ASD Helping Hands

www.asdhelpinghands.org.uk

Before and After a Diagnosis

A guide to seeking a Diagnosis and what to do after

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1. About Autism Spectrum Disorders

Autism is a lifelong developmental condition that affects how a person experiences the world. It influences how they communicate, interact with others, and process information.

One way to understand autism is to think of the brain as running on a different operating system — not broken or wrong, just different. People with autism may think in a way that is highly logical, structured, and detailed. This can sometimes be described as “black-and-white thinking,” meaning they may see things in very clear terms, without the grey areas others might accept.

Autistic people often experience the world more intensely. They may find social situations confusing, be very sensitive to sounds, lights or textures, and prefer routines or predictability to feel safe and secure.

Autism is a spectrum, which means each person is affected in their own unique way. Some may need significant support in daily life, while others may live very independently but still face hidden challenges.

Autism is a spectrum condition, which means it affects people in many different ways. No two autistic individuals are the same — each person has their own strengths, challenges, and ways of experiencing the world.

There is no single definition of "normal." People who do not have autism are often referred to as neurotypical. This simply means their brains are wired in a way that is more typical of the majority of the population. Being autistic doesn't mean someone is not normal — it means they may think, communicate, or behave differently.

It's important to understand that we live in a world designed around neurotypical social expectations. Social rules, communication styles, and daily routines often reflect what works best for neurotypical people — not necessarily for autistic individuals. This can make everyday life more challenging for those on the spectrum.

While neurotypical people may be seen as the 'norm', they can also act in ways that are irrational, emotionally driven, or inconsistent — things that may seem confusing or frustrating to someone who prefers logical, clear, and consistent patterns. From an autistic perspective, it’s not autism that’s different — it’s the world that isn’t built to include different ways of being.

All Autistic individuals find it harder to manage the world the way it is.
Autistic individuals often find it more challenging to navigate a world that is not designed for them. They experience and process the world differently, which can affect how they manage everyday situations.

Autism is typically characterised by differences in two key areas:

Social Communication and Interaction
Autistic people may find it difficult to understand social cues, interpret tone of voice or body language, or know how to respond in social situations. Building and maintaining relationships can be more challenging, not because they don't want to connect with others, but because the expected rules of social interaction may not come naturally.

Restricted and Repetitive Patterns of Behaviour, Interests, or Activities
This can include having a strong interest in specific topics, preferring routines, and engaging in repeated behaviours (such as hand-flapping or repeating words). These behaviours often help the person feel calm and in control. Many autistic individuals also experience sensory differences — they may be over- or under-sensitive to sound, light, touch, smell, or taste, which can make certain environments overwhelming.

These differences do not make someone less capable — they simply mean the person experiences and interacts with the world in a unique way.

"If you've met one person with autism, you've met one person with autism."

Dr. Stephen Shore

2. Children and Young People Diagnosis

Starting the journey towards a diagnosis can be overwhelming. Many parents and carers face early challenges — for example, being told by a GP that their child is "too young" to be assessed. It's important to know that early identification and support can make a big difference, and there are steps you can take to ensure the process gets off to the best possible start.

Step 1: Speak to Your Child's Educational Setting

Begin by talking to staff at your child's nursery, school, or college. Diagnosis often requires evidence that behaviours are present in more than one environment (e.g. home and school).

Ask to speak to the Special Educational Needs Coordinator (SENCO). Even if your child isn't having regular meltdowns, there may be more subtle signs — such as difficulty following instructions, delayed processing, or trouble staying focused — that staff may have noticed.

Their observations and written reports will be an important part of any referral for assessment.

Step 2: Contact Your GP

Once you've gathered information from school, book an appointment with your GP. Explain your concerns clearly and ask for a referral to the Community Paediatrician (for younger children) or Child and Adolescent Mental Health Services (CAMHS) depending on your area.
Be prepared for the possibility of waiting lists — but starting the referral process early is essential.

Step 3: Keep a Diary

Start recording daily behaviours and traits at home. Include:

- Patterns of behaviour
- Emotional responses
- Sensory sensitivities
- Social difficulties
- Sleep issues

This diary will help professionals get a fuller picture of your child's needs and can be shared during appointments.

