



Acting Together for Autism

**Commissioning for Brighter Futures:
The Commissioning and Contracting Framework for
highly vulnerable autistic people with complex needs
2021-2025**



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1. Introduction: our ambition and our aims

This Commissioning Framework should be read in conjunction with the Northamptonshire All Age Autism Strategy 2018-2021. Our priorities and intentions are laid out in the Strategy and represent the changes that need to take place to improve the experiences and health and well-being outcomes of autistic people in Northamptonshire.

The Health and Social System in Northamptonshire has been in a difficult place but we are resolute in driving through stepped change in improving the service and community offers available and accessible to autistic individuals and their families who often experience extreme barriers to participating in community and family life. An active autism champions network and steering group continue to work through and exploit opportunities for improved and accessible community services as well as ordinary life opportunities through campaigns for change and reasonable adjustments in the County. However, as commissioners we are also passionate and committed to very specific actions that will change the future direction and life chances of specific autistic individuals through a concerted effort to focus, innovate, and inspire the provision of high quality and workable commissioning solutions for those individuals who are perceived to be at the 'top end' of need, that is; individuals who continuously lead highly fragile and vulnerable lives in environments that have lacked understanding and purpose and which have focussed on managing and holding risk rather than nurturing independence and opportunity through highly individualised support arrangements that work for each individual. Quite simply - we need to raise the bar in our commissioning aspirations, and we need to raise the bar in our contractual expectations.

Throughout this Framework the term 'autistic people', 'autistic individuals' and 'individuals' are used purposefully to describe individuals 'who are' autistic rather than 'who have' autism. This is a fundamental point in improving care and support understanding of autism and its impact on people. Many individuals want to recognise 'being autistic' as an element of who they are, alongside of and inherent in a multitude of other characteristics and personality nuances that make each and every one of us unique.

What matters

Autistic people in Northants have made it clear what matters to them the most – they have told us they want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have an income, have relationships and friendships, enjoy social activities and have a place they can call home, have the right connections when things aren't going well, have choices and make choices. As providers you are integral to making 'what matters' become the reality – to do this we must give each individual the opportunity to be heard, give you the opportunity to listen well, and give you the contractual permission to respond as creatively as is necessary to what you hear.

The 'What Matters' have been defined by autistic people, their families and social circles – these descriptions form the overall aim of the Autism Strategy:

Outcome 1

People feel educated, equipped and able to respond to individuals with differing needs

Priority 1: Raising awareness and understanding regarding the complexity of autism

Outcome 2

People get the right help at the right time

Priority 2: Providing effective, quality assured pre and post diagnosis support

Outcome 3

Autistic People have a sense of self-worth and social equality

Priority 3: Enhancing education, employment, accommodation, social and leisure opportunities

Outcome 4

Changes are anticipated, understood and supported

Priority 4: Promoting seamless progression throughout periods of transition

Outcome 5

Autistic people feel supported, safe and able to make progress in their life

Priority 5: Providing effective and enabling care and support

Following the introduction of the **Autism Act 2009**, the government's first strategy for autistic adults in England, **Fulfilling and Rewarding Lives** was published in 2010. This addressed the long term ambitions about how public services must reflect and adapt to the needs of autistic adults. It set out the government's overarching vision; 'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.' (Fulfilling and Rewarding Lives: the strategy for adults with autism in England, 2010). The national strategy was refreshed in 2014 with the release of **Think Autism**. This set out a programme of action to improve the lives of autistic people and brings a renewed emphasis on involvement and awareness of autism within the local community, as well as ways to look differently at support and engagement. A series of 15 Priority Challenges for Action are identified to highlight the key themes that the strategy aims to deliver. The government announced in late 2018 that a national autism strategy review will be conducted during 2019, which will see the strategy extended to include children and young people. Statutory guidance was produced in 2010 (and updated in 2015) to accompany the national adult autism strategy. It sets out responsibilities and legal duties that Local Authorities and NHS bodies must achieve in line with the Autism Act 2009. It also specifies responsibilities that should be delivered and achieved to ensure autistic people are supported. **The Care Act**

2014 provides a coherent approach to adult social care in England and sets out new duties for local authorities and partners and new rights of service users and carers. Some of the responsibilities placed on local authorities through the Autism Act 2009 and accompanying papers are strengthened by the introduction of the Care Act, as the new legislation highlights the need for improvement of services and support for autistic people. Similarly, the **Children and Families Act 2014** does the same and has an emphasis on personalisation, outcomes and integration of services. It provides a change in the way services provide support for children, young people and those with Special Educational Needs and Disability (SEND) and focuses on the best outcomes for each individual. In 2015, **Building the Right Support**, a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition, was published. The document sets out a requirement for Clinical Commissioning Groups, Local Authorities and NHS England to work together to develop local Transforming Care Partnerships. **The NHS Long Term Plan**, released in early 2019, has highlighted learning disabilities and autism among the key priorities for NHS services over the next 5-10 years, and sets out a series of commitments to improve the services and support currently being provided.

The Government's vision is: "All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents".

As Providers you should already be aware of some of these mandates that come from national bodies down to local systems and you should certainly be familiar with the Acts and Policies that drive improvements in health and well-being for autistic people and their families. Specifically, you should familiarise yourself with the **2020 Care Quality Commission** reports **Out of Sight – Who Cares?** and **Right Support, Right Care, Right Culture**.

Locally we continue to make progress in amplifying the voice of autistic people through training programmes and programmes that focus on enabling access through reasonable adjustments and training for better awareness. The local strategy and implementation plan has been

coproduced and the champions forum continues to grow and hold local systems to account. An important output from our coproduction activity is the following set of autism standards agreed and published for Northamptonshire:

Northamptonshire Autism Standards

<p>Knowing the individual</p>	<p>As autism affects every individual differently it is essential to know the person you are working with and how their autism impacts on them. Knowing their preferred method of communication, what they like doing, what they find difficult and any sensory issues will assist you in developing a relationship that supports interaction, independence and participation</p>
<p>Environment</p>	<p>Providing physical structure to the environment should reduce anxiety by enabling the autistic individual to anticipate what should happen where Visual structure, e.g. schedules and task systems should also make expectations clearer. Reasonable adjustments should be made to accommodate sensory preferences e.g. attention given to lighting, noise and proximity of others.</p>
<p>Collaboration</p>	<p>Working together and communicating closely with the autistic individual, family and support staff as well as other services and teams should ensure joined up working within the support circle. This should facilitate seamless transitions and reduce the negative impact of change</p>

Time for Change

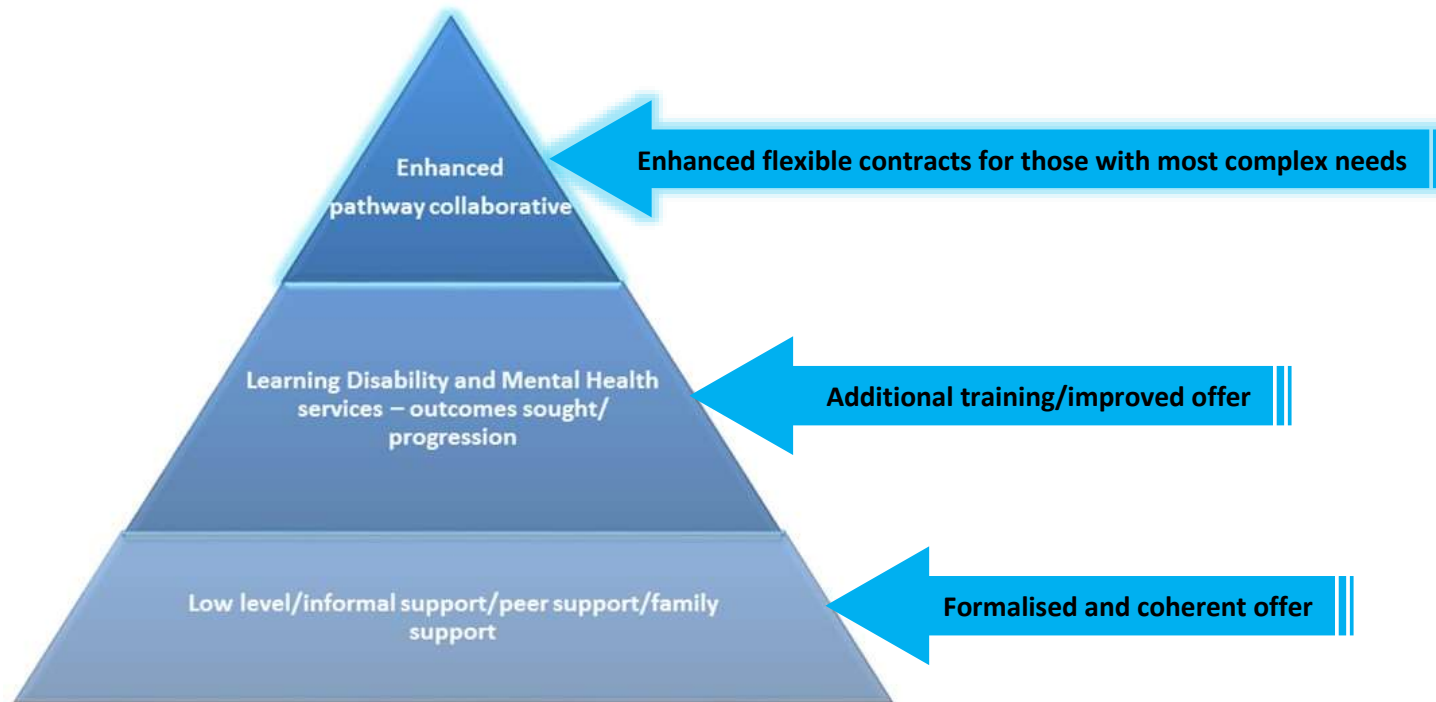
This Commissioning Framework aims to **inspire brighter futures** for an identifiable group of autistic individuals with autism and/or attachment disorder, some of whom will also have diagnosed mental health problems, where we have found it consistently difficult to apply the right support and mentoring arrangements by virtue of expecting 'one size fits all' services to be able to flex and work outside of the traditional commissioning approaches used to date. These are unique individuals who require us to think outside of the box in order to apply consistent and stable services that have the tenacity and creativity to provide the platform for brighter futures. We fully acknowledge that these individuals have presented us, all statutory agencies as well as our care, support and education providers, with challenges associated with:

- Criminal behaviours
- High risk behaviours such as substance misuse
- Sensory needs fulfilled by regular contact and use of emergency services and which are soothed by self-harm
- Self-neglect
- Vulnerabilities associated with cuckooing/gangs/exploitation
- Hoarding and OCD
- Family/parental anxiety and dysfunction
- Frequent engagement and then disengagement
- Histories of failed/wrong support arrangements which can escalate risk and cause further problems
- Challenges that increase as they enter adulthood
- Childhood traumas that have been inadequately supported or are untreated therapeutically
- Child inpatient = adult inpatient

In identifying the intended recipients of the services that will be generated through this Contract Framework we have defined an absolute commonality across adult and children and young people's services:

- All individuals have been assessed under our statutory frameworks
- Individuals do not fit into mental health services
- Individuals do not fit into learning disability services
- The experience is that unmet need as a child becomes an unmet need as an adult – with serious consequences
- All Partners recognise the need to ‘do something different’

Many of the needs and challenges described above lead individuals into restrictive settings. There is so much more we can do to stop this happening. This Framework is intended to lay down the basis of a set of contracts that will help us ‘do something different’ and is part of a system wide commitment to improving our response to autistic people and their families. In the diagram below these individuals fall within the ‘top tier’ of the response pyramid:



2. The foundations of this Contract Framework - cultural competency and recognising autism as personal

This Framework is not about helping providers 'fit' individuals into their services – it is intended as a guide to thinking, behaving and responding differently. If we do not think and behave differently then we will always continue to fall short of what is needed.

