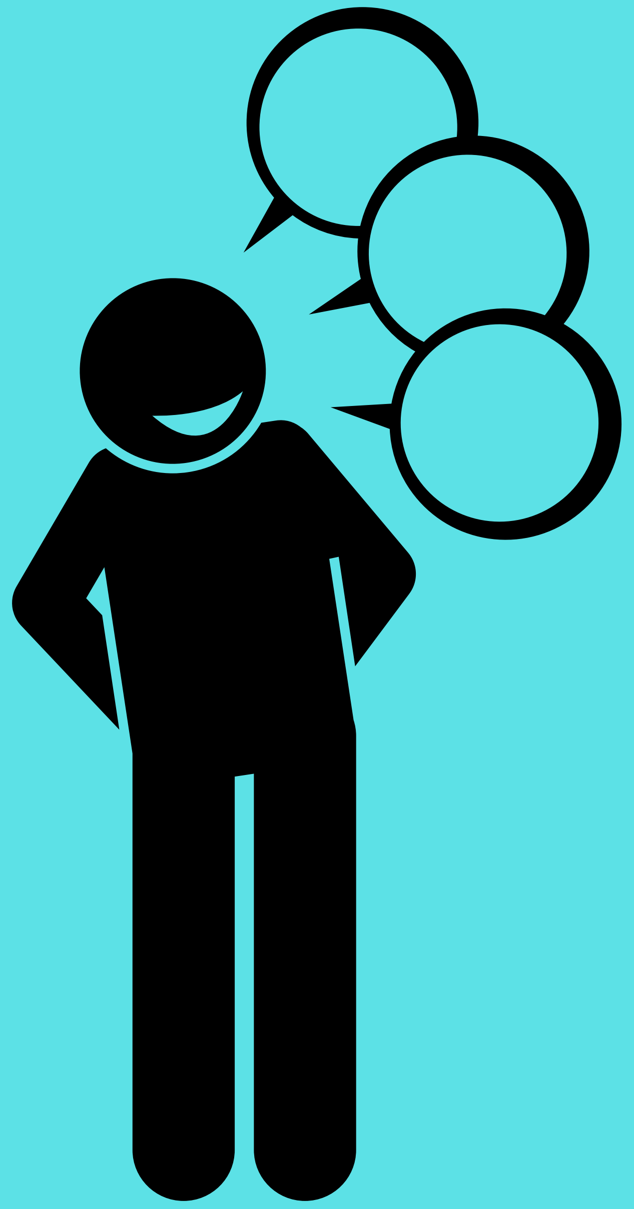


Talking About Down's Syndrome?

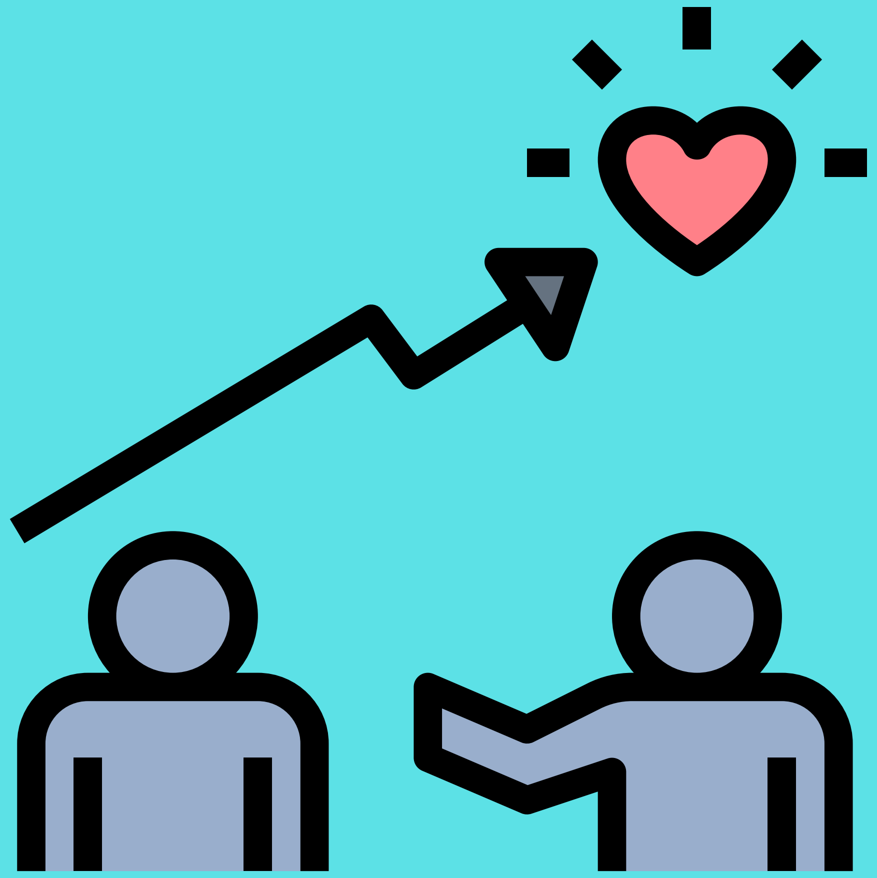
Imagine Sophie, who has Down's Syndrome, is in the room with you, what would you say?