While You Wait for an Assessment

The time between referral and diagnosis can be one of the most difficult periods. You may feel uncertain, frustrated, or isolated — but you are not alone. Here's how to make the most of this time:

Find Peer Support

Other parents and carers who've been through the process can offer practical advice and emotional support. Look for:

- Local support groups
- Online forums or Facebook communities
- Charities or parent networks

Talking to others can help reduce feelings of isolation and give you space to share and learn.

Educate Yourself About Autism

Use this time to learn more about autism and how it may affect your child. Reliable sources include:

- The National Autistic Society
- NHS Autism Guide
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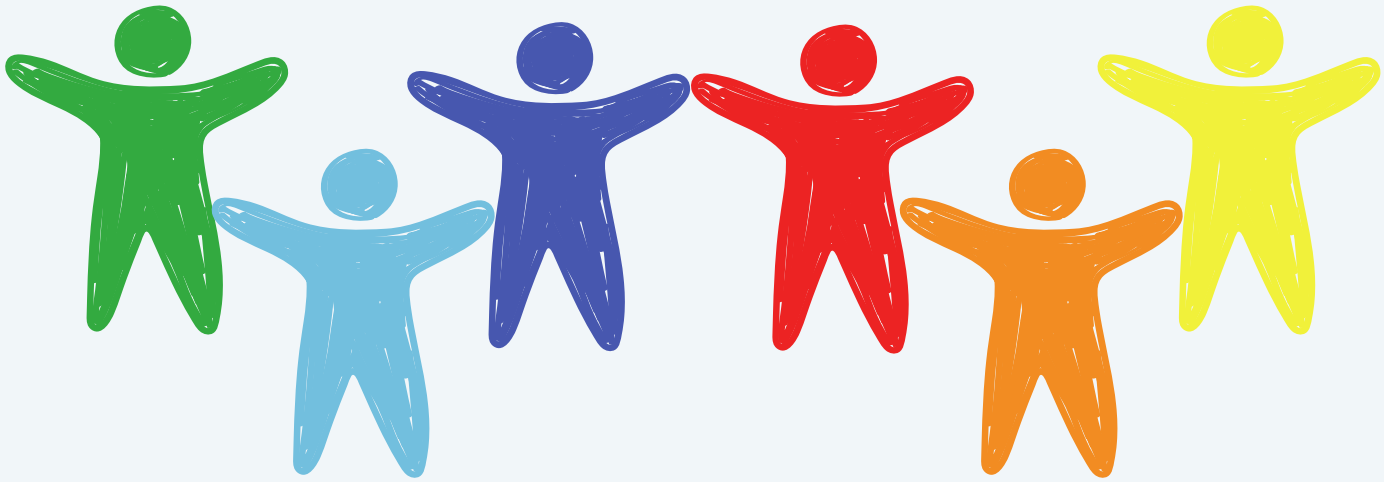
Avoid unverified or sensationalised sources. A good understanding will help you feel more confident and better prepared to support your child.

Try Autism-Friendly Strategies

You don’t need to wait for a diagnosis to try supportive techniques. Many families find the following helpful:

- Sensory supports (e.g. fidget toys, quiet spaces)
- Visual schedules or timetables
- Social stories or scripts
- Calm-down tools and mindfulness techniques
- Clear, simple instructions

If something works, keep using it — these approaches can ease everyday challenges for your child (and you).



Accessing Support

Talk to the School or Educational Setting

Let your child's school know about your concerns and any strategies you're trying. They may be able to:

- Offer support through the SENCO
- Provide one-to-one support
- Adjust expectations or routines
- Create a personalised support plan

This support does not require a diagnosis — it's based on need.

Ask for Reasonable Adjustments

If you're a young person or adult navigating your own diagnosis journey, you can ask your school, college, or employer for reasonable adjustments. These could include:

- Flexible deadlines
- Quiet working spaces
- Written instructions instead of verbal ones
- Additional time for processing

Let them know what helps and request support to make things more manageable.

Check Your Local Authority's Offer

Most local councils provide services such as:

- Family Support Workers
- Short breaks or respite
- Parenting workshops or courses
- Help with accessing education support

Look on your Local Authority's website under the Local Offer to see what's available in your area and how to access it.