Because we are all unique, it is difficult to describe every nuanced consideration that should be made when supporting autistic individuals – the whole point of doing things differently is to acknowledge that we cannot and should not tell providers how an autistic individual should be supported - **it is for the individual to describe that to you**. At best we can ensure that we lay down the foundations for an individual to experience commitment and hopefulness that Commissioners are asking for the right things - in this case the principles, thoughts, considerations and cultural approach required to establish successful supportive relationships that mean that many autistic individuals can re-define or confirm their future goals and aspirations, and that there is a genuine focus on achieving them.

Areas for thought and for examining cultural competency

The following sub sections are intended to make you think and act – they do not at all describe the experience or thoughts of every autistic individual, but they are common themes, experiences and feelings expressed by autistic individuals who are in and out of statutory support services at various or continuous points in their lives and/or are contributing to improving our understanding of life as an autistic individual. Many of the issues will resonate for us all as human beings, doubtless you will have 'read and learnt all about autism' but there are very few mass produced learning tools that help connect that sense of humanity and individuality to managing an 'autistic view' at the same time. This is because **every autistic view is different** – absolutely in the same way that our thoughts and feelings are created uniquely and manifest themselves in different ways. Much of what is written about autism, including health and social care contracting documentation, describes deficits or difference, severity of need and challenges, usually because they are designed to prepare support services for how they should train staff, or how a particular issue ought to be managed. Those guidelines have their value, but they do not substitute **listening** well.

Listening well

We need to be much better at listening to each and every autistic individual we work with. For many individuals, we are listening to body language and what isn't being said verbally, just as much as we are listening to what is actively verbalised to us. **Listening is an art that is described as 'the ability to accurately receive and interpret messages in the communication process'**. There are 4 types of listening:

Appreciative Listening

When you listen for appreciation you are listening for enjoyment. Think about the music you listen to. You usually listen to music because you enjoy it. The same can be said for appreciative listening when someone is speaking. Some common types of appreciative listening can be found in sermons from places of worship, from a motivational speech by people we respect or hold in high regard, or even from a stand-up comedian who makes us laugh.

Empathic Listening

When you listen empathically you are doing so to show mutual concern. During this type of listening you are trying to identify with the speaker by understanding the situation in which he/she is discussing. You are stepping into the other's shoes to get a better understanding of what it is he/she is talking about. Usually during this type of listening you want to be fully present in the moment or mindfully listening to what the speaker is saying. Your goal during this time is to focus on the speaker, not on yourself. You are trying to understand from the speaker's perspective.

Comprehensive Listening

If you are watching the news, listening to a lecture, or getting directions from someone, you are listening in order to understand or listening to comprehend the message that is being sent. This process is active. In class, you should be focused, possibly taking notes of the speaker's main ideas. Identifying the structure of the speech and evaluating the supports he/she offers as evidence. This is one of the more difficult types of

listening because it requires you to not only concentrate but to actively participate in the process. The more you practice listening to comprehend, the stronger listener you become.

Critical Listening

Have you ever had to buy an expensive item, such as a new appliance, a car, a mobile phone or tablet? You probably did some research beforehand and listened closely to the salesperson when you went to compare brands. Or perhaps your best friend is telling you about some medical tests he/she recently had done. You listen closely so you can help your friend understand the results and the possible ramifications of the findings. Both of these scenarios are examples of critical listening. Critical listening is listening to evaluate the content of the message. As a critical listener you are listening to all parts of the message, analysing it, and evaluating what you have heard. When engaging in critical listening, you are also critically thinking. You are making mental judgments based on what you see, hear, and read. Your goal as a critical listener is to evaluate the message that is being sent and decide for yourself if the information is valid.

Growing up and risk activities

Between the ages of 18 and 25 individuals are engaged in a prolonged period of (self) exploration. During this period the need for security and stability is coupled with the desire for exploration and spontaneity, as such, emerging adulthood can provide a fertile ground for developing risk behaviours such as substance misuse or sexual behaviour and for some autistic individuals the period of emerging adulthood can last well into mid-life. We know that all transitions bring with them some uncertainty and for some autistic individuals 'risk activities or behaviours' are often triggered by feelings of not fitting in or of feeling different. These feelings can be linked to difficulties in identity formation, which are often exacerbated by a protracted process of diagnosis. The compounded impact can be enduring anxiety, depression and a much reduced sense of self-worth. Individuals describe various ways of coping with these emotions; for some, there is a thin line between what they considered to be 'coping' and 'failing' mechanisms, namely risk behaviours.

Research – based on listening to personal accounts – tells us that a lack of service provision, social support and guidance can be a contributory factor in risk behaviour. Parents and carers of autistic people discussed in great detail the difficulties, frustrations and anxieties associated with the process of obtaining and coming to terms with a diagnosis of Autism and the impact that this had on the family as a whole. Several parents spoke about their own problems in their personal relationships, which were often caused by the stress and added responsibility of raising an autistic child and trying to obtain appropriate professional help and support for them and for the rest of the family. Some parents believed that these difficulties were to blame for the breakdown of their relationships. Such problems were also multiplied if one of the partners was considered to be on the autistic spectrum as well.

Such tensions, combined with lack of the ‘right’ support, are often catalysts for engagement in risk behaviour by parents of people on the autistic spectrum. The ‘normalisation’ of such behaviour in families affected by ASD might have an impact on the behaviour of young autistic adults growing up in this environment but it is not a question of attributing blame, but of noting the complex interpersonal dynamics in families under pressure.

Parents also described how their children vented their frustration in response to stress or anxiety, and the negative impact of these outbursts on family life and on the physical fabric of the home; for some a great deal of patience and effort were required in order to avoid situations or topics that triggered aggressive or anxious reactions in autistic family members. The practical and financial consequences of incidents of aggression, anxiety or violence need to be acknowledged – parents, for example, who report being concerned about how the state of their households, with the marks of wear and tear born out of frustration and aggression, would impact upon other people’s perceptions of how they were coping, or failing to cope, with the challenges of raising an autistic child or young person. The cumulative effect of these diverse pressures has a potentially very significant impact on the family environment of an autistic person. It is perhaps not surprising that in some cases they, and indeed their parents, are prone to seek refuge in risk behaviours.

On 'being different'

As a society we like to think we celebrate 'difference' - it is a common mantra we use collectively and individually, in our interactions and in our personal thinking. Human nature dictates that whilst difference is and should be celebrated we still need to be able to 'place' things or people into a perception framework of some description that enables us to make sense and accept and therefore make the choice to relate and include. Whilst we are all unique, we also have what might be considered to be 'majority or societal norms' – social norms are the unwritten rules of beliefs, attitudes, and behaviours that are considered acceptable in a particular social group or culture. They provide us with an expected idea of how to behave and function to provide order and predictability in society. For example, we expect students to arrive to a lesson on time and complete their work. Social roles are the part people play as members of a social group. With each social role we adopt, our behaviour changes to fit the expectations that we and others have of that role. Each social role carries expected behaviours called norms and each social situation entails its own particular set of expectations about the way we should behave. There is considerable pressure to conform to social roles. Social roles provide an example of social influence in general and conformity in particular. Most of us, most of the time, conform to the guidelines provided by the roles we perform, but to do that we must be able to have absorbed and interpreted what the expected norms are and have a sense of the roles we play in society as a whole. Frequently, we all have influencing factors that may take us outside of what is construed as a 'norm' for a particular situation or setting although as a society our ability to recognise and 'celebrate' different norms evolves all the time – for the large part we all want to be considered as 'different' at least some of the time - whether that's at work or at home or in our social circles, for what we achieve or for what we do for others.

We know that recurring mental health problems or making dangerous or unconventional choices can result in a person being perceived as odd, different or extravagant in some way. These experiences could in turn negatively shape one's self-perception and so serve to intensify the severity of risk behaviours. Having very few close friends and experiencing exclusion, social isolation or rejection by potential friends or colleagues are frequently identified in the accounts of autistic adults and young people - feelings of anger, hopelessness and acts of self-harm were identified as

common responses to such incidents and often individuals find support outside their conventional peer groups. We also know that the experience of having been bullied can be associated with engagement in various forms of risk behaviour. Although it is difficult to determine whether there is a causal relationship between risk behaviours and the experience of being bullied by peers, colleagues or even service providers, it is reasonable to consider that being bullied can be a contributory factor in substance abuse, depression and anxiety.

Some autistic individuals are more prone to undertake risk behaviours than others. We know that human nature can predispose us to sensation seeking – the thrill of a new experience whereby the outcome may be certain but new, or a new experience with an uncertain outcome that is just a bit ‘scary’ but probability is understood. As we mature and make decisions and take actions based on learnt experiences, and on what we know about risk and we become tuned-in to ‘calculated’ sensation seeking. For some individuals a core feature of their autism includes a variety of sensory needs that can manifest in what appears to be the novelty or intensity of sensory stimulation that describes ‘high sensation’ seekers, but a more probable explanation for undertaking risk behaviours is a lack of understanding of social norms and the desire to fit in rather than thrill-seeking per se.

Self-harming

Self-harm is when somebody intentionally damages or injures their body. It is usually a way of coping with or expressing overwhelming emotional distress. Sometimes when individual’s self-harm there is an underlying intention to die, but the intention is more often to punish themselves, express their distress, or relieve what has escalated as unbearable tension – or a mixture of all of these things. Self-harm should always be taken seriously, no matter the reasons behind it. Being autistic can mean that you find it hard to communicate with and understand others, which incorporates being able to make sense of feelings, being able to communicate what those feelings are and being able to interact and socialise with others. These challenges frequently manifest themselves into a higher (than non-autistic) incidence of anxiety and depression, which in turn can increase a vulnerability and predisposition to self-harm.

