

AUTISM AND AUTISM + LEARNING DISABILITY

# GM Children and Young People

Why we do not want to take part in  
coproduction, and what can change that

"How can I possibly  
advocate for myself  
when I use all of my  
energy just trying to  
survive?"

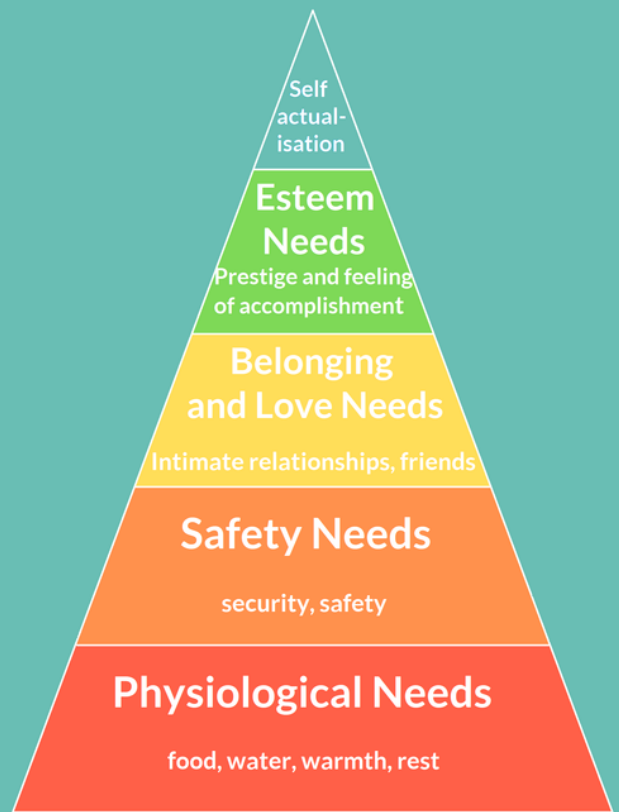
**SUMMARY DOCUMENT (July 2019)**

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# CHILDREN AND YOUNG PEOPLE'S PRIORITIES

Our ten main priorities, both to ensure our needs are met, and to enable us to engage in coproduction by making us happier, making our lives easier and giving us hope and motivation to contribute to change.



## 1 TRAUMA

Under recognised and under supported, despite huge amounts of research showing higher prevalence and less support when we experiencing trauma. Trauma is a huge sticking point for some of us, especially those seen as 'challenging' or at crisis point

## 2 SENSORY INTEGRATION

Sensory regulation and accommodations are key to ensuring we are able to have positive experiences. However, there is a huge lack of sensory understanding and support, meaning needs are not being met, which both increases difficulties and stops us from reaching our full potential

## 3 SELF ACCEPTANCE

We need to be taught that it is ok to be different. The most important thing in life is to not try and fix the negatives of your disability, but instead to accept and embrace them, and live the best disabled life you possibly can

## 4 MENTAL HEALTH

Many of us do not get the access they need to mental health services, due to diagnostic overshadowing, services refusing to support autistic people, or refusal to adapt therapy and/ or make reasonable adjustments

## 5 LONELINESS AND "OUR" COMMUNITY

As a whole we are all incredibly lonely, but surrounding our lives with people isn't the solution. Being surrounded by the wrong people is what makes us feel the loneliest

## 6 PARENTAL ATTITUDES AND SUPPORT

What a parent is told about autism post diagnosis has a huge impact on their attitude towards autism and how to support their child. Parents need to be given the right message and need to have the right support networks around them.

## 7 SCHOOL SUPPORT

The biggest challenge most of us face is school. 98% of parents say schools don't understand autism enough, and that is also reflected in the thoughts and feelings that we have shared with you.

## 8 PEER ACCEPTANCE

We do not want to just strive to not be bullied (bullying is a huge problem for the majority of us). We want to be accepted for their differences, so we can be happier with who we are, and not be consistently mistreated.

## 9 HAPPINESS

So much time is spent measuring progress, and trying to introduce new therapies and interventions. But you forget what is the most important thing for us: happiness.

## 10 COPRODUCTION

We have developed a promising coproduction diagram they wanted to share, but the first 9 priorities must be met to ensure it is successful.

**NOTE: The term 'autistic' in this document is inclusive of autistic people with learning disabilities**

# WHO HAS CONTRIBUTED TO THIS DOCUMENT?

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## 9,500

### PEOPLE COMBINED

Parents, carers, relatives, professionals and more have shared their views through "A Spectrum of Possibilities" via polls, surveys, comments and more. This includes 1:1 support with over 400 families over email and online and face to face support for over 200 families who live in Greater Manchester. The views of parents and others have increased understanding of reasons behind certain thoughts, feelings and priorities.

## 350

### AUTISTIC ADULTS

This includes over 55 face to face meetings with autistic adults within Greater Manchester. These views are very powerful as autistic adults have the benefit of hindsight and have a lot of insight into what can be improved and what is going well.

## 2,900

### CHILDREN AND YOUNG PEOPLE

This includes the voice of over 450 children and young people across Greater Manchester. 182 children and young people have met face to face to share their views, 19 of whom were home elected, 37 were in special school placements, 107 were in mainstream, with 31 'significantly struggling', 19 were in enhanced provision attached to mainstream schools.

This report has been written based primarily on the views of the children and young people within Greater Manchester. However, these views have been benchmarked against national views of children and young people to increase identification of key themes and issues.

About 90% of children and young people who have contributed have an autism diagnosis and about 10% are autistic and have a learning disability.

## Other

This report has been influenced by my personal and professional experience.

A Spectrum of Possibilities has had a reach of over 13.5 million, and over 900,000 engagements (likes, comments, shared, link clicks and messages). All of these interactions have been reflected upon to ensure the views of children and young people are represented in the best possible way. However, I am unable to quantify how many of these interactions have fed directly into this.

I have lived experience as an autistic adult, who has also read over 200 books about autism.

I am in contact with some of the UK's leading autism professionals who have supported this document, and am aware of a variety of related research.

**NOTE: The term 'autistic' in this document is inclusive of autistic people with learning disabilities**

# THE GAPS

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## NON VERBAL AUTISTIC CHILDREN

Most non verbal autistic children only have access to closed communication methods such as PECs, so are unable to share how they truly think or feel.