3. Adult Autism Diagnosis (18+)

Many people are not diagnosed with autism until adulthood. This may be due to their needs being misunderstood or masked during childhood, or because awareness and recognition of autism, especially in women or people without a learning disability has only improved in recent years.
Receiving a diagnosis as an adult can be life-changing. It can bring clarity, help explain past experiences, and support a stronger sense of self-understanding and acceptance.

Why Adults Seek a Diagnosis

There are many personal reasons why an adult might seek an autism assessment, including:

- A desire for self-understanding
- Finding an explanation for lifelong challenges
- Seeking validation or acceptance
- Accessing support at work or in education
- Gaining reasonable adjustments
- Improving mental health and well-being

Whatever your reason, pursuing a diagnosis is a valid and personal decision.

Accessing an Autism Assessment

In most areas of the UK, adult autism assessments are provided through the NHS, often via specialist neurodevelopmental teams. Services vary by region, but the general process is:

- Step 1: Speak to your GP and share your concerns. They can refer you for an autism assessment.
- Step 2: In some areas, you may be able to self-refer — check your local NHS or Integrated Care Board (ICB) website.
- Step 3: If eligible, you will be added to a waiting list for a diagnostic assessment.

Waiting times can be long, but you can access support and resources while you wait. Most NHS services provide assessments for adults without a diagnosed learning disability. If you do have additional needs, your referral may be directed to a more appropriate service.

What the Diagnostic Service Can Offer

The autism diagnostic service typically offers:

- Screening and triage for suitability
- A full diagnostic assessment using recognised tools
- Feedback on the outcome
- A post-diagnosis report

Some areas also offer limited pre- or post-diagnostic support, such as short workshops, signposting, or referral to local support organisations.
However, they usually do not provide long-term mental health or social care support.

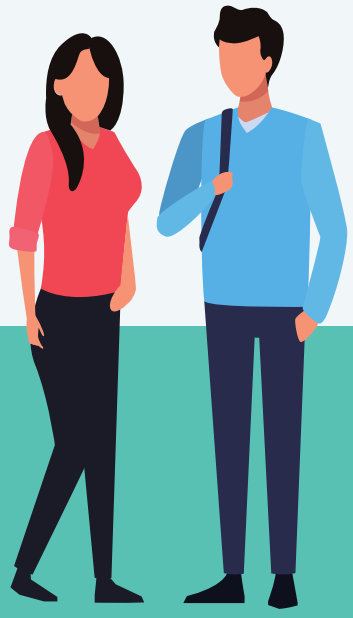
What to Do Next

- Talk to your GP to discuss a referral.

- Use trusted sources to learn more about autism in adults, such as:
  - National Autistic Society
  - NHS: Autism in Adults

- Connect with local autism charities, support groups, or online communities for advice and shared experiences.

- Look into reasonable adjustments in work, education, or daily life — a diagnosis may support your rights under the Equality Act 2010.



4. Patient Choice: Your Right to Choose a Diagnostic Provider

Whether you are seeking an autism diagnosis for a child or as an adult, you have the right to Patient Choice under the NHS in England. This means that you can choose which provider carries out your autism assessment, as long as:

- The provider is commissioned to offer the service by the NHS.
- Your GP agrees that a referral is appropriate.

What Does Patient Choice Mean for You?

If the waiting time for an autism assessment in your local area is very long, you may be able to choose an alternative NHS-approved provider elsewhere in the country with shorter wait times.

You can ask your GP to refer you to another provider if:

- You or your child are on a long waiting list.
- You want to access a specific service that better suits your needs (e.g. offers specialist experience, more accessible location, or remote assessments).

This applies to both children and adults, although pathways may differ slightly between age groups.

Important Notes

- Not all private providers are NHS-funded — make sure you are choosing an NHS-commissioned service if you want the assessment to be free.
- You cannot use Patient Choice to skip waiting lists entirely but you can use it to find a provider with a shorter wait.
- Patient Choice applies only in England. If you are in Scotland, Wales, or Northern Ireland, the process may differ.
- Always ensure that the provider you are using is NICE compliant to ensure your diagnosis is accepted by the Local Authority and NHS.