It is thought that between 10 and 20% of young people self-harm - This means it is likely that at least two young people in every secondary school classroom have self-harmed at some time. Someone's reason to self-harm can be very different from other people who self-harm. Some of the reasons that young people report as triggers or reasons that lead them to self-harm include:

Difficulties at home

School pressures

Bullying

Arguments or problems with friends

Depression and or Anxiety

Low self-esteem

Transitions and changes such as changing schools or leaving school

It is important to try and understand why a person might be self-injuring. What are they trying to do or say with their actions? Self-injury may be caused by stress, anxiety or sensory problems or it may be an attempt to communicate. There are many articles and accounts from autistic individuals who have self-harmed. Providers may find the following literature helpful in understanding and working with autistic individuals who self-harm:

Greenwood, G. (2017) [Autism and self-harm. Seeing double, understanding autism](#)

Jubaris, M. (2019) [Bleeding: An Insider's Account](#). Spectrum Life Magazine

Sam (2017) [Autism and Mental Health: Proving Everyone Wrong](#). Young Minds

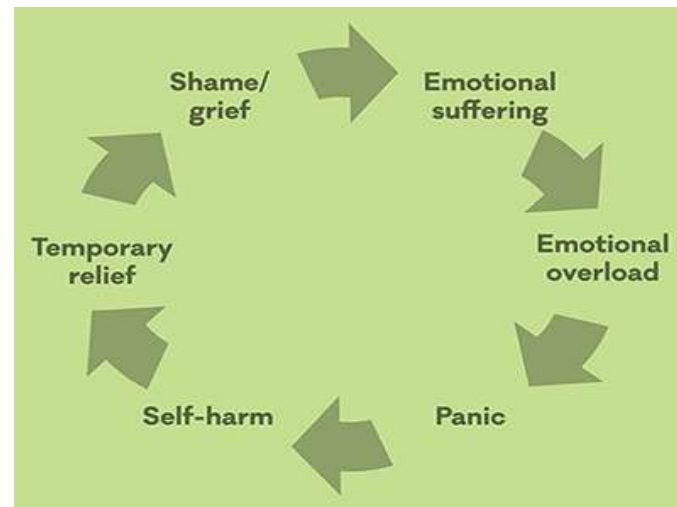
SwedishRebornMum (2012) [My life story - self harm](#), Aspergers, anxiety, suicide attempts. YouTube

You may also wish to follow 'Life Signs' – a user led organisation set up by individuals who self-harm, and who provide a range of guides and offer a network of support: [Lifesigns user led](#)

Some of the most common causal factors in self-injury are:

- Reacting to illness or pain
- A high pain threshold or being under-sensitive to touch
- Sensory problems – trying to block out or reduce an uncomfortable sensation
- Continuing behaviours that are usually seen in younger children - such as hand mouthing, which is common in babies and toddler
- Demand avoidance
- Habit or learned behaviour
- Repetitive behaviour or routine

Self-injury could be caused by a combination of these issues, or they could originally have been caused by one thing and become a habit or routine. It is important to try to tackle these issues as quickly as possible to prevent the behaviour from becoming habit. For many, self-harm usually starts as a way to relieve the build-up of pressure from distressing thoughts and feelings. This might give temporary relief from the emotional pain the person is feeling but it is important to know that this relief is only temporary because the underlying reasons still remain. Soon after, feelings of guilt and shame might follow, which can continue the cycle:



Autonomy and the freedom to make choices

Decision-making under uncertainty is central to daily functions, because our lives are filled with incomplete, ambiguous, and unpredictable components.

Personal autonomy and empowerment are defined as the opportunity to make choices and decisions regarding one's quality of life free from interferences. These choices and decisions are central to the principles of self-determination and the ability to be autonomous in terms of making meaningful life choices, however, in reality people do not make life choices entirely free from external influences or interferences; they are influenced by a variety of enabling *and* constraining factors enmeshed in a web of human relationships. For autistic individuals, the latter can be often more problematic than lack of autonomy, as difficulties with deciphering complex meanings and connections of social aspects of life are part of being autistic. In addition, perceived loss of control has negative implications for self-esteem and self-concept, which are fluid, overlapping and integrated with consciousness, memory and self-awareness - how we come to see ourselves is partly a reflection of how others perceive us. The 'self' can be conceptualised as the 'fundamental organiser of a person's social world, providing the conceptual means to establish a unique and distinctive personal identity' and yet our general orthodoxy of service provision emphasises the importance of integration with the local community, irrespective of the challenges this may present to autistic people. As we have seen from the examples above, the perceptions of other people are not necessarily positive, and this can negatively impact on the perception of self and compound any pre-disposition on the part of the autistic person to engage in behaviour that is ultimately self-harming or destructive. The autonomy of autistic individuals can also be limited for other reasons; lack of control over simple aspects of daily life, such as sensory environments, and limited ability to plan for the future can be associated with an increased risk of mental health problems.

It seems that the more autistic individuals are aware of their differences, the more likely they are to negate or compensate for them by modifying their appearance and behaviour in attempts to match their subjective perception, which is not always accurate, of how others expect them to behave i.e. conform. Clearly these kinds of compromises can have a negative impact on an individual's mental wellbeing and self-esteem and many autistic individuals see themselves as sacrificing their own integrity for the sake of social acceptance. It is common for individuals to establish

behaviours as strategies for coping with these difficulties with others learning to accept their differences and to embrace them by following behaviour patterns, routines and establishing mechanisms that help them to function in everyday life while allowing them to maintain their sense of identity.

Trust and Unity

Trust is an essential element of supportive relationships for all of us but is particularly essential for autistic individuals with complex needs and their supporters – if relationships generally can be difficult, then knowing you can trust the person supporting you is vital to growth and stability and having a sense of unity. Only with this trusting relationship as a foundation do individuals and their supporters feel they can give and receive support successfully. If trust is not developed or if it is violated in any way, unity within the relationship is prohibitive or at best is strained. Trust usually develops naturally over time but for many relationships, especially in relationships involving paid support staff, the development of trust is often established in a different manner – for example, often the need for constant support is strong, and many individuals find that they do not have time to develop trust slowly with their supporters. Instead, there is an asserted ‘forcing’ or speeding up the development of trust so that support can be seen as successful. This is particularly the case when there are changes in staff. The sense of urgency to develop trust does not diminish the importance of establishing trust, nor make the process any easier. Autistic individuals often emphasise that trust within a supportive relationship involved much more than it does in a typical relationship because there is an awareness of vulnerability – i.e. they know they are the vulnerable member of the relationship and have more at stake than the other person does. In this sense trusting is vital, but also involves risk – supporters often have responsibility for daily assistance and the individual is ‘taking a chance’ that the supporter is actually ‘responsible enough.’

“Trust is extremely important in a relationship especially when someone has been through traumatic or extremely stressful life situations or has had a large range of professionals and services who don’t seem to know how to support them. When they have been moved around from pillar to post without people seeing their perspective of what that might be like. Also trust and unity is important with what support someone needs or when understanding their needs, communications styles or how to build a relationship with them. Trust is important to ensure they

can be safer because it means they have a trusting relationship with someone they can reach out to but who will also reach in for them.

Trusting someone means that you think they are reliable; you have confidence in them and you feel safe with them physically and emotionally and without that how can you build a relationship because that relationship will be quick to topple or be unstable.”

Many individuals develop often unconscious strategies to **test for trust**, so that the process can be moved along faster while still ensuring that trust can be established - in order to build a relationship, an individual must know that they can trust the person who is going to support them. In order to know this, the supporter may be put through a ‘test’. Where individuals are aware of testing, they describe the test as a way to know how that person will react to them when they are pushed to their limits - ‘I can’t trust them until I know how they will treat me when they are mad’. Often these tests are used when an individual is managing emotional responses, such as being fearful of a transition of staff. Some individuals are not aware of testing:

“Do I test? Possibly, but if you are unaware of that then you don’t know you have done it. It’s possible that the tested stage has long gone, and it isn’t even worth testing professionals anymore as they can’t be trusted. However, if the testing is happening it’s probably by seeing if they break my trust or say they will do something and don’t or how they respond to my actions and behaviour or if they will give up on me or say I’m not a good person and treat me with no respect and like a lower class citizen.”

“I have been reading a book called “Living with PTSD on the autism spectrum”.....and I’ve never read something that literally feels like my brain and I’m only halfway through but it has given me a lot more clarity about a lot of my responses and traumas that I will have been told weren’t traumas..... but to me it was. I can literally see the lines between that and my social interactions and relationships with others and the knock on effect into my daily life and wellbeing with greater anxieties and social isolation and of course trust in others. And in addition to the usual expected events which can cause PTSD, for the autistic population it includes things like social relationships, support, professional

interactions, offhand comments, challenges finding support, social neglect, invisibility etc. And it's true - the way you are treated by those around you and those who support you is just vital. Support needs to be offered from the perspective of the person it is being given to, i.e. in an accessible way for them "

"It's not 'testing' and while I understand the need for the question I also felt very triggered by it because it puts the onus onto the person being difficult on purpose which is something I was frequently told and accused of when those trying to support me did not understand me, my presentation or autism and I did not feel safe with them. So many have tried to assert they know, only to show they don't at all and I just want people to be honest about what they know. I have in fact been told to think differently [by services] several times, cultural competency is not treating me as stupid or challenged - support has always failed when my intelligence has been underestimated or I have been treated as though I don't know what I want or need and someone tries to take over my life. These things all happen so much and so often that any recognisable hint of it means game over - it's not testing"

"I told him [psychologist] there was no point to living as everyone dies in the end so who cares when that happens - this was a genuine feeling, not a test, but the response to this was as important as if it had been a test, the response was one that validated my view even though it wasn't agreeable and was presented with logic which my brain will accept. My psychologist knows I will accept opposing views from myself more readily than others so he will ask questions that prompt me to respond in a way that disagrees with whatever I have asserted. Everyone has tests for others just often it's more searching for "markers" in people than explicitly testing what they know. "

Unity is identified as an essential component of supportive relationships from both individuals and their supporters. In fact, feeling a sense of unity was so critical that many argued that it was not possible for them to give or receive support successfully if that unity did not exist. Unity can be described as a ‘deep connection’ that involves common interest, and action, whereby the relationship is productive and comfortable.

“If I can’t trust someone it’s game over. If I don’t trust you, you won’t be able to help me or step into my world. If I trust you I will show you what my world is like and explain it to you. Trust is essential. Collaboration and flexibility - I need a person to come to me and where I am and not expect me to go to them. I have to feel valued as a person and seen as a person, I don’t want to be seen as a client or a patient. I can’t cope with those formal relationships. Possibly due to trauma. I need to feel like it’s a team and we are working together but not in a patronising way in an equal sense. There are times that I am less capable and I need my supporter to step in. I need to be encouraged and taught how to reward myself.”

Read the person, not just the book

For all autistic individuals it is essential for their supporters to presume their competence and to see their personhood – a person with thoughts, emotions, a sense of humour, and a personality. There is a critical balance in play in understanding each individual personality and also understanding the impact autism has in that person’s life – **knowing the individual and not just knowing about autism**. No autistic individual is the same as the next – you must work with each individual to learn and talk about all you need to know about them as a person. **Knowing about ‘autism’ does not mean you know the individual.**

“Yes you might have worked with autism or know about autism but you haven’t worked with me and you don’t know me...my brain works differently, it’s set up differently - it’s never going to work like yours, you can make me try to act like you but it won’t be natural, it will wear me out and make me feel stupid while denying my strengths and reinforcing that being me isn’t ok or good enough. I find life more tiring because I’m constantly having to try and think how the things I do would be perceived by NTs in order to do things. I need a support person

that I don't need to do that with, a support person who tries to think how I would think or see something and to not force things on me because it's "the way to do it", it has to be about what meets my need in a way that makes sense to me and using the strengths I already have. I need validation and acceptance. And if a support person cannot be expected to "think differently" in order to support me, how can I be expected to in order to get support and live?"

Collaboration

Although it is important that individuals have control over their lives and the support they receive, for many, support has to be delivered through collaboration. In a lot of instances individuals may not be able to describe or know what kind of support they need; and input alongside of insight may be needed from people around them. Equally supporters may not always be sure how to provide support and will need feedback from the individual. Essentially these relationships involve a great deal of collaboration and teamwork and constant dialogue. This has been described as **talking a lot and figuring things out together**; a support worker describes a typical starting conversation as 'how do you think we ought to approach this or what do you think we should do? I'll do whatever you think is important? What do you want me to do?' Sometimes he doesn't know and I tell him what I see us doing and we talk about that. We talk about support together, but it is always his choice. I always ask him first.'

