

# ComPASS

Supporting Carers of Autistic Children  
Throughout the Assessment Journey



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Current  
system

02

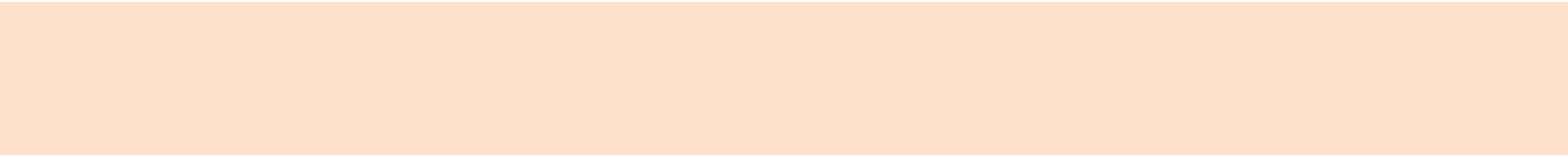


Opportunities  
& Insights

03



Intervention:  
ComPASS



# Autism is...

a spectrum condition and affects people in different ways.

It affects how they communicate, experience and interact.

*\*INFORMATION SOURCE: NATIONAL AUTISTIC SOCIETY*

There are 700,000 autistic people in the UK, that's

If you include their carers, autism is part of daily life for

more than

**1 in 100**

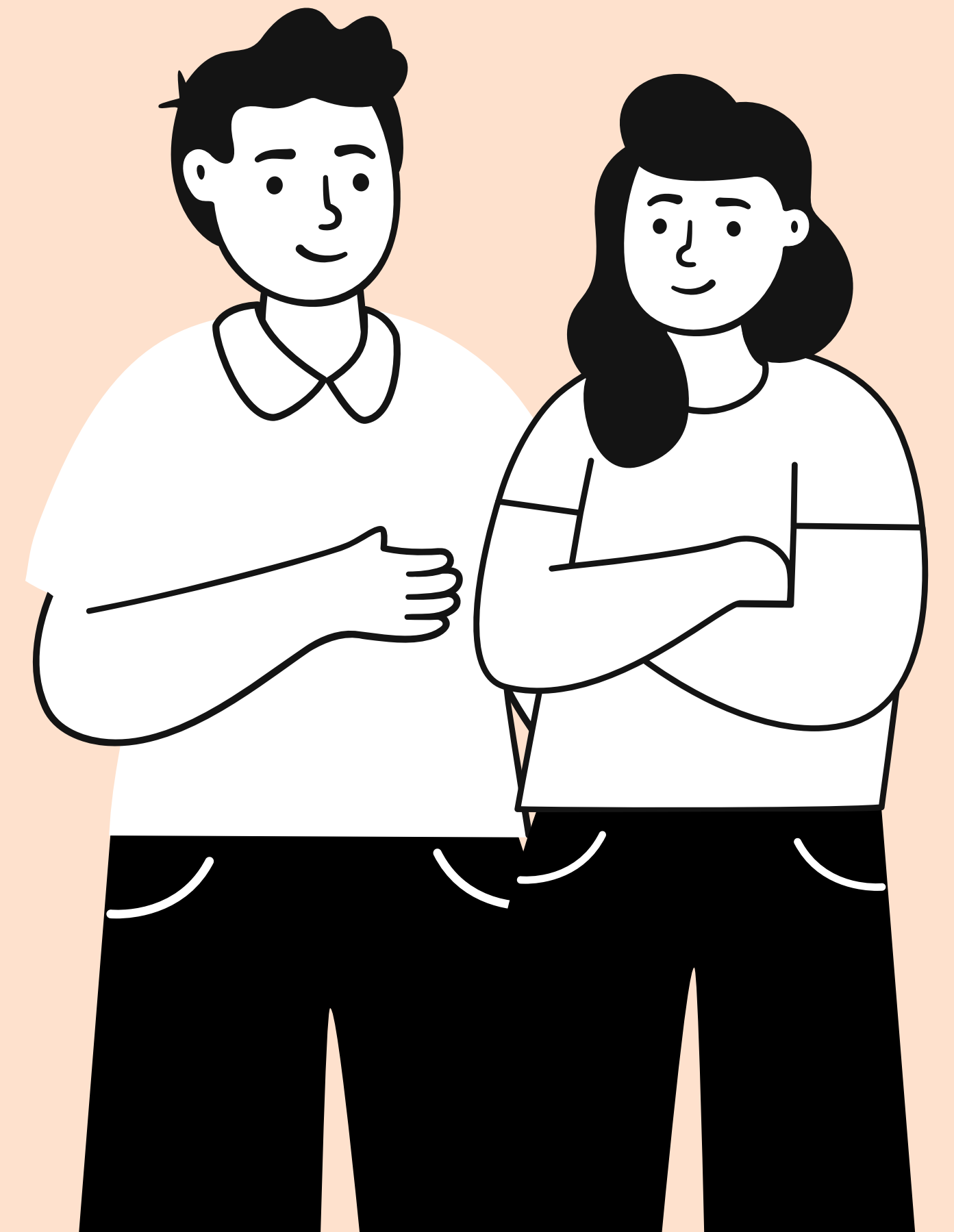
**2,800,000**  
people

*\*DATA SOURCE: BEYOND AUTISM*

# Cares are...

**family members, friends, or dedicated individuals**

who often have to navigate a complex system of services and supports, while also managing their own emotional and practical needs



# Research

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Carers

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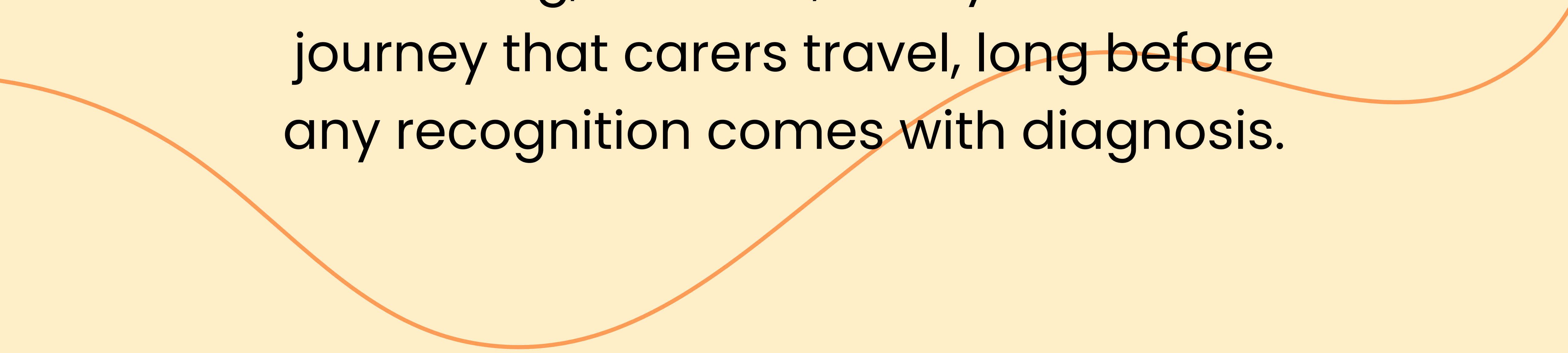
Professionals

1

Organisations

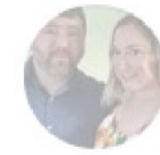
8

Facebook Groups



It is a long, arduous, lonely and silent journey that carers travel, long before any recognition comes with diagnosis.

People and their  
carers seek autism  
assessments for  
**various reasons...**



Cheryl Louise Eady

Its a double edged sword it affords him legal protection in terms of managing his needs as he gets older and can help him understanding his brain better. But it also brings challenges as certain careers will automatically be off limits, he may be looked ar as different . But to be honest to make his teen and early adult hood easier its not enough to just self diagnose you will need that piece of paper to advocate for access to services . He wont be 6 forever and getting the diagnosis now makes getting support easier



Emma Hesperus 🙋

Schools will only change things with an official diagnosis. You might need different exam things put in place for SATs and GCSEs. Now is a good age to start as the waiting list is 18-24 months.