How to Use Patient Choice

Do Your Research

Search for NHS-commissioned autism diagnostic services in other areas. The NHS website and National Autistic Society may list providers.

Speak to Your GP

Let your GP know that you wish to use your right to Patient Choice and request a referral to the service you have identified. You may need to provide contact details or the name of the provider.

Check Eligibility

Some services may have age or diagnostic criteria (e.g. only assess children, or only adults without a learning disability). Check this before requesting the referral.

Get Referred

Once your GP agrees, they can make a referral through the NHS e-Referral Service (e-RS) to the provider of your choice.

5. Managing the Diagnosis

Feelings and Reactions

Receiving a diagnosis of autism — for yourself or a loved one — can be an emotional and overwhelming experience. It’s not uncommon to feel shocked, heartbroken, or even as though you're grieving. Many people describe the process as similar to the stages of grief: denial, anger, sadness, acceptance.

This reaction is natural. It often stems from being thrust into a new world with unfamiliar terms, systems, and expectations. For many, it marks the beginning of a steep learning curve.

It’s also common to feel isolated. Some parents report that friends or family become distant or dismissive, still believing the child is “just badly behaved” or “seeking attention.” In some cases, people assume the child’s behaviour is learned, not neurological.

Mothers and fathers may respond differently. Emotions such as guilt, worry, sadness, anger, or confusion can all arise — sometimes all at once. These feelings are valid and part of adjusting to new understanding and expectations.

Understanding the Positives

A diagnosis can also bring clarity and relief. It may explain years of challenges and validate your instincts. For some, it finally confirms that behaviours aren’t due to poor parenting or laziness but a recognised neurological difference.

With a diagnosis often comes access to:

- Specialist educational support
- Additional funding or benefits
- Tailored strategies and adjustments
- Support from professionals and charities
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It also gives you a way to explain things to others — something tangible people can learn about and understand.

Managing Expectations and Beliefs

In the early stages, many parents and carers turn to the internet for answers. While this can be helpful, be cautious. Much of the information online, particularly on forums and social media, is based on American systems or personal anecdotes. It may not reflect how diagnosis and support work in the UK.

Try not to compare your child to others you read about online. Every autistic person is different, and what's true for one child or adult may not apply to another.

Stick to reliable UK-based sources such as:

- National Autistic Society
- NHS Autism Information
- Local autism charities or support networks

Coping with Professionals and Others

It can be challenging to deal with people — including professionals — who don't yet know your family or understand autism well. Meeting new people may also be difficult for your child, particularly if verbal communication is hard or anxiety is high.

This can complicate assessments and appointments, especially when professionals are trying to gauge a child's wishes, needs, or feelings quickly.

Here are some ways to make this process easier:

- **Keep involvement consistent:** Where possible, try to keep the same professionals involved over time. Consistency helps build trust and understanding.
- Document everything: Ask professionals to confirm discussions or decisions in writing — even after informal meetings. Keeping records helps protect your rights and ensures clarity.

- **Know who's involved:** Make a list of all professionals linked to your child or family, and label whether they're from health, education, or social care. This helps you keep track of roles and responsibilities.

- **Stick with one GP:** If you can, request that one GP be responsible for the ongoing care of your child or yourself. This avoids the need to repeatedly explain your history at each visit — something that can be distressing for autistic individuals, especially during short or urgent appointments.

This is a journey of learning and discovery — and the autistic person is your guide. Listen to them, learn from them, and remember: their experience is valid, and they are the expert on themselves.

6. Some important misconceptions about Autism Explained

There are many myths and misunderstandings about autism. These misconceptions can lead to stigma, confusion, or false assumptions — even among well-meaning people. Below are some of the most common myths, and the facts that help to correct them.

✗ Myth: Autistic people cannot make eye contact

Fact: Some autistic individuals find eye contact uncomfortable or overwhelming and may avoid it. Others may maintain intense or prolonged eye contact to compensate. Like many traits in autism, eye contact varies widely from person to person.

✗ Myth: Autistic people prefer to be alone

Fact: Autistic people often want social connection, but they may struggle to navigate the complex and often unwritten rules of social interaction. They may withdraw not out of preference, but to avoid negative experiences, social anxiety, or sensory overload.

