



Talkback

Buckinghamshire Autism Strategy

Community Feedback: August 2022

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Method

- An online quantitative survey was conducted in June 2022:
 - 3 different but similar questionnaires were created and mailed out via our network of contacts in the different organisations and services working with autistic people in Buckinghamshire. In addition links to the surveys were 'advertised' via social media.
 - In total 356 responses were received:
 - 104 autistic adults responded to their version of the questionnaire
 - 136 parents/carers responded to their version of the questionnaire
 - And 116 professionals responded to their version of the questionnaire
- In addition, in July 2022 Talkback facilitated:
 - 3 face to face workshops, mostly but not exclusively attended by parents
 - 4 online workshops, mostly but not exclusively attended by parents
 - 11 face to face individual interviews with leaders from the VCS and education sectors, representing over 1000 Buckinghamshire residents
 - 13 online individual interviews (9 with autistic people, 2 parents and 2 professionals)

} Attended by
74 people

In total, we heard 484 different voices directly, with some of these representing over 1000 more. Many told similar stories – and selections* from these voices have been included in this report.

* Some of those taken from the survey responses have been edited to correct spelling/grammar

Summary: Issues and Recommendations

Why change ? We have over 400 reasons - from the sad to the possible. Here are 10 to start with

1. *"At school I was bullied. People made fun of my needs, it made me cry"*
2. *"The assessment did not adhere to NICE guidelines as it did not include any input from Speech & Language or Occupational Therapy, so pretty much all 'recommendations' made were based on highly generic umbrella diagnostic terms rather than any genuine insight"*
3. *"Stoke Mandeville is horrible, A&E waiting room is not ASD friendly at all, people rushing past all the time, bright lights and sudden loud noises"*
4. *"(Need to) have greater collaboration between health, education, CAMHS, social care so that families are heard, supported and have a clear and consistent pathway of support, with everyone working towards the same plan"*
5. *"I have so far been discouraged from applying for an EHCP as I am told we won't get one"*
6. *"The attitude is 'your child should not have an EHCP' as it's extra work for us"*
7. *"CAMHS is a total mystery to everyone. Long delays and lots of hands off ... they think a 6 week course will sort out anxiety"*
8. *"Have a special unit that specialises in schemes for autistic people. I benefited from a scheme at the council called Back 2 Base. They introduced me to Berkeley Homes. Sadly I've been told Back 2 Base has been abolished during the council's reorganisation"*
9. *"The EHCP's are being deliberately written (often cut and pasted) excluding services to ensure costs are cut"*
10. *"I also work in private practice myself and see some terrible diagnostic reports and practices from around the country and people with diagnoses of various neurodivergent conditions that are unlikely to be accurate"*

Overall summary

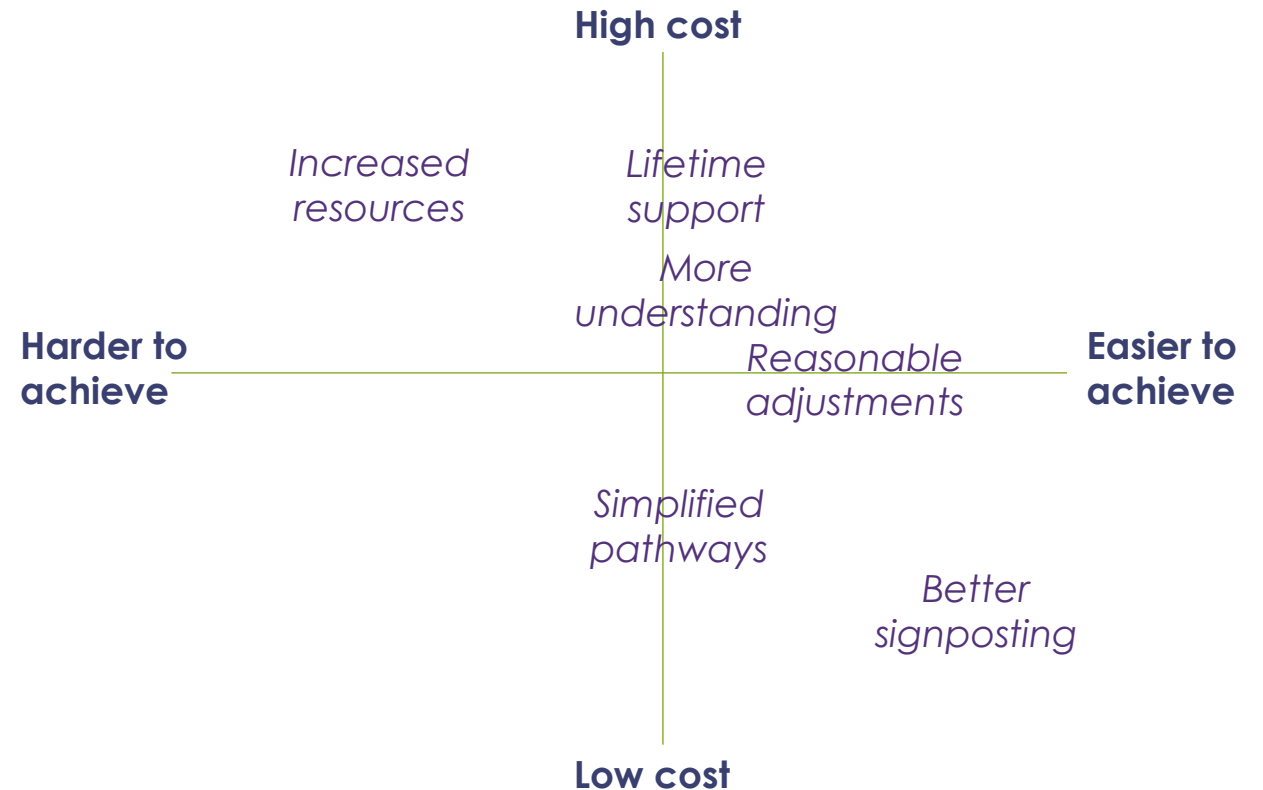
- 6 overall issues:

1. Lack of understanding and acceptance
2. Lack of reasonable adjustments
3. Lack of resources i.e. primarily staff and specialist facilities (and focus on cost rather than need)
4. Diagnosis delays → support delays
5. Complicated pathways from referral onwards
6. Lack of lifetime support + Lack of awareness of support services/groups that exist



Significant burden on mental health service and benefits system
+ significant stress on family life and budgets

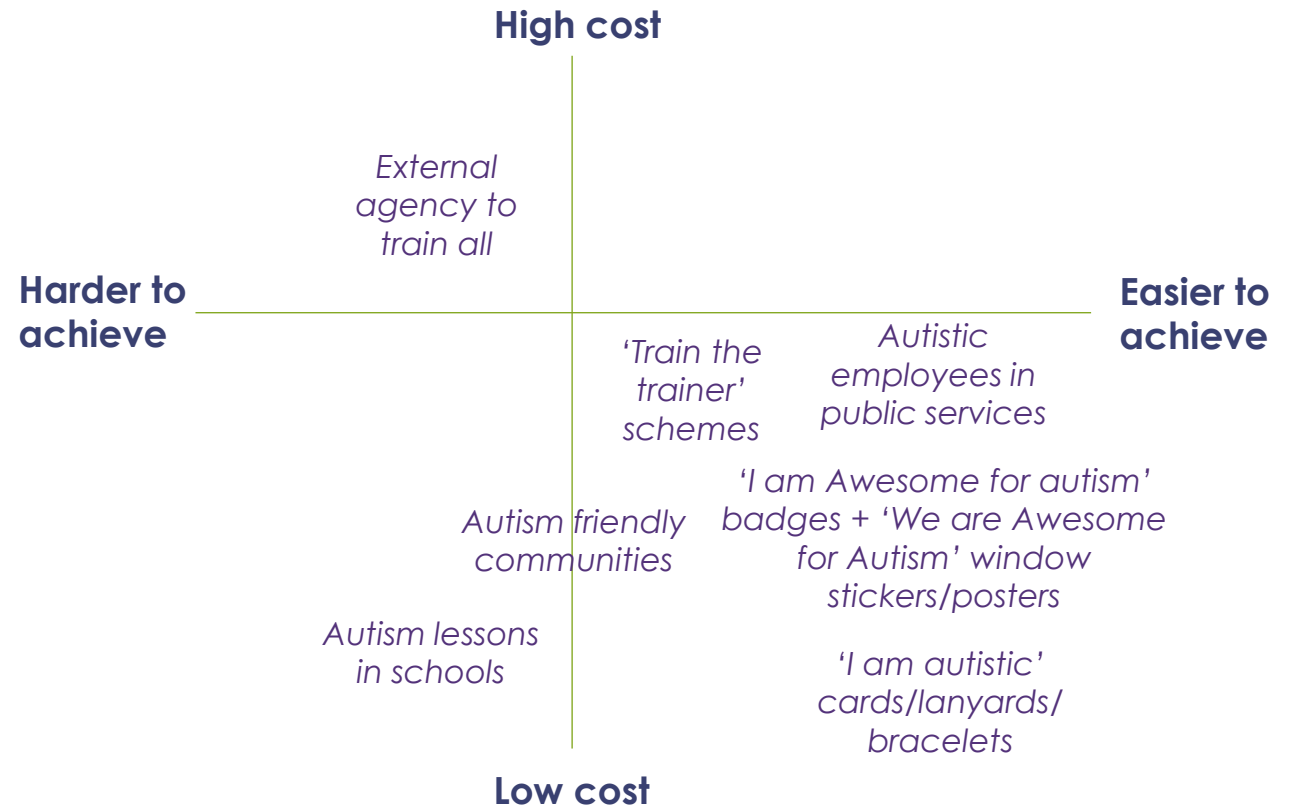
Mapping the solutions by cost and ease of making the change



Improving understanding and acceptance: Summary

- All working in all frontline services (public and private) need more education/training re autism and the reasonable adjustments needed, ideally delivered by autistic people who understand the needs of both adults and children, and understand the needs of all on the spectrum (including PDA).
- Need to be educated re behaviour management strategies as well as understanding that most autistic people do not fit the stereotype:
 - Autistic girls/women present differently from autistic boys/men
 - Autism doesn't affect IQ, but it does affect ability to function in a mainly neurotypical world without support and reasonable adjustments
- More cost-effective options for delivering include:
 - Creation of autism friendly communities run by volunteers → 'Awesome for Autism' scheme with awards for local services and businesses run by Talkback
 - 'Train the trainer' schemes → Training of autism champions within each service who then go on to train others in service. All trained to wear 'I am Awesome for Autism' badges