For all individuals, support is a constant negotiation that requires both the supporter and individual to work together as a team. **Support providers do not need to have all the answers, nor do the individuals, but the relationship should be such that both are willing to work together at figuring it out. What makes a supportive relationship work?**

"Listening, doing what you say you will do, helping me achieve, understanding my perspective, having compassion, care and empathy, non-judgemental, believing, understanding needs, patience, time, respect, trust, no persecution, support not hate, no pressure"

“Confidentiality. Being valued and believed in and an equal human with something to offer. Being able to see the real you even when you have lost yourself.”

“The best supportive relationships tap into aspects of my personality, I use a lot of humour to deflect stress and so humour is important in support. Acknowledgement and validation are essential, honesty with me and about what you know. I can’t stand those who think they know it all as in my experience all of those people have ended up letting me down. Support taking the time to get to know who I am as a person and what I value and where I want to go in life. There is no point me having any support if the goal is to take me for a cup of coffee every week to access the community if I don’t like coffee and I’d rather be accessing the community by exploring interests and social opportunities. I want social opportunities with people I can be friends with not just going out with a support person. The goals need to be my goals that make a difference to my life.”

3. Flexible Contracting: enabling bespoke arrangements and innovation

The purpose of contracting more flexibly is to allow an organisation to meet someone’s needs with truly unfettered bespoke support. The council’s fundamental duty is to meet the person’s needs and to advance their well-being and this duty is part-cascaded through contractual arrangements for care and support but in addition Providers are agreeing with the key partners to work flexibly in the person’s best interests and according to an agreed set of rules. Our recent joint Contract Frameworks have sought to move away from the consideration of provider organisations predominantly in relation to the services supplied, this implies a rather static role, and instead encouraging and requiring organisations to think about the full range of roles that can be transacted in supporting people within the community and towards their stated personal outcomes. Creativity and responsiveness can be difficult to drive through contracting or tendering arrangements and since the early 1990’s contractual

relationships between commissioners and providers have tended to dictate both the kinds of services provided and the organisations that have provided them. However, the Care Act 2014 describes the task of shaping diverse local markets as a ‘shared endeavour’ in which providers and community organisations have a real contribution to make – this means that **the individual *and* their support provider should be treated, not as a passive recipient, but as a dynamic partner**. The **focus on achieving individual outcomes, stability and progression** (whatever this might mean for each individual) allows us to evaluate the success of a support arrangement without hindering the ability of providers to agree with individuals nuanced or inspired changes to support arrangements in order to make achievement of outcomes real and tangible. With this in mind, you are being asked to:

- **Play an active role in promoting innovation and in developing appropriate individual support solutions**
- **Form meaningful relationships with the people you work with and these should form the basis of new understandings and possibilities**
- **Accept authority to agree changes or improvements in the support you offer the person**
- **Offer significant expertise or insight that is used to guide the individual with decisions**

What do we mean by flexible support?

There are 5 key elements to flexible support:

1. **Accountability** - Flexible support means ensuring that you make your services accountable to the person. Each individual should know their personal budget and also their rights to terminate services and to seek alternatives. Service providers should be clear about how they are co-managing someone’s personal budget, any rules that apply and how they will keep the individual or their representatives informed and active participants in decisions.
2. **Individualisation** - Flexible support means individualising support and ensuring that someone’s needs are met in the most effective way possible - to fit them, their life and their community. Providers of flexible support will tailor the overall design of the support, the staffing

arrangements, technology, adaptation, housing, policies and procedures - anything necessary - so that the person's needs are met and their wellbeing is advanced.

3. **Responsiveness** - Flexible support means being able to change, innovate and be creative. It means not restricting the use of the funding to some narrow range of services but building on all the capacities and capabilities of the person and the community to maximise the outcomes the person can achieve. It means responding as quickly and as sensitively as possible to help people improve their own lives.
4. **Partnership** - Flexible support means working in partnership with the person, their family, friends or other representatives. It means sharing power and control and finding the right balance of responsibilities for the person. Some organisations are now established to provide Shared Management in this way – which is a formal way of agreeing the right balance of responsibilities with each person.
5. **Empowerment** - Flexible support means working to enhance the power and connectedness of the person. The best support links people to peers, enables people to learn from others and to exercise collective power. Increasingly forms of peer support or 'cooperative care' enable people to collaborate and influence the wider system and community.

Having policies and procedures that are a help and not a hindrance

It is essential that your policies and procedures are tuned into creating a **culture of flexibility**. The fundamental principle of good health and safety practice is to make proportionate judgements of risk and act accordingly. Despite this it is quite common for health and safety policies to specify a standard approach to a whole range of daily life issues: how best to lift someone, how best to manage medication, how to avoid risks in relationships, how to help people if they become angry. The unfortunate side effect of this kind of generalised approach is that it can increase risk overall. This is because it cannot be sensitive to the full range of individual factors involved. It is for this reason that some service providers are taking a very different view of how best to manage risk. For example, you should develop specific working policies which help everyone in a team understand how best to support someone. These policies are called working policies because they are constantly reviewed and changed in the

light of what is being learned. The focus needs to be on talking about good lives* and the natural worries that are part and parcel of them – in a typical approach to planning, ‘risk management’ and ‘risk enablement’ are often so cumbersome and complex that they frustrate people’s natural desires for a good life, this then leads to further problems, including damage to the relationship between the person and their supporters, whereas the key to good support is to **focus on ongoing planning as a natural part of the support relationship**.

*(defined by each individual, a life that has meaning to that person, that holds choice and control when needed, that allows us to think and feel and that brings out the best in us).

4. Expected good practice and tools that enable good practice

An overarching **ethos of ordinary life** forms the basis of all outcomes and their measurements. This is the basis on which we commission services – your role as Providers is to work with individuals to ascertain what is important to them, what their aspirations are, what you are going to achieve together and how are you going to do this. The written plan that describes the outcomes is a key document - you will need to agree intervals to check back on that plan and monitor how far along the described journey an individual is progressing, making adjustments as required. This **outcomes plan is never static** – we expect to see changes and progress and a number of practical descriptions on the ‘how’. Achieving the things we set out to do are rarely defined by one action – getting from a) to b) is a journey that requires thought and steps and often requires trying things out that help us learn and adapt.

Be prepared to have conversations about taking risks – what is the risk? Is it real or perceived? How can you or others help manage that risk? What is gained by taking the risk? We all take risks every day – most of them are considered and known risks – your role is to talk through the what ‘might happen’ and ‘will happen’ and help individuals take risks safely and in a well managed way. Ultimately the conversations will be about whether a risk is worth taking; a lot of the time it will be. Be creative with individuals – think outside of the box.

We expect all providers to deliver **strengths and progression based services**. Progression and independence means different things to different people – small steps and big steps. **Independence is not at all considered as meaning being without or free from support** because all services should be enabling ordinary living and citizenship and should only be there for the period they are required. As an individual grows in confidence and ability services should ‘step away’ in a graduated, planned and safe way in order to allow that individual to flourish.

Contingency plans and plans that describe the ‘in case of..’ should be discussed and understood by all; safety nets are important in understanding and managing risk but also in reducing anxieties and in managing our statutory responsibilities.

Historically, and traditionally, most statutory health and social care assessments of need highlight what people have difficulty with, or cannot do; eligibility criteria is based on assessing the ‘gaps’ and the statutory role is to understand the deficit and establish whether the impact of that deficit makes an individual eligible for support and our support arrangements are asked to ‘plug’ the deficit; help ‘fix’ a problem or make something ‘better’. **Strengths based approaches**, on the other hand, concentrate on an individual’s assets, not deficits, what is right, not what is wrong:

- **Utilising strengths, resources and support networks - Assessments must be narrative based, a holistic picture of the individual’s life**
- **Risk is an enabler, not a barrier (or something to be avoided)**
- **Community, as well as ‘self’, is a resource not a hindrance**
- **Using multi-disciplinary support – health & social care in the widest sense – right skills right time right place**
- **Person centred, not service centred**
- **Listen - let the person speak, help to form a narrative, don’t focus on form-filling**
- **Agreeing a way forward, with achievable, measurable goals**
- **About stabilising the present, planning for the future - progression**
- **Questions (i.e. 3 conversations) “what would a good life look like for you”?**

Conversation	Needs assessment and Support Planning questions
1. Initial contact	How can I connect you to things that will help you get on with your life –based on your assets, strengths and those of your family? What do you want to do?
2. If people are at risk	What needs to change to make you safe and regain control? How can I help make that happen?
3. If long-term support is needed	What is a fair personal budget and what are the sources of funding? What does a good life look like? How can I help you to use your resources to support your chosen life?

As commissioners we will be monitoring how well providers are defining outcomes with individuals, how they are supporting individuals to achieve those outcomes and how individuals are supported to progress and ‘fine-tune’ their use of formal services. Our lives change and evolve all the time – your role is to help individuals be everything they can be and to shift support around an individual as changes occur and needs evolve. There are a range of services to help with understanding why changes in an individual’s presentation are happening - make use of them and make sure you talk to those people who know the individual best. We expect all support staff to have received and absorbed this document - use it in training and in inducting staff.

Embedding an enabling framework of support for people who challenge us and our services

Providers must embed proactive frameworks for supporting people who exhibit behaviours that present a challenge. Providers have a responsibility for ensuring that staff have the appropriate skills to assess people’s needs and behavioural responses on an individual basis and develop positive behaviour support plans with **the aim of reducing the need to use any and all physical interventions**. The term 'physical

interventions' refers to 'any method of responding to challenging behaviour which involves some degree of direct physical force to limit or restrict movement or mobility' (Harris et al, 2008). Three broad categories of physical intervention are identified:

- Direct physical contact between a carer and a person with challenging behaviour (e.g., self-protective 'breakaway' techniques for escaping from grabs and chokes or minimal restraint to briefly immobilise the person)
- The use of barriers, such as locked doors, to limit freedom of movement
- The use of materials or equipment to restrict or prevent movement (e.g., the use of arm splints to reduce self-injury)

Proactive Frameworks and Positive Behaviour Support Plans deliver dignified prevention strategies to avoid any need for physical restraint. As a contracted provider you must keep up to date with current best practice. It is highly likely that restraint in any form will become regulated in due course. The following guidance will help you improve your knowledge and skills and stay up to date:

Restraint Reduction Network Standards

We expect Providers to develop models of support that focus on the **prevention of behaviours that challenge** rather than the management of such behaviour. This can be done through:

- √ Improving skills within the workforce and delivering focussed training
- √ Implementing and supporting an appropriate culture and ethos which places people at the centre of their care
- √ Improving communication and access to interpreters and accessible information
- √ Emphasising good practice and sharing good practice across services
- √ Offering appropriate support to employees
- √ Delivering care within a framework that acknowledges and protects people's human rights. Including the rights of employees
- √ Implementing procedures to reduce and eliminate the use of restraint and seclusion

Complementing strengths based approaches and the use of outcomes in evaluating the impact of services is **Positive Behaviour Support** (PBS).

PBS is accepted internationally as current best practice and is specifically recommended by key national government and professional organisations in numerous guidance documents. You can find a lot of information about PBS at the Centre for Positive Behaviour Support affiliated with BILD: [PBS](#)

PBS is in full accord with current adult and child legislation in that it:

- Promotes physical and emotional well-being,
- Addresses physical and mental health issues,
- Emphasises personal and skill development,
- Supports and encourages family and personal relationships,
- Provides opportunities for social well-being and inclusion,
- Promotes human rights, dignity and respect,
- Emphasises the 'fit' of an individual's living accommodation and the environment.