*\*INFORMATION SOURCE: FACEBOOK GROUP*

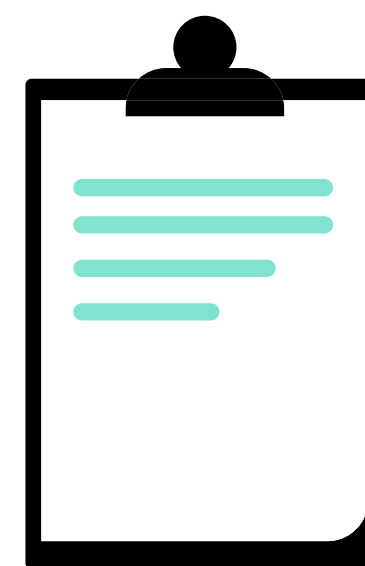


# Autism assessment unlock support...



## Legal document

A proof for requesting special education service, disability accommodation and government allowance



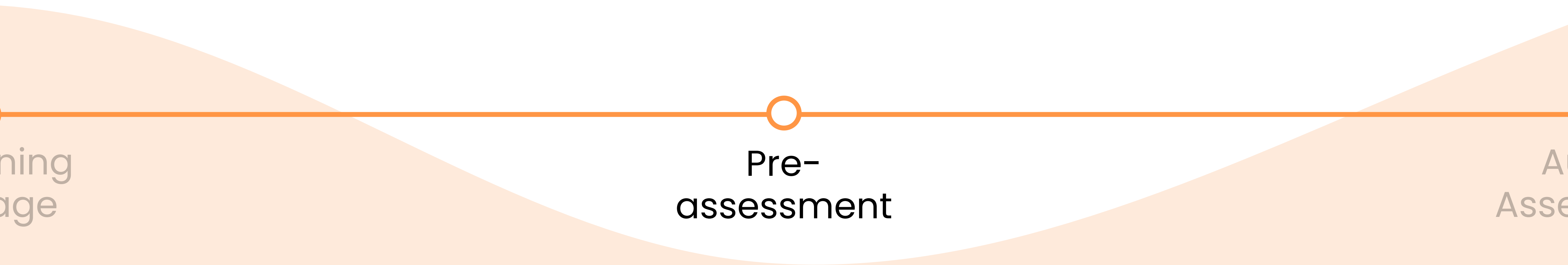
## Guidance

A framework for schools, communities and medical institutions to offer specialised support

# Assessment journey



# Assessment journey



Pre-  
assessment

ning  
age

A  
ASSE

Children aged 5-11  
are **too young to  
advocate for  
themselves...**



Child



Child



Carers

Carer exert greater effort to **navigate the complex system** and **advocate for their child...**

# Navigate the medical system



Carers



Health Service

# For carers...



**Becca Liz**

28 July 2021 · 🌐



Hi all,

I'm feeling really let down and fed up today.

My daughter has been on the NHS waiting list for assessment for 3 years. There is no end in sight so we were referred to Healios for assessment with them. Paid for by the NHS.



**Mandy Smith**

6 May at 12:30 · 🌐



Question regarding pathway.

I got a phone call booking me in for the second meeting with paediatrician....

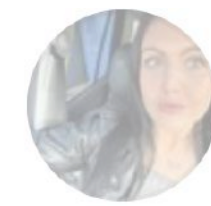
The next day I got another phone call for the next stage of the assessment.

According to the lady on the phone on the second day, the first appointment is just a follow up face to face meeting. ( nearly 11 months ago!)

What's discussed in this meeting? I'm actually very confused as I assumed it was the next step... any advise would be much appreciated x 💙

*\*INFORMATION SOURCE: FACEBOOK GROUP*

# For carers...



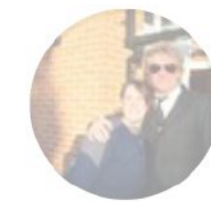
Amiee Louise White

27 January 2022 · 🌐



I was informed today that current wait for paediatricians in my area is 17-19 months just to see paediatrician then you go onto the autism assessment list which is currently 2.5-3 years

I cannot believe it will take me over 4 years to get my non verbal son assessed 😞



Sarah Jane Whitaker

4 February · 🌐



Having a thoughtful moment....

If there's a 4 year waiting list for our kids on the ASD pathway. What percentage of children have autism now? If it's such a massive number, why aren't things put into place by now? Why aren't all teachers ta's and staff trained fully by now? Why isn't there ASD schools? Support for siblings and families? Are we just living in a time of denial? Is it all just getting swept under the carpet by government because of the financial pressures? Where do we actually go from here? How can we change this and make it better?

Maybe best not to think too much? 😞😞🙏

*\*INFORMATION SOURCE: FACEBOOK GROUP*




# For health service...



The screenshot shows the top navigation bar of the NHS website. On the left is the NHS 75 England logo. In the center is a search input field. On the right is a 'Search' button.

Date published: 5 April, 2023  
Date last updated: 4 May, 2023

 Download as a PDF

[Integrated care](#), [Learning disabilities and autism](#)

## A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards

### Foreword

Demand for autism assessments has risen rapidly over the past 20 years. Investment in autism assessment capacity has not kept pace with this growth; demand now far exceeds available capacity. Waiting lists for autism assessments across England have reached unsustainable levels. In July 2022, NHS Digital reported there were more than 125,000

\*INFORMATION SOURCE: NHS



# For health service...

Demand for autism assessments has risen rapidly over the past 20 years. Investment in autism assessment capacity has not kept pace with this growth; demand now far exceeds available capacity. Waiting lists for autism assessments across England have reached unsustainable levels. In July 2022, NHS Digital reported there were more than 125,000 people waiting for assessment by mental health services; an increase of 34% from October 2021 (1). These data show that most people wait longer, often much longer, than the three-months recommended in clinical guidelines for an autism assessment to begin (2) and the 18-week maximum waiting time for treatment to begin, as set out in the [NHS Constitution](#) (3). As demand continues to grow and capacity has remained stable or has dropped, the demand-capacity gap continues to widen.

In addition to long wait times, improvement in other areas of the autism assessment pathway is also needed. This includes improving the quality of information and support provided during and after assessment, increasing the ease and efficiency with which people transition through stages of the pathway and reducing people's uncertainty about the process. We know services are working extraordinarily hard to keep pace with rising demand, but on account of the demand-capacity gap, the ability to provide timely assessment and support for people is not often currently possible. Strategic action is needed.

\*INFORMATION SOURCE: NHS



What will be the next step to be taken?



Carers

Carers struggle to **navigate the complex medical system** alone...

We are working extraordinarily hard to keep pace with rising demand.



Health Service

# Advocate for support at school



Carers



School

# For carers...



**Mollie Baldwin**

23 November 2022 · 🌐



Has anyone gone for a private diagnostic assessment due to such long waiting lists? What are your thoughts? Was it worth it? My daughter is 5 and masks heavily at school. They basically don't believe me so she is getting no support there and then she explodes at home.



**Adele Marie**

10 January · 🌐



Why do school staff not seem to understand 'masking'? Do they call it something different ?  
They look at me as if im speaking another language when I mention it being something my daughter does as a coping strategy.

*\*INFORMATION SOURCE: FACEBOOK GROUP*

# For carers...



**Adele Marie**

10 January · 🌐



Why do school staff not seem to understand 'masking'? Do they call it something different ?

They look at me as if im speaking another language when I mention it being something my daughter does as a coping strategy.



**Hazel Holland**

5 November 2022 · 🌐



Not really sure why I'm writing this but I guess for me this was a huge reality check

Today i visited a potential school for my toddler he will be 4 in march and has asd, recently he was declined an ehcp which I wasnt sure what that meant for him, but after visiting the school I asked the head teacher what additional support my son could get without an ehcp and pretty much she said back that without one my son would get very little support or help as they wouldnt get funding for it which to be

*\*INFORMATION SOURCE: FACEBOOK GROUP*

# For schools...



[Joining the NEU](#) | [Get involved](#) | [More](#) 



[Home](#) > [SEND Crisis](#)

## SEND crisis

Despite increases, SEND funding faces a £2bn annual shortfall. This means inadequate provision, children educated in inappropriate settings, and over 1,000 children not receiving any education at all.

The Government is failing children with special educational needs and disabilities. Without adequate high needs funding, thousands of children are losing out on a proper education and the

\*INFORMATION SOURCE: NATIONAL EDUCATION UNION



# For schools...

The Government is failing children with special educational needs and disabilities. Without adequate high needs funding, thousands of children are losing out on a proper education and the support they need to learn.

There are now 390,109 pupils and students with an Education Health and Care Plan (EHCP), an increase of 10 per cent on 2019 and 62 per cent on 2015. This is far more than anyone anticipated. Because the system cannot cope with the increased number of pupils with EHCPs, greater numbers are being educated in inappropriate settings. In the past year there has been a 15 per cent rise in the number of pupils with EHCPs attending independent schools, which are not independent special schools. There has also been a 17 per cent rise in the number of pupils with EHCPs in Pupil Referral Units (PRUs). In the worst case, children are not receiving any provision at all - 1,260 pupils are of compulsory school age and not in education.

\*INFORMATION SOURCE: NATIONAL EDUCATION UNION





# For schools...

As a result of member feedback, the NEU has called for:

- Adequate and dedicated funding for the timely educational provision of children and young people with Special Needs and Disabilities. The SEND funding shortfall must be urgently addressed. All children have the right to access appropriate education.
- Reduction in unnecessary and excessive workload for teachers working with children and young people with additional needs. Members highlighted the time consuming and often admin driven aspects of their working day, which keeps them from working directly with young people who need their specialist skills.
- Greater consideration of the impact of mid-year movements of children with EHCPs on a school's budget. Schools are not offered adequate and timely financial support to address unexpected provision for children who arrive after the start of the academic year. Schools should not have to simply "find the money" from elsewhere in an already over-stretched system.

\*INFORMATION SOURCE: NATIONAL EDUCATION UNION





Carers

School does not believe me, so my little one is not receiving any support.

Carers find it hard to **advocate necessary help at school...**

Special needs is beyond crisis in schools, it's sucking the money from budgets!



