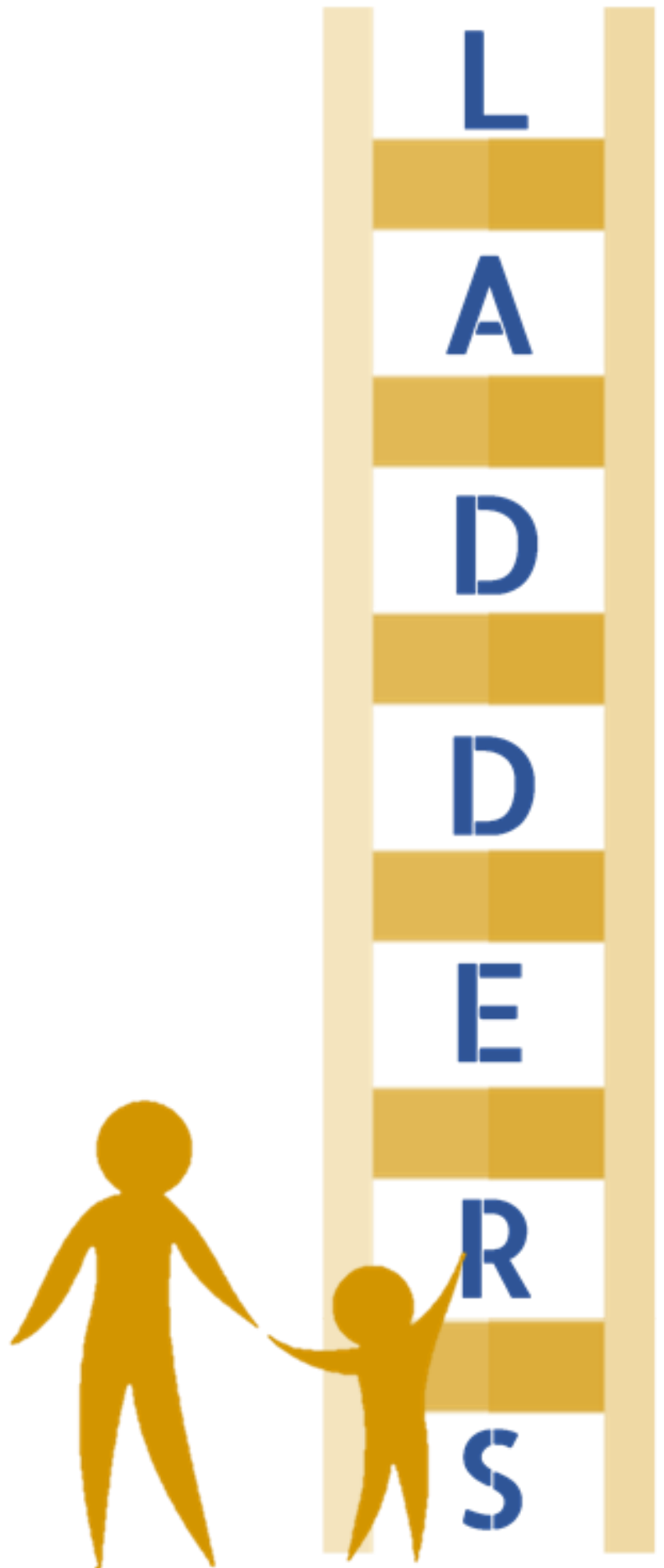


# APPENDICES



## Contents

Appendix Title	Page Number
A.....	3
B.....	4
C.....	5
D.....	7
E.....	12
F.....	13
G.....	15
H.....	19
I.....	21
J.....	26
K.....	27
L.....	31
M.....	32
N.....	37
O.....	42
P.....	43
Q.....	45

## APPENDIX A

Table 1: Indicative illustration of the 16-week intervention

Week(s)	Title	Description
1	<i>Introductory session to boost alliance with the therapist</i>	Discussion of the structure of the weekly sessions and fostering an environment of genuineness and empathy. Baseline measures will be completed. An initial discussion will take place about the goals for the intervention, and possible feared situations to focus on.
2	<i>Introduction to escape-maintained and avoidance behaviours</i>	Parents will learn about escape maintained and avoidance behaviours associated to anxiety using generic examples unrelated to their child. Parents will be asked to observe for examples of escape or avoidant behaviours over the next week.
3	<i>Parent emotions in relation to child anxiety and avoidance</i>	Encouraging parents/carers to identify the emotions that they experience when their child engages in avoidance or escape behaviour. This session will utilise mindfulness strategies to help parents notice when they are experiencing these emotions.
4	<i>Strategies for management of parent emotion</i>	This week will reinforce learning from week three and discuss emotional regulation strategies that help to reduce anxiety.
5	<i>Preparing for the intervention</i>	This week will focus on thinking about factors that may affect the success of the intervention, such as the role of tiredness, hunger, illness etc. Additional strategies will be proposed for sensory impairments and communication difficulties, if these are applicable to the child.
6	<i>Psychological formulation of child avoidance in a specific situation</i>	The parent will work with the therapist to select a situation with a clear antecedent/trigger that can be 'operationalised' in which anxious avoidance is present (but will not cause significant distress or place the child at risk. The parent and therapist will discuss what happens in that situation for parent and child.
7-8	<i>Co-creation of an intervention plan</i>	Parent and therapist will work together to consider aspects of the formulation and how avoidance can be gradually reduced using graded exposure techniques; focus on increasing parent and child coping skills through the creation of an evidence-based toolkit.
9	<i>Barriers to intervention</i>	Discussion with parent about barriers to intervention and possible ways to overcome them. During this week, the therapist and parent will draft a list of warning signs and calming strategies that can be used during intervention.
10-16	<i>Implementation of the intervention</i>	Parents will spend 7 weeks implementing the intervention plan with weekly support from the therapist. In week 16, outcome measures will be collected, and parents will be able to discuss future goals, fading of rewards and generalising skills.

## APPENDIX B

### Screening and Eligibility Document

#### Screening Eligibility

Using participant database, identify children and families meeting the following criteria:

	Eligible (Y/N)
<b>Child age</b> (Child must be aged between aged 4-15 years)	
<b>Clinical diagnosis of autism</b>	
<b>Clinical diagnosis of moderate to profound ID with or without an autism diagnosis</b> (diagnosis letter seen by research team)	
<b>Diagnosis of a moderate to profound ID</b> , with associated communication impairment.	
	If yes to all, proceed to invitation and eligibility screen

#### LADDERS Eligibility

During eligibility phone call ask parents the following questions. Note parent responses in the 'notes' column. Discuss eligibility with qualified clinician.