No thank you	Yes please
risk	chance/probability
abnormality/disease/ problem/disorder	difference/variation/ condition
good/bad difficult news	expected/unexpected or different news
normal	typical/typically developing
suffer	have
a Down's a Down's baby	a baby with Down's Syndrome
mental handicap retarded	with a learning disability
severely affected	more complex

LANGUAGE MATTERS!

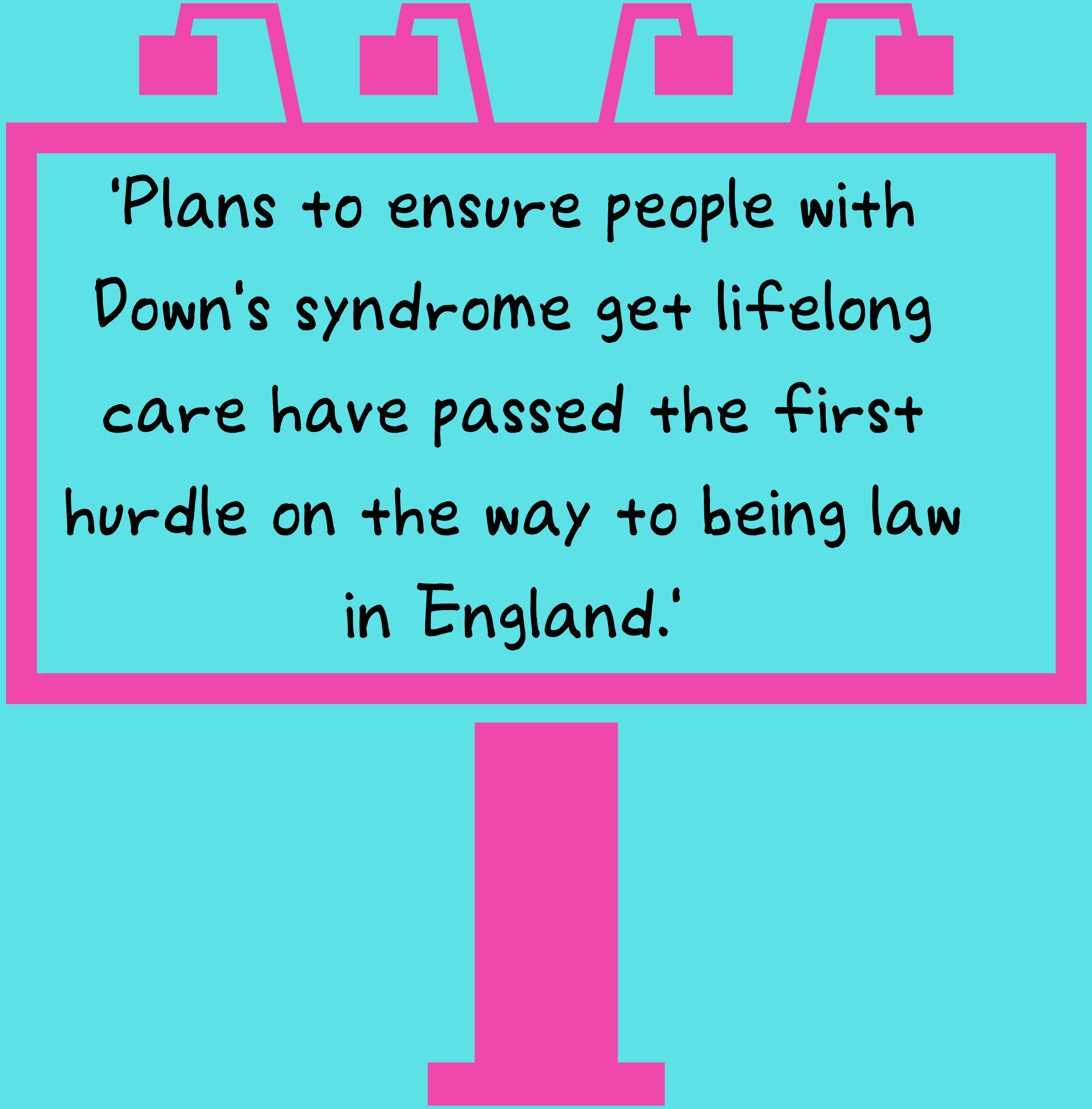


Policy & Key Agenda



Rose Payne - Stockton Parent Carer Forum

It's time for change!