The Environment needs to be considered in its widest sense:

- **Communication & body language**
- **Preferred activity or object or person**
- **Predictable routine and structure**
 - **Feeling well and happy**
- **Interaction styles – how do you talk to the person?**
 - **The built environment**
 - **Sensory needs**

Our preferred partners for this contract will be supporting the discharge and step down of individuals over the age of 14 from specialised units.

It is important that you are up to date with current legal and good practice approaches in reducing restrictive practice. It is also important that staff of all grades are aware of the impact of restrictive practice. Read the following CQC report: [Out of Sight - Who Cares?](#)

5. The Contract in action: Individual Service Funds

In recent years an increasing number of people have used direct payments to manage their own support, while others have received council managed services, organised using contracts with private or third sector organisations. While both can work well, there is often an unnecessarily wide gulf between direct payments, which have high levels of choice and control, plus high levels of responsibility; and council managed services, with low levels of choice and control, and where responsibility remains with the council. There is a middle option, which although much less used, will suit individuals who need flexible support, but without all the responsibilities that come with managing a direct payment. This option is called an **Individual Service Fund (ISF)** and refers to an arrangement where the service provider works with the person to provide flexible support.

An ISF is an internal system of accounting by a key service provider that makes the personal budget transparent to the individual or family. This helps provide flexible support by making the organisation accountable to the person. ISFs were developed in 1996 as an alternative to direct payments and originally they were used by people who were unable to take advantage of direct payments (Fitzpatrick 2010). At its simplest an ISF is a commitment by a service provider to respect the integrity of the funding that they receive on behalf of someone they work with, and to make themselves accountable to them or their representatives for how that funding is spent. The Individual Service Fund offered service providers a different way of thinking about their role. Instead of providing fixed support to a predetermined specification, their role was to provide flexible support, and this included making best use of someone's available budget. Instead of being accountable only to the council, their role was to be accountable to the person and family, and this includes ensuring they were accountable for how any available budget was spent.

Providing **flexible support means working with the person to design, develop and manage the best possible support, and being able to alter that support with minimal fuss when changes are needed.** Using an ISF is a way in which a service provider can work in partnership with the person – to respect their needs and wishes - but also to respond intuitively and spontaneously to opportunities and challenges in every-day life.

Why use an ISF?

Decision-making: is located with someone who has the right information, motivation and expertise to make the best possible decisions – the people closest to the individual.

Responsive services: decisions can be made quickly and easily, as problems and opportunities occur. There is no undue delay or contractual restrictions. When service providers have used ISFs and begun to provide more flexible support there have been multiple advantages for the person; evidence suggests that flexible support can improve well-being, efficiency and trust within local communities.

Resources: can be used flexibly and creatively in order to build on the person's assets and community. Resources are not tied into particular kinds of service or support. The contract is such that a nominated provider has delegated responsibility to design, deliver and change the support necessary to meet someone's needs

Clarity: can be established about everyone's rights and responsibilities. There is no confusion, unnecessary dependence or undue complexity in the arrangements.

The evidence in support of flexible contracting using ISFs

As it stands, the available evidence on ISFs supports the following hypotheses about why their use, and the use of flexible support, seems to create such significant improvements in outcome and efficiency:

1. Clearer focus – When people have more control over their own support they are able to agree exactly what support is most helpful, and also when less support might be possible. An ISF enables people, families and professionals to develop a more trusting and positive conversation about how to make best use of someone's available resource

2. Greater capacity – When people know what they are entitled to, and can use it flexibly, then it encourages self-development and greater independence, especially when this is in the context of some reasonable degree of security about the future. Support which is conditional on

immediate need can encourage people to become unnecessarily dependent on others. It is more empowering to know that support will not be immediately withdrawn, even if you start to increase your independence; this then gives you security and an incentive to test out greater independence. There is an important balance that needs to be struck here, to encourage independence without creating uncertainty and insecurity

3. Stronger relationships – Most support is not provided by social care services, but by family and friends. However, people who are entitled to social care are often fearful that they will lose their entitlement to state support if friends or family start to increase their role. This can often lead to a vicious circle where people become more dependent on paid support than is ideal, simply to ensure they remain entitled to it. ISFs provide a more secure framework, where budgets can be used flexibly, and where the support of friends or family does not lead to the immediate withdrawal of resources. In the long-run this strengthens relationships and can increase efficiency.

4. Greater inclusion – traditionally commissioned care services can sometimes be segregated and leave people with only limited access to ordinary community opportunities. Such services are not in the best position to make use of the support that is available in the community or in mainstream services. ISFs open up opportunities for greater social inclusion or greater collective action, for example, when people pool their budgets.

Evidence of who can benefit from an ISF

The available evidence suggests that some groups of people will particularly benefit from ISFs, these include:

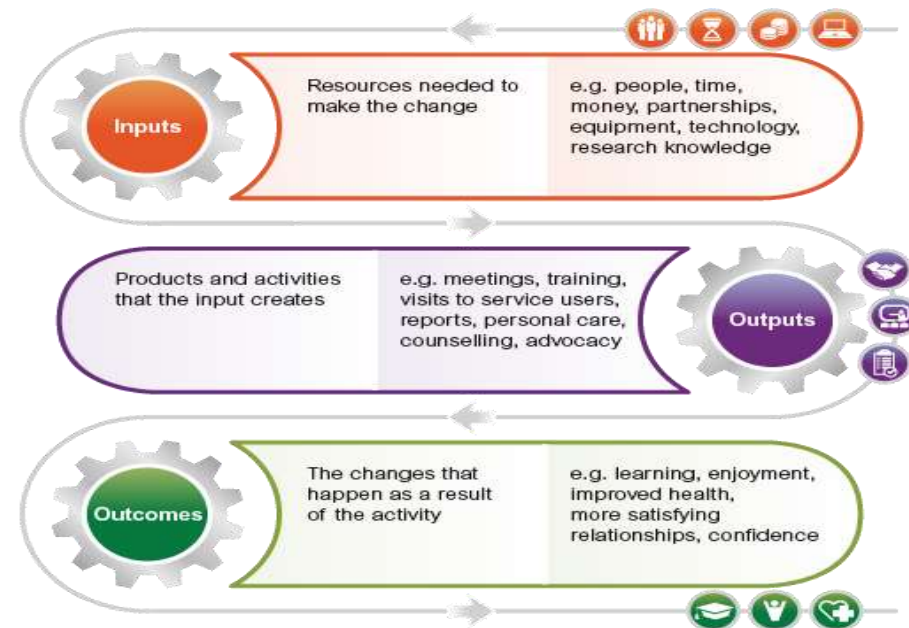
- **People who want to change things** – Many people do not want rigid support, they want to be able to react quickly to problems or opportunities, their lifestyle may be quite flexible and they do not want to work to a fixed care and support plan. Flexible support would allow them to change their plans as needed, and without seeking permission from the funding body
- **People who want choice over who provides support or what the support is** – Sometimes people have a strong preference for a particular support option. Contracting flexibly with a provider who can deliver an ISF can give people who receive services more choice over who provides support or what the support is, and the right to terminate any sub-contracted arrangements that aren't working for the individual

- **People who want specialised support** – Sometimes people will benefit from support from a particular organisation, perhaps because they have just the right expertise or perhaps because they are in just the right location. Often practitioners know which organisation, or a particular service type would suit the person best but current contracting arrangements can make it hard to put the person and the right organisation together.
- **People who want or need their support to be simplified** – Sometimes people may be getting support from several sources and this can create confusion, communication problems or bureaucratic restrictions which can lead to mistakes being made or problems being missed. Using an ISF can be useful to integrate funding from different sources, and to enable one service provider to take primary responsibility for coordinating any necessary support.
- **People who don't want burdensome responsibilities** – Sometimes people want flexible support at home, but do not want to become an employer or to take on responsibility for managing support or funding. Using an ISF ensures that one individual or organisation can take the lead and work in partnership with the person to minimise stress, but give them control over what really matters.
- **People with complex needs** – Sometimes people need support that is highly personalised, responsive and creative, to be safe and to avoid the hazards of institutional care. For example, those people currently inappropriately placed in specialist units require highly personalised support to thrive in the community. Using an ISF maximises the chance of success, combining flexibility with clear leadership from a skilled provider. Indeed, there is an opportunity to implement ISFs for people receiving personal health budgets and 'integrated personal budget holders'.
- **People who want to work in partnership** with a service provider – Often family and friends want to be part of providing support or people want to save their budget when they are with family or friends. Using ISFs gives people the security that their budget will still be safe when they do, and it provides people with greater incentives to build on these relationships when people know that their budget won't be lost when this happens (Greenwich 2015).

- **People with creative ideas about how to get support** – Sometimes people want to find imaginative new ways to meet their needs and they seek a ‘partner’ to do this, not so much to provide services, but to broker good solutions for their needs by building on people’s skills, interests and natural resources. Service providers can also act with more freedom, for example, replacing paid support with technology or using the available funding more creatively in order to support individuals achieve their outcomes.
- **People who want to pool funds and have different experiences** – Sometimes people still want to meet up with friends and social contacts and do things together. Using an ISF can allow people to pool their resources, pay for someone to coordinate things, find community options and make best use of all the available funding. Sometimes people want to be part of giving and sharing care of support arrangements together – participating in collective and cooperative care, rather than purchasing a service.

Individual Service Funds, care and support plans, and outcomes

Firstly- understanding outcomes. An outcome is the impact of an activity or action, and should be defined and understood as what matters to the person, so the starting point is to work with the individual to define what is important to them, and to plan activities and support from there. Do not confuse Outcomes with inputs and outputs.



To make ISFs work, a change in thinking is required - in allocating an ISF the Commissioner is delegating a budget for service provision that meets assessed needs to the service provider and the individual. **This is distinct from delegating care and support planning** which is legally different. An ISF contract will use clauses that enable providers and individuals to be flexible in how they meet needs; the Commissioner responsibility is to provide a care and support plan that is outcome focused and which enables providers to respond in creative and innovative ways. The following practices, which are quite common, **are not** consistent with flexible support:

- A care and support plan which is passed onto the provider, and which specifies the services to be delivered (for example, by reference to a number of hours, a model of service etc.) rather than outcomes that need to be achieved
- A provider needing permission from the council to change how support is provided

The flexibility of an ISF should allow people to try things out, make mistakes, change their mind and learn from each of these opportunities - an ISF must enable the support arrangement to change as the person's life changes.

The benefit for service providers of implementing ISFs is that they will be able to improve the quality and efficiency of their work, by focusing on needs and well-being, in partnership with the individual and the people who are important to them. The rules around the use of the ISF will be transparent and simple enough so that everyone understands how it will work and what their role is. The provider and the individual will be given the freedom and flexibility to apply creative solutions to sometimes complex, emotional and intimate situations. **We will use a very simple rule of thumb, if it meets an agreed outcome, doesn't harm anyone or place a person at unreasonable risk and it's legal, it should happen.** If a person chooses to work with a service provider, they should be able to tailor the support they receive in a way that makes sense for them. The cost of any service provided should be clear and transparent; this does not mean it needs to be broken down into an hourly rate. Many of the services we value are not broken down into hours, nor do they use hourly rates - a visit to the hairdresser, a meal in a restaurant, a visit to the dentist, going to the cinema, joining a club, are all assessed on the outcome they achieve, not on how long it took and what it cost by the hour. It is

important for a person to know what outcome they want to achieve and what this may cost. Support arrangements designed using an ISF should focus on every day, community and experience-based mainstream options, in addition to specialist services. The purpose of an ISF is to ensure that the person at the heart of the plan has choice and control over the support arrangement, the purpose of which is for them to remain healthy and well and live a good life.