Details of escape or avoidance behaviours			Eligible? (Y/N)
<b>Does he/she avoid (or try to avoid) certain objects or places?</b>	<ul style="list-style-type: none"> <li>○ When are avoidance behaviours most likely to happen?</li> <li>○ When are avoidance behaviours least likely to happen?</li> <li>○ Where are the behaviours most likely to happen?</li> <li>○ Where are they least likely to happen?</li> <li>○ What activities are least likely to produce the behaviours?</li> <li>○ What could you do to make the behaviour occur?</li> <li>○ What could you do to make the behaviour not occur?</li> </ul>	<b>Notes</b>	

# APPENDICES

	<ul style="list-style-type: none"> <li>○ What is the impact of this behaviour?</li> </ul>		
<p><b>Does he/she ever run away or hide from certain objects or situations?</b></p>	<ul style="list-style-type: none"> <li>○ When are avoidance behaviours most likely to happen?</li> <li>○ When are avoidance behaviours least likely to happen?</li> <li>○ Where are the behaviours most likely to happen?</li> <li>○ Where are they least likely to happen?</li> <li>○ What activities are least likely to produce the behaviours?</li> <li>○ What could you do to make the behaviour occur?</li> <li>○ What could you do to make the behaviour not occur?</li> <li>○ What is the impact of this behaviour?</li> </ul>	<b>Notes</b>	
<p><b>Does he/she live at home?</b></p>	<ul style="list-style-type: none"> <li>○ Does child spend any time in care/residential/respice settings? If so, how many days a week/month?</li> </ul>	<b>Notes</b>	<b>Y</b>

Eligibility decision.....

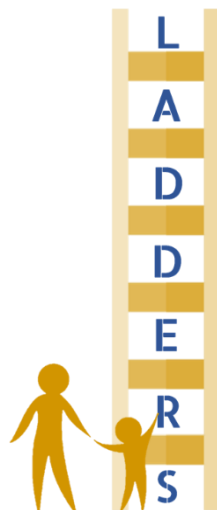
Date.....

Initials of therapist.....

## APPENDIX C

### The Ladders Intervention – Summary

<b>Weeks 1-4</b> Psychoeducation	<ul style="list-style-type: none"><li>• Learn about anxiety and avoidance behaviour</li><li>• Focus on your's and your child's emotions and how you respond to anxiety</li></ul>
<b>Week 5</b> Intervention preparation	<ul style="list-style-type: none"><li>• Ways to make intervention more effective</li><li>• Consideration of the environment and child's needs</li></ul>
<b>Weeks 6-8</b> Formulation & designing	<ul style="list-style-type: none"><li>• Making sense of your child's anxiety based on what have learnt in previous weeks</li><li>• Thinking about goals and building the plan for intervention</li></ul>
<b>Week 9</b> Barriers	<ul style="list-style-type: none"><li>• Considering what barriers you may face during intervention</li></ul>
<b>Weeks 10 onwards</b> Intervention	<ul style="list-style-type: none"><li>• Parent to complete the intervention with check-ins from therapist</li><li>• Thinking about beyond the end of the intervention</li></ul>



## APPENDIX D

### Week 1 – Background to Child’s Anxiety and Goal Setting

What is the main trigger for anxiety that you would like to address during this programme?

.....

.....

.....

What behaviours does X display when he/she is feeling anxious?

- a)
  
- b)
  
- c)
  
- d)
  
- e)
  
- f)

1

## SPECIFIC

What do I want to accomplish?

2

## MEASURABLE

How will I know when it is accomplished?

3

## ACHIEVABLE

How can the goal be accomplished?

4

## RELEVANT

Does this seem worthwhile?

5

## TIME BOUND

When can I accomplish this goal?

Describe what you would like the goals of this programme to be for you. Think about 3 short term goals important for you and your child that we might be able to reach by the end of the 16 weeks. We will revisit these goals each week.

My first goal is:

.....  
.....

My second goal is:

.....  
.....

My third goal is:

.....  
.....

## APPENDIX E

### Parent/Carer Handout: Week 2 – Understanding anxiety and avoidance

#### What is anxiety?

Anxiety and fear are normal emotions and something that we all feel every now and again. However, for some people anxiety can occur often, or in scenarios that prevent them from being able to engage in activities they enjoy or that will help them achieve their full- potential (e.g. school). People can feel anxiety or fear about lots of different things for several different reasons. Many individuals with an intellectual disability also show autistic characteristics. Research suggests that children with these characteristics are more likely to experience anxiety than those without them, although the reasons for this are not yet fully understood. For example, studies have shown that around 40% of autistic children experience clinically significant levels of anxiety

~~Anxiety is more common in children who have autism compared to children who do not. The reasons for this are not yet fully understood. Research has shown approximately 40% of autistic children will also experience anxiety.~~

Anxiety can be a problem when we feel fear and worries in response to situations that are not actually dangerous. It is a particular problem if they affect a person’s quality of life or prevent them from taking part in activities that are part of day-to-day life or an important part of life.

Anxiety is a normal feeling that most people will feel sometimes. Anxiety can even be helpful sometimes (e.g. helps us to perform better). However, anxiety can become problematic when:

- It occurs very regularly
- A person responds to anxiety in a very extreme way (e.g. behaviours that challenge)
- The trigger for anxiety is not actually something that is dangerous or something likely to cause harm
- It has a significant impact on the life of the individual or that of their family
- It is associated with lots of avoidance

Whilst anxiety is very common in children with a moderate to profound ID who may also be autistic, autistic children if it is starting to impact quality of life, it is something that you might want to try and address. Reducing anxiety isn’t about changing a person’s autism/neurodivergent identity.

#### Fight or flight

Fear and worry are natural feelings, designed to prepare us to deal with threat. The symptoms we experience when we feel scared are reactions to help us to either ‘fight’ the threat or run away from it (‘flight’). When we feel anxious or scared, we may experience several symptoms affecting our biology, our behaviour and our thoughts and attention. Some examples are below:

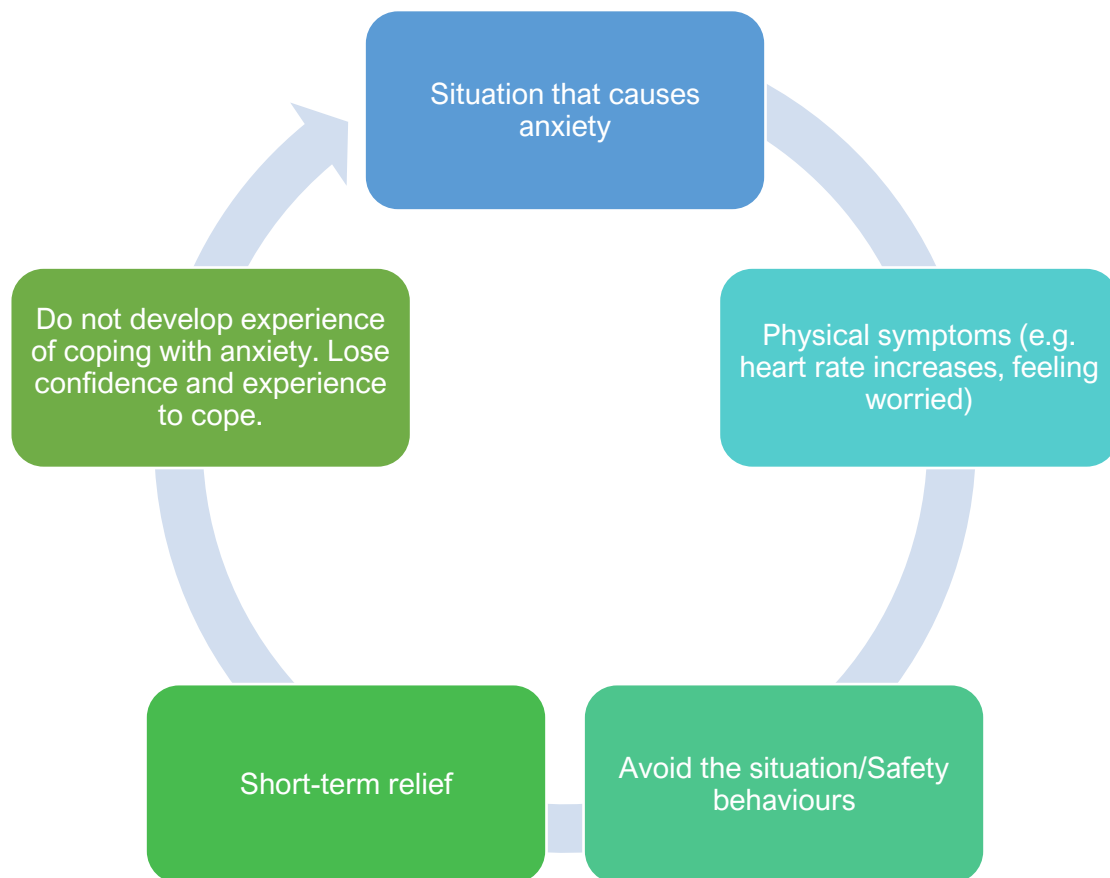
Changes to body	Changes to thoughts	Changes to emotions	Behaviour
Heart rate increases or heart beats faster	Cannot concentrate	Worry	Fight (aggression)
Changes in breathing	Cannot relax	Distress	Run away
Increased sweating	Search for potential threat	Crying	Pacing
Muscles become tense	Being on ‘high alert’	Irritability	Fidgeting
Shaking or twitching			