✗ Myth: Autistic people don’t show affection

Fact: Autistic individuals can be very affectionate, though their ways of showing it might be different from what neurotypical people expect. Affection might come through actions, special interests, or consistency rather than hugs or eye contact.

Myth: Autistic people have no empathy

Fact: Many autistic people feel empathy deeply. However, they may struggle to interpret non-verbal social cues such as tone of voice, facial expressions, or body language, which can make it harder to respond in ways others expect. In fact, some autistic individuals experience too much emotional empathy, which can be overwhelming.

Myth: Autism is caused by bad parenting

Fact: Autism is a neurodevelopmental condition. It is not caused by parenting style or upbringing. That said, consistent and supportive parenting can help an autistic individual navigate a world not designed for them just as inconsistent or harsh parenting can make things more difficult, as it would for any child.

Myth: Autism is caused by the MMR vaccine

Fact: This theory has been widely and thoroughly discredited. There is no scientific evidence linking autism to the MMR vaccine. The original study suggesting this has been withdrawn and disproven.

Myth: Autism is more common now than it used to be

Fact: Autism has always existed, but awareness, understanding, and diagnosis have improved over time. Many people who would not have been diagnosed in the past especially women or people with fewer visible traits are now being recognised. What seems like a rise in cases is more likely due to better identification.

7. Seeking Support

Education Support

If you have concerns about your child's development, behaviour, or learning needs, schools are often the first place to seek support.
You can:

- Speak to the school's Special Educational Needs Coordinator (SENCO) about your concerns. They can help identify whether your child may need extra support and guide you through the next steps.
- Review your local authority's SEND Local Offer, which outlines what support is available for children and young people with special educational needs or disabilities in your area.
- Ask your child's school about any advice packs or professional guidance they use to support students with additional needs.
- In some areas, school staff may be able to access advice from educational psychologists or neurodevelopmental services to help assess and support your child.

It is important to maintain regular communication with your child's school and be part of any discussions around support strategies or referrals.

Mental Health Support

Mental health support is available for autistic individuals and those going through diagnosis, including parents and carers. Services vary across the UK, but common options include:

- Local NHS Mental Health Services: Your GP or local referral hub can direct you to the most suitable service for mild to moderate needs in children and young people.
- Self-referral services: Many areas allow self-referral for mental health support for people aged 0 to 25.
- Online educational resources such as free webinars or courses on mental health for young people. Search for recovery or discovery colleges in your area.
- Mental health advice websites created for families supporting young people with emotional difficulties.
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National helplines and support include:

- Childline – call 0800 1111
- Papyrus (young suicide prevention) – call 0800 068 4141 or text 07860 039967
- Samaritans – call 116 123 or email jo@samaritans.org
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These services offer confidential emotional support for parents, carers, and young people alike.

Family Support and Information

There are many organisations and online resources available to support families on the autism journey:

- SENDIASS services offer free, impartial advice about special educational needs and disabilities (check your local version).
- Positive Behaviour Support (PBS) courses offer practical parenting strategies for supporting behaviour in a positive and structured way.
- Parent Carer Forums provide an opportunity to meet others, share experiences, and influence local services.
- Charities and associations in most regions support autistic children, young people, adults, and their families with advice, activities, and advocacy.
- Recovery or Discovery Colleges may offer online courses about autism and mental health topics for adults and older teenagers.
- Autism-specific charities such as:
  - ASD Helping Hands
  - Autism Central
  - Autism Anglia
  - PDA Society
  - ADHD Foundation

These organisations provide workshops, family activities, peer support groups, and trusted resources for understanding autism, ADHD, and related conditions.

8. The Welfare system for those with a disability

If you or your child has a diagnosis of autism (or is going through the process), you may be entitled to financial support. Some of these benefits are non-means-tested, which means they are not affected by your income, savings, or employment status.

Disability Living Allowance (DLA)

For children under 16

DLA is a benefit for children who need extra care, supervision, or help with mobility.