'Plans to ensure people with Down's syndrome get lifelong care have passed the first hurdle on the way to being law in England.'

Why do we need The Down Syndrome Bill?

Increased rates of stillbirth

Lack of support during pregnancy and for new parents

Limited specialist training about Down syndrome available to professionals

'Postcode lottery' for therapies

Only 5.6% of adults with a learning disability are in paid employment

Longer & more frequent hospital stays

Life expectancy remains 28 years below general population

Just £5 per person with Down syndrome is spent on research

"At the moment in the UK, babies can be aborted right up to birth if they are considered to be "seriously handicapped". They include me in that definition of being seriously handicapped – just because I have an extra chromosome! Can you believe that?

What it says to me is that my life just isn't as valuable as others, and I don't think that's right. I think it's downright discrimination!

The United Nations Committee on the Rights of Persons with Disabilities recently said that the United Kingdom should change its abortion law to make sure that people like me aren't singled out because of our disabilities.

Sadly, the Government decided to ignore their recommendations and didn't change the law. So now, I am going to take the Government to court with other members of the Down's syndrome community to make sure that people aren't treated differently because of their disabilities."

Q&A Session

So, why are we doing this????

Well, here is why.........

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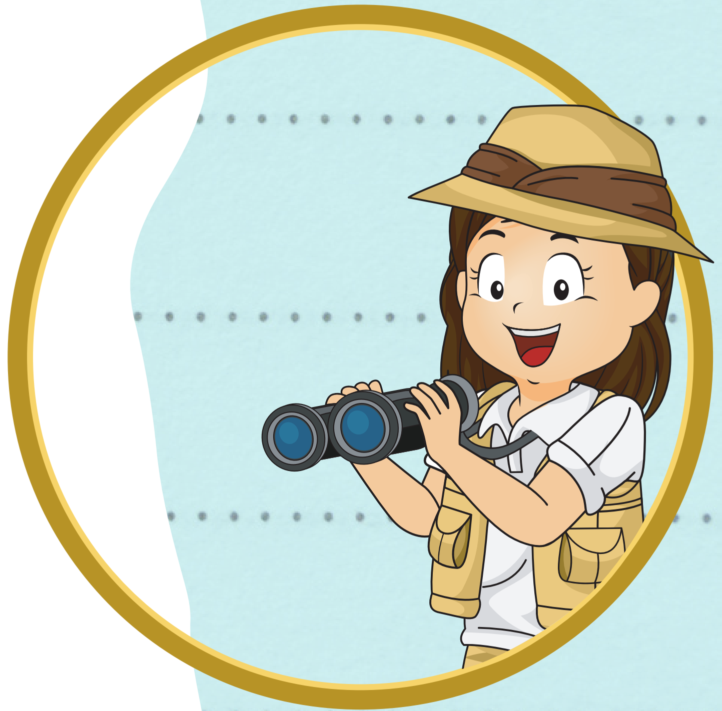