Blood moves away from digestive system (e.g. feeling sick, dry mouth)			
Eyes widen			
Adapted from Waite, J., Royston, R., & Crawford, H. (2016). <i>Anxiety Guide: A Guide for Parents. Cerebra.</i>			

Have you noticed any of these symptoms in your child when they are experiencing anxiety?

## Avoidance

Everyone has felt worried or scared at some point. Most people would agree that anxiety is not a nice feeling. It is therefore very natural to try and find ways to reduce feelings of anxiety. A common way to reduce anxiety is to avoid situations or things that we find scary or threatening. In the short-term, avoiding or removing ourselves from a scary situation is a very effective way to stop feeling anxious. However, in the long-term, avoidance can actually do more harm than good. The reason is because when we avoid situations, we take away our chance to learn that situations are not actually that scary or dangerous. We also lose chance to gain confidence in facing our fears. This means that anxiety about a situation continues and may even get worse. This is known as a cycle of anxiety (see the diagram below).



## Mark's example

Mark has always been scared and worried about doing presentations at work. Because of this, he always avoids doing them. This includes calling in sick on days when he was due to present. At other times, Mark waited for other members of staff to offer to do the presentations so that he didn't have to do it. In the short-term Mark felt better, because he was no longer worried about the thought of giving a presentation. Because avoidance successfully reduced his worry, he carried on avoiding them every time he was due to do one at work.

However, one day Mark's boss came to him and told him he had to do a last-minute, important presentation at work. There were no other members of staff available, and the success of the company was dependent on Mark successfully delivering the presentation. Because Mark avoided giving smaller, and less important presentations in the past, he lost lots of opportunities to build confidence in giving presentations. He also lost chances to learn that presentations are not actually dangerous. Now that Mark has to do a presentation that he cannot avoid, the anxiety feels a lot worse and he feels very scared.

Individuals with a moderate to profound ID who may also be autistic will also try to avoid situations that they find scary. Again, this is a completely understandable response. When faced with a trigger for anxiety, a child will also experience the fight or flight response and their body will prepare for them to fight danger, or run away from it. Aggression, running away, and self-injury are therefore very natural responses to anxiety. But they can also be very concerning and challenging behaviours for parents and carers to manage. It is completely understandable that parents will remove their child from situations they find scary and avoid them in the future.

Avoiding the situation, along with safety behaviours, are good ways to help manage anxiety in the short-term. They might help to reduce feelings of anxiety quickly. However, in the long-term they might actually maintain the cycle of anxiety. Safety behaviours are behaviours that though enabling an individual to access a situation, stop them from fully experiencing the situation. Examples of safety behaviours include reassurance seeking (asking repetitive questions) and reliance on certain individuals to access a feared situation.

## Tom's story

Tom is 4 and has recently started school. Whilst Tom is at school. Mum stays at home with his baby sister. Tom can be anxious when he is out of the house. He is happiest when he is at home with his iPad.

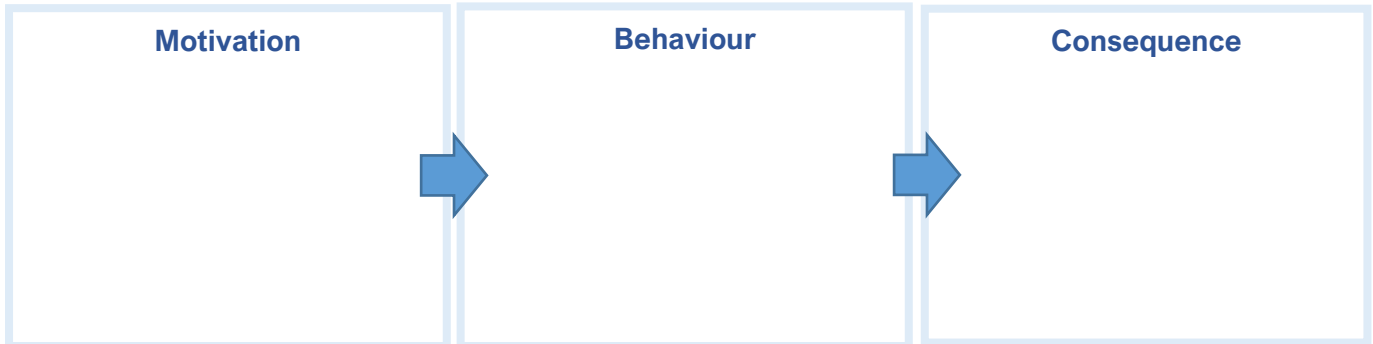
Tom does not like loud noises. There is a girl in his class who sometimes screams loudly. One time when she screamed, Tom became very distressed and pulled her hair. She then screamed louder. Tom remained very upset and the school decided he should go home for the afternoon.

A couple of days later, Tom was in school again. The next time the girl in his class screamed, he pulled her hair again. Tom has learnt that hair pulling might be a way of allowing him to avoid the situation. This is called a learnt behaviour. We will discuss this further below.

## Learnt behaviours

Learning from past experiences is an important part of our development. It helps us to predict or guess what might happen in the future and behave in ways which are important for our survival and well-being. If a behaviour or event is likely to benefit us in some way, we are more likely to repeat that behaviour again in the future.

- What was your motivation for that behaviour?
- How did you feel after the behaviour?



We are more likely to repeat behaviours in the future if we learn to associate that behaviour with pleasure or a positive outcome. This is called 'reinforcement'.

Behaviours are not just reinforced by gaining something, like food or money, but they can also be reinforced if they are associated with a reduction in a negative experience, like removal of a demand or situation that we don't like.