School



Too young to advocate

SEND funding crisis



**Pre-assessment support is crucial**



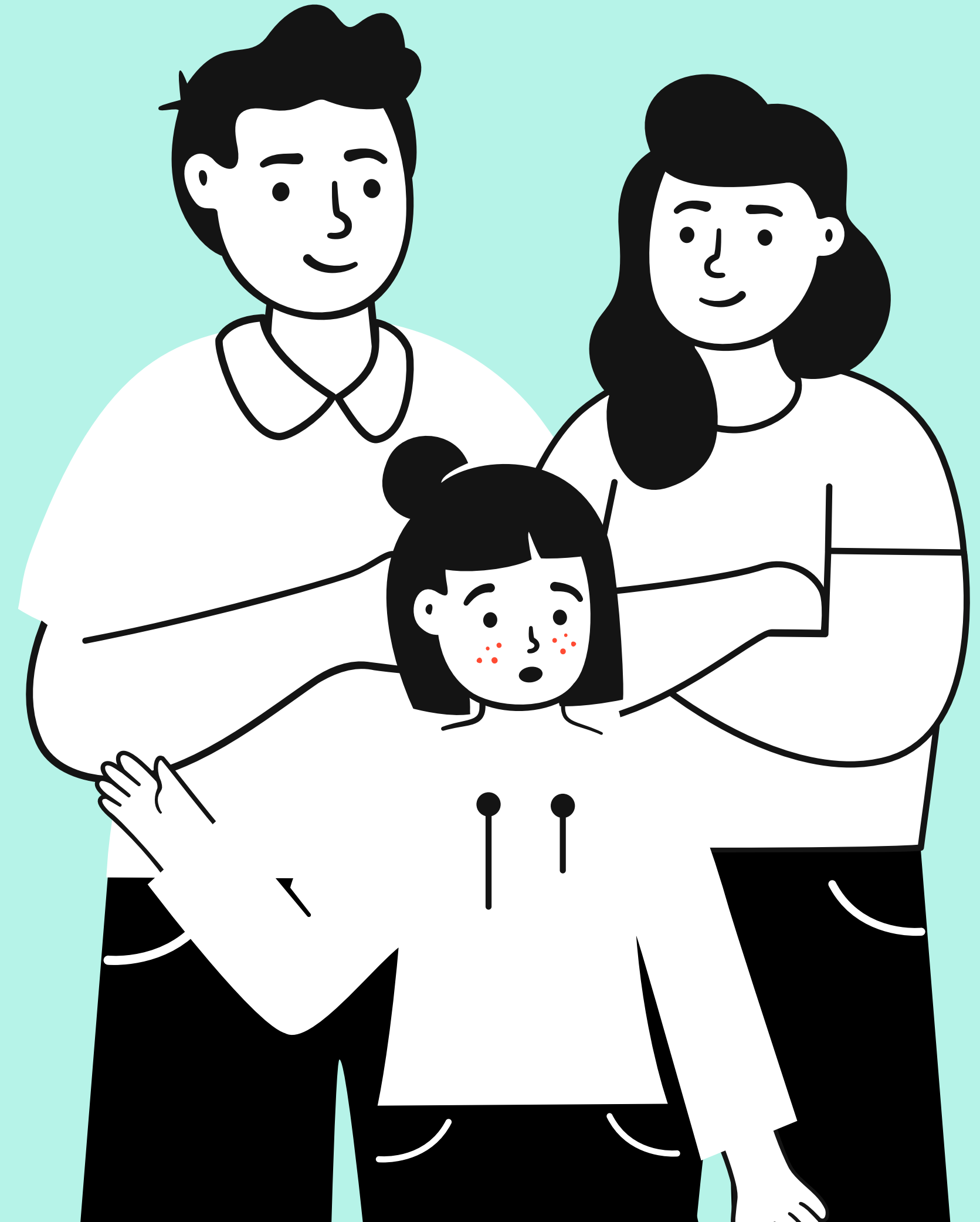
Unsupported

Demand capacity gap



# How might we

provide autistic children and their carers with the **pre-assessment support** they need to navigate the complex system and advocate for support with ease?





# ComPASS

A comprehensive support platform that empowers carers, schools and health service to collaborate effectively and support children with special needs.

# ComPASS

01

## Navigation

Reduce uncertainty and provide a sense of agency

02

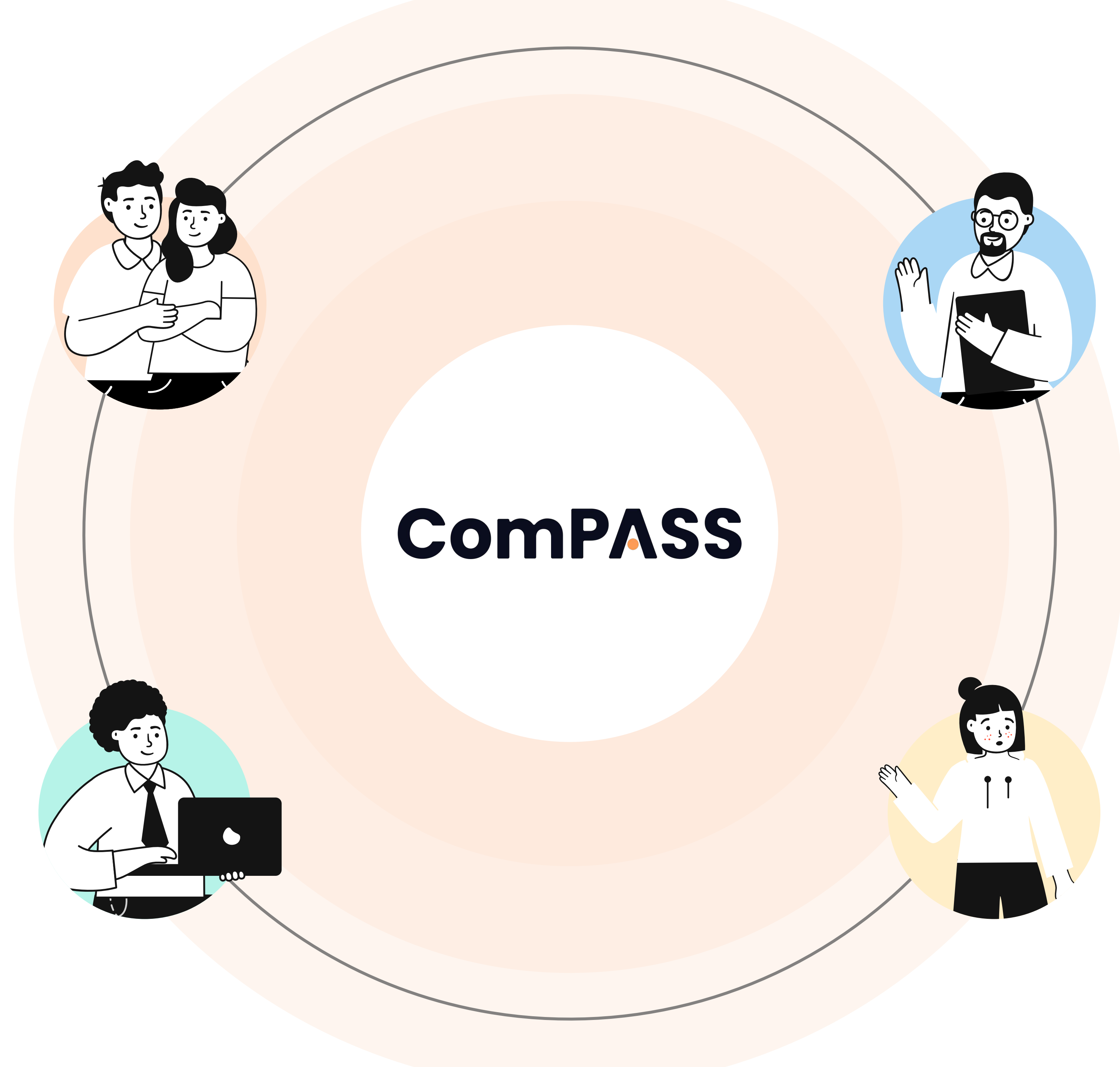
## Communication

Streamlining communication between stakeholders

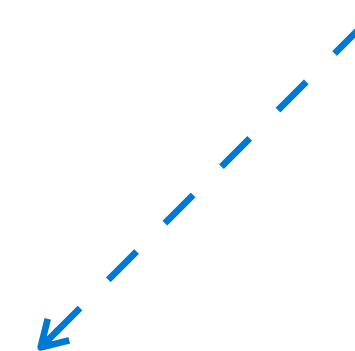
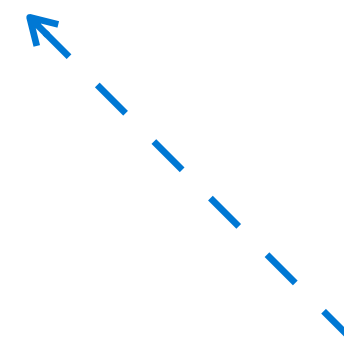
03

## Synchronisation

Timely information sharing and ensure effective support



**Carers**  
benefit from...



**ComPASS**



Carers  
benefit from...



**ComPASS**



Carers  
benefit from...



**ComPASS**



Carers  
benefit from...