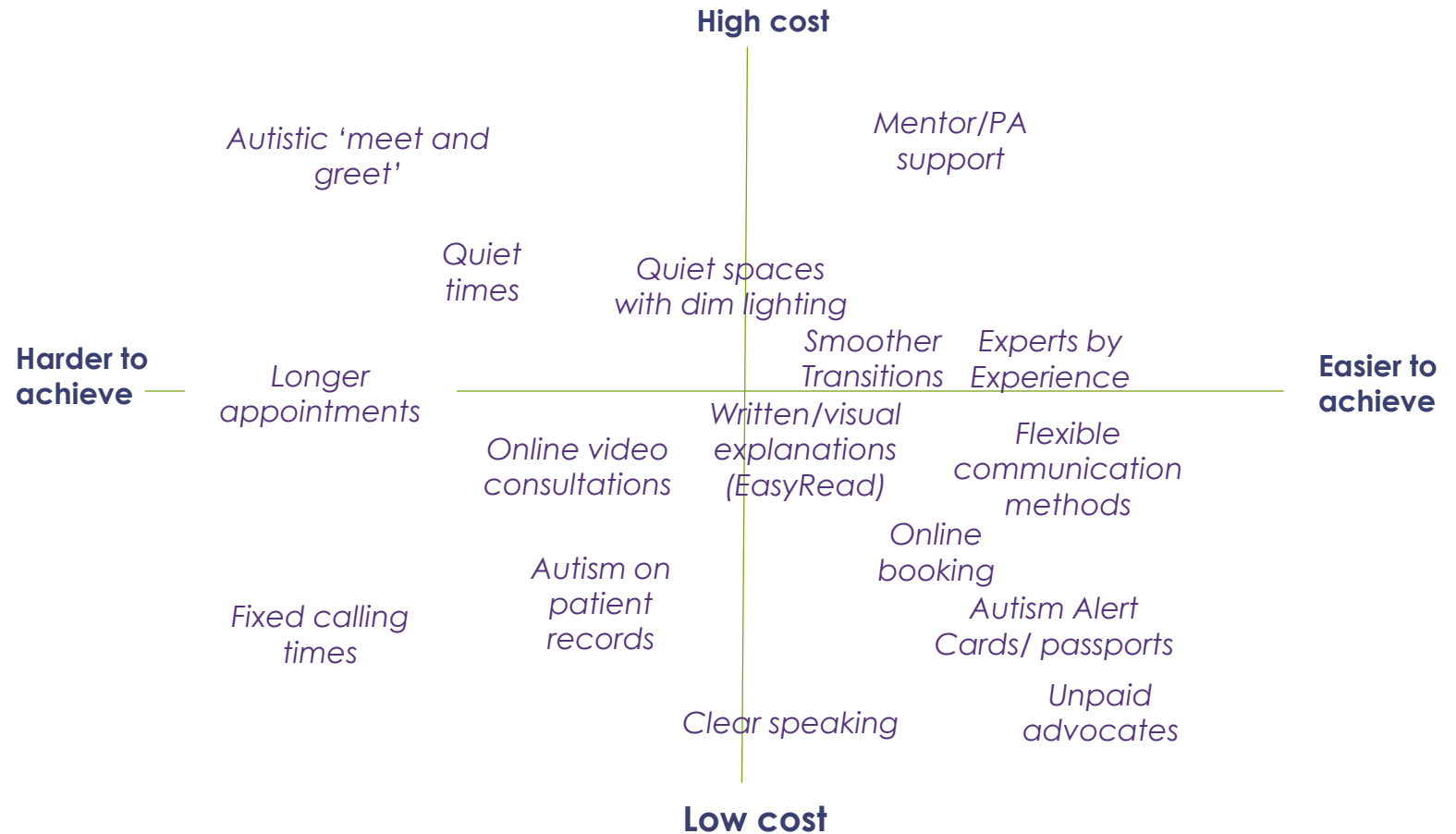
Mapping the solutions by cost and ease of making the change



Improving reasonable adjustments: Summary

- Many of the reasonable adjustments needed are in healthcare settings.
- But others are in schools, colleges, workplaces and leisure services.
- Needs a team of 'Experts by Experience' to monitor and feedback on adjustments made.
- Discrimination on the grounds of disability is against the law.

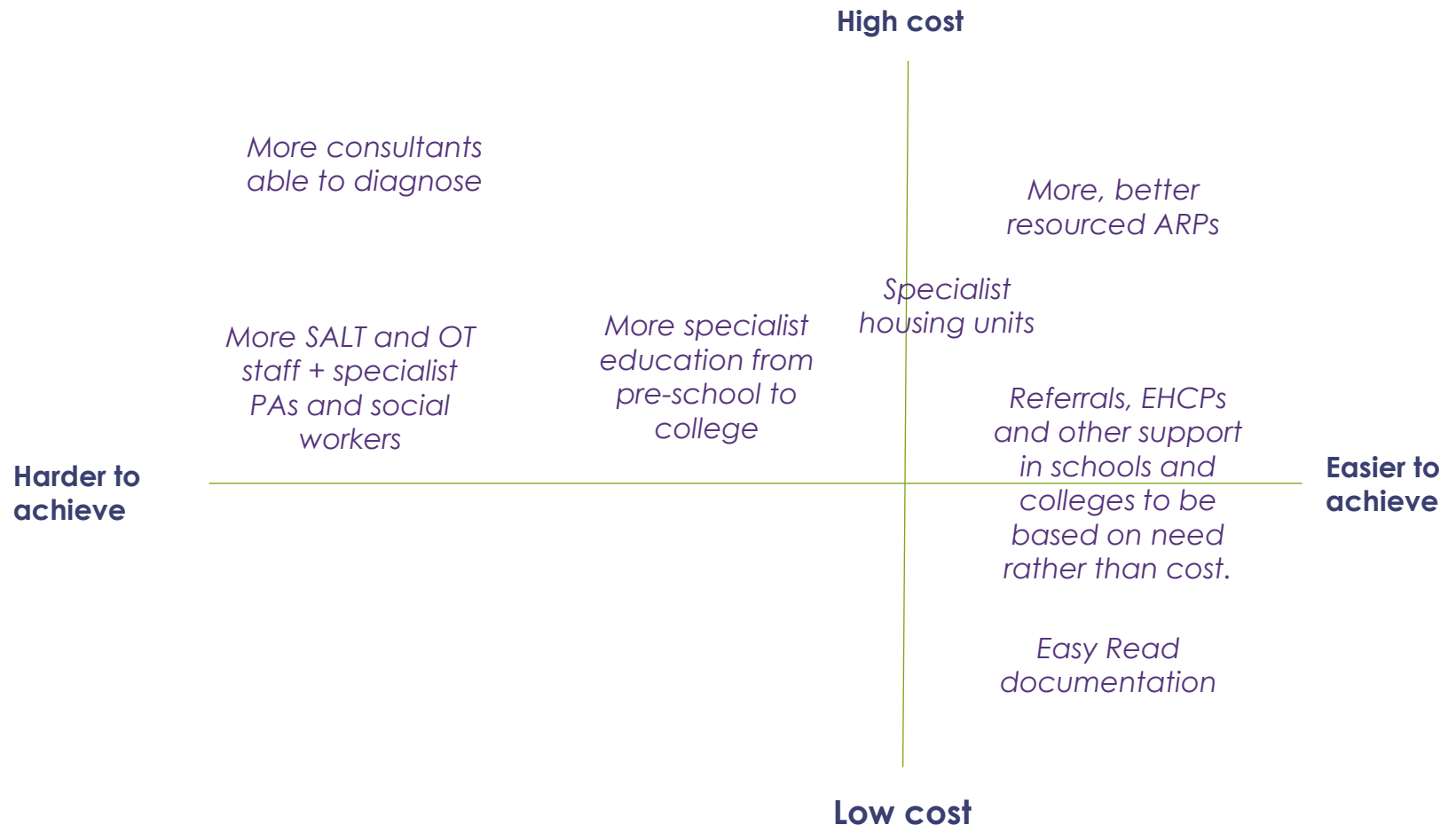
Mapping the solutions by cost and ease of making the change



Improving resources: Summary

- Improving resources (staffing, buildings, materials) is highly desirable but most are high cost.
- In particular, more needs to be spent on early intervention to reduce the negative impact of living with autism without support, and spirally costs later when dealing with the long term consequences of that negative impact.