There are cases of non verbal autistic children who have learnt to communicate independently by first using assisted communication such as 'Facilitated Communication' or 'Rapid Prompting Method', but this is very uncommon in Greater Manchester. There is also no best practice guidance on how to enable other non verbal autistic children to do the same. For these children, their main barriers to communication are their sensory and motor difficulties, and more understanding and support is needed to enable them to express their views.

## AUTISTIC CHILDREN WHO ARE THRIVING AND HAVE HAD WHOLLY POSITIVE EXPERIENCES

The majority of autistic children, young people and families have been in contact due to their negative experiences, and actively looking for resolution and positive changes to be made. There is a lack of views from autistic children and young people who have had wholly positive experiences, due to less motivation to share their experiences.

There has however been input from autistic adults who have learnt by experience what the most positive aspects of support are and the best practice in ensuring autistic children and young people can thrive.

## AUTISTIC CHILDREN WITH SEVERE LEARNING DISABILITIES

Autistic children who have severe learning disabilities have also been unable to share their views, due to their primary communication methods being needs based, such as using echolalia or PECs.

There are huge gaps in knowledge in understanding the challenges people with severe learning disabilities face and enabling them to develop more functional methods of communication.

## 16-18 AGE RANGE

Less than 20 people have been in the 16-18 age range, including only 2 people in the age range who have been met face to face.

# YOUNG PEOPLE DO NOT WANT TO ENGAGE IN COPRODUCTION – REASONS WHY AND THE SOLUTION

The purpose of this work was to gather the views of children and young people and create forums to increase future coproduction.

However, it has been hugely difficult to gather views and attempt to put these systems in place. Luckily, I have been in contact with young people and their families through my Facebook Page "A Spectrum of Possibilities". Without this, this document would have been incredibly difficult to create. This page will explain why.

The majority of autistic children are constantly in survival mode.

They are misunderstood by others, there are no opportunities to begin to understand themselves, they are mistreated, isolated and singled out at school. They are left unregulated and feeling anxious and unsafe. A young person said that he feels like he is an actor in a movie, but everyone has the movie script except him.

The priorities listed in this report don't just show the needs of these children which need to be met. Meeting these needs will result in children and young people having more capacity to contribute via coproduction.

Meeting these needs will also give children and young people hope; hope that things will get better and that things will change. Children and young people will be able to start dreaming and thinking about the future rather than having to focus all of their energy surviving in the present. This is a chicken and egg situation. Children and young people need to share their views so their needs can be met, but their needs also need to be met before they are able to fully share their views. Therefore, **this document can be used as a snapshot of current needs that have been identified and need to be addressed going forward to enable future coproduction to take place.**

Right now, there are three main groups of children and young people who mainly contribute to co-production:

Children and young people who have faced extremely challenging situations, so feel the need to retaliate and need a sense of justice

Children and young people who get involved with coproduction for professional development

Children and young people who attend due to their parents asking them to attend, without much motivation to contribute

Meeting the needs listed in this document ensures the views of as many children and young people are heard. The young people who have contributed have also written a framework for effective coproduction, which can be viewed at the end of this document.

Recently I created a survey to capture the views of more children and young people, and the result was very bleak. Some of the views were expressed through this video:

<https://www.youtube.com/watch?v=hCrv8K5F2Ss>

1



# TRAUMA

**"Why do I feel so angry all  
of the time?"**

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NOTE: All quotes and case studies in this document are from children and young people who live within Greater Manchester

# TRAUMA



## WE FACE INCREASED RISK OF TRAUMA, DUE TO:

- Increased rates of bullying and other forms of abuse
- Being more likely to be socially isolated
- Communication difficulties
- Being more prone to victimisation
- Overwhelming sensory experiences resulting in trauma
- Higher levels of family stress
- Heightened trauma responses due to difficulties with self regulation
- Being more 'in the moment' and unable to see 'the forest for the trees' due to increased anxiety
- Using expressive suppression as a main coping strategy, which is maladaptive as a primary method of emotional regulation, as opposed to cognitive reappraisal
- Feeling out of place and misunderstood by others

## BUT...

"Despite the many factors that make children with ASD more prone to the experience of trauma, there is a paucity of research in the field." and

"Currently, there is no evidence based practice for the treatment of trauma [for autistic individuals]". Slack and Lucyshyn (2018)

## THE MAJORITY OF THE TIME, YOU ARE NOT SUPPORTING AN AUTISTIC CHILD, YOU ARE SUPPORTING A TRAUMATISED AUTISTIC CHILD.

It can be difficult to discriminate between autism and trauma as both are behaviourally defined, but lack of identification and support of those of us that are traumatised is having a tremendous impact on their lives.

Hyperarousal, flattened affect, difficulties with attention, self-injury, inflexibility and more of what are seen as the 'negative traits' of autism reduce dramatically when both the person's support needs are met and they are supported through trauma.

Currently, you have to be seen as a 'problem' to receive an autism diagnosis. Once you have enough 'concerning behaviours', you receive a diagnosis and are entitled to support, even though you are born autistic.

This has huge implications in practice, as trauma related behaviours are seen as part of autism, when we need real opportunities to recover from traumatic experiences.

# TRAUMA

## LACK OF AFTERCARE AFTER NEGATIVE LIFE EXPERIENCES

Traumatic experiences become a 'sticking point'. A lot of us feel constantly 'angry', 'anxious' or 'empty'. How can we be expected to thrive whilst also trying to cope with constant negative thoughts and feelings?

## THE BEACON HOUSE BOTTOM UP APPROACH TO TRAUMA

A clearly effective method of supporting us through trauma is by using the Neurosequential Model and using a bottom up approach to trauma, which is clearly explained by Beacon House through the blog and resource on their website.

*"I am diagnosed with PTSD. I am really struggling and have absolutely no idea how to overcome it"*

- Leah, 16

## CASE STUDY

Fred has failed two education settings, and is likely to fail his third in a specialist setting. The private psychologist working with Fred (when his parents can afford them) has stated they believe he would thrive at school, as he craves socialisation and is desperate for friends. Fred is academically able but needs the right professional support and understanding to help him come to terms with the trauma caused by school.