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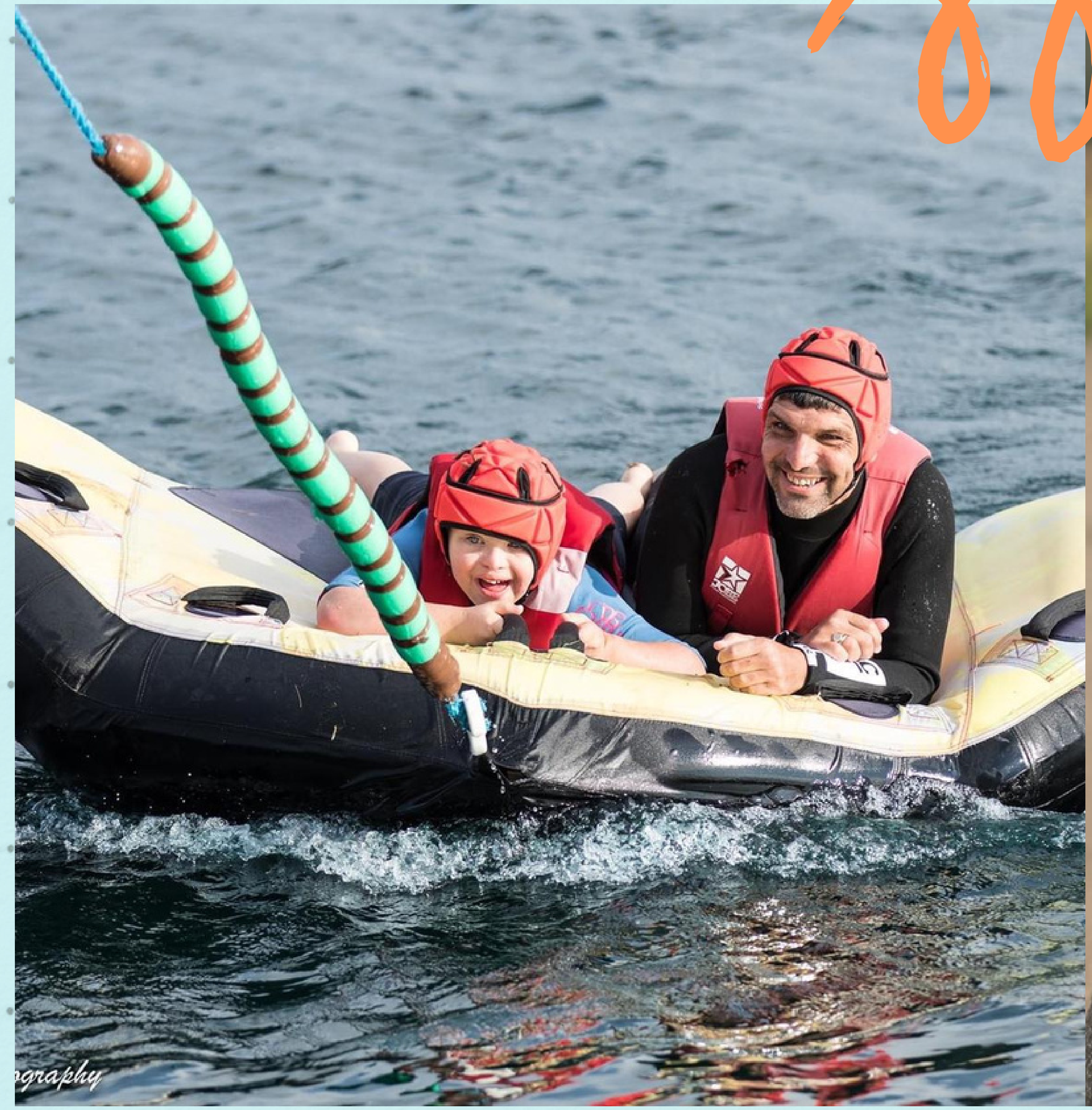

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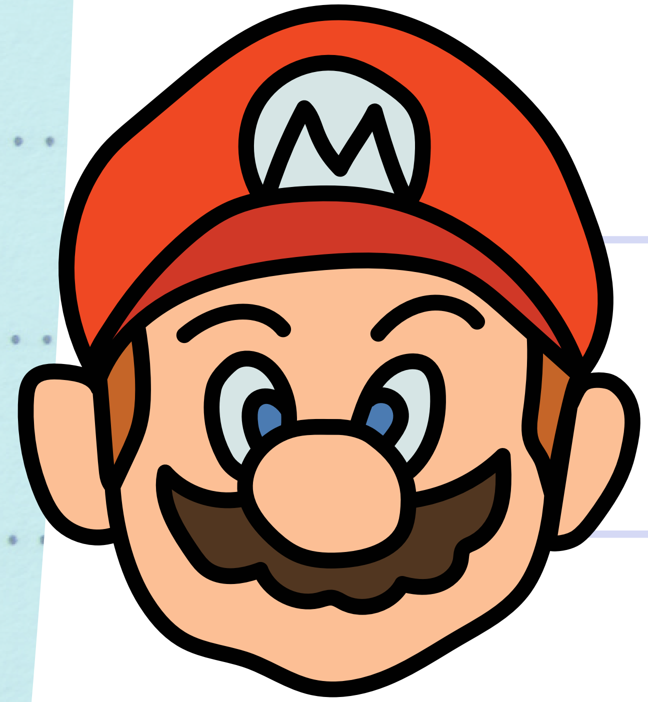

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What Happens Next?

NEXT

NEXT

NEXT

NHS

Hartlepool and
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THANK YOU

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