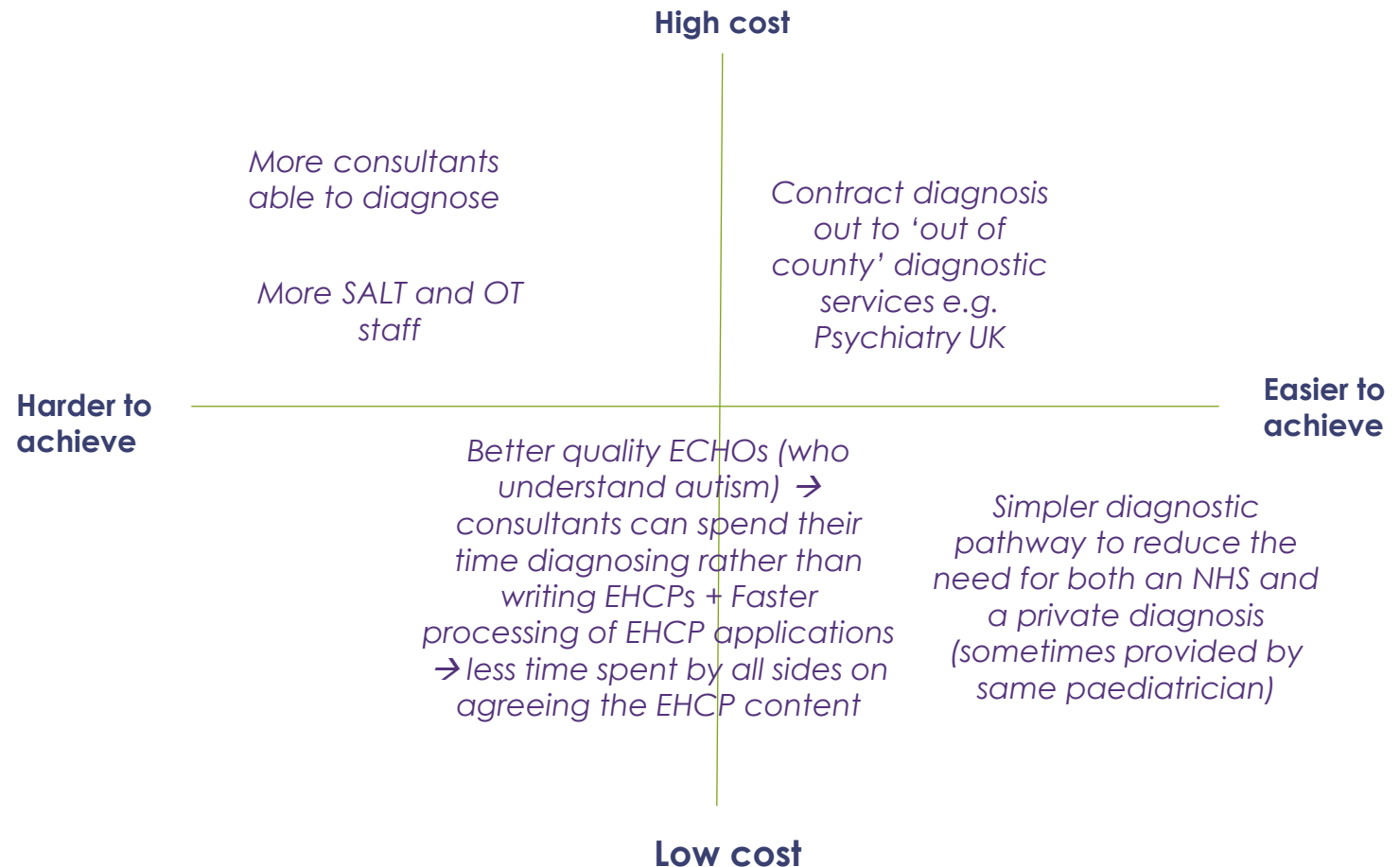
Mapping the solutions by cost and ease of making the change



Reducing diagnosis (and support) delays: Summary

- Child diagnosis and support delays → loss of education, childhood trauma and family stress + considerable money wasted by both Council and families on tribunals.
- Adult diagnosis delays → mental and other health services left to pick up the pieces.
- Early intervention is key.