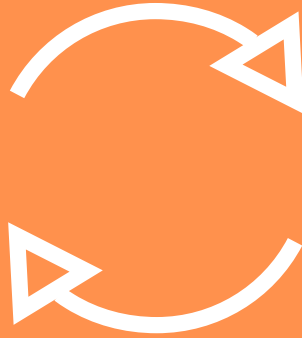
Fred no longer believes he is able to learn and is afraid. He has no sense of self worth and often refers to himself as dumb or stupid. He sees no opportunities for the future and in his lowest moments says 'there is no point to life'.

Fred has been out of school for a year, and whilst he has been given a place at a specialist school, he has been unable to attend due to extreme anxiety and panic. The school say they can only help him if he is attending.

Fred is giving up on himself. He has stopped taking part in hobbies, has lost a place at a music college, and is scared of learning. He is lonely and frightened. No one has any idea how to get him the help he needs.



2



# SENSORY INTEGRATION

*"The better the day I've had, the  
worse I feel when I get home"*

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# Sensory integration

Sensory integration is about how our brain receives and processes sensory information so that we can do the things we need to do in our everyday life. Due to sensory differences in autistic children and young people, sensory integration is often a challenge. We wanted to share the two main concepts that need to be considered in order for our needs to be met:

## Self regulation

Self regulation is the ability to adjust or regulate your level of alertness to be at the optimal state for attention, communication, social and emotional demands and more. The majority of us struggle with self regulation and need support to maintain an optimal state of arousal. This can result in meltdowns, frequent fight/ flight/ fright responses and high levels of stress and anxiety when arousal levels are too high, or inattentiveness and drowsiness when arousal levels are too low.

### CASE STUDY

Julia had a really fun weekend and was very excited throughout.

When she got home on Sunday, the excitement quickly became anxiety and she started feeling worried and highly stressed: *"How can I ever be happy when the better my day was, the worse I feel afterwards?"*

This feeling is due to difficulties with sensory regulation which are very common in autistic children and young people. She needs the skills and knowledge in order to self regulate, or needs support from others to regulate, so that she is at the optimal state or arousal for relaxing when she is at home.

She now goes on a walk with a heavy backpack between coming back from an activity and relaxing or getting ready to sleep in order to self regulate. If that isn't enough, she will go on a walk with a family member or do some exercises.

# Sensory integration

One of the common reasons for our difficulties with self regulation is differences in one of the 8 sensory systems: interoception.

Interoception is the process of feeling your internal bodily sensations and translating them into emotional and bodily states e.g. hunger, thirst, anxiety, happiness, anger. just as with the other 7 senses, some of us are oversensitive to interoception, resulting in constant feelings of overwhelm. Some of us are also undersensitive to interoception, meaning that we may not be able to properly recognise the emotions we are feeling until it is too late and we are having a meltdown.

Another challenge is alexithymia - this is where you have a body-brain disconnect; you can feel the internal bodily sensations, but your brain does not tell you what they mean. This can cause confusion, as well as difficulty identifying emotions, and knowing what action to take as a result.

## CASE STUDY

John reports feeling an uncomfortable feeling in his chest, which intensifies and lessens throughout the day, but he has never understood what it is. After a session with a psychologist, it was determined that this feeling is one of the internal sensations he feels when he is anxious he has a body-brain disconnect with his emotions so needs to work on manually interpreting his internal bodily sensations so that he can properly understand them and work out how to respond.

*"Help me with my sensory diet - sensory regulation is key to learning and emotional health"*  
- Jessica, Aged 17

A basic proprioceptive based sensory diet and a 5 point scale (to be used proactively) or similar system is the absolute basic support for sensory regulation that every autistic child should have access to.

*"Let me move, stand up, wiggle and walk around."*  
- Alisha, Aged 13



Rating	Looks/Sounds like	Feels like	I Can Try
5			
4			
3			
2			
1			

# Sensory integration

## Sensory Accommodations

It is common for autistic children and young people to have 'extreme' sensory differences, meaning the world can be much louder, brighter and scarier, but also more dull and quieter for us. As well as these sensory differences making the world more difficult to navigate, they make it hard to self regulate - someone who is hyper-sensitive to sound is likely to be in a constantly high arousal state if they do not have support with this.

Comments from some of us regarding sensory differences include:

"Shower water feels like knives are piercing through my skin"

"Labels on clothes feel like spiders crawling underneath their skin"

"The hand dryer feels like a lion is roaring inside my skin"

"You don't know what it is like to be me, when you can't sit still because your legs feel like they are on fire"

We need accommodations to make the world easier to navigate and tolerate, and to ensure we are able to be at the best possible arousal state at all times. In order to do this, sensory needs need to be identified and knowledge about sensory differences needs to be increased.

*"Don't trivialise feelings. If I say it is too noisy, too bright, or I am sad or scared, believe me. Then please help me find solutions"*

- Sarah, 18

*"Let me bring sunglasses into school"*

- Rowan, Aged 8

*"I feel safer at school when teachers don't shout."*

- Carter, Aged 9

## CASE STUDY

Bob is hyper-sensitive to sound.

As a result he massively struggles to tolerate fire alarms. The overwhelming effect of fire alarms, in addition to the uncertainty of knowing when a fire alarm will go off means Bob is in a constant state of anxiety when he is indoors - he is terrified of another fire alarm going off, due to it being completely unsuited to his needs.

His mum recently purchased a 'smart smoke alarm' for the home. Now, rather than an alarm noise which Bob cannot tolerate, a voice says "smoke has been detected", starting at a low volume, and increasing as time goes on, with the option to turn off the smoke alarm from a mobile device.

Bob can tolerate this much better, and it still lets the family know that there is a possible danger.

Unfortunately, alarms like this are not common practice and he still struggles in other environments.

3



**SELF**

**ACCEPTANCE**

*"It is difficult when no one understands you, it is even worse when you don't understand yourself."*

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# Self Acceptance

In a survey, as part of the research for this project, one of the questions was:

*“If you could change one thing about your life right now, what would it be?”*

Here are some of the responses:

*“My autistic behaviour”*

*“I wouldn't have the conditions that I have”*

*“I'd go back in time and stop myself being born”*

*“I would be dead, or I would of won the lottery so I could fix what I see wrong with the country”*

*“To not be autistic and not suffer from mental health problems”*

*“The impact of autism on the rest of the family”*

*“To not have autism”*

These responses show a very sad story. How can you live a happy life and thrive when you have learnt to despise an integral part of who you are?