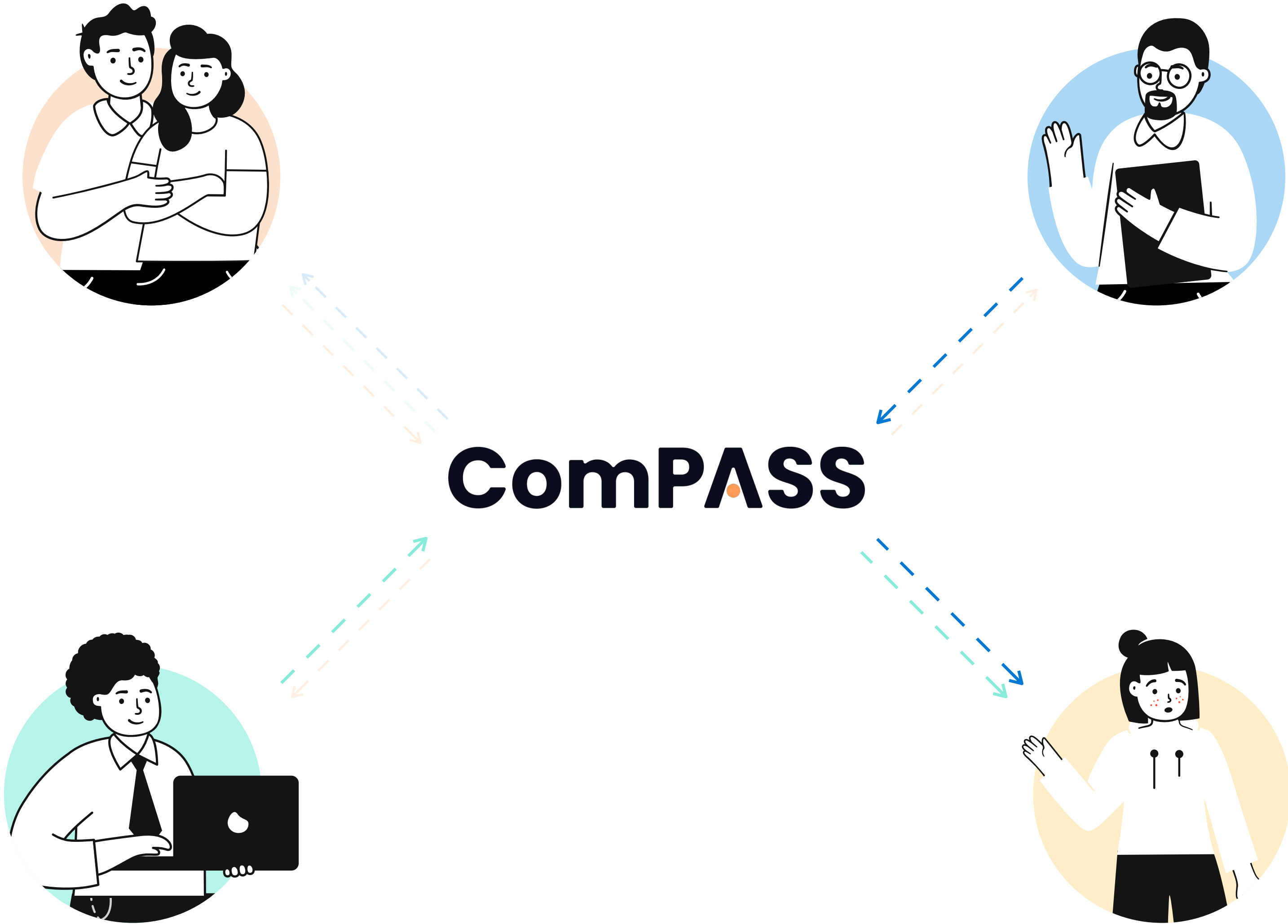
**ComPASS**



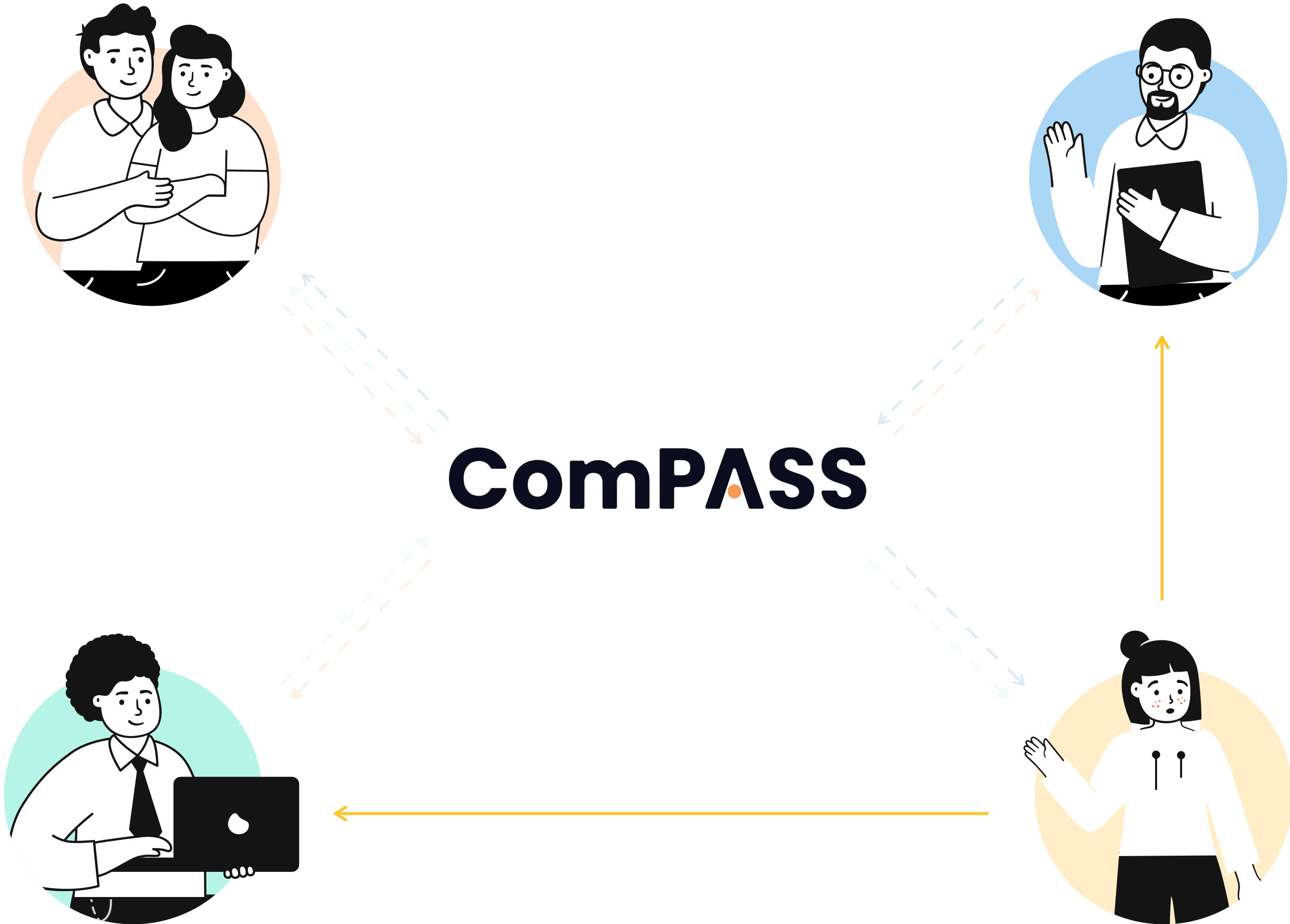
# Carers

can have increased confidence in navigating the system and advocating for their child.

Children  
benefit from...



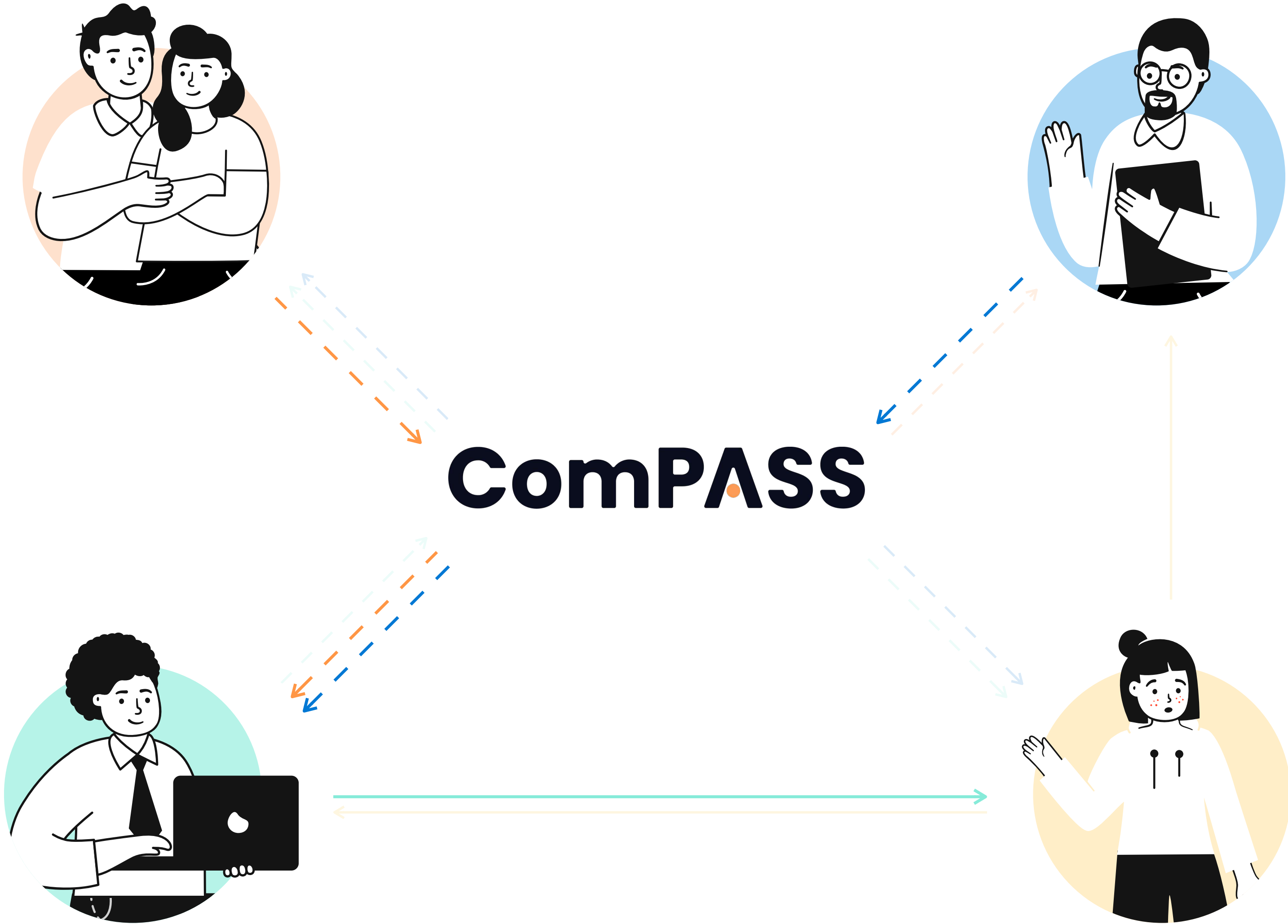
Children  
benefit from...