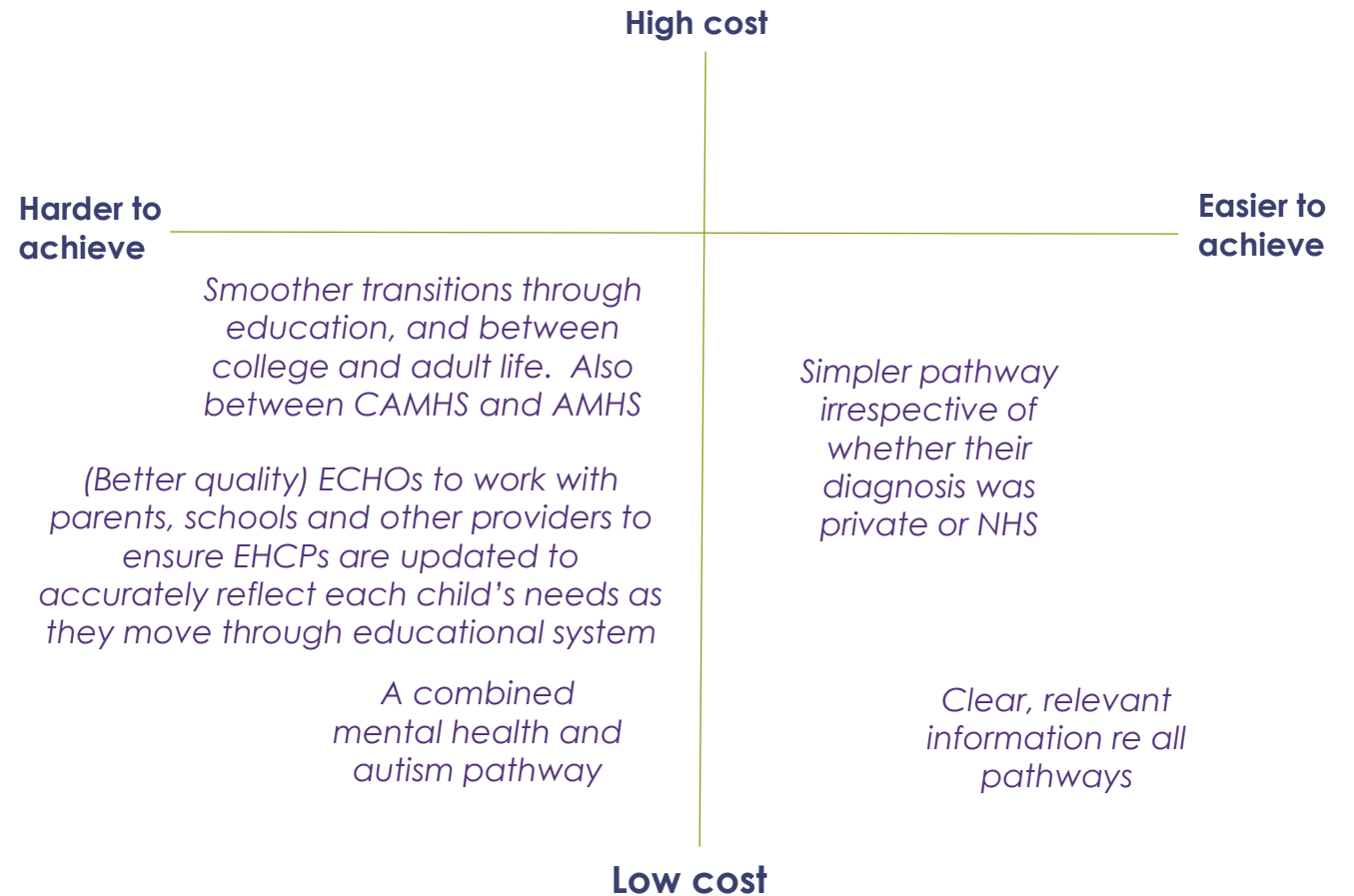
Mapping the solutions by cost and ease of making the change



Simplifying the pathways: Summary

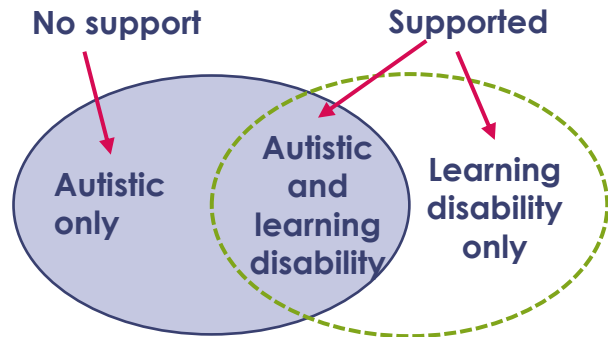
- Parents are confused about how best to support their children from the point initial concerns are raised through diagnosis, then education, and finally on to adult life – particularly when transitioning from one school stage to another, and when transitioning from CAMHS to AMHS. The system needs simplifying.
- Autistic adults struggle to gain good, consistent support when they experience mental health issues.
- Lack of clarity re the pathways, and leaving parents in particular to feel they need to pursue more than one, wastes scarce resource and causes considerable stress → clear, simple information re the pathways (to include FAQs) needs to be communicated.