When you receive diagnosis of autism, you do not have any opportunities to understand what this means and have adequate support. This means a lot of us learn to blame any mistreatment by others, and any struggles and challenges they face on autism, resulting in self hate or trying to dissociate from autism, both of which have very negative implications. We learn to be ashamed of autism or to hate it, because we do not understand what being autistic means.

## CASE STUDY

Matilda has been taught from the start that being different is ok and she should be proud of who she is. Her mum, who is also autistic, talks to her frequently to ensure she understands what being autistic means. Matilda has been through some very difficult situations; being excluded from school, bullied, attacked by strangers and neighbours, and Matilda is only 10 years old.

However, since she has been taught about her differences and what they mean, she understands that the mistreatment and suffering she has gone through is not her fault, it is as a result of others misunderstanding her and mistreating her, rather than her blaming herself and autism, which is what frequently happens. Opening up a dialogue about autism not only promotes self acceptance, but helps young people to become more resilient mentally stronger, according to Matilda.

# Self Acceptance

Diagnostic overshadowing can also have negative effects in this respect. We learn that feelings of anxiety, depression and more are part of autism and are seldom given the opportunity to distinguish between autism and other conditions. Here is a list of conditions that are either often conflated with autism or are frequently under recognised, resulting in needs not being adequately met:

Anxiety, Depression, PTSD, Complex PTSD, Irlen's Syndrome, Trigeminal Neuralgia, Dyspraxia, Alexithymia, ADHD, OCD, Dyslexia, Dyscalculia, Learning difficulties, Synaesthesia, Hypermobility, Ehlers Danlos Syndrome.

Autism is a powerful word. Knowing that you are autistic can be empowering - helping you know you are not alone and there are millions of other people who think and feel the same way you do. Talking about autism also helps you to understand yourself and self advocate. However, autism often becomes a word people are ashamed of and despise, because autism and autistic people are so frequently misunderstood and mistreated. Parents and professionals have a variety of opportunities to learn about autism, for example via training, but what about us? We need to learn about autism more than anyone else, but get the least opportunities.

We should be talked to about autism through the concept of Neurodiversity: there are lots of different types of brains, all with their own positives and negatives, but all are ok. Then we will be able to distinguish between which parts of our thoughts, emotions and behaviour need to be accepted and which can be changed, but also what autism is and what it is not.

*"I would like to be proud of who I am"*  
- Todd, 12

*"I want to know it is ok to be me"*  
- Zohaib, 13

*"Difference isn't a bad thing, stop trying to make me normal"*  
- Andrew, 10

## CASE STUDY

Alan has been diagnosed with autistic traits, but not autism itself. Not knowing whether or not he is autistic and feeling like he doesn't fit anywhere has left him in a constant state of uncertainty. What he wants more than anything is confirmation of who he is, without being left in a state of limbo.

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# MENTAL HEALTH

**"We can't help you as anxiety is part of autism"  
- A Healthy Young Minds professional to an 8  
year old autistic girl who was immensely  
struggling**

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# Mental Health

**There is a complete lack of support for those of us who are experiencing mental health difficulties**

For the majority of us, it feels like there is no way to get mental health support, and the few who get support are lucky to have access to it through a local Third Sector Organisation.

When young people have support from Healthy Young Minds, either:

- We are informed that anxiety and/ or depression are a part of autism so we cannot be helped (just to be clear, both anxiety and depression are **NOT** part of autism)
- The interventions that are used are not adapted to meet our needs, so the huge majority of support is ineffective, and sometimes has a negative impact.

There is a clear lack of understanding of how mental health difficulties present in autistic children and young people, and more importantly what can help.

Furthermore:

- Support from Healthy Young Minds uses a top down rather than a bottom up approach. We are given coping strategies to continue surviving in our current life position (even if it is a very negative one), rather than working together and putting plans in place to improve the situation we are in, and alleviating mental health difficulties as a result
- Healthy Young Minds and Education have a complete lack of understanding of masking, including the damage it causes and what needs to be done to support someone who masks at school

*"Please stop saying 'everyone feels like that sometimes'"*

*- Daryl, Aged 12*

## CASE STUDY

*Jacob appears quiet but content at school. However, when he gets home, he displays very challenging behaviour, has several meltdowns and struggles for the rest of the day.*

*Jacob's parents asked school for support with this, and they were sent on a parenting course. Jacob's behaviour remained the same after school despite his parents trying some new strategies and techniques, and they were unsure of what can help him.*

Jacob is a **masker**. He finds his school environment completely overwhelming, and uses all of his energy to focus on fitting in and looking 'normal'. As a result he looks fine and is relatively quiet. However, as the day progresses his levels of stress and anxiety get higher and higher, then when he gets home and is in a comfortable environment, his emotions come out. The reason for Jacob's difficulties is not home, but in fact it is because school is not adequately meeting his needs. However, for Jacob and many other young people who display with the same behaviour, parents are blamed for the behaviour by both education and health changes, and as a result they continue to struggle every day.

5



# LONELINESS AND 'OUR' COMMUNITY

**"I always felt alone and out of place, until I  
learned that there are lots of people out  
there who think and feel the same way  
that I do"**

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# Loneliness and "our" community

So many of us are incredibly lonely. In fact, 94% of autistic children and young people said they want to be able to make more friends.

There are three things that have been expressed by almost every single one of us:

- We would like more friends
- We would like more social opportunities and fun things to do
- We would like more opportunities to meet and learn from others who are also autistic

Young people do not want one social opportunities service commissioned. We hope to have a variety of activities to get involved with based on their interests.