Going back to Tom's example above, when he pulled hair, he was removed from school and sent home. Tom does not like school and instead prefers to be at home. He was motivated by leaving school and being at home. Therefore, he is more likely to repeat behaviours that means he can be removed from school and go home.

This does not mean that **children with a moderate to profound ID who may also be autistic autistic children** engage in behaviours on purpose to escape from situations. However, if they feel anxious, and are unable to communicate this, the behaviours may be more likely to be repeated. Learnt behaviours are things that everybody engages in every day.

## Sensory processing differences and anxiety

Many **individuals with a moderate to profound ID who may also be autistic individuals** may experience sensory processing difficulties, where some sensory experiences may be very aversive or painful. If this is the case for your child, then it is understandable and ok that they want to avoid situations where the aversive sensory experience may be present. At an early stage, sensory interventions may be enough to reduce avoidance behaviour.

Sometimes, the avoidance of sensory experiences can lead to the emergence of anxiety. Especially if the individual's sensory processing difficulties are not appropriately addressed early on. This is likely to have a bigger impact on the individual's quality of life. Consider the scenario below:

### Anisha's story

Anisha is 6 years old and has autism. She is also hyperresponsive to sounds. Every Saturday morning Anisha and her mum go food shopping and meet her Grandma in the café afterwards. Anisha always looks forward to this Saturday morning routine and seeing her Grandma.

Sometimes when Anisha and her mum are shopping, the security alarms go off. Because of her hyperresponsiveness to sound, Anisha finds this noise painful. She will cover her ears and start shouting. Over time, Anisha has become more clingy to her mum and impatient when shopping. She just wants to go straight to see her Grandma at the cafe.

The last few times when leaving the supermarket, the alarm has gone off as Anisha has walked through. This resulted in an escalation of behaviour and both Anisha's mum and Grandma could not calm Anisha down. Now every Saturday morning, when asked to put her shoes on, Anisha will start throwing things and hitting out. She doesn't even want to go and see Grandma in the café. Anisha now also becomes distressed when she goes to any supermarket with her mum.

This scenario shows the escalation of Anisha's anxiety. At the beginning she would not avoid going to the supermarket, although she would not want to spend too long there. Gradually the avoidance of going to the supermarket impacted on activities she looked forward to, such as seeing her Grandma, and then became generalised to going to any supermarkets. At this stage, sensory interventions may not be effective on their own as Anisha's anxiety has extended to the anticipation of going to a supermarket.

## APPENDIX F

### Week 2 – Behaviour Recording Handout

Over the next week make a note of any behaviours you think your child might be displaying to escape from a situation or demand. We will discuss these next week, as well as starting to think about your feelings when your child is experiencing anxiety.

Possible avoidance behaviours

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

What was happening when you saw this behaviour?

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## APPENDIX G

### Week 3 – Parent/Carer Handout

At the end of last week, we discussed behaviours that your child might engage in to escape or avoid behaviours. This week, we are going to build on these behaviours to think about what happened, and the impact it might have had on you.

Think of the most extreme example of that behaviour that has occurred this week. If the behaviour has not happened this week, try and think back to the last time it happened. Then answer the following questions.

**What was the trigger?**  
**What behaviours did (name of child) display?**  
**How did *you* feel?**  
**How did *you* respond?**

**What happened?**

The diagram consists of four downward-pointing chevrons on the left, each connected to a horizontal text box on the right. The chevrons are colored blue, teal, green, and dark green from top to bottom. The text boxes are white with rounded corners and a thin border matching the chevron color.

Trigger	
Behaviour	
My feelings	
My response	

**Last week, we focused on the first two stages of this diagram. The anxiety trigger and your child's behaviour in response.**

**Today we are going to focus on about the last stages in this process**

**How did you feel?**  
**How did you respond?**

Your feelings and response in these situations are very important. When thinking about anxiety, it is important to think about **your** well-being as well as your child's.

Well-being for the whole family should be an important aspect of any support programme.

If you feel well, and equipped, you will likely feel much more able to support your child.

So today, we will focus on **you** and strategies that might help **you** and **your** well-being, and then ultimately your child's.

## Being a parent in automatic pilot

Everybody lives very busy lives, particularly parents of children with complex needs. It is very easy to therefore act on auto-pilot. This means doing things without consciously thinking about it. For example:

**Have you ever eaten something and then not realised you have eaten it? E.g. got to the bottom of the crisp packet without recognising you have eaten them all?**

**Driven to collect your child from school, arrived and realised you have no recollection of getting there?**

Being on auto-pilot is very common, but it means that sometimes we might respond to things automatically, without thinking about whether it is the most effective thing to do in that moment.

Can you think of a time that you did something without thinking? Or just reacted to something in the moment?

.....  
.....

How would you have reacted differently, if you were *not* in auto-pilot?

.....  
.....

## APPENDIX H

### Week 4 – Parent/Carer Handout

Mindfulness is a technique that encourages us to pay attention to the present moment and to the world around you. In a number of scientific studies, mindfulness has been shown to improve well-being.

**“Mindfulness is the awareness that emerges through paying attention on purpose, in the present moment, and non-judgementally to things as they are”**

**Williams, Teasdale, Segal, and Kabat-Zinn (2007)**

By engaging in mindfulness, it is possible to come out of auto-pilot and bring ourselves into the present moment to acknowledge how we feel. Being mindful is a skill and takes lots of practice. With practice, the areas of the brain that are used when being mindful can develop new connections and become stronger; in this sense mindfulness is like a muscle.

#### Strategies for being mindful

There are several ways you can incorporate mindfulness in your day-to-day life, some may work better for you than others. Throughout the range of exercises, there are some core features to completing them mindfully:

- Being non-judgemental: Trying not to interpret situations/thoughts/feelings, but just observing them as they are
- Staying focused: Trying to avoid thinking about what happened before the task, or what will happen afterwards, but remaining focused on the present task
- Not overcomplicating the task: Do what works for you to complete the task. Try not to impose additional rules or routines that might make you lose focus or worry about whether you are right or wrong.

**Here are some examples of ways to practice mindfulness:**

#### Being mindful during day-to-day activities:

Some everyday activities can be a chore to complete, and we do not focus our attention on the tasks, our mind instead wandering onto the next task and so miss out on positive aspects of the activity. By doing these activities in a focused way, not in autopilot, we can make these activities opportunities to increase wellbeing.

Some example activities could be:

- Washing up or loading/unloading the dishwasher
- Journey to/from work or school
- Cooking a meal
- Eating a snack

Can you think of any activities that you could focus your attention on, that would make the activity more enjoyable?

- \_\_\_\_\_
- \_\_\_\_\_

**There are other ways to practice getting out of autopilot, using formal exercises:**

- *Body Scan:* Spending some time paying attention to how your body feels by focusing on different body parts. Body scans can help us recognise our internal markers for different emotions and tell us when to use our quick strategies (which we talk about later in this session).
- *Observation of an object*
- *Take a 'bird's eye' view:* Try to imagine a situation as though you are looking down on it from above, or as though you are watching a video of the event. Consider your/your child's emotions and your/your child's behaviour. This activity can be helpful when reflecting on past events.
- *Focusing when walking*
- *Focusing on breathing*

You can find more information about formal mindfulness strategies in the 'Mindfulness Exercises' handout or on the LADDERS website.