Mapping the solutions by cost and ease of making the change

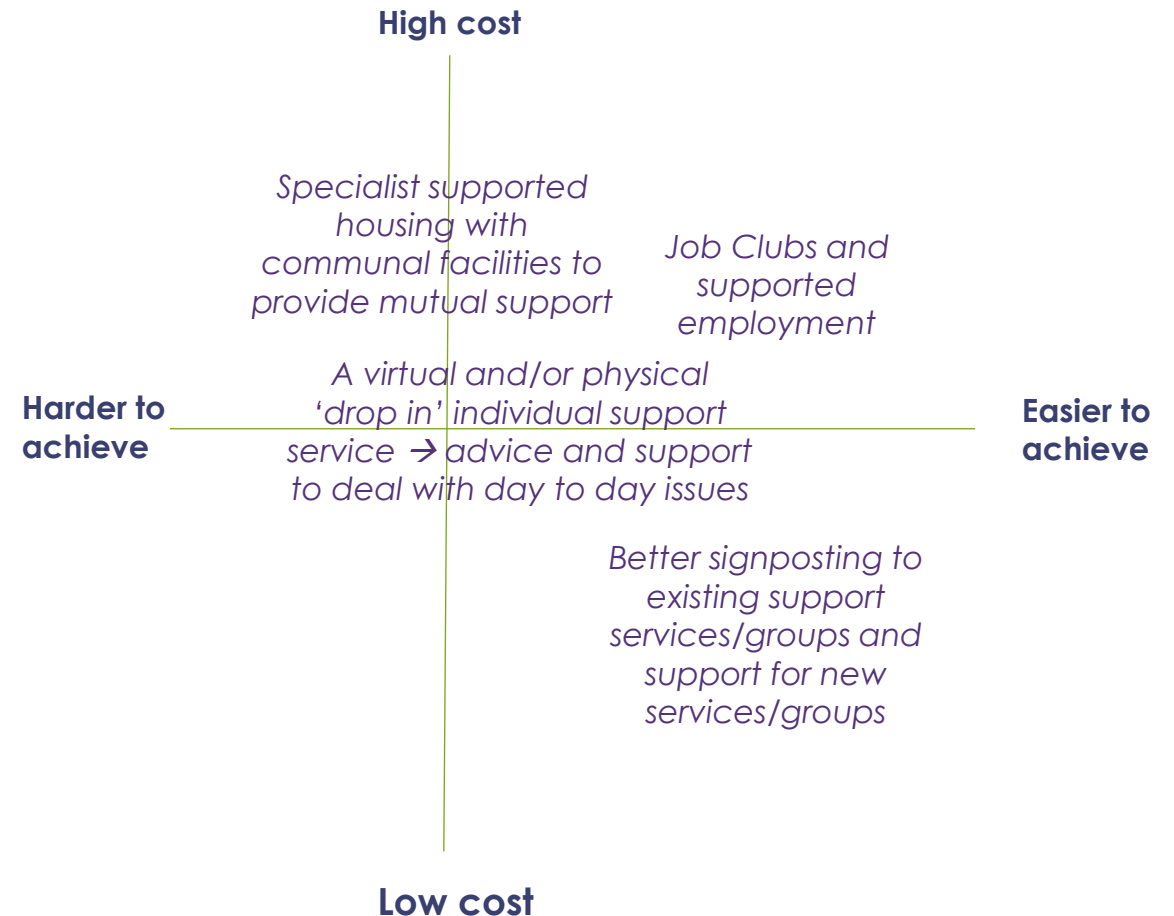


Lack of lifetime support and awareness of groups/services that exist: Summary

- Autism is never cured.
- Autistic people can 'fall off a cliff' or go from 'hero to zero' at any time, and need support to help them regain their mental health and confidence throughout their life, before they reach crisis point. NB with support, they may revert to 'hero', but may then drop back to 'zero' later (in maybe a few months or maybe many years) and will need further support when they do. This is a particular issue for those without learning disabilities.



Mapping the solutions by cost and ease of making the change



Understanding and acceptance

Understanding: Issues and Recommendations

Issue	Recommendations
<p>There is a lack of understanding and acceptance by professionals and others working in frontline services</p>	<ul style="list-style-type: none"> • Consider a 'train the trainer' programme to achieve the understanding needed given limited budgets: <ul style="list-style-type: none"> • Ensure autistic people are involved in creating and giving the training. • Training to cover the need for empathy and flexibility as well as understanding ... and strategies for managing when an autistic person has a meltdown. • Encourage all who have been trained to wear 'I am autism friendly' or 'I am Awesome for Autism' badges • All services to employ more autistic staff • Create autism champions within each service • Recruit a team of 'experts by experience' to review reasonable adjustments offered by public sector buildings and on public transport • Start with Council buildings/workforce • Include in all Council strategies

Voices

"All council employees need to have studied about Neurodiversity and the Double Empathy problem"

"Have a Cabinet Member on the council cabinet that deals with autistic and neurodiverse people as part of the portfolio and it would help if that person was autistic themselves"

"Ask the Council how many of those agreeing the strategy have had any training in Autism"

Understanding: Issues and Recommendations



Issue	Recommendations
<p>There is a lack of understanding and acceptance by the wider public</p>	<ul style="list-style-type: none"> Consider introducing neurodiversity lessons as part of the school curriculum (in the same way different religions are taught) → would help combat bullying and improve tolerance amongst peers. <p><i>“More education in schools and workplaces. Especially around those without an obvious learning disability”</i></p> Create positive marketing campaigns celebrating autistic achievement. Learn from the creation of dementia friendly communities to create autism friendly communities. Create autism champions within each community. Recruit a team of ‘experts by experience’ to review reasonable (autism friendly) adjustments offered by supermarkets, gyms, cinemas, theatres etc. Encourage shops etc (where staff have been trained) to display ‘We are autism friendly’ or ‘We are Awesome for Autism’ posters.
<p>Many members of the autistic population do not like identifying themselves as autistic</p>	<ul style="list-style-type: none"> Educate the autistic population that by informing people of their autism prior to an interaction, it will help them meet their needs. In particular, encourage all to carry cards or wear an ‘I am autistic’ identifier (all to say ‘I am autistic’ rather than ‘I have autism’)



Change to autism friendly



Diagnosis



Diagnosis: Issues and Recommendations

Issue	Recommendations
Professionals failing to recognise signs → not referring	<ul style="list-style-type: none"> • More education of all frontline professionals re signs to look out for • Advise parents to take videos of behaviour when professionals not present
Long waiting times	<ul style="list-style-type: none"> • Recruit more consultants capable of diagnosing • Consider alternative (faster) diagnostic pathways e.g. out of County, Psychiatry UK
Lack of information and support pre diagnosis	<ul style="list-style-type: none"> • Provide information and support between referral and diagnosis: <ul style="list-style-type: none"> • Updates on waiting times • Information re alternative (faster) diagnostic pathways • Information re support groups • Behaviour management strategies
Concerns re accuracy of diagnosis	<ul style="list-style-type: none"> • Review diagnosis approaches • Ensure consistency in diagnosis between consultants • Recognise PDA
Lack of information and support post diagnosis	<ul style="list-style-type: none"> • Provide information and support post-diagnosis: <ul style="list-style-type: none"> • More and better signposting by teachers/social prescribers/diagnostic services(both NHS <u>and</u> private) to support and social groups • Behaviour management strategies • Lifelong support, not just a 6 week course • Individual as well as group support • More multi-disciplinary support (especially for children)
Confusion re pathways following NHS and/or private diagnosis	<ul style="list-style-type: none"> • Create a single, clear pathway that applies to both

Need to shift thinking (and action) from short term to long term.