We also want two types of groups:

- Groups specifically to socialise with others who are like us
- Groups that are available for everyone, but which are inclusive from the start so they can be accessed and enjoyed

*"I would like to worry less and have more opportunities to socialise"*

- Abbie, 12

*"I don't do anything or talk to anyone after school"*

- Zach, 10

*"I want to do things that interest me rather than being forced to socialise"*

- Tim, 13

*"I'm really desperate to have just one friend"*

- Tristan, a 9 year old boy who has attend the only locally commissioned social opportunities service for 3 years

*"I am really isolated and have no friends"*

- Dominic, Aged 12

*"There is nothing that I like to do in my area"*

- Noah, 9

*"I want to learn how to make more friends"*

- Freya, 14

*"I have no social life or friends"*

- Jack, 15

*"I want to feel like I fit in somewhere"*

- Lee, 11

*"I am so lonely and my life has no purpose, what is the point?"*

- Ryan, 12

*"I would like to meet someone who understands me"*

- Kaylan, Aged 10

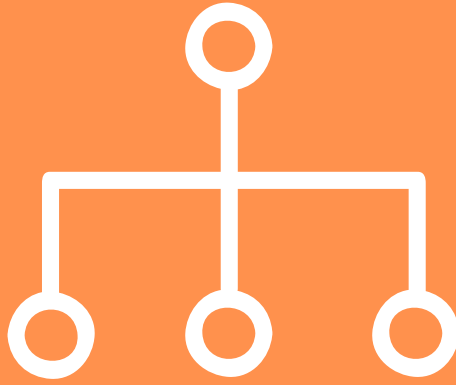
## CASE STUDY

Beth is 11 years old and autistic. Her favourite time of the week is Monday as there is a Pokemon club that runs in her area every Monday evening.

The group started with a main room and a designated quiet room if people find the main room too loud. It also has 2-3 mentors at every session who support new players and people who are looking to improve their strategy and gameplay. Whereas Beth does not attend any other social opportunities, she loves going to Pokemon club because Pokemon is one of her favourite things, and the club has adaptations in place to make it inclusive.

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6



**PARENTAL  
ATTITUDES AND  
SUPPORT**

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# Parental Attitudes and Support

Just as we go on a journey of discovery and self acceptance, parents must too, and they need to be supported with that.

Every parent has their goals, dreams and aspirations, and their children usually fit into that.

However, we know that when our parents have autistic children, their lives may not be how they previously expected them to be.

Just as autistic children need to learn that we need to live a 'different from the norm life', parents of autistic children need to be taught that and given support with this too.

Parents also need to have a support network around them to help with this.

The below article from Debby Elley, founder of Aukids Magazine is a perfect explanation of this concept:

# Positive about autism

*Debby Elley looks at how we can help children with autism to feel good about themselves*

**M**y twins were diagnosed with autism on the same day in November 2006. By the time the autism assessment test (ADOS) had come around, we were pretty much expecting the outcome to confirm that they were both on the spectrum. There had been pointed hints in this direction for about a year and although no-one wanted to nail their colours to the mast, phrases like "speech delay" and "social communication impairments" had us prepared for the inevitable.

We were expecting it, but I still felt miserable after the news was broken to us in a quiet and tactful way. The twins – cute, bubbly and interactive – were each given a score and it felt like they

*It took me many years to come to the conclusion that autism isn't a disaster but a difference*

had failed the test for "normal". The new label temporarily destroyed my happiness. Worry over the unfamiliar was mixed with a lack of clarity over how impaired they would be and what it meant for their future.

I can't recall the follow-up meeting, only that it involved arranging a series of referrals. The thing is, I can't remember anything positive about the experience,

but then how many parents do feel good in those months post-diagnosis?

## **Too much negativity**

My twins Bobby and Alec are now 14 and are as charming as ever (although with a giant dash of teenage stropiness).

It took me many years to come to the conclusion that autism isn't a disaster but a difference. The question I'm pondering is: is it really inevitable that this should take years? An autism diagnosis is by no means insignificant and can't exactly be laughed away, but should it really make parents feel so downcast?

There are several problems with feeling miserable after a diagnosis. The



first is that it stops you from “hitting the ground running” with any intervention, as instead you’re going through a period of mourning. The second is that it robs you of any sense of power in your own parenting. The third is that it leads you to consider your children are somehow lacking or lesser beings. As well as affecting you, this emotional response in parents transfers to their children.

Longer term, there is too much at stake for this issue not to be addressed. How parents first understand and process the news that their child has autism can colour their entire approach towards parenting, including their thought processes when things go wrong. This in turn will affect how they cope.

Whether you perceive autistic difficulties as “impairments” (the child is a faulty version of a non-autistic one) or the result of different neurological wiring will have a huge impact on your state of mind. In short, how are our kids going to grow up feeling positive about their autism if a parent’s original response to news of their condition was shock and depression?

What makes me smile (in a cynical way) is that there are now several good books on the market dedicated to telling your child about their autism. The authors have had to write these to meet demand. Why? It’s because parents fear that in telling their child about their autism, they will transfer their own emotions from that rather traumatic post-assessment time. It requires a self-help book to unpick that negative thinking and knit it into a more positive approach. That’s right, we have to undo any notion of the sense of “faulty” or “wrong” for the sake of our kids, when the same courtesy wasn’t afforded to us as parents.

### Autism is ever changing

So, what should professionals be telling parents in those delicate early days? Well, there are some key things that I learnt about autism that I think would have helped me to come to terms with it a lot more easily.

Autism is a life-long condition. However, that phrase gives the impression that autism is like a solid brick, which stays the same over time. In reality, autism changes and is mouldable. Although the autism itself may never disappear, the core difficulties associated with it can greatly reduce with intervention, maturity and time.

Of course, practitioners may suppose that to over-promise will raise expectations, only for them to be dashed. Yet wherever you sit on the spectrum, things do change. My twins have greatly varying communication abilities, but both of them have made dramatic improvements. In fact, I don’t know a child who hasn’t. To be positive isn’t to promise the world, but we need to get across the message that although these difficulties are very real, they can be reduced and they are simply a logical response to a different interpretation of the world.

It isn’t that professionals try to be misleading. Rather, in the absence of information like this, parents reach their own rather despairing conclusions.

Every aspect of the spectrum – communication, social interaction, rigidity of thought and sensory difficulties – can be heavily influenced by our understanding of the difficulties that underpin them and by intervening with simple strategies. Even rigidity of thought – something that I thought we were stuck with – can bend if you apply the right strategies. No-one told me. I learnt that the hard way.

Plus, we know that anxiety is linked to many of the difficulties experienced in autism. If a parent isn’t anxious about their child being autistic, they won’t transfer that emotion onto the little one, and kids then stand a better chance of building resilience and confidence in who they are.