General Principles:

- 1. Having an ISF means that people don't fit into services, they have the kind of support that suits them, when they want it**
- 2. The starting point for service design should be consideration of the individual's skills, gifts and aspirations, their assets and the resources available to them in their existing relationships and community**
- 3. The person must always be at the heart of the thinking, planning and doing**
- 4. Support must change as the person's life changes**
- 5. The person can use their individual budget to access a range of additional resources**
- 6. If the person uses the money to purchase the services of a provider organisation they should have the opportunity to tailor how they get their support, in a way that makes sense to them**
- 7. Costs for services must be clear and transparent. The service designed for each person should be tailored to them, be creative and offer the chance to use ordinary, everyday solutions as well as specialist supports**
- 8. Every service design and plan must support the person to remain healthy, safe and well**

Many of what are considered the most important things in life cannot be bought: love, health, friendship, trust, happiness... the list goes on. That said, money, in the form of an individual budget, can make life significantly easier for people with additional support needs. It is however important

to recognise that an individual budget (whether or not it's managed through an ISF) should be used for the person to achieve a good life - not just to purchase a service. It should help individuals to have higher aspirations and assist them in getting the help they need to achieve this.

Historically 'traditional types' of services have tended to regard those who make use of services as 'passive recipients of support' who have things 'done' to meet assessed need. ISFs provide the opportunity to co-create a support arrangement that works for each unique individual. ISFs also harness the opportunity to draw on a far wider range of resources and opportunities that exist within the individuals own skills and gifts, within their families, neighbourhoods and communities at large. This enables creative thinking beyond what 'service land' can offer. It is important that plans for a good life draw on the widest range of resources and clearly detail how the person's individual budget will be used to achieve their desired outcomes.

For the purposes of accountability, to the funding authority and the individual, the use of a nationally recognised outcomes tool will be required in order to chart the progress of each person's very specific and personal and wellbeing outcomes. Working in this way ensures transparency and accountability without restricting the flexibility that is a key component of an ISF. This level of openness and accountability also ensures that people who have previously been in receipt of support delivered through more traditional approaches can be assured that their support needs will continue to be met and that they will remain safe and well. **Using an ISF enables more creative solutions - these can often be simple in their application, but life changing in the affect they have on an individual's quality of life.** There are many outcomes measurement tools available, including some specific tools relating to autistic people such as the 'Spectrum Star'™. The Spectrum Star covers nine key areas: Physical health, Living skills & self-care, Well-being & self-esteem, Sensory differences, Communication, Social skills, Relationships, Socially responsible behaviour and Time and activities. The Spectrum Star meets what is being asked for in the Autism Act and in the NICE guidelines on Autism:

[DH Guidance implementing the Autism Strategy](#) [NICE guidance - Autism](#)

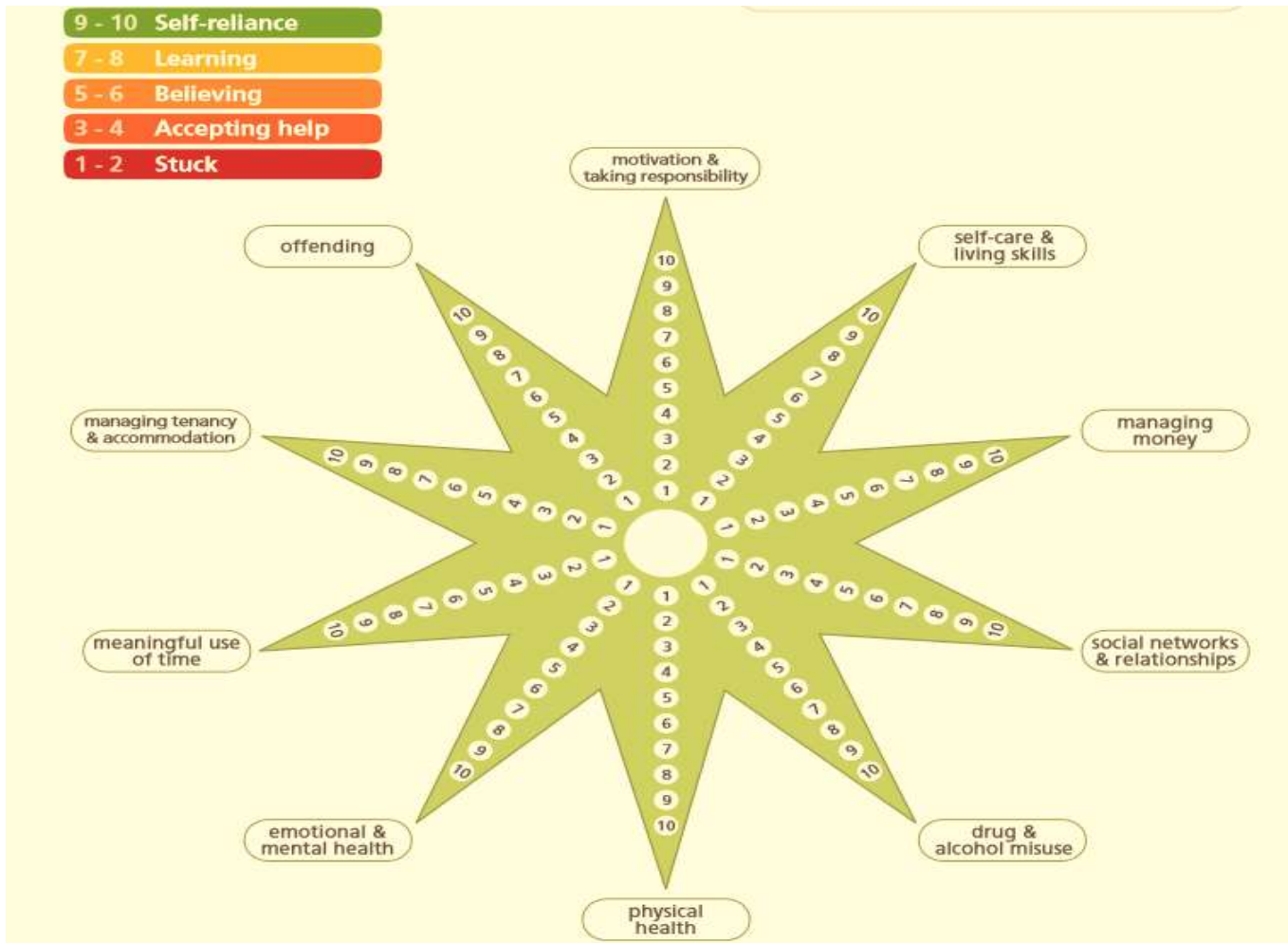
WELLBEING WHEEL MOVING INTO ADULTHOOD



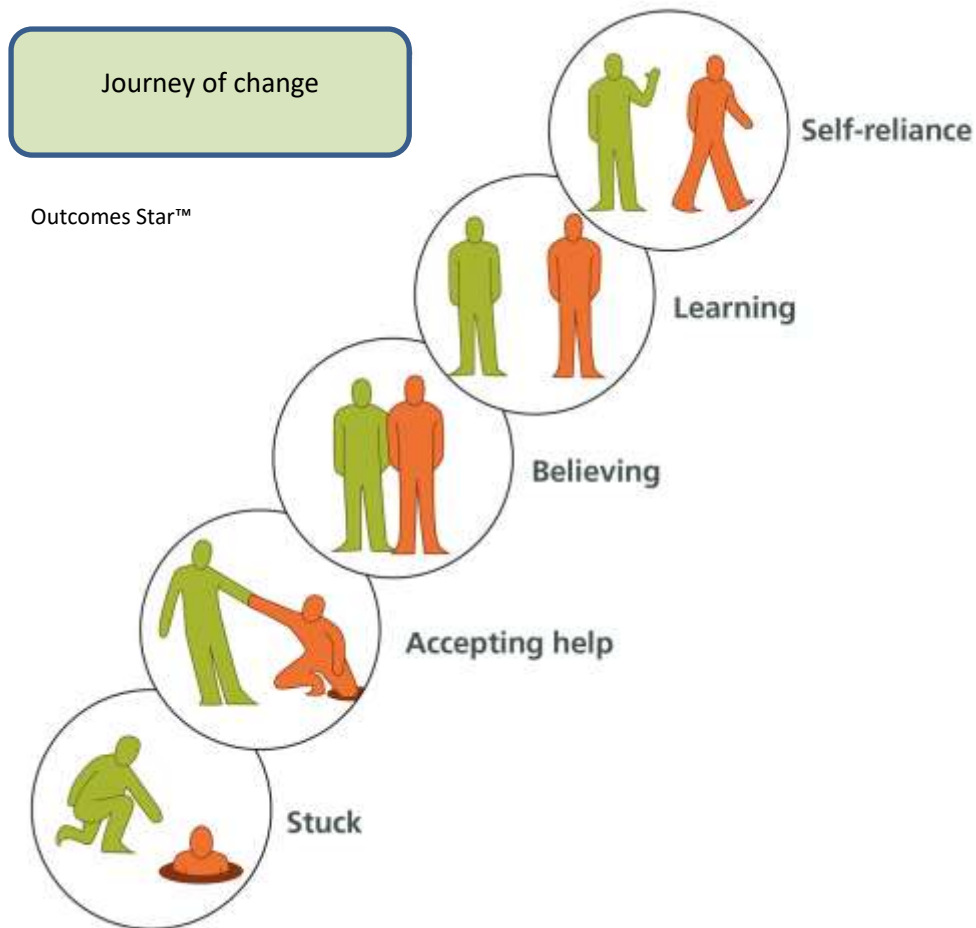
This is an example of a well-being wheel used for young adults. It can be translated into specific outcomes themes to plot progress for each individual. Each section, or domain, can be adapted to ensure they are relevant for each individual. Older adults for example may wish to use different life domains.

The outcomes measurement tools will provide a more interactive and visual method of goal setting and progress monitoring





Each area of 'wellbeing' can be plotted using an outcomes star which supports showing progress and goals through each aspect, allowing for which aspect is most important to the individual.



This diagrammatic aims to depict a support journey – it could be any kind of support journey for all of us; using friends as the support system, or indeed using support systems that are commissioned.

The concept of self-reliance will mean something different to all of us - it could mean having better coping mechanisms or being in receipt of the right type of support that allows us to focus on getting on with life or moving forward with our goals.

Accepting help can be the biggest barrier – consider what has been said earlier about trust and unity and our difficulties in providing the right type of support to many autistic people.