General health



General health: Issues and Recommendations

Issue	Recommendations
Lack of understanding by those working in health and social care	<ul style="list-style-type: none"> • More education of all frontline professionals (including receptionists), to include education re PDA • Ensure <u>all</u> receive Oliver McGowan training
Lack of reasonable adjustments in most healthcare settings	<ul style="list-style-type: none"> • Ensure as much continuity of care as possible (any change → anxiety) • Introduce an autism coding to patient records (visible to receptionists as well as medical staff) • Offer quiet rooms with subdued lighting (when close observation not needed) • Offer longer appointments • Offer maps of hospital layouts + written/visual explanations where possible • Have an autism specialist ready to greet autistic patients and take them where they need to go • Talk clearly and succinctly (avoid ambiguities) • Encourage autistic people to carry Autism Alert Cards and/or Passports (particularly those with weaker communication skills and/or in need of more adjustments)
Inflexible appointment systems	<ul style="list-style-type: none"> • More flexibility → lower anxiety → fewer health inequalities. • Allow patients to book online as well as by 'phone. • Offer video and/or face to face appointments • Aim to call autistic patients within fixed time periods
Exclusion of parents/carers at 18	<ul style="list-style-type: none"> • Encourage doctors to allow parents/carers/other advocates to attend with adult patients



Mental health



Mental health: Issues and Recommendations

Issue	Recommendations
No clear and supportive mental health pathway for autistic adults	<ul style="list-style-type: none"> An easy to understand and clearly communicated pathway, with multi-disciplinary support A smoother transition from CAMHS to AMHS → supportive care for all whatever their age
No ongoing access unless in 'crisis' i.e. suicidal	<ul style="list-style-type: none"> Access to occasional support to prevent person reaching 'crisis'
Unsuitable/inflexible treatments	<ul style="list-style-type: none"> Consider the validity of CBT for autistic adults Consider ways of providing continued access to support once treatment 'finished'
Inflexible administration	<ul style="list-style-type: none"> More empathy with the problems autistic patients face when asked to fill in pre-appointment questionnaires, and when appointment times change – and more flexibility when managing such patients Consider the withdrawal of withheld telephone numbers

Voices

“A defined support pathway from referral stage with no end point. For support to be accessed throughout life as and when needed”

“Either mental health services or learning disability need to be commissioned to provide multi-disciplinary support to people with autism whose needs are more complex, or there needs to be a separate service”

“My grandmother changed her carpet 6 months after my grandfather died It took me 6 months to get used to it it's upsetting to talk to different people”

“Understand that people need access to support sometimes, not all the time ... people will have a wobble”



Social Care



Social care: Issues and Recommendations

Issue	Recommendations
Lack of support	<ul style="list-style-type: none">• Easier/faster access to support (to help autistic people cope with long and short term problems)
Lack of understanding by social workers and PAs → poor support	<ul style="list-style-type: none">• Mandatory training for all working in social care• Look at alternative model to PA's – using smaller social group interactions
High staff turnover	<ul style="list-style-type: none">• Incentivise staff to stay



Education



Education: Issues and Recommendations

Issue	Recommendations
<p>People believe the system is structured around budgets and not needs</p>	<ul style="list-style-type: none"> • Structure the system around needs and not budgets: <ul style="list-style-type: none"> • Schools to support all referrals: <ul style="list-style-type: none"> • If proven to have no needs, nothing to fear • If child has needs → more funding • Make it easier for schools to refer (less paperwork)
<p>Lack of understanding at many schools, both pre and post diagnosis</p>	<ul style="list-style-type: none"> • Teachers, and all school staff, to have training on ASD (not covered by teacher training): <ul style="list-style-type: none"> • Long term, improve all teacher training to understand SEN better. • Use outreach from SEN settings to do this cost effectively. Also use autistic teachers and autistic pupils (past and present) to deliver. • Run autism (awareness) classes from primary school age for pupils • Send lesson plans in advance so trigger topics can be identified before the lesson begins • Learn behaviour management strategies adopted by PRUs
<p>Lack of support at many schools, both pre and post diagnosis</p>	<ul style="list-style-type: none"> • Stop parent and child blaming. Assume potentially autistic until proven otherwise. • Provide support from the point parents/schools raise concerns • Maintain access to support throughout their education. Autism is never 'cured'! • Learn from what other counties are doing e.g. BERKSHIRE Parenting Special Needs run very helpful workshops for parents, young people, and adults pre and post diagnosis • Fund multi-disciplinary support teams in all schools (to include SALT and OT) • Recruit (more) ELSAs (Emotional Literacy Support Assistants) to work in all schools. These are creative educators and have been proven to make a huge difference with children.

Education: Issues and Recommendations (cont.)

Issue	Recommendations
Lack of support at college	<ul style="list-style-type: none"> • Create Specialist units within colleges • School to college passports written by people with an understanding of how college life differs from school life, and how that might impact an autistic young person. • Prescribed support levels to be supported by Council.
School environments are often not suitable for autistic pupils	<ul style="list-style-type: none"> • More, better resourced ARPs catering for the academically able as well as the less able, with children able to choose how much time spent in the ARP and how much in mainstream • More support for bullying for children attending ARPs • More “safe spaces” in school (quiet corners/rooms) where autistic children are able to self-regulate + allow autistic pupils to excuse themselves from lessons when they need to self-regulate (without asking)
Lack of support for the more academically able autistic children	<ul style="list-style-type: none"> • Understand that academically able autistic pupils still have support needs • A specialist school in Buckinghamshire for academically able autistic children who are unable to cope with mainstream education (or extend the role of existing school)
Variable quality of SENCOs	<ul style="list-style-type: none"> • All SENCOs to be fully trained • SENCOs to be f/t roles (potentially spilt across more than one school?) • SENCOs to be more willing to work in partnership with parents

Education: Issues and Recommendations (cont.)