### Valuable qualities

And what of autistic strengths? Is it really fair to present autism as “impairments” right from the start, when autistic thinking can be so useful for society? Not everyone with autism is a “savant”

## *Even rigidity of thought can bend if you apply the right strategies*

or genius nor should we pretend they are. But those with autism, once they love something, become specialists in it. This focus and attention to detail can lead to immense achievements. There’s the logic, systemising, creativity, recall, honesty and tenacity – and the list goes on. Must we put such weight on social “impairments” when there is so much more to autism than that?

Autism doesn’t necessarily equal lack of ability or intelligence. Parents should know this from the start. It’s quite simple, really. All I ask is that they are shown both sides of the same coin, rather than feeling that their precious currency has suddenly been devalued. [Read more](#)

### Further information

Debby Eley is the Co-Editor of AuKids Magazine. Her new book *15 Things They Forgot to Tell You About Autism* is published by Jessica Kingsley. [www.aukids.co.uk](http://www.aukids.co.uk)

7



# SCHOOL SUPPORT

*"I would rather be dead than go to school"*

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# School Support

There is a universal lack of understanding of autism as a whole and how to meet the needs of autistic children in mainstream schools.

There is also very little inclusive practice present across Greater Manchester. 98% of the young people we spoke to who were in a mainstream school (or mainstream school is the last provision they attended) said that school staff do not understand autism enough.

Schools need to be much more inclusive, but that inclusion is not just practical and defined by provision, but also includes feeling valued and wanted, and like we belong at the school. Inclusion is a feeling, not a place, and a lot more needs to be done to achieve that feeling across Greater Manchester.

Another barrier preventing us from getting the right support in school is the attitudes of education staff. There seems to be a culture of autistic children being seen as a problem rather than a positive challenge. We know we are different and need more or different support as a result, but many of us feel we are viewed as an inconvenience, which does not fit with true inclusive practice.

*"Stop expecting me to be the same as the rest of the pupils"*

*- Kelsey, Aged 13*

*"Don't offer support for the child you want me to be, but the child I am right now"*

*- Elliot, Age 12*

*"Stop punishing me for the things I find the most hard - memory, talking and concentration. It is never going to help and just makes me feel bad and frustrated"*

*- Ollie, aged 13*

# School Support

## QUOTES FROM YOUNG PEOPLE ABOUT MAINSTREAM SCHOOL IN GREATER MANCHESTER

*"School makes me feel like I don't want to be here anymore" - Marco, 13*

*"Find positive ways to deal with my traits rather than punishing me" - Charlie, Aged 9*

*"I'm not naughty. If I could do better, I would" - Celia, Aged 9*

*"I struggle every day but no one will help me" - Steven, 9*

*"I won't be able to tell you I am struggling, but I am" - Evie, Aged 11*

*"I may be quiet, and I may not be trashing the classroom, but that does not mean I'm okay." - Bianca, Aged 10*

*"When I am running out of class or hitting myself, I am not being naughty or disrespectful, I'm not coping and don't know how to say it!" - Siena, Aged 10*

*"Having plenty of experience of autistic children does not mean you have experience of me" - Robert, Aged 13*

*"Understand masking and anxiety better" - Harry, Aged 12*

*"I'm trying my best, I REALLY want to succeed" - Max, Aged 11*

*"There is a lack of empathy and understanding from school" - Ellie, 15*

*"School don't understand me and its noisy" - Ethan, 9*

*"I hope that one day school will understand me" - Beth, 10*

*"Believe me and my mum when we tell you things are hard for me" - Brad, Aged 11*

*"I really, really hate school" - Fin, Aged 9*

*"I wish people had more understanding of autism in general" - Christian, Aged 15*

*"Why can't teachers and others in my class just understand?" - Freya, Aged 8*

*"School is one of the reasons I have depression and it has failed me all my life" - Harvey, Aged 12*

*"I hate school and I cry every single day because of it" - Jasmine, 11*

*"Get some training please" - Owen, Aged 14*



# Peer Acceptance

Many of us are bullied at school. There are anti-bullying policies and procedures in place in education to try and prevent this, these procedures do not always work and even when they do, it isn't enough: "We shouldn't strive to just not be bullied, we should strive to be accepted".

Just as there are people with different eye colours, different hair colours, different genders and more, there are also people with different types of brains. We want to increase understanding of different types of brains, and promote the fact that all of these differences are ok. The term neurodiversity has been coined for this exact purpose, and we want neurodiversity to be accepted and celebrated as much as diversity is both in their education settings and in the local community.

One young person said he wants it to be ok for him to walk around the classroom so he can get sensory feedback and be able to concentrate better on what is being said. Another young person said he wants to have a timetable detailing exactly what is going to happen and when. Another young person has asked if the lights can have dimmer switches to reduce the chance of being overwhelmed by her light sensitivity. We don't just want to have this support in place, but we want it to be accepted by peers and staff that we need this support and we shouldn't be judged or mistreated as a result of that.

*"I am friendly and I like your company. Even when I am frustrated and it looks like I am mad at you, I am just struggling with my emotions. I mean no harm and would like some help"*

*- Paige, Aged 10*

*"Please stop the bullies!"*

*- Niall, Aged 9*

*"I feel like nobody understands me"*

*- Tim, 13*

9



# HAPPINESS

*"I'm stuck with this life whether I like it or not, so I might as well try to enjoy it!"*

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# Happiness

People often forget that despite being autistic, we are still children. There is too much of a focus on 'fixing our negatives' rather than focusing on positives and what makes us happy:

- We are asked what causes stress, but not what makes us excited or cheerful
- Intervention is focused on recovering from anxiety or depression, rather than having good emotional wellbeing
- We are given strategies on coping with their current situation, rather than support to be successful and getting out of the bad situation (whatever that means for the individual)

We believe the thinking of professionals is a step behind as a result of this and that they need to be striving for the best possible outcomes, not just trying to minimise the negative ones.