**Being mindful can also be applied to parenting**

Think about how you appear to your child. If you appear anxious and stressed, your child may pick up on this. As we learnt during week 2, when your child is feeling anxious, they are likely to be on high alert. This means they will be on the lookout for danger and therefore may be able to pick up on signs that something is wrong. Children who display more anxiety may be more likely to do this than children who are not so anxious.

## Hasan's story

Hasan is 10 years old. He is autistic and is hyperresponsive to loud sounds. Because of this, hand dryers in public toilets can be distressing for Hasan. He can quickly become very upset. Hasan's Dad knows that if Hasan gets very upset, his behaviour can escalate and then it can be very hard to calm Hasan back down in public places. This makes Dad feel worried and stressed as soon as they enter the public toilet. Hasan's Dad therefore sometimes rushes Hasan out of the toilet, tells Hasan he doesn't need to wash his hands, or if he does wash his hands, that he only needs to hold them under the dryer for a very short time before pulling Hasan's hands away.

While Hasan's reaction to the hand-dryer may be understandable for an autistic child, rushing Hasan out of the toilet, telling Hasan he does not need to wash his hands, or pulling his hands away quickly from the hand dryer, he might be signalling to Hasan that hand dryers are something that can harm you, or that the public toilet is an unsafe place to be.

In week 3 you said you felt (insert name of feeling) when (insert name of child) is faced with (name of trigger).

Can you think of a time you may have inadvertently communicated to your child that something might be unsafe when it is not?

### What happened?

.....

.....

### How did you feel?

.....

.....

By being mindful of how we feel in a situation can bring us out of autopilot, and we are better able to *respond* to our child rather than *react*.

***React- being guided by our own emotions, acting in auto-pilot***

***Response- a mindful approach, taking account of how we feel, accepting our feelings, making less automatic responses***

In Hasan's example, Hasan's Dad was worried about the distress that Hasan might feel, and consequently his behaviour in public. Hasan's Dad obviously wants to protect him, and to reduce distress for Hasan, he has got into a pattern of avoiding hand dryers with Hasan. Thinking back to the anxiety cycle, avoidance can help to maintain the anxiety cycle. Having awareness of this cycle, and when we might do it in our lives is important to make sure that children are given opportunities to overcome their fears. We can support children in other ways for them to overcome their fears and live more fulfilled lives. We will discuss strategies for this later in the programme.

However, it is important to remember here that having fears and anxieties are normal and common both for children with a moderate to profound ID who may also be autistic and neurotypical children, and of course parents. There may be other factors that need to be considered when supporting autistic-these children, such as sensory processing differences. **Where sensory processing differences lead to distress, we may consider the situation causing distress to be understandable (e.g. loud noises that may cause pain), and therefore *not* a focus of this intervention.**

Therefore, it is very important that you do not start these strategies with your child now, or make your child feel their anxieties and worries are not normal. We will think about the factors involved in your child's anxieties in the next sessions, when we will begin to start developing some step-by-step strategies that will help your child to face their anxieties in meaningful manageable steps that both you and your child are happy with.

## Strategies for developing mindfulness skills

In challenging situations, remembering to respond in the most helpful way can be difficult, especially when big emotions are present. It can be helpful to have short strategies to ground you back in the present, and prevent an auto-pilot response:

Some strategies you could use are:

- '1, 2, what do I do?'
- Create a meaningful phrase that you link with mindfulness skills
- '5, 4, 3, 2, 1' – Find 5 things you can see, 4 things you can hear, 3 things you can feel, 2 things you can smell and 1 thing you can taste.
- STOP: **Stop** what you are doing. **Take** a deep breath. **Observe** your thoughts, feelings, and body sensations. **Proceed** mindfully.

Can you think of any strategies that may work for you? Write them below and try them out over the next week.

- \_\_\_\_\_
- \_\_\_\_\_

## APPENDIX I

### Mindfulness Exercises Handout

*All YouTube links and referenced material in this document are from existing resources in the public domain. The references for the resources can be found in the 'References' section of the Therapist Manual.*

#### **Body scan - soundtrack:**

[Mindfulness Meditation Body Scan - YouTube](#) [Mindfulness Meditation Body Scan - YouTube](#)

#### **Body Scan - script (Kabat-Zinn, 1982):**

Try tuning in to your breath wherever you find yourself, whether that be lying down or seated upright. Starting from the toes, work your way up your body, focusing your attention on each region; the feet, the legs, the pelvis, the belly, the chest, the back, the shoulders, the arms, the throat and neck, the head, the face, the top of your head. Notice any areas of discomfort, without trying to change these sensations. Notice any areas of tension. Listen carefully to what your body is telling you about your emotional state. Watch the sensations in the body flux and change. Watch your feelings about them flux and change.

#### **A combined breathing and body scan soundtrack (approx. 10 mins):**

[Reset: Decompress Your Body and Mind - YouTube](#)

#### **Observation of an object:**

Choose a natural object from within your immediate environment and focus on watching it for a minute or two. This could be a flower or an insect, or something larger like a lake, or passing clouds. Just notice the thing that you are looking at, perhaps labelling what you see without judgment. Look at this object as if you are seeing it for the first time. Watch the object for as long as your concentration allows. Try not to judge yourself if the time you can concentrate for is shorter than you expect.

#### **Thinking about a past or future event (Reid, Gill, Gore & Brady, 2015):**

This exercise can be helpful when planning for future events or reflecting on past events. It can also be used in the moment when difficult situations feel overwhelming.

Imagine you are looking down on the situation with a bird's eye view, or imagine you are watching the event take place as you would watch a film. Observe your behaviour as you watch the event; consider how watching the event makes you feel. Turn your attention to your child, and consider their behaviour, their possible thoughts, and their feelings. Were there other ways that the situation could have been managed, were there more effective ways that you could have responded to the situation? Do not judge what your responses were; just recognise that there are often multiple ways to approach a difficult situation.

## **Focusing when walking:**

This can be as simple as counting your steps as you walk around the house or to the shops. For example, you may choose to count your steps 1-10 and then start again. You could also pay attention to every time you lift your foot up and place it back down. It is completely natural and normal for your mind to wander, but that's ok. Just guide your mind back to walking when you can. You might also choose to direct your attention to other parts of the environment. For example, if you are outside, you could take in the smell of fresh cut grass, or sound of birds singing. Again, your mind might wander and that's ok. Just bring your attention back when you can. Being mindful becomes easier with practice.

## **Focusing on the breath – a very short soundtrack:**

[Headspace](#) | [Mini meditation](#) | [Breathe - YouTube](#)

## **Focusing on the breath – script:**

Sit in a comfortable, but upright position. If you wish, close your eyes, or you could lower your gaze to your lap.

Turn your attention to your breath. Try not to change your breathing, but just notice each inhale and exhale. Is your breathing fast, or slow? Is it shallow, or deep? There is no right/wrong answer.

Take a deep breath in through your nose. Notice how, as you inhale, your body expands to accommodate the air. Where do you notice these sensations? As you exhale, notice the feeling of air flowing out of your nose/mouth, whether it is warm or cold, and how your body responds to this change.