There is a contractual expectation that the preferred partners will

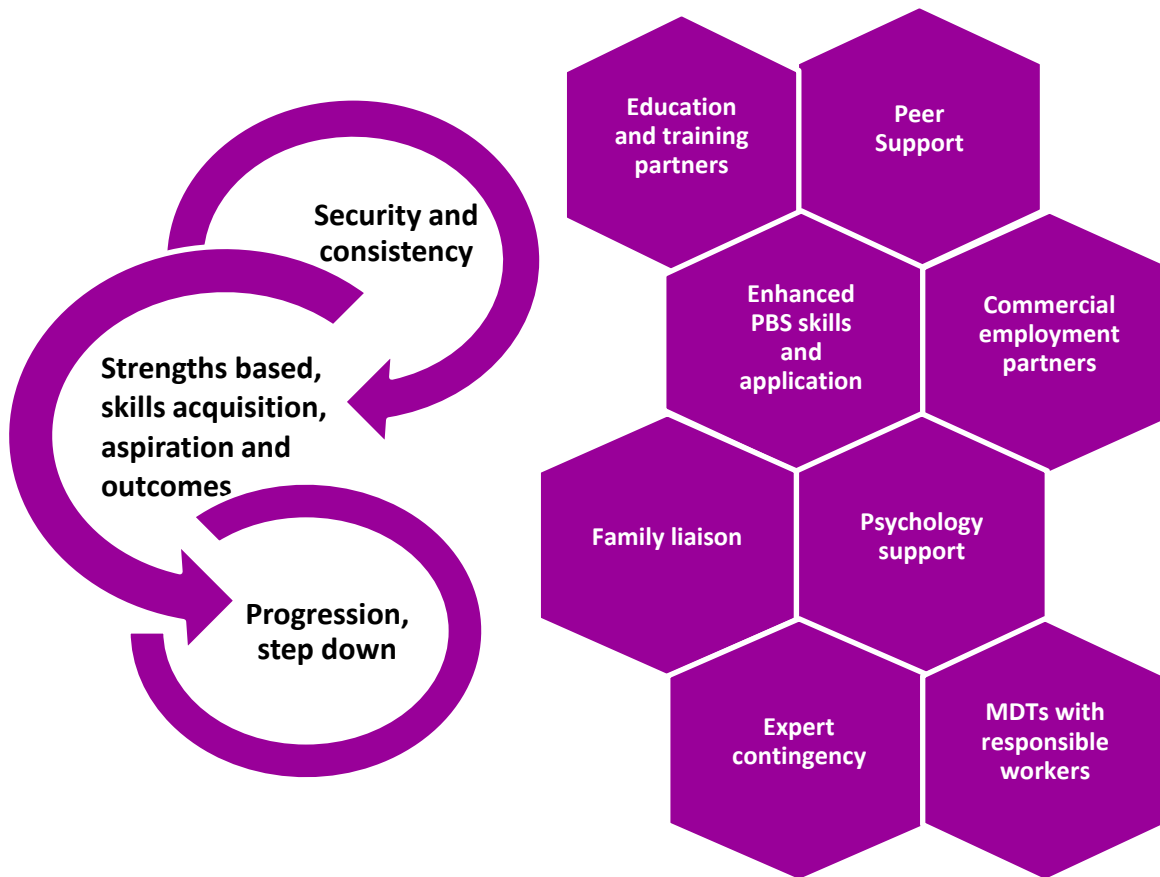
care and support – the key aim is to focus on progression and ‘step down’ and enabling self-reliance and self-management. For many individuals this will mean maximising the skills and experience offered under this contract framework in order to enable a step down to a life-long support arrangement that is determined as suitable and of value to each individual in maintaining a good life. Step downs will be evaluated against progress with the outcomes and in discussion with the individual and their support systems. Changes will be personalised and managed with due care and attention to the individual.

Our explicit intention is to establish a contracted set of providers who have evidenced their ability to work collaboratively to meet the core aim of the contract:

- Working together creatively and uniquely to pursue achievement of the stated outcomes for each and every individual determined as benefitting from support under this contract framework

This will be achieved through:

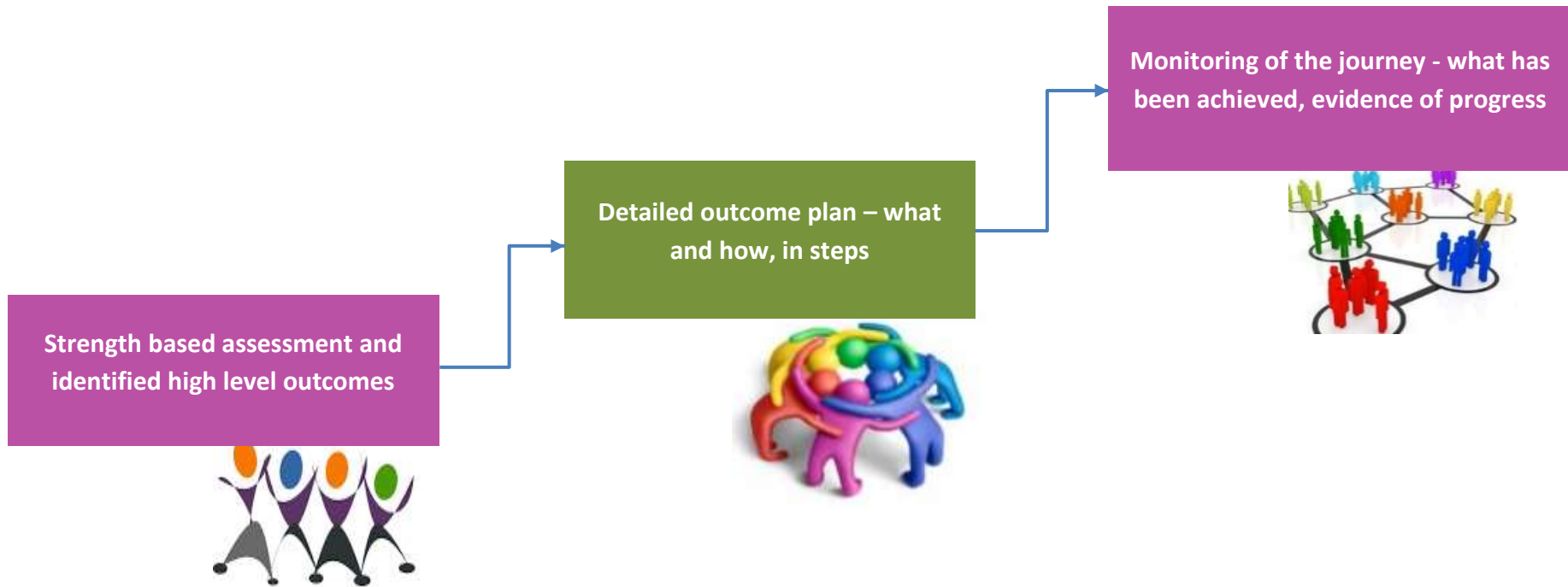
- Maintaining integrity to the contractual and practical intentions of Individual Service Funds
- Committing to a shared ethos of focussing on solutions and of sharing creative or innovative practice
- Teaching and learning in equal measure, with autistic individuals and with all key partners



The contracted providers will be required to participate in a fortnightly 'Brighter Futures Forum' that will meet to discuss and establish:

- Individuals who will benefit from being recipients of the contract approach
- The progress and outcomes of the individuals supported
 - Solutions and suggestions for overcoming barriers or sticking points
- Whether an individual would benefit from specific clinical support
 - Agree the additional support or response requirements where an individual is at risk of admission to a specialised unit with an explicit aim of preventing avoidable admissions
 - Learning from good practice
- Opportunities to influence the wider support and care network

The Outcomes Thread



The Outcomes Thread will be embedded by using approaches that are fundamental to the use of Individual Service Funds.

Needs Assessment: Strength based, Conversational, Outcome Plan

Support plan: Aspirations, Strengths, Areas of focus, Design, Goals and Steps, Outcomes

Delivery: Bespoke, Flexible, Creative, Innovative, Team

Monitoring: Outcomes progress and achievement, quality of experience, key performance indicators

6. Rules of the Flexible Contract and Contract Monitoring: Individual Service Funds (ISF) and what is expected

This Commissioning and Contract Framework is a joint endeavour between the Local Authority - Northamptonshire Adult Social Services and Northamptonshire Childrens Trust - and Northamptonshire Clinical Commissioning Group Adult and Children and Young People Complex Care. It is supported by Northamptonshire Healthcare Foundation Trust. The Framework is intended for individuals who are 14 years +.

Our stated ambition with the Northamptonshire Autism Strategy:

Ambition: Care and support will meet need and support autistic people to progress.

Success will look like: Person-centred care and support focuses on positive outcomes, autistic people are better able to manage their own lives

Our stated Children First Northamptonshire Vision:

The vision of Children First Northamptonshire is that every Child in Northamptonshire will live in a safe, stable, permanent home, nurtured by caring and responsible families and strong communities.

Children First Northamptonshire wants the best for all of Northamptonshire's Children and is specifically dedicated to supporting vulnerable Children.

Children First Northamptonshire values a highly skilled workforce that is passionate about making a difference for Children. Families are the best place for Children to develop.

Children First Northamptonshire will support families to understand and consider Children's needs and put them first.

Key principles:

An individual budget managed using an ISF should support a good life not just the purchase of a service. In a time of reduced funding and increased demand providing the same traditional services with less money is not feasible. We need to be prepared to think differently, be creative and consider responses that are not about services; by using an ISF, resources can go further by thinking differently. Solutions can be sought that may be simple but make a real difference to people's quality of life.

The use of money from the Individual budget must be clearly related to the outcomes specific to the person and their plan. Support planning needs to be clear and transparent, people need to be assured that their support needs will still be met and that they will be safe and well. Relatively small creative solutions can have a significant positive impact on a person's quality of life.

The purpose of contracting more flexibly is to clearly transfer the responsibility to meet someone's needs, and to do so in a way which enables the service provider to provide bespoke support – in doing this the Provider is agreeing with the Council to work flexibly in the person's best interests and according to an agreed set of rules. **An ISF is not a contract, it is an arrangement, developed by a service provider, to make itself more accountable to the person, as part of providing more flexible support. However, without the right contractual agreements, service providers may believe that they lack the necessary authority and flexibility to work in this way:**

What the Provider must have in place in order to offer an Individual Service Fund:

1. Clarity about what you can and cannot offer
2. Transparency about all the costs attached to the services provided
3. Capacity, experience and skill in personalised planning and service design
4. Recruitment and employment processes that are personalised
5. Flexibility to respond quickly and appropriately to the person's life changes
6. Creativity to work with individuals and families and about different ways of doing things

7. The facility to identify each person's Individual Service Fund and systems to track how it is spent
8. The ability to routinely report to the person on how their budget has been spent and what is being achieved
9. The ability to think creatively and draw on resources outside of its own organisation
10. Resources to ensure an ongoing process for planning with people, budgeting and changing things with people as their life changes

What commissioners must have in place if they are contracting for and funding an ISF:

1. An awareness of the connection between how the budget is used and the personal outcomes achieved
2. Flexibility and a reasonable measured response to changes in people's lives, their outcomes, plans and how money is spent to achieve this
3. A case management approach that is based on drawing up the intended outcomes for a good life
4. A transparent system for the allocation of the annual Individual budget
5. A least restrictive set of rules about how a budget can be spent
6. A contract that clearly delegates the authority to change how support is offered to the Provider in discussion with the individual
7. Assurance that the safety and wellbeing of the person is explicitly addressed
8. An agreement on efficiency sharing
9. Clarity about how decisions are made and by whom
10. Sensible systems to help explore conflicts of interest without undue bureaucracy.
11. Practitioners have a role in ensuring that decisions are made based upon the persons will and preferences

ISFs are similar to Direct Payments because:

- The personal budget is clear to the person and/or their representative.
- People have a high degree of flexibility in how support is defined and provided.
- Decisions can be made and changed immediately, without the permission of the funding body.
- Rights and responsibilities of the person are clear.

ISFs are unlike Direct Payments because:

- The Commissioner is delegating service provision, auditing and management of the personal budget that meets the persons assessed needs to the ISF managing organisation.
- An ISF must be contracted for by using clauses that enable the organisation to be flexible in how they meet a person's outcomes i.e. they must not specify how and when support will be delivered each day.

What should you see if an ISF is being managed well?