We have said:

- Autism should not just be defined by deficits and difficulties, here is a great definition of autism as an example:

*"Autistic individuals share a neurological type, which is qualitatively different to that of non-autistics, and which will necessarily impact, both positively and negatively, on aspects of their thinking and learning; sensory processing; social relational experiences; and communicative style, abilities and preferences. An autistic person's experience of and ability to be successful in the world, will be dependent on the closeness of compatibility, between their individual profile of skills and requirements and their physical and social environment. Levels of sensitivity to environmental factors vary between individuals, and within the same individual over time, so that the presentation of autism is ever changing. A person's neurological type, however, remains constant, and being autistic is a lifelong identity" - Julia Leatherland, Sheffield Hallam University*

# Happiness

- We want it to be ok to spend time on and enjoy our special interests. There is no better way to spend time than spend it doing what you love
- Having a purpose to work towards is essential. We usually don't need support to be resilient, but need a reason to **continue** to be resilient (read the quotes throughout this document, we are resilient enough!)
- Don't make us part of the community, help us find **our community** - and ask what that might look like
- We hope for **autism acceptance**
- We want more practical support that supports the autistic brain. For example, utilising spoon theory through an energy timetable, being taught to self reflect and self advocate using methods that work for us
- We want it to be ok to have a bad day - it is difficult living in a world that isn't made for you
- Most importantly of all, **we want more opportunities to have fun, laugh and smile.**

*"Help me progress in the things I'm good at, not just the things I'm not good at."*

*- Toby, Aged 10*

*"I would love some support to feel more motivated and confident"*

*- Tyler, 12*

*"Understand there is nothing wrong with me, just different and I'm brilliant in some amazing and unusual ways (just like everyone else"*

*- Marcus, 13*

*"Life is different for me compared to other people, but it is still fun.*

*To be honest, everyone is different, but not everyone is brave enough to admit it."*

*- Ellis, Aged 15*

*"Never underestimate me."*

*- Nathan, Aged 7*

*"The little things make a big difference! Just ask me what those little things are"*

*- Fatima, Aged 14*

10



**COPRODUCTION**

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# Coproduction

**Coproduction is:**

- **Recognising that children, young people, parents/ carers and practitioners all have vital contributions to make in order to improve the quality of life of people and communities**
- **Using this recognition to involve and value children, young people, their parents/ carers and practitioners as equal partners to design, deliver and develop practice**

# Coproduction

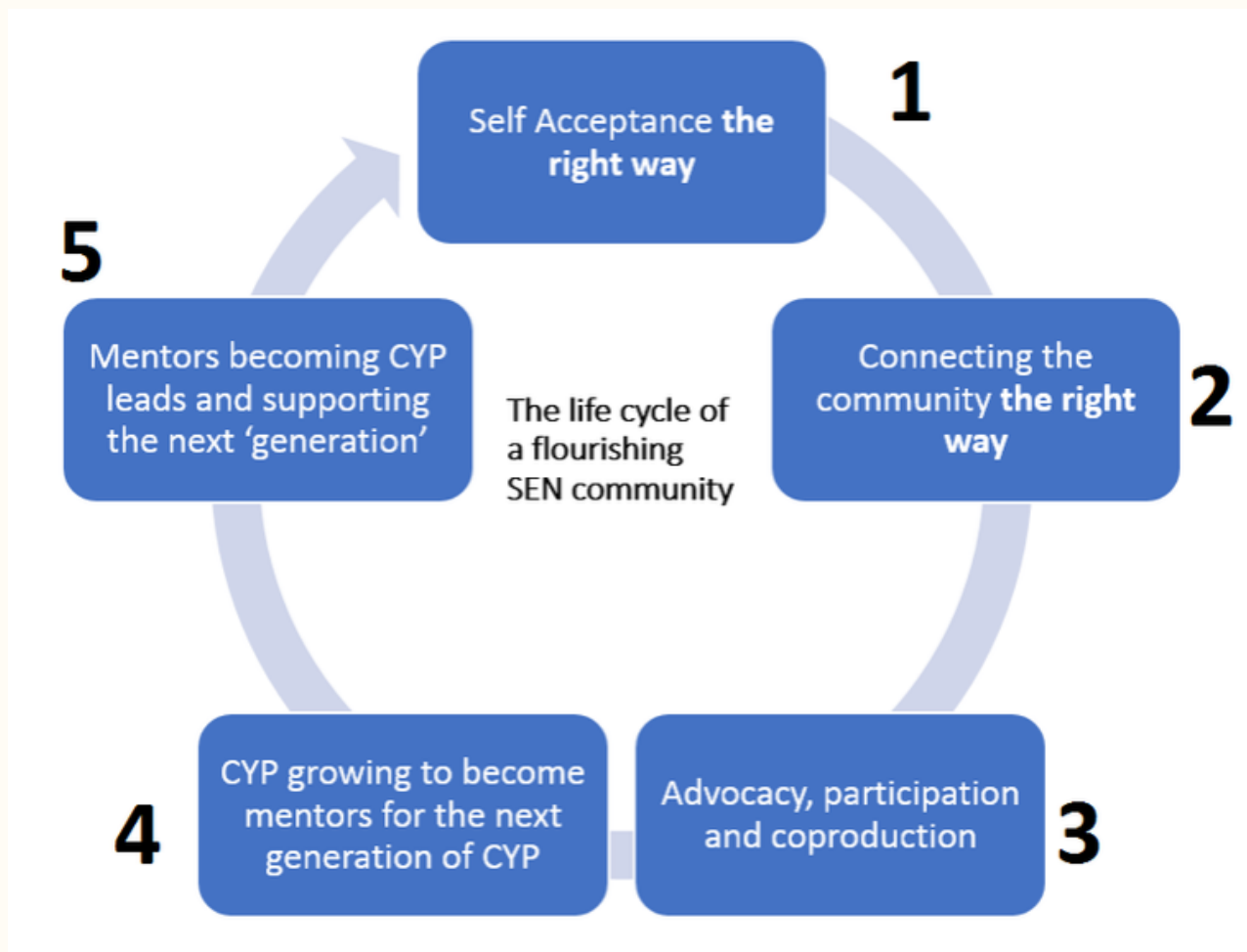
- **Recognising that children, young people, parents/ carers and practitioners all have vital contributions to make in order to improve the quality of life of people and communities**

# Coproduction

- **Using this recognition to involve and value children, young people, their parents/ carers and practitioners as equal partners to design, deliver and develop practice**

As detailed on page 5 of this document, there are lots of reasons why we do not engage with coproduction, and it has been recognised that action needs to be taken on the above priorities before we can start to be properly engaged in coproduction and to ensure there is both wide and continuous representation.