Your mind will wander during this exercise. That is ok. When you notice that your mind has wandered on to other events of the day, gently bring it back to focusing on the breath by inhaling deeply. Congratulate yourself for noticing your mind wandering.

When you are ready to finish the activity, slowly bring your mind away from the breath and back to the room that you are sitting in. Try not to immediately rush on to your next task; take your time to bring your attention purposely with you as you move on with your day.

## APPENDIX J

### Week 5 – Parent/Carer Handout

#### Setting Events

Today, we are going to start to think about other factors that may have an impact on anxiety and how consideration of these factors may lead to potential helpful strategies.

One factor to consider is setting events. Setting events can be defined as broad, background factors that may increase the likelihood of anxiety occurring.

An example of a setting event could be poor sleep. If someone experiences poor sleep, they may be more likely to experience anxiety. This could be due to reduced tolerance or a reduction in an individual's ability to manage an anxiety-provoking situation.

Let's have a think about setting events that may be relevant for your child.

Have you noticed any background factors that seem to make your child more distressed and less likely to easily calm down?

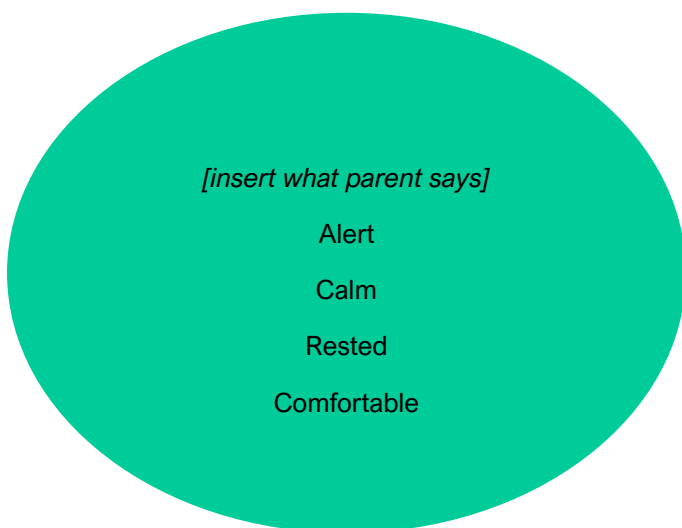
.....

.....

Have you noticed any background factors that seem to help make your child calmer and more relaxed?

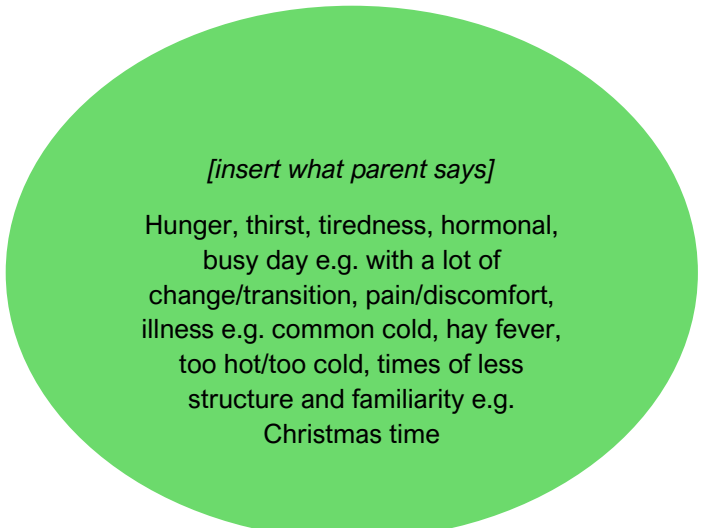
.....

.....



*[insert what parent says]*

- Alert
- Calm
- Rested
- Comfortable



*[insert what parent says]*

Hunger, thirst, tiredness, hormonal, busy day e.g. with a lot of change/transition, pain/discomfort, illness e.g. common cold, hay fever, too hot/too cold, times of less structure and familiarity e.g. Christmas time

**It's important to consider these factors when working on strategies to manage anxiety-provoking situations, for example, it may not be best to work on exposure strategies after your child has had a long day at school.**

Turning our focus to one particular setting event, pain or discomfort. It may be difficult to identify if a child who speaks few or no words is in pain or experiencing discomfort as they may not be able to communicate this to you.

Below you will see some behaviours that may be observed when a child is in pain or discomfort:

- Crying, screaming, sobbing, whining, whimpering
- Squirming, rigid or jerky body activity
- Frequent quivering of the lips and/or chin
- Kicking legs or legs drawn up/curled up
- Difficult to console or comfort

**It's important to note that the behaviours above may also be associated with anxiety. If you do observe these behaviours and you are concerned that your child may be experiencing pain or discomfort, we advise for your child to receive a full health check-up from an NHS professional.**

## Toolkit – Sensory Processing Difficulties

Sensory processing differences may also have an impact on anxiety. [Autistic individuals with a moderate to profound ID who may also be autistic](#) may experience sensory over reactivity e.g. sensitivity to sound or sensory under reactivity, or both at different times and in different situations.

If your child's environment is providing too much sensory stimulation for them, they may find exposure to an anxiety-provoking situation overwhelming. Therefore, we may want to consider reducing the amount of sensory stimulation in the environment when implementing the intervention. For example, reducing/removing background noise (e.g. radio, TV in the background, moving to a quieter space), making sure the lights aren't too bright. Additionally, after an exposure task you may find it helpful to give your child some time and space to burn off energy or engage in sensory strategies to allow calming.

**If you believe sensory processing differences are having a significant impact on your child's day-to-day functioning, please seek support from an Occupational Therapist.**

Make a note of what sensory strategies you may use with your child during the exposure-based tasks below.

## Sensory toolkit

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Toolkit – Enhancing communication

When a child has communication difficulties it can be difficult for them to understand what is going on and also express what they need. This can increase anxiety for the child and so it is important that they have strategies to help support their understanding and expression.

Sometimes, when in an anxiety-provoking situation, the amount of information given to a child can be overwhelming. It can be useful to break down the amount of information you are providing the child by using key words and short phrases or supplementing what is being said with communication aids. This can help support them to understand what is going on. Some examples of communication aids that may be helpful in these situations are visual cues (e.g. picture cards, objects of reference), visual schedules in a now-then format or social stories.

It is also important when in an anxiety-provoking situation that your child is able to effectively communicate that they want an activity to stop or to leave the situation. This may be through speech, a non-verbal behaviour (e.g. a specific vocalisation, pushing an item away) or through the use of an alternative communication device such as a PECS card or a communication switch.

**Teaching a child to effectively use communication strategies is very intensive and may not be achievable within the timeframe of this intervention. However, introducing and modelling strategies now may help develop these skills in the future.**

What strategies does your child currently use to help with their understanding and expression?

## Communication toolkit

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Toolkit - Self-regulation

Does your child have a way to self-calm?

Most people have things they choose to do that help them feel calmer when they are experiencing anxiety. Some examples, are talking to a friend, taking a break, having a relaxing bath, going for a run. Often [children with a moderate to profound ID who may also be autistic](#) ~~autistic children with intellectual disabilities~~ have not learnt these strategies or need help to use them.