It has two components:
Care Component (per week):

- Lower rate – £29.20
- Middle Rate -£73.90
- Higher rate – £110.40

Mobility Component (per week):
Lower rate – £29.20
Higher rate – £77.05

To claim DLA, call 0800 121 4600 or visit: www.gov.uk/disability-living-allowance-children

Support
The charity Cerebra offers a helpful DLA Guide to assist with filling out the form.
https://cerebra.org.uk/download/disability-living-allowance-dla-guide/

Personal Independance Payment (PIP)

For individuals aged 16 and over

PIP replaces DLA for people over the age of 16 and is awarded based on how your condition affects your daily life and mobility, not the diagnosis itself.
There are two components:

- Daily Living Component
- Mobility Component

Each has a standard rate and an enhanced rate, which vary depending on the level of support needed.
To start a PIP claim, call 0800 917 2222 or visit: www.gov.uk/pip

Support
Disability Rights UK has a detailed PIP Guide that walks you through the application process.
ASD Helping Hands also offers a PIP Support Service (Charged service). For more information, click here

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Carers Allowance

If someone looks after a child or adult who receives DLA (middle or higher care) or PIP (daily living component), they may be entitled to Carer's Allowance.

To qualify, the carer must:

- Be aged 16 or over
- Spend at least 35 hours per week caring
- Not be in full-time education
- Do not study more than 21 hours per week
- Earn no more than £139 per week after tax, National Insurance, and expenses
- Have lived in England, Scotland, or Wales for at least 2 of the last 3 years
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More information is available at:www.gov.uk/carers-allowance

Other Financial Support

You may also be eligible for additional benefits, such as:

- **Universal Credit** – for families with low income or out-of-work support
- **Housing Benefit or Council Tax Reduction** – depending on your local authority
- **Disabled Facilities Grants** – to help with the cost of home adaptations
- **Blue Badge Scheme** – for parking support related to mobility difficulties

9. The Autism Information and Advice Service

Our Autism Information and Advice Service is here to support autistic individuals, families, and carers by offering personalised guidance based on your specific needs.

We understand that navigating life with or alongside autism can be challenging, whether you're managing a recent diagnosis, struggling with education or benefits, or seeking to understand challenging behaviours. Our team is here to offer clear, practical information to help you feel supported and informed.

What We Can Support You With

Our Autism Advisors can offer information and advice on a wide range of topics, including:

- Special Educational Needs (SEN) Support, including EHCPs (Education, Health and Care Plans)
- Autism diagnosis pathways for both children and adults
- Disability benefits guidance, including help understanding the system, completing forms, and appealing decisions
- Understanding and managing behaviour related to autism
- Short Breaks applications and support for young carers
- Adult social care, personal budgets, and support planning
- Access to training, events, and local social groups
- Signposting to other services or organisations where additional support is needed

You can access the service by completing our referral form. Once submitted, you will be able to book a telephone appointment with one of our advisors, or we will contact you directly.
Visit: www.asdhelpinghands.org.uk/autism-information-and-advice-service

What We Cannot Provide

While we aim to help as much as possible, there are limits to the support we can offer.

This service cannot:

- Provide direct support to adults (18+) without their consent (though we can advise family members on possible steps)
- Offer a diagnosis or make judgements about whether someone may or may not be autistic
- Provide advice in cases involving high levels of mental health crisis – please contact your GP or mental health services instead
- Guarantee outcomes at appeals or tribunals, though we can guide you through the process
- Offer hands-on or in-person support in the home, school, or community environment

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Receiving or pursuing an autism diagnosis can feel overwhelming, but you are not alone. Whether you're at the start of the journey, navigating daily challenges, or looking for support and guidance, there is help available.

Understanding autism, accessing the right services, and connecting with others can make a huge difference for both individuals and families.

We hope this booklet has helped you feel more informed, more confident, and better equipped to take the next steps. Remember: support is out there, and every step forward is progress.

ASD Helping Hands

Our Mission

“Empowering autistic individuals and those around them, ASD Helping Hands is dedicated to fostering confidence, independence, and inclusion at every stage of life. We provide guidance, education, and resources to help individuals, families, and professionals navigate autism with knowledge and empowerment.

We champion the rights of autistic people, striving to create a more inclusive society while ensuring our services remain accessible, reliable, and built on trust.”

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