Once we are at that point, we have devised a model system for coproduction, as well as raised some of the key barriers and solutions to enable sustainable and increased coproduction, which will all be explained in the next few pages.



The above diagram was developed by us to explain what our local SEN community should look like and the process that is needed to first get more young people involved with coproduction, then ensure that this involvement continues, consistently grows and improves:

# Coproduction

## 1) Self acceptance **the right way**

- We need to know that it is ok to be different. Rather than having a life focused on trying to fix the negatives of their disability, we need support to accept and embrace them, focus on our positives and learn to live the best disabled life we can. This is the bridge to step 2

## 2) Connecting the community **the right way**

- Once you have learnt to accept yourself as different, you have purpose and reason to meet with and connect with others like you. There are two steps to this process:
  - Developing a mutual understanding and connection with each other
  - Have adequate opportunities to meet with, socialise with and develop relationships with other autistic young people

Once this has been achieved, it is time for step 3

## 3) Advocacy, participation and **coproduction**

- Young people are now ready for coproduction through means that work for them. There is no harm in using extra methods for capturing the voice of young people such as surveys, meetings and social media, but we have detailed the best ways to ensure we are heavily involved with coproduction, which are outlined below:
  - **We want coproduction opportunities to be fun and engaging.** The best way to obtain our voices is through either creating or meeting with us during social and fun activities. This is the method that resulted in the most qualitative and detailed information for this document. However, there is currently a huge lack of social activities which the young people can access, so increasing social opportunities needs to be a focus.
  - **We want to be engaged through events and activities that also meet our needs.**
    - An example of this is self acceptance: While supporting a young person with self acceptance directly, you can use it as an opportunity to find out their barriers to self acceptance, see their views on what can be done better in the area, and then develop a method of coproduction with them.
    - Another example is the need for more social opportunities: Why not attend a social activity we currently attend, speak to us about what we think, what else we wish was available, and work with us through that social activity to create other social activities and projects which meet our needs?

# Coproduction

- **We need open communication and feedback.** There are a lot of young people who have been involved with coproduction in the past, and have either stopped being involved or became less motivated and passionate than they previously were. The main reason for this is the complete lack of communication and feedback when they have shared their views. An example is a group of young people who created a coproduction strategy for their local authority to follow, which was presented and highly praised. However, 6 months later there has been no further acknowledgement of the coproduction strategy, no update on any impact it has had and next steps for being involved with coproduction further. Therefore, over half of the young people who worked on the coproduction strategy no longer engage with the local authority.
- **We need the development of coproduction champions.** There are three types of coproduction champion we would like to see:
  - **Senior leaders:** To show true commitment and belief in coproduction. These people will have the power to ensure coproduction becomes standard practice.
  - **Young people:** Young people, who represent other young people from all services. They work together to share the views of other young people in their settings/ services and ensure there is wide and accurate representation of young people, whilst also identifying gaps, areas of needs and proposing solutions and actions to take to practitioners, services and commissioners. These young people will also attend meetings, review services, be involved with commissioning and more, as well as potentially feeding back on progress and giving updates to young people within their services.
  - **Frontline staff:** gathering the views of young people, working with them to develop solutions and passing on any gaps and areas of needs to other practitioners both in their service and in their local authority needs to be standard practice. Frontline staff who are coproduction champions can ensure this is done.

# Coproduction

- **A key theme (and one of the most important ones) is the need for reciprocity**
  - Practitioners are paid for their time and support, but why aren't we? We have come up with an innovative solution to tackle this issue:
    - For every hour a coproduction champion (who is a young person) consults, gives feedback, attends meetings and more, money is put into a pot held by the local authority. The coproduction champion steering group can then decide how that money is spent. The impact is twofold:
      - If coproduction works and needs are being met, we can use the money for exclusive and premium events to support each other, make new friends and learn new skills e.g. YouTuber visits, workshops, events.
      - If some of our needs are not fully addressed by the work through coproduction or there is something that we really want which is not completely relevant to the process of coproduction, we can use this money to create and deliver our own projects and more (supervised by a practitioner) to meet those needs; whether it is creating and running social activities, creating resources and videos, creating links, investing in the community and more.

**This does not mean that there is less need for coproduction if this system is in place. This is an incentive in addition to the changes that will be made as a result of coproduction, just as your incentive to work and make a difference to the lives of children and young people is a wage/ salary.**

# Coproduction

- **What do we want the coproduction process to look like?**

- 1) We identify or are supported/ asked to identify what is going well, what isn't going well and also any unmet needs and gaps, with the option of also sharing proposed solutions and action points
- 2) Practitioners meet with us, and have an **open and honest** dialogue about resources, barriers and possibilities
- 3) We work together with the practitioners to create solutions, or modify proposed solutions (it doesn't matter whether it is low level such as offering training, or high level such as commissioning a new service, the approach is the same)
- 4) The agreed solution is actioned
- 5) We work with the practitioner (and others) to review outcomes and check progress
- 6) The cycle continues

## A BEST PRACTICE MODEL FOR REVIEWING OUTCOMES: USING YOUNG INSPECTORS

This is where young people are recruited as 'young inspectors'. Their responsibility is to visit services and settings and inspect them, then share their findings, and develop reports and recommendations. There are clear benefits to this:

- Services better meet the needs of children and young people
- Young inspectors are valued by Ofsted
- The young inspector and other young people they meet develop more skills
- There is another way to make sure the voices of young people are heard and used to positively influence practice and services

The time the young inspectors spend inspecting can also contribute to the 'coproduction pot', as mentioned on the previous page to ensure the young people are rewarded for their time and effort.

# Next Steps

This document will be reviewed and updated as young people provide additional insight on their experiences of coproduction and the priorities they believe practitioners need to focus on.

As there is a lot of action that needs to be taken before young people fully engage with coproduction, the ideal coproduction processes and systems written in this document have room for improvement. Regardless, this is a very strong starting point in ensuring coproduction is done right and becomes a sustainable process.

This report will be next updated by January 2020 with more information and best practice on how to truly coproduce with young people.

For any further information or if you have any questions, please do not hesitate to email me at [andy.smith@pathwaysassociates.co.uk](mailto:andy.smith@pathwaysassociates.co.uk).