# Children

can have a greater chance for learning and progress, ultimately developing to their full potential.

Schools  
benefit from...

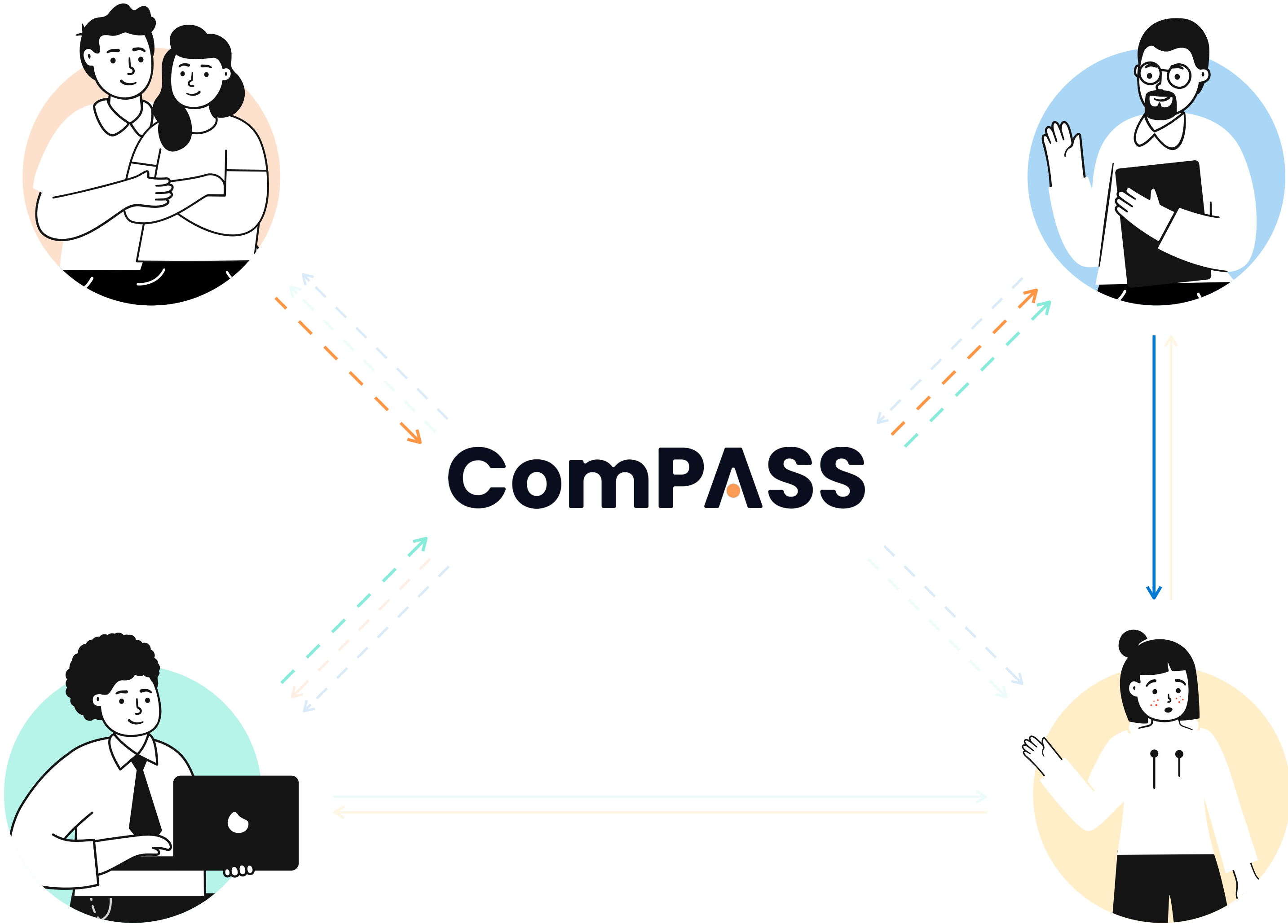




# Schools

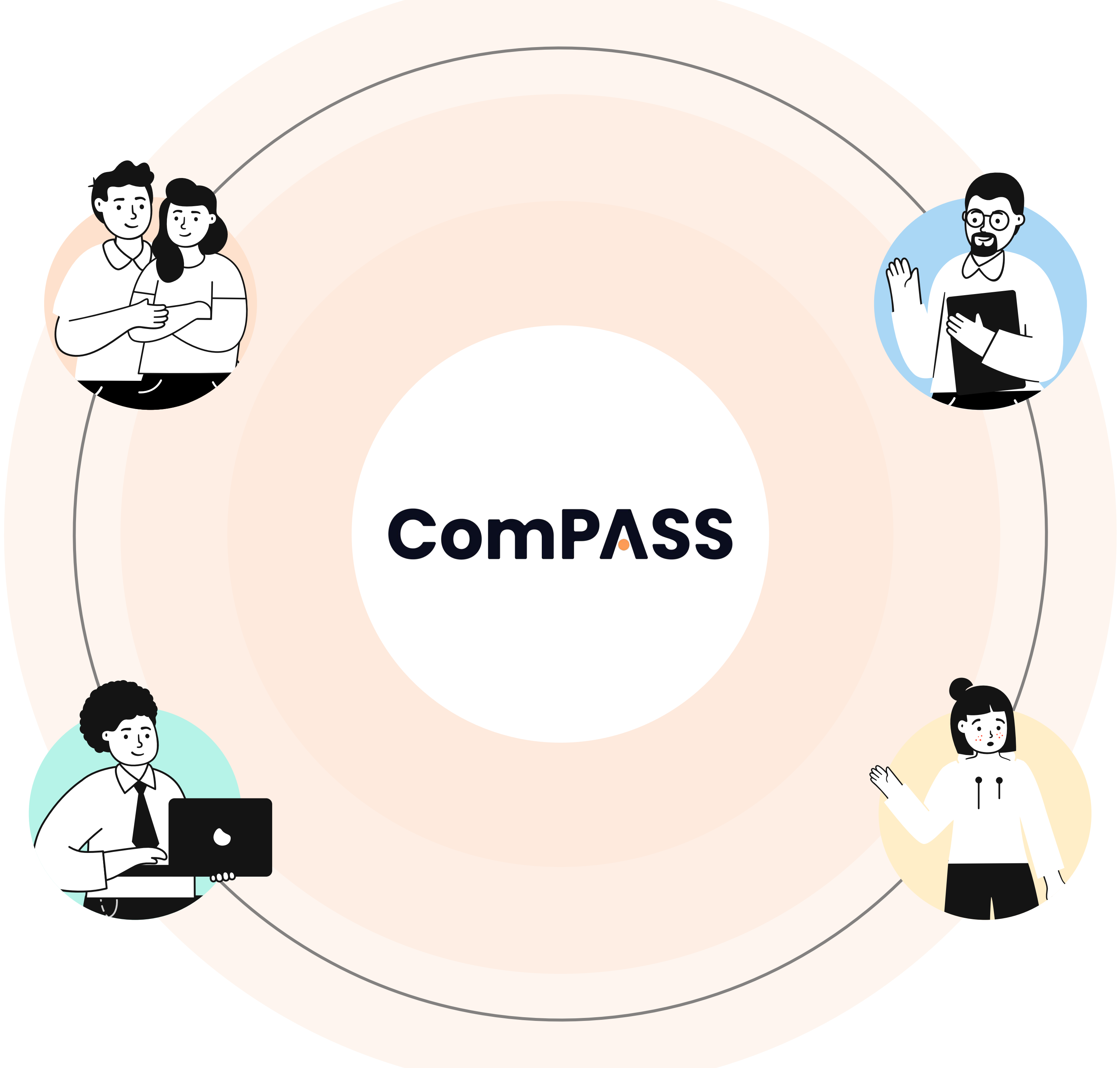
can be empowered to provide effective support,  
ultimately leading to better outcomes for these students.