Some strategies that can be helpful include:

- Listening to calming sounds of music
- Taking a big deep breath and letting it go
- Tightening our body and then letting it go floppy
- Squeezing a ball
- Chewing on a chewy tube
- Self-massage
- Eating or drinking something comforting (in moderation)

People may often need a need prompting or support to carry out these actions. After lots of practise some children eventually start to do these actions by themselves. Does your child do anything that helps them feel calmer, or have you noticed anything that has helped? Make a note of some strategies below that may be helpful for your child.

## Self-regulation toolkit

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Toolkit - Parent Wellbeing

Over the past couple of weeks, we have thought about strategies that may increase your wellbeing and help you respond rather than react in situations where your child experiences anxiety. Have a look back over some of these strategies and make a note below of the ones that you have found useful.

## Parent wellbeing toolkit

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

Next week, we will begin to think about the anxiety-provoking situation you want to work on with your child for the remainder of the intervention. Over the course of the next week have a think and observe what situations may be appropriate and which ones you may like to focus on.

## APPENDIX K

### Setting Events Checklist

Lists of setting events can be readily accessed for free online, and will contain lists of environmental, social, and physiological/emotional factors that can increase an individual's vulnerability to anxiety and/or behaviour that challenges.

For copyright purposes we have not included a specific list in this document.

## APPENDIX L

### Week 6 – Parent/Carer Handout

#### Formulation

Over the past few weeks we have:

- Learnt about anxiety, what factors may maintain anxiety and how they do this
- Thought about the types of behaviours your child shows when they are anxious
- How you may respond or react in situations which make your child anxious
- Thought about the factors which might impact anxiety (e.g. Setting Events, sensory processing) and considered what might need to be added to your toolkit prior to thinking about exposure-based tasks.

We are now ready to start thinking in more detail about our plans for the exposure-based tasks. We will work on this together over the next few weeks.

To start, we need to consider which situations where avoidance/escape behaviours are present we may want to target. When we first made contact with you about this intervention we through a short assessment on the phone. You said that:

Avoidance/running away behaviours are most likely to happen when:

.....

Avoidance/running away behaviours are least likely to happen when:

.....

The behaviours are most likely to happen when:

.....

And where: .....

You said that .....increases the behaviour

And that .....decreases the behaviour.

Today we will need to consider exactly which situations where avoidance and escape behaviours are present you would like to focus on for the remainder of this programme. In which situations would you like to try and reduce anxiety in your child?

In your initial discussions with the research team, and when we completed the goal setting worksheet in Week 1, you wished to consider working on [insert situation(s) specific to the family]. However, we have covered lots of material in the sessions following these discussions, and you may now wish to focus on a different situation where you think that your child shows behaviours related to avoidance and anxiety.

We are therefore going to return to these questions in more detail.

Today is the first step on our plan to help reduce anxiety related avoidance. We need to carefully think about which avoidance/escape behaviours and situations you would like to work on for the remainder of the programme. We will go through a series of questions specific to your child and the situation/behaviours that you have chosen, and these will help us to develop a formulation to explain your child's anxiety. A formulation is where a joint understanding is reached between the therapist and the individual/family about the factors leading to an individual experiencing distress.

Important things to consider are:

1. There might be more than one situation or object where avoidance is present that you want to address. However, we need to work in manageable steps for you and your child, and therefore will just focus on one initially.
2. Which situation where avoidance is present has the biggest impact on your child and important parts of their life?
  - a. Important factors to consider are their ability to engage in community activities, their ability to go to school or reach their potential at school, factors that prevent you from doing fun things together as a family. This intervention might take up lots of your time, so we want to make sure we are trying to change a behaviour/avoidance that is likely have the most impact on your child's quality of life.

After considering all of this, if there is still more than one situation you would like to address, let's think about the one you think might be the easiest to achieve. When you have achieved it, you might choose to move onto another aspect later if you feel able and you think your child is ready. By choosing a goal that is easier to achieve, you will increase your confidence in the skills and the toolkit, which will increase the likelihood that future goals are also successful.

Which situation and anxiety-related behaviours would you like to address?

- 

Tell me what happens from start to finish:

- 

What do you usually do when this happens?

- 

Returning to our discussion at the start of the previous session, are there any factors that make behaviour less likely to happen/more likely to happen/happen with more intensity?

- a)
- b)
- c)

Is the behaviour more or less likely to happen with certain people?

-

This information is the basis of our formulation. A formulation is flexible and can change depending on new information that we might learn through the course of the intervention. We may review some of our hypotheses from this session as you begin working on the goal that you have chosen, to ensure that it is relevant and correct.

To summarise our discussions today, our plan is:

We are going to help your child overcome their anxiety about.....

We will make this more manageable for your child by.....

We will help your child to learn that ..... is safe. We will do this in manageable steps. We will start planning the steps next week.

Though it may feel that we have spent lots of time discussing these different factors, having a detailed understanding of a situation, your child's experience of anxiety and the context in which this occurs is important when developing a plan for managing anxiety. It is particularly important when we are thinking about individuals who speak few or no words, as they may find it more challenging to tell us about the factors that increase their anxiety or help them to feel better.

In the next session we will start to formally develop a plan to work on the goal we have discussed in today's session. We will also consider what strategies might be helpful for your toolkit, from what you have already told us and from what we have thought about in Week 5.

## APPENDIX M

### Reinforcement Inventory

Reinforcement inventories can be readily accessed for free online, and will contain lists of possible motivators for children (and sometimes adults), that could be used within reward-based systems.

For copyright purposes we have not included a specific list in this document.

## APPENDIX N

### Week 7 & 8 – Parent/Carer Handout

#### Part 1 – Designing the Facing Your Fears Ladder

Using the notes and tools you have made over the past few weeks, we are now going to create an individualised ‘fear ladder’ for your child to help reduce avoidance of anxiety-provoking situations. We are going to bring together the information and tasks you have completed over the past 6 weeks to create a range of tasks and strategies that will help reduce the anxiety your child experiences through gradually exposing them to situations that may cause anxiety. This will be done in a very supportive and manageable way for both you and your child.

It is important to acknowledge that this intervention is likely to be difficult and challenging, especially if your child has an intellectual disability. This is because there might be slightly more challenging behaviour, or it may take your child a little longer to learn that something is in fact safe. But by helping your child to overcome their anxiety, you will also be helping them to improve their independence and self-esteem, and this is the best way to help your child to achieve the long-term goals we thought about in Week 1.

Some other important things to remember during the intervention are to not push your child too much, too soon and don’t push yourselves. You are the expert on you and your family, and it is important to set manageable and small steps that you feel able to continue. Additionally, you do not need to wait until your child is really anxious to implement the intervention, it can be used as a preventative intervention.