Issue	Recommendations
Variable quality of EHCPs	<ul style="list-style-type: none"> • All ECHOs to be well trained and to work in partnership with parents and SENCOs • All EHCPs to be updated prior to transitions from Primary to Secondary, and from Secondary to College • There needs to be an independent quality check on EHCPs as they are failing in 90% of the cases
Overall	<ul style="list-style-type: none"> • Schools to stop trying to fit square pegs into round holes. Focus more on what autistic children <u>can</u> do: <ul style="list-style-type: none"> • <i>"It's about education. Telling people from a young age that they are special, they add value"</i> • <i>"She went to a football stadium and played football. It gave her loads of confidence. She was scared of the ball, but because people cheered her on she felt happy and tried her best"</i> • Introduce school youth forums as per the Reading model (gather views of autistic pupils/students to feedback to teachers, moderated by external facilitator) • Buckinghamshire Council to learn from other Councils that have received better OFSTED reports on their SEN provision

Training and work

Training and work: Issues and Recommendations

Issue	Recommendations
Lack of help to make training and work choices	
Lack of understanding among careers teachers → some follow unsuitable employment pathway	<ul style="list-style-type: none"> • Better trained and/or specialist careers advisers in schools and colleges
Lack of confidence among autistic people → don't apply for jobs	<ul style="list-style-type: none"> • Provide support and encouragement via Job Clubs • Continue to provide support when employment begins • Encourage them to work for 'We are Awesome for Autism' employers
Lack of understanding and acceptance by employers → low recruitment and retention	<ul style="list-style-type: none"> • Educate employers on the value autistic people can add • Encourage companies to: <ul style="list-style-type: none"> • Have champions in the workplace • Recruit via work experience rather than via interviews (and questionnaires) • Make the necessary reasonable adjustments e.g. quiet rooms → employee retention • Join the 'Awesome for Autism' scheme • Offer p/t and WFH roles
Lack of 'good fit' jobs i.e. jobs that fit their interests	<ul style="list-style-type: none"> • Will be achieved by achieving the above
Lack of support to gain and retain employment	<ul style="list-style-type: none"> • Increase funding for supported employment schemes • Maintain at least some support throughout each individual's working life



Housing



Housing: Issues and Recommendations

Issue	Recommendations
Lack of specialist housing that meets the needs of autistic adults	<ul style="list-style-type: none"> • Consider creating a specialist housing unit for autistic adults without learning disabilities, offering varying levels of support according to need. • Specialist unit should offer independent rooms/flats, quiet spaces, and a communal area for socialising / mutual support – the demand is there • Learn how other counties have offered specialist housing
Lack of specialist support to find suitable housing and to support the transition	<ul style="list-style-type: none"> • Ensure all support staff are trained in autism, and the reasonable adjustments needed
High staff turnover	<ul style="list-style-type: none"> • Ensure new staff in supported housing / care homes are gently introduced to residents.

“It has to be staffed to cope with crises ... explosions can be managed ... it’s the implosions, the closed down moments that are more difficult. They’re the ones that are missed” (Professional)



Community Access



Community access: Issues and Recommendations

Issue	Recommendations
Lack of social groups suitable for autistic children and adults	<ul style="list-style-type: none"> Increase awareness of and support for groups that exist, and support the formation of new groups
Many autistic adults struggle with accessing services and making benefits claims	<ul style="list-style-type: none"> Education of all working in public services re the communication challenges faced by those with hidden disabilities Offer more flexibility re access to support services (not just phone / just online) Provide help with form filling
Many struggle with using public transport	<ul style="list-style-type: none"> All front line staff employed in public transport to receive training Signage on public transport to educate the public on hidden disabilities Travel training to give young autistic adults the confidence to use public transport. Schools to do for all pupils? Specialist PAs to support adults who struggle to travel alone.
Many struggle with accessing leisure and other facilities	<ul style="list-style-type: none"> More quiet times with reduced lighting Discounts for those on benefits Free/reduced cost access for accompanying carers PA support to encourage attendance Training on hidden disabilities for all frontline staff Council (or other) to produce a list of autism friendly services and businesses – checked by Experts by Experience
Lack of support for parents	<ul style="list-style-type: none"> Increase awareness of and support for groups that exist, and support the formation of new groups



Criminal and justice

Criminal and justice: Issues and Recommendations

Issue	Recommendations
<p>Lack of understanding and acceptance by many working in the profession (as well by jury members) → failure to make reasonable adjustments</p>	<ul style="list-style-type: none">• Education of all working in frontline services + jurors in cases where the defendant is autistic• Autism Alert cards (or similar) to enable arresting officers to identify autistic individuals• Everyone who is an autistic person should have the right to an advocate to be alongside them throughout the process• Police and solicitors need training in recognising the responses and the communication styles adopted by different people.



Final words



Analysing the verbatim responses using Tag Clouds (visualises the relative use of words in the free text responses)

Autistic adults: What, if anything, could be done to address these concerns?

access adults autism **autistic** education groups health help mental
 people reduce school **services** **support** understanding

Parents/carers: Please type in the box below anything else you would like to share about your experience as a carer for an autistic person and any suggested improvements in the help needed

acceptance access adults asd autism **autistic** awareness community deal
 different education etc fidget greater information kids needs pens **people** person
 public school services social **support** teachers things think toys **training**
 understanding writing



Autistic adults want mainly a clear pathway of support – but also understanding
Parents/carers want mainly understanding – but also a clear pathway of support

Tag Clouds (cont).

What one improvement would make it easier for you to live in the community in Buckinghamshire?

Autistic adults

access autism **autistic** health mental people social **support**

Parents/ carers

access authority **autism** autistic behaviour best bucks care carers child children community
 diagnosis due education effect family feel fight functioning fund gets given groups health **help** individual legal local
 mental money needs offer **parents** people person private professionals rather **school**
 services social **support** teachers therapy trained understanding wait work years



For both groups, the big difference would come about through greater support

“If you’ve got autism and you’ve got communication issues – you need support” (Professional)

Final, final words: The need for greater understanding and support

- It's clear from the analysis of the final questions (visualised by the Tag Clouds on the previous 2 pages) that **for the strategy to make a difference it needs to focus on creating greater understanding and on providing more support:**
 - Support for autistic children through their education, from pre-school to leaving college – helping them with life skills and bullying prevention as well as academic learning
 - Support for parents to help them navigate 'the system' in their pursuit of giving their autistic children the best chance in life – even if that is just a simplified pathway which makes it easier to navigate
 - Support for autistic adults to help them cope with living in a neurotypical world, so help with work, housing, health issues, filling in forms and other issues (if and when needed) – and support for those times when they are beginning to 'fall of a cliff' (to prevent them actually falling)
- Such support needs to be provided by all public services and by more funding for the VCS sector – as well by enabling autistic people and their carers to support each other.
- Any increased spending in the short term will be more than offset by subsequent savings on mental health expenditure and benefit claims in the longer term. **Early intervention should be a priority.**



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