If an ISF is genuine and is being delivered in a flexible and adaptive way that is controlled by the person and their close family, you should expect the person being supported to be able to make the statements illustrated below:

What	I can use my budget flexibly and can choose what I am given support with
Where	I am supported where it makes sense for me, at home and out and about
Who	I choose who I want to support me. My support workers know me and I know them
When	I get support on the days and at the times that are right for me
How	I choose how I am supported and my support workers know this is important to me
Coproduction	I and the people important to me are fully involved in decisions about my own support and how the budget is used

Choosing to take an ISF

An ISF agreement should not be seen as a complex or legally binding contract (as usually accompanies Direct Payments) it can therefore be presented as more of a simple yes or no decision around whether a person wants to have more choice around their daily support options - mental capacity regarding the management of an ISF is therefore far less of an issue. As the provider organisation holds the ISF budget for the person and is responsible contractually to the Commissioner for how it is spent and accounted for there isn't a great deal of risk presented to an individual in choosing to have an ISF in terms of what can go wrong for them or the commissioning authority. Unlike Direct Payments should there be any issues regarding use of the ISF, the local authority is able to pursue the ISF organisation, as a business entity, via its contractual arrangement.

The ISF agreement should always be tailored to the person individually and should describe in plain English (or easy read) how the person will be supported by their ISF organisation to make any decisions around using the budget. If the person (or their deputy if there is one in place) isn't able to sign the agreement or understand the decision to take an ISF then a best interest decision can be made and the persons circle of support could be used to sign off the ISF agreement.

Working out the ISF budget

It is important to note that ultimately an ISF is still a commissioned service, albeit far more flexible, and the ISF holding organisation remains accountable at all times for the delivery of the person's outcomes.

Commissioners are adopting a tiered approach to the allocation of the ISF. That is, a small range of budget amounts aligned to the extent of an individual's needs and commensurate with the expected input required to work with an individual in achieving the intended outcomes. A separate document will describe the tiers and the commensurate budget allocation.

ISF administration charges

We intend to provide an upfront administration contribution to the Provider in order to acknowledge the costs of managing the person's support as detailed in their ISF agreement and administering the budget in terms of management time, support planning, accounting for expenditure and auditing systems. The ISF administration fee will be set and apportioned dependent on individual circumstances.

Support planning using ISFs

As with Direct Payments, ISFs can be used in a much more versatile way than traditionally commissioned services, of particular benefit is the ability to undertake 'costed support planning' that can be done with the person and their circle of support. The planning will then attach a budget to the individual steps and goals agreed in order to meet the identified outcomes and this can be done by any means that work for the person (rather than traditional time and task based approaches). Creative approaches using ISFs are starting to be used more widely for example buying personalised technology, such as iPads to help support people at home, this has empowered individuals to take more control of their support and provided the flexibility for them to decide how best to meet their identified outcomes. ISFs work really well for people who have a fluctuating need and where traditional inflexible commissioned services are unable to be tailored adequately to the needs of the person. In these scenarios the budget can be left to accrue over periods when it is not needed and can then be utilized more intensively when necessary. As with any unspent budget, if it is not required it can be returned to the commissioning organisation or, if necessary, held as contingency for future use.

Managing unspent ISF funds

Unused ISF funds that have accrued with the provider organisation, or on a prepaid card if we implement this system, will be returned to the Commissioning Body by the provider organisation. It is important for the Commissioning Body to discuss reasons for the underspend and understand this prior to requesting a return – for example where a sum is being accrued in order to achieve a specific outcome.

The Key Performance Indicators

We asked autistic people who have used, or are using, commissioned support services “How do you know a service is a good service?” and this is what they said:

- They listen to the voice of the autistic person, family, professionals involved that the autistic person trusts
- They ensure a well-planned transition is in place before a move and access any training they need before the move
- They complete a one-page profile or similar
- They make reasonable adjustments and don't see it as a bother
- They follow person centred procedures-checking interests, what a good/bad day might look like etc.
- They communicate in the way that is needed
- They don't assume the autistic person or family can move forward as easily as them due to traumatic history
- They understand trauma from past support [services] is real
- They have understanding of comorbid diagnoses and how they may impact
- They have a range of quality qualifications not just tick box stuff
- They don't assume their needs come first – [their] own agenda of what needs to be done rather than the best interest of the autistic person
- They contact other specialist services or the MDT, or arrange a Review if any issues arise etc. (they ensure they have contact details as part of the transition)
- They don't assume or judge
- They work to build relationships and understand that this group may take time or be more 'complex' to build relationships
- The ethos should not be a paper exercise it should be caring and empowering a quality of life throughout the service
- The care staff and housing staff have to be on the same agenda and have the same understanding and compassion
- Clear assessments, transition process, care plan, understanding behaviour or communication should all be recorded and on file
- There will not be a quick turnaround of staff or lots of duty staff
- Have a good understanding of the disparities of expressive communication to receptive communication (vice versa)
- The manager and/or staff will be involved in the local autism professional groups to ensure they are learning/sharing up to date information
- They don't blame if things aren't working - they use a solution focussed approach
- They have clear care plans that are person centred and meaningful to the person not just them
- They build relationships with the family
- They understand how to monitor and respond to risk/safeguarding
- They will have a clear understanding and be able to describe the person's interests, care plan and dislikes etc.
- The care plan and support should clearly promote dignity, interests, human rights etc.

- They should respond to complaints appropriately and with kindness
- They should have clear procedures of how they will identify the correct interventions and strategies
- There should be clear weekly plans so all staff know what to do if anyone is absent
- They have clear knowledge of different strategies that might be used
- When speaking with autistic people, family or staff it is clear they are happy or feel they can speak out to complain/raise something
- The building is sensory friendly
- They gain valuable advice from those with lived experience (sensory, reasonable adjustments etc.)
- They don't use language such as the person is challenging, choosing etc. and have a good level of understanding of why things might happen or why someone might do something etc.
- They are part of the autistic community and know what is happening in that community
- They don't take the funding and do nothing!!!!
- The monitoring process is thorough and they passed not just by a paper exercise

The stated key performance indicators represent the measures we will use across the life of the contract. They give the Commissioner, and Providers, an indication of the quality and success (impact) of services commissioned. We will tell you how to report these performance measures to us. The Commissioners may wish to make changes to the Performance Indicators during the contract period. Any changes will be discussed with the Contracted Providers.

Key Performance Indicator	Measurement
Effective and mutually beneficial partnership work across Preferred Partners	Evidence of cross fertilisation of training and learning opportunities
	Attendance and contribution to Brighter Futures Forum
	Cross-Provider peer group formation
	Evidence of collective purchasing
Effective partnership working with other disciplines and Agencies	Evidence of multi-disciplinary working to reduce risks
	Evidence of effective and appropriate use of CTRs and CETRAs
	Evidence of appropriate admission avoidance
	Evidence of effective contingency planning and crisis support plans
Enabling progression and step down	Progress in individual goal attainment
	Progress in individual outcome attainment
	Individuals report that they have gained skills in self-management
	Numbers stepping down into less intense support arrangements
	Reduction in spend**
Enabling independence and autonomy	Numbers accessing education
	Numbers returning to education
	Numbers accessing vocational training (including voluntary work)
	Numbers accessing employment
	Numbers reporting having a sense of choice and control
	Numbers actively engaged in designing their support plan
Improving well-being	Reduction in episodes of self-harm
	Reduction in episodes of crisis

	Individuals are able to self- report feeling unwell
	Individuals report having a 'tool-kit' for managing feelings
	Individuals report having improved confidence and self-worth
	Individuals report feeling a sense of ongoing achievement
	Numbers maintaining positive relationships with family
	Numbers maintaining positive relationships with friends and peers
	Numbers reporting positive and trusting relationships with supporters
	Numbers accessing annual health checks
	Numbers with a Health Action Plan
	Numbers accessing primary care universal services
	Numbers accessing secondary care services where this is needed

**Research indicates that over a period of 3 years the cost of support reduces by approximately 44% when Individual Service Funds are offered and used with integrity and that there is a significant improvement in the quality of people's lives with multiple outcome improvements/achievements reported by individuals, families and professionals. Improved efficiency was achieved by working with individuals to help them achieve better lives.

In order to fully understand the performance of the Contract, The Commissioners Representative will agree with the Provider the relevant Performance Indicators for each individual. For example, some individuals will not have a history of self-harming, others will be looking at employment rather than education.

6. Contractual obligations and monitoring

What we expect from you

- The Commissioning and Contract Framework, Service Specifications and Outcome Based Support plans lay out the detail of our expectations. These documents form the basis on which a contractual relationship is established and in which we will monitor and hold providers to account.
- Any provider experiencing difficulties in either the provision of care to an individual or in the viability of care to a group of individuals must make those issues known to Commissioners as soon as is practicable, being mindful of the risks of continuing to provide those services where the safety, well-being and best interests of an individual/s is compromised.
- The Provider will facilitate access to the individuals using services under this Contract for the purposes of carrying out any and all of our statutory responsibilities as the Commissioning Body, including well-being checks. We will require representatives of the Provider to make themselves available to us for the purposes of assuring the safety and well-being of an individual/s and in respect of progress in delivering against the requirements of the contract.
- You will work with us to deliver high quality, cost effective services as a continuous cycle – bringing to our attention potential efficiencies, options for development and improvement and opportunities for collaboration across the provider market.

What people using your services should expect from you

- Commitment, transparency and creativity
- Respectfulness, integrity and honesty
- Open communication and accessibility as required by the individual and/or their family
- Due care and attention to all legal and policy requirements
- To be asked, and for you to listen well

What you should expect from us

- We will listen to concerns and act responsively and responsibly.
- We will be transparent and collaborative in communicating the commissioning needs of our population; supporting development and innovation, celebrating good practice, defining service improvement requirements and being fair in provider opportunities.
- We will hold provider forums specific to care and support of autistic people and provide opportunity for learning and the show-casing of good practice; sharing knowledge about what works well and what doesn't work well.
- We will have an annual dialogue with those providers in receipt of a contract under this Framework in respect of uplift provisions.

N.B. 'We', 'our' and 'us' refers to any officer of the Council, Trust or Clinical Commissioning Group or their delegated representatives.

The Contract will be monitored by

- Asking for the insight and experience of autistic individuals and their close contacts as to the success of the arrangements and what is working well as well as what is not working well
- Evaluating progress against goals and outcomes, paying particular attention to evidenced experiences and goal achievement
- Evaluating the outcomes measurement tool for each individual and the goals that have been defined to achieve the overall outcomes
- Evaluating the numbers of individuals who have been supported through periods of ill-health and who have been supported to remain in the least restrictive setting with positive outcomes
- Evaluating success against the Key Performance Indicators agreed as relevant for each individual and assessed across the whole cohort

Contract mobilisation

The Commissioners intend to award Contracts under this Framework to a small group of Preferred Providers evaluated as suitable following Contract Tender. On Contract Award the Preferred Providers will work with the Commissioning Bodies for a period of contract development and mobilisation which will include action learning sets led by Experts by Experience and training sessions focussed on the application of Individual Service Funds. All Preferred Providers must participate in this development and mobilisation phase.

A key intention of the Contract is to formulate a set of Providers who have evidenced a commitment and enthusiasm to work collectively and dynamically with each other to support individuals and their outcomes. It is expected that the relationship between this network of Preferred Providers will be strong, productive and mutually supportive and will act in accordance with the requirements and ethos as laid out in the totality of the Contract. This Commissioning and Contract Framework document is a key contract document.