#### **Worksheet 1: Graded exposure ‘Facing Your Fears’ ladder**

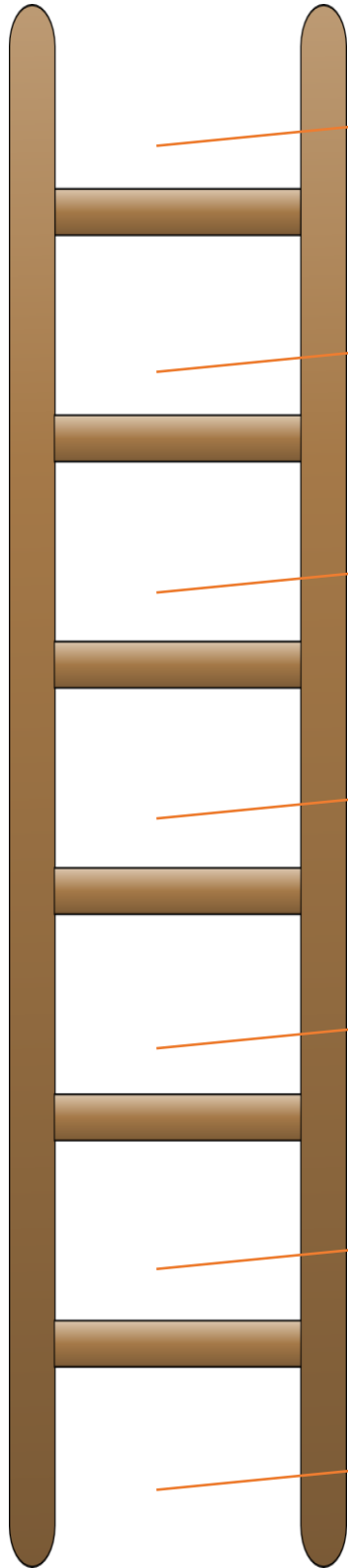
Worksheet 1 is an exposure ladder, called the ‘Facing Your Fears’ ladder. For each step of the ladder, you should outline an exposure task related to the anxiety your child experiences that you think will help your child build up confidence and reduce avoidance behaviour. Each step should be a bit more challenging than the last.

At the top of the ladder is your end goal, use the goals you noted down in week 1 to help you decide what you want to achieve at the end of these 10 weeks. If you want to you can amend any of these goals based on what you have learnt over the past 5 weeks. The goal needs to be reasonable, so think about something that would improve your day-to-day living within the next 6 months.

After you have thought about your end goal, starting at the bottom of the ladder, outline a series of tasks or steps that will help your child to achieve this end goal. You can think about different methods of exposure (e.g. watching videos on YouTube) and/or different lengths of exposure (e.g. starting off with 30 seconds, then increasing to a minute). Other things you may want to consider are how easy and frequently you can do exposure (e.g. easy to go to the shops every day, but may not be able to guarantee seeing a dog at the park).

Although there are seven steps on the ladder, you do not have to do seven tasks if you think reaching your goal can be done in less. However, we recommend that you do not do more than 7 steps for this intervention.

## THE GOAL!



Step 7:

Step 6:

Step 5:

Step 4:

Step 3:

Step 2:

Step 1:

## Worksheet 2: Reinforcement and ABC Charts

Now you have chosen the steps on your exposure ladder, we need to think about the behaviour we want to replace the avoidance behaviour with and the reinforcement strategies you will use to achieve this. Worksheet 2 consists of ABC charts (like those that you worked on in week 2) for each of the 7 steps of the exposure ladder, where you can note down the antecedent (the exposure task from the ladder), the target behaviour and the consequence (the reward you will give for the target behaviour). We will now think about the behaviour and the reward and reinforcement aspects of these charts.

### *Behaviour:*

The behaviour that you will want to reward for each step is likely to be tied to the goal of each step (e.g. walking to the front door of supermarket). But it is helpful to clearly define the behaviour you want to see, so that it is clear when you should reinforce and give the reward. It may also be useful to think of the behaviours you don't want to reinforce, so you can remember to not respond to them. Additionally, you do want to think about the negative or challenging behaviours that your child is likely to show during the tasks and think about the level of distress you are comfortable for your child to experience. Remember, the tasks need to be challenging, but should not expose your child to more distress than they would experience day-to-day. We will think about these types of behaviours more in our next session.

### *Rewards & reinforcement strategies:*

Now we have thought about the behaviours we want to reinforce, we need to consider the rewards we will use to reinforce the new behaviour. Remember that the reward needs to be more motivating than avoiding or escaping the situation! Below are some other things that are useful to think about when deciding on a reward:

- Don't choose your child's most favourite item, in case they end up associating it with anxiety
- It needs to be something that can be given promptly to your child
- If you need to go somewhere for your exposure tasks (e.g. the park), it will need to be able to be taken with you
- It needs to be sustainable (e.g. you may not want to give a whole chocolate bar)

The size of the reward (i.e. spending longer on the iPad) can change relative to the difficulty of the exposure task. For example, you may want smaller rewards for tasks nearer the bottom of the exposure ladder and then increase the size as the tasks get more difficult.

The reward, especially in the beginning, **needs to be consistent and immediate every time** your child shows the target behaviour, and the reward should only be given to the target behaviour. However, if your child shows other positive behaviours or fewer negative ones during an exposure task, give them lots of praise and encouragement. Also, try to ignore and not to reward anxious behaviour, warning signs and challenging behaviour for as long as it is manageable and safe.

If you're struggling to think of anything, have a look through the Reinforcement Inventory (Appendix L) and see what may work for your child.

Step 1	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 2	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 3	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 4	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 5	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 6	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>
Step 7	<ul style="list-style-type: none"><li>• Antecedent:</li><li>• Behaviour:</li><li>• Reward:</li></ul>

## Building Your Supporting Toolkit

In week 5, we began to think about several different strategies that you may already use with your child in other situations that may be helpful to use in the exposure-based tasks. Now that we have planned out our Facing Your Fears ladder, we can think about which supportive strategies may be the most useful to help you achieve your goal with your child. These will form your 'toolkit'. Thinking about the four core areas of strategies (**Sensory, Communication, Emotional Regulation, Parent Wellbeing**), choose up to 3 core strategies that you will use alongside the exposure-based tasks. You can have as many supplementary strategies as you like, but we want to avoid too many core ones so you and your child find the tasks manageable.

Remember that if you have not used strategies that your child already has in this situation before, it may take a while for your child to begin to use them. This is okay, just keep persevering and your child may pick it up over time. You may find it useful to practice strategies with your child outside of the exposure-based tasks too when they are calmer.

Make a note of your strategies below:

My core strategies are:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_

My supplementary strategies are:

- 
- 
- 
- 
-

## APPENDIX O

## Week 9 – Parent/Carer Handout

## Communicating exposure-based tasks to your child

We have all experienced anxiety at some point in our lives. You will likely have experienced the feeling of anxiety when a situation is uncertain, or there is an aspect of a situation that you do not understand. This is particularly relevant for children with a moderate to profound ID who may also be autistic ~~an autistic child who speaks few or no words~~, as they may find it more challenging to make sense of what is happening in the world around them. We want to try to reduce this anxiety as much as possible, by helping your child to understand what will be happening when we begin the exposure-based tasks and increasing the predictability of a situation. We can do this in several different ways:

- *Social Stories™*: We can develop a short story that will help your child to make sense of the situation that is occurring, and reassure them.
- *Visual Schedules*: We can use a schedule to show your child when to expect an activity. This could be a longer schedule (such as a daily timetable) or a short schedule (such as a now/next card).
- *Cue cards/objects of reference*: By showing your child a visual cue of a situation/