Health  
Service  
benefit from...



# Health Service

can improve work efficiency, speed up the assessment process and bridge the demand-capacity gap.



# With carers, schools and health service...



## Autism Family Support

Last active 2 minutes ago



## Autism Support Group

Last active 3 hours ago



## Autism parents support group in United Kingdom

Last active 8 hours ago



## London Autism Group

Last active about an hour ago



## Autism Parents Support Group

Last active 10 minutes ago



## UK Autism Spectrum Parents Support Group

Last active 2 minutes ago

# With carers

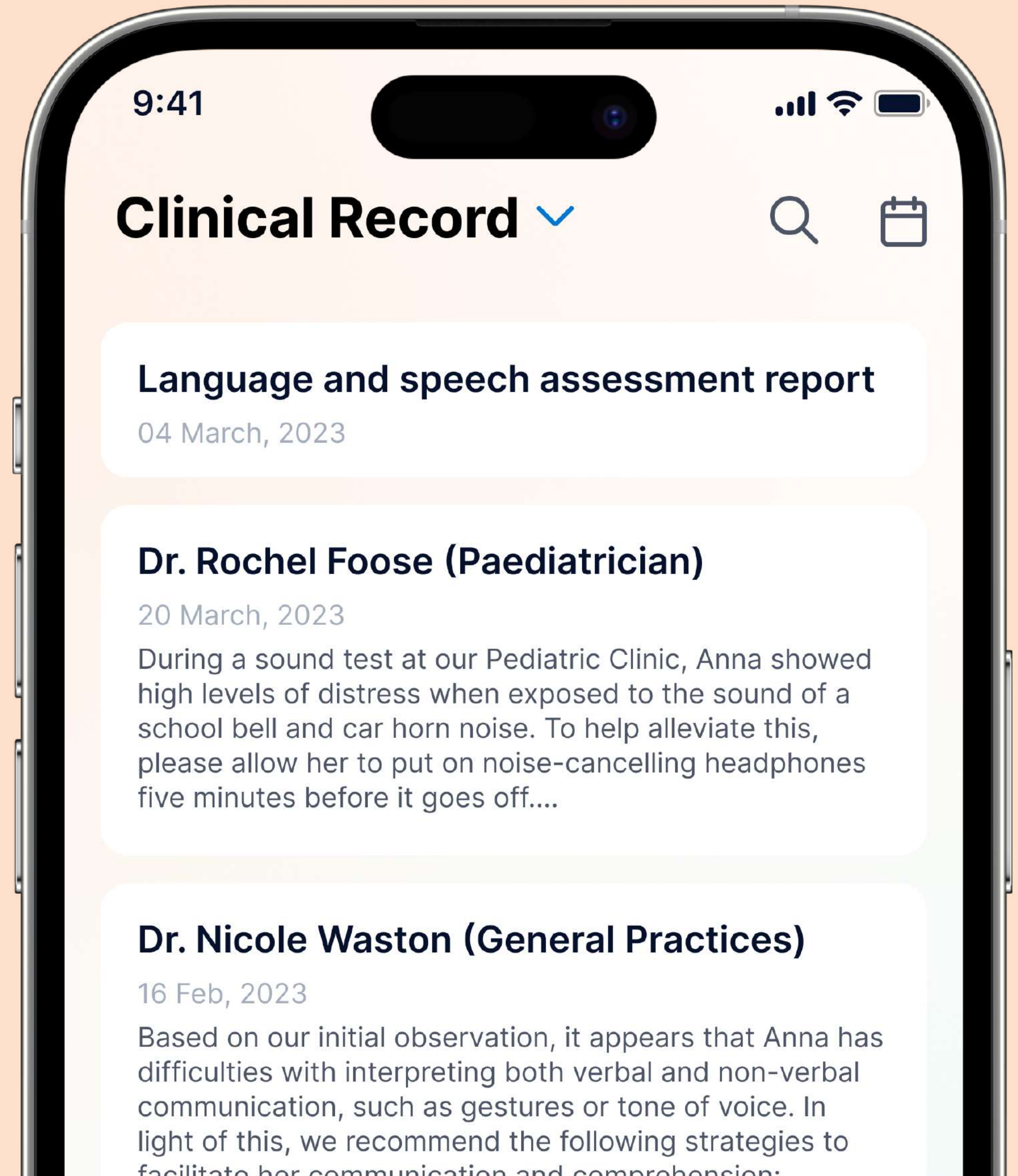
"It is a good idea to have a space to keep a journal of your child's strength and needs! Because in appointments and meetings I always forget to mention important information."

*\*FEEDBACKS FROM FACEBOOK GROUPS*



# With carers

“Definitely having a log from clinicians of everything they did, everything they offered and what they said - vital for evidence.”

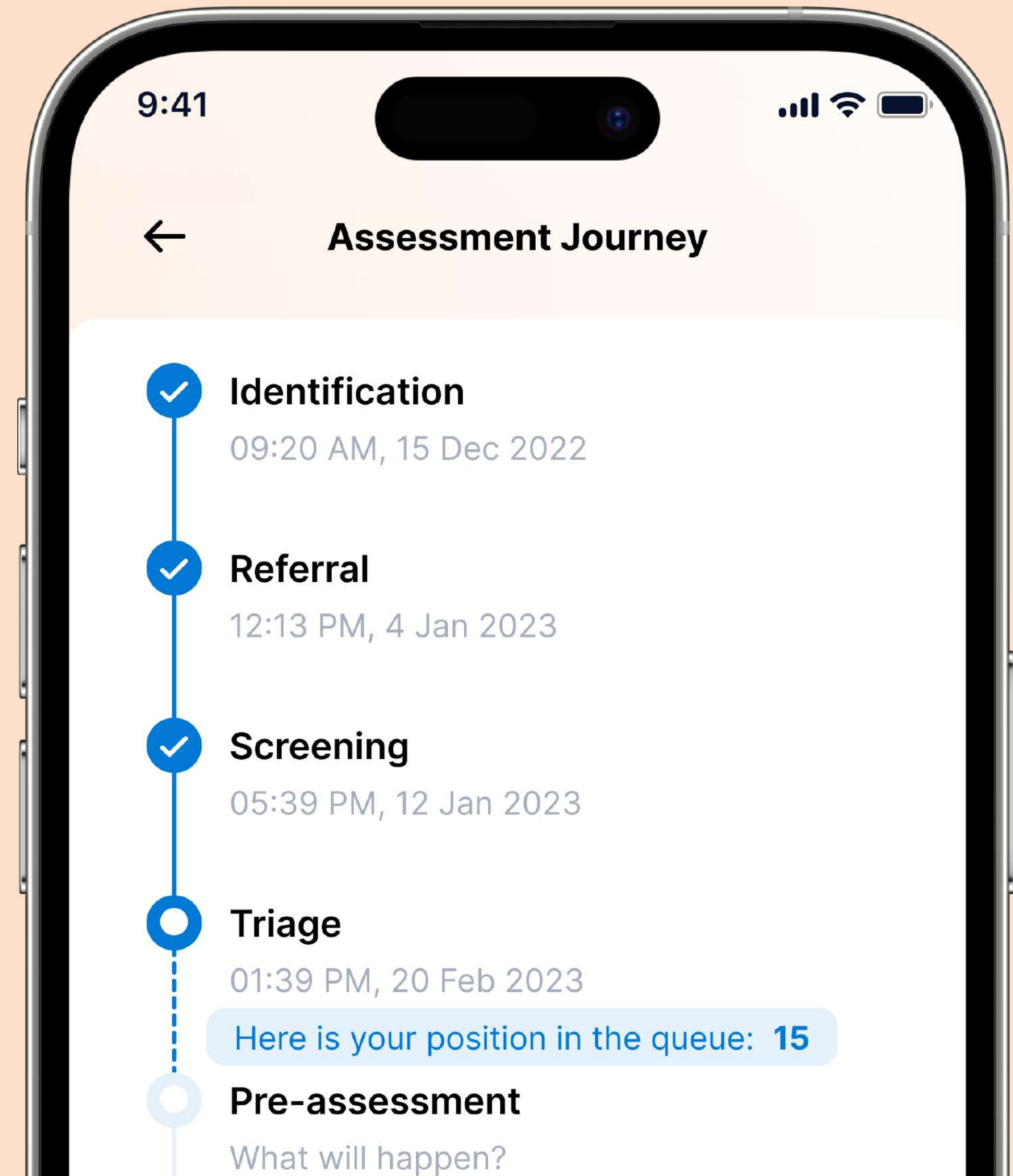


*\*FEEDBACKS FROM FACEBOOK GROUPS*

# With carers

“Great to have like a kind of visual representation of a timeline or a journey, so that I can see what I need to go through to get the outcome, know where I’m at on the on the journey and how to get to the next step.”

*\*FEEDBACKS FROM INTERVIEW*

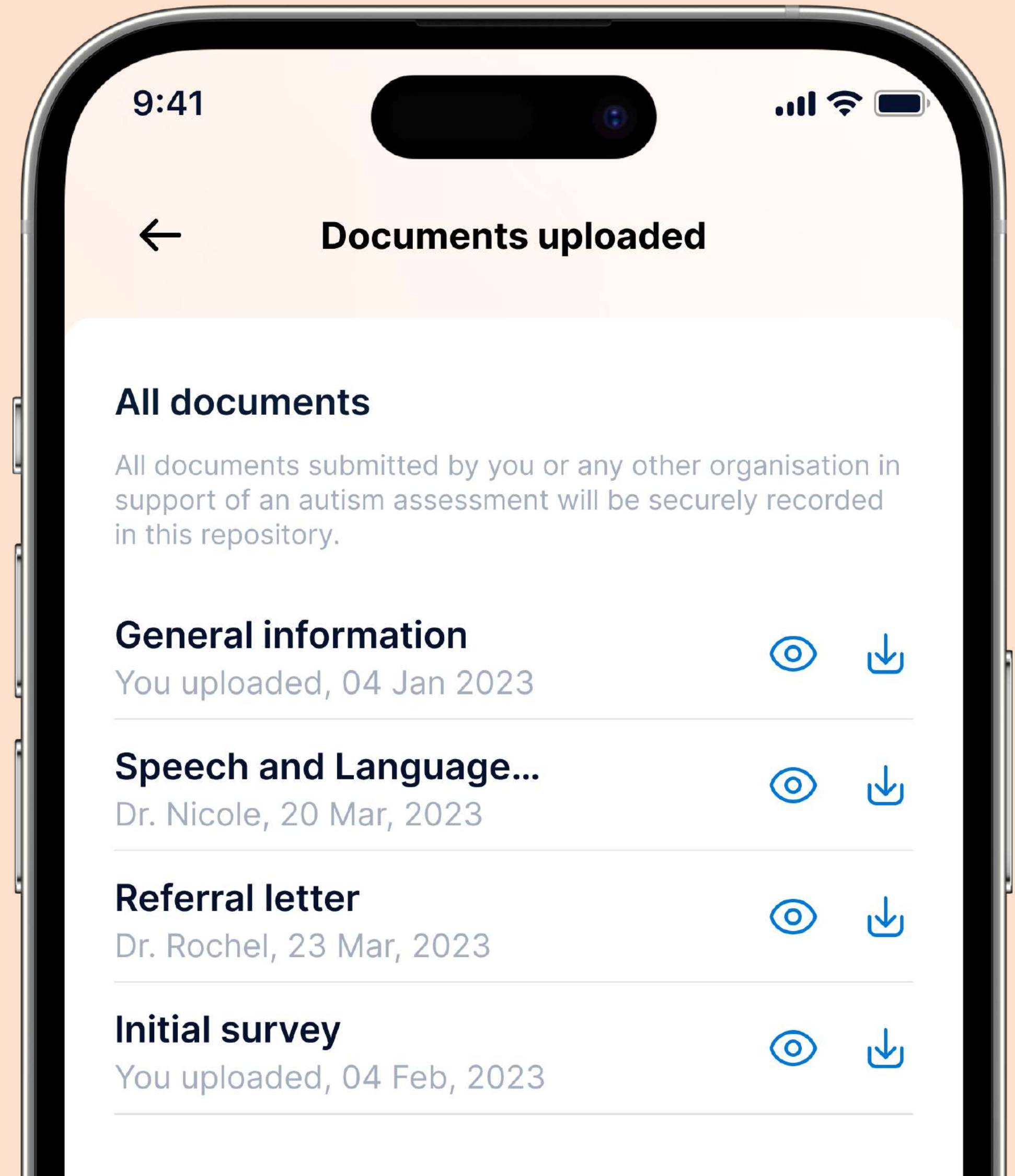




# With carers

“Yes, a big part of the journey is trying to tie in all the different assessments and reports from school, occupational therapy, speech and language therapy, and presenting it to the local authority for an EHCP assessment.”

*\*FEEDBACKS FROM INTERVIEW*

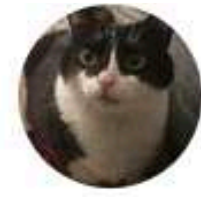


# With school



## SENCO Network

Facebook group



**Adriana Vittoria**

20 May at 22:48 · 🌐



Hi all, hive mind needed. I've got a little year 6 who was greater depth in autumn and spring. Mum has recently had a baby and new partner is present. He has gone from being a really confident child to full blown emotional regression. He breaks down in class (it sounds like a toddler crying away), talking in a infant like voice, reacts only when spoken to and treated like a much younger child. Does anyone have experience of this and have strategies we can put in place to support him before we transition him to secondary? Any ideas or resources welcome.



**Samantha Carney**

I'd agree with Simone. Sounds to me like the child has experienced, is experiencing, what for them is a traumatic experience - change, change... and they need help working out what their new life is, how to make it secure and predictable.... Add to the per... **See more**



**Simone Godwin**

My now teen did this in year 2 when moving up to Juniors then again from year 5. They finally got diagnosed as Autistic when they were 14. The regression was due to being so stressed they couldn't mask.

VALIDATION

# With school



## SENCO Network

Facebook group

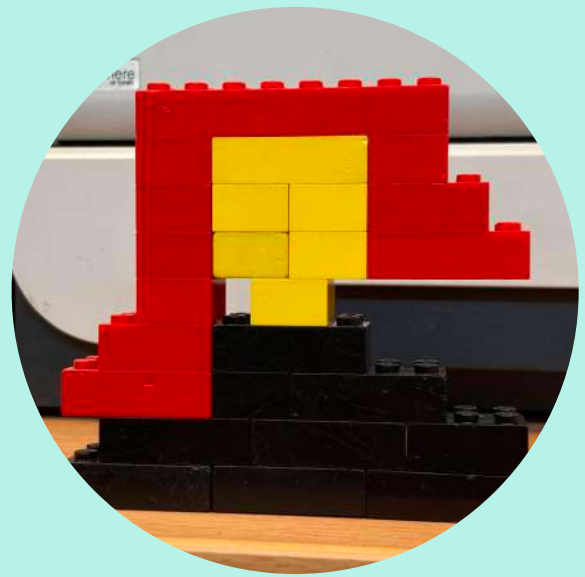
06

A screenshot of a web application titled "SEN Dashboard" on a tablet. The browser address bar shows "compass.ac.uk/sendashboard". The interface is divided into several sections:

- My students:** A list of three students: Anna Adams (Year 1), Simon Varnes (Year 1), and Jordan Smith (Year 3).
- Tasks:** A list of four tasks:
  - Observation Checklist (Mar 2023) by Jordan Smith: "This is a quarterly check to monitor Anna's behavior..."
  - Observation Checklist (Mar 2023) by Jane Cooper: "This is a quarterly check to monitor Anna's behavior..."
  - Form Submission for Assessment by Nadia Varnes: "This is a quarterly check to monitor Anna's behavior..."
  - Observation Checklist (Dec 2022) by Anna Adams: "This is a quarterly check to monitor Anna's behavior..."
- Anna Adams Profile:** Located at the top right, showing "ASD Year 1" and contact icons for phone, email, and location.
- Key Features:** Two boxes below the profile: "Daily Check-in" (Mark down something special from today!) and "Individual Support Plan" (Unlock the potential of every student!).
- Carer Note:** A section with tabs for "Carer Note", "Assessment Journey", and "Clinical Record". It contains two entries:
  - Julia Adams (Anna's Mother):** Dated 20 Mar, 2023. Title: "Sensory tent 🏠". Text: "If Anna behaves in a destructive manner at school, such as throwing toys, breaking them, screaming, shouting, or drawing on everything, please give her some space in a compact area, such as this tent. This will help her calm down and process her emotions before she speaks with you." Includes a photo of a white teepee tent.
  - Steve Adams (Anna's Father):** Dated 10 Jan, 2023. Title: "Ear defenders". Text: "We conducted a sound test at the pediatric clinic today and found that Anna showed high levels of..."

VALIDATION

# With school



Hannah Cresswell

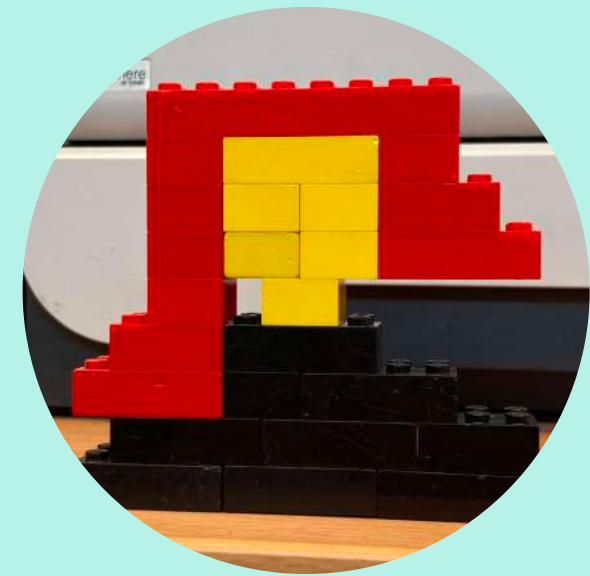
SENCO

06

“As a SENCO I know how challenging it can be deciding how best to speak to parents...”

VALIDATION

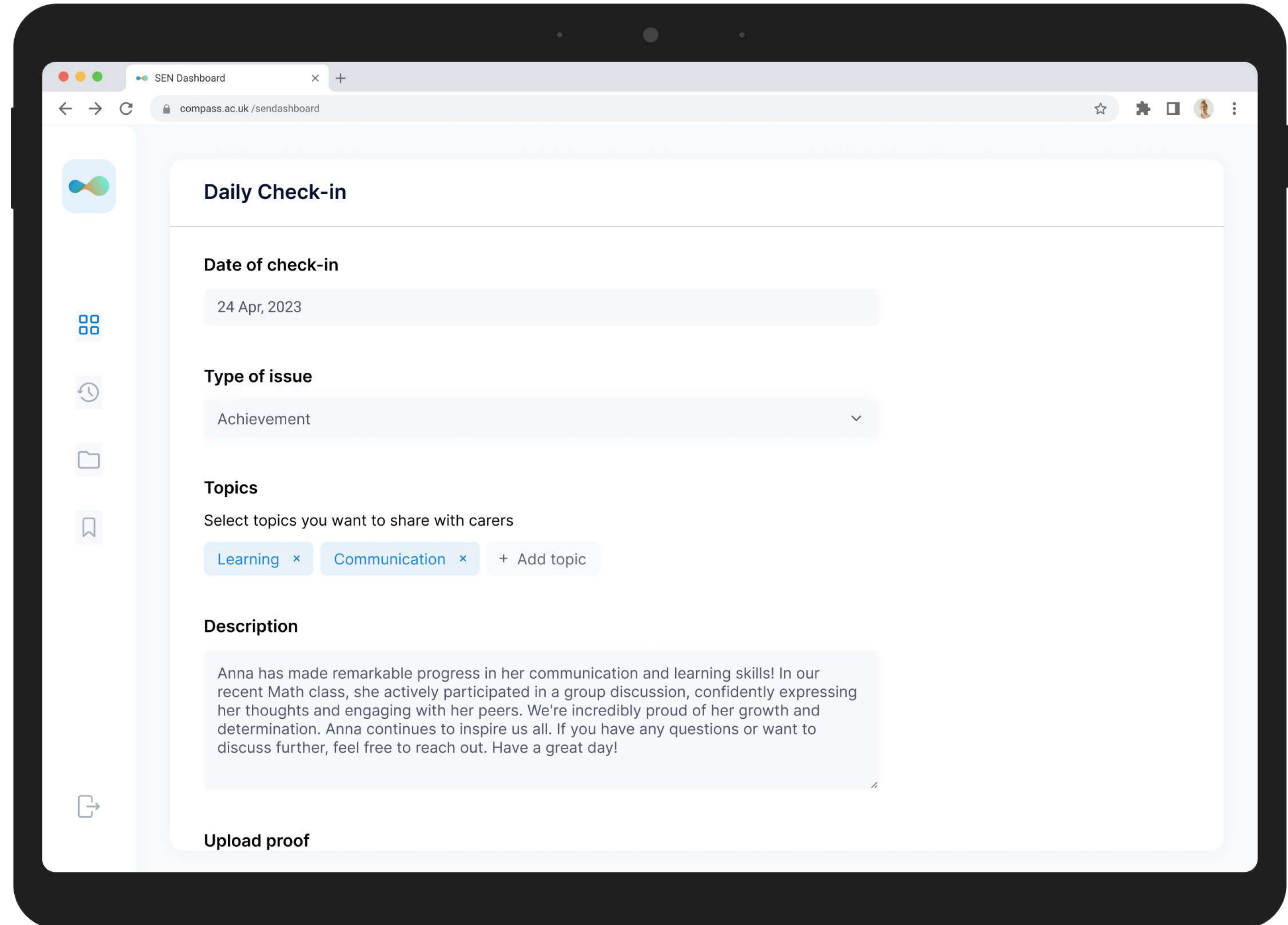
# With school



Hannah Cresswell

SENCO

06



# With health service



## Dr Sian Holdridge

CAMHS Staff Grade Doctor, Getting Help Team

South London and Maudsley NHS Foundation Trust

“I thought it it's a really good idea. Because parents find it very difficult to navigate the system with autism assessment, and I can speak from my experience of being a parent of an autistic child, and I found it very hard to navigate the system. So I can imagine how hard it is for parents who don't work in CAMHS already.”

# With health service



## Dr Sian Holdridge

CAMHS Staff Grade Doctor, Getting Help Team

South London and Maudsley NHS Foundation Trust

“I was wondering how the schools will feel about. There's quite a lot of documentation that they would be required to do. I think they might be a little bit worried about the amount of reports and things that they have to upload. So I just wondered if there was a way to just streamline that.”

# With health service



## Dr Sian Holdridge

CAMHS Staff Grade Doctor, Getting Help Team  
South London and Maudsley NHS Foundation Trust

“I noticed that the app requires CAMHS to say where the patient is in the waiting list. And I think you might have some issues from getting those dates from CAMHS, because we don't really like to give waiting dates and waiting times because if urgent cases come up, we sometimes have to prioritize other cases. So you may have issues with CAMHS, giving they don't want to be pinned down on dates.”



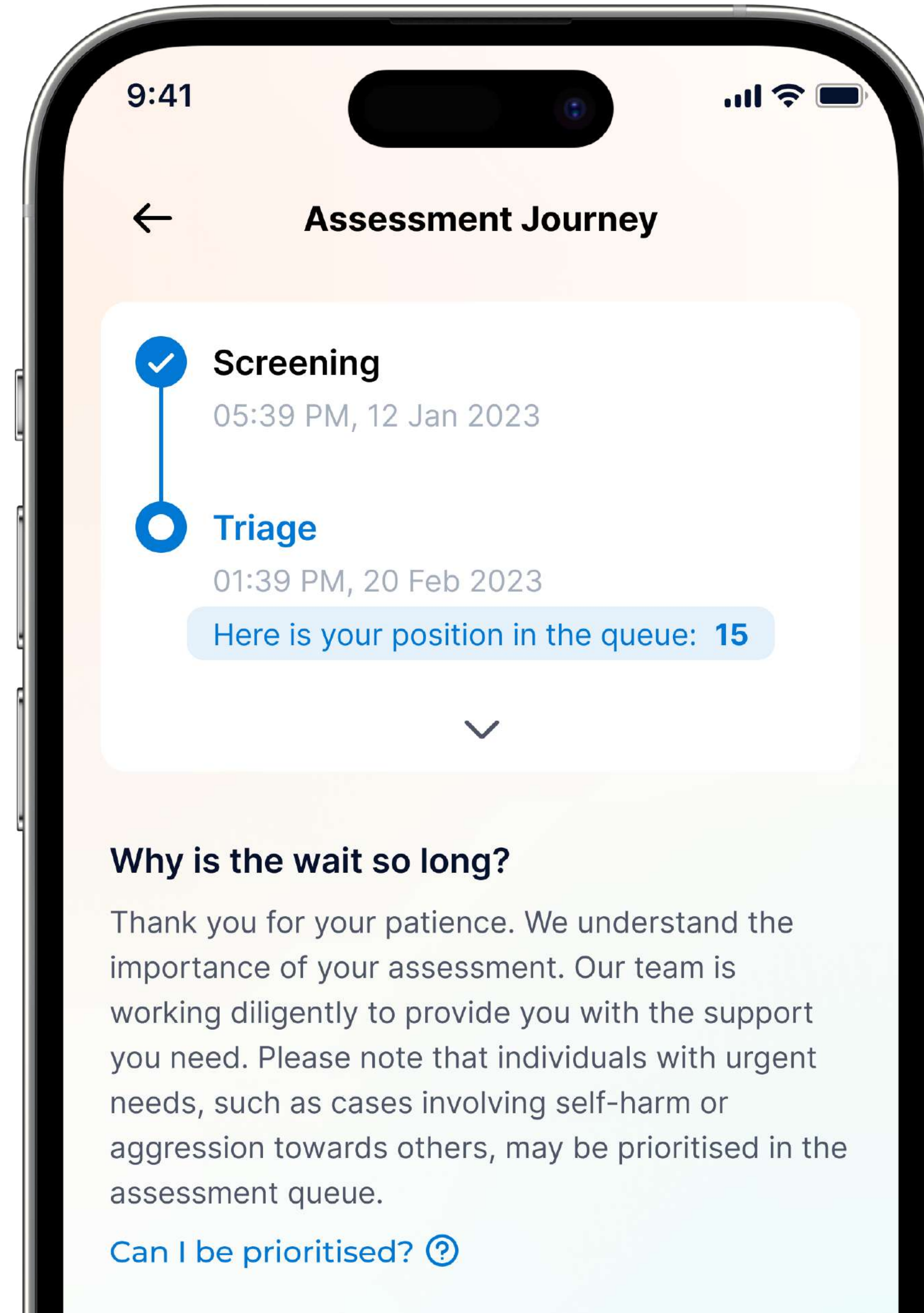
VALIDATION

# With health service



## Dr Sian Holdridge

CAMHS Staff Grade Doctor, Getting Help Team  
South London and Maudsley NHS Foundation Trust



## Current Mission

support carers of autistic  
children aged 5-11

## Future Vision

support all neurodivergent  
individuals and their families/carers



# Thank You!





**AZEB ATARO**

Carer & Founder for EESNC



**BIYUAN CHEN**

Paediatrician



**DR SIAN HOLDRIDGE**

Carer & CAMHS Doctor



**FIONA TAI**

Worked in NAU



**HANNAH CRESSWELL**

SENCO



**PENGJIE YANG**

Phd Student



**TUGCE CENTINER**

Phd Student



**XING LIU**

Clinical Social Work/Therapist



**YUSUKI KANDA**

Alumni, Service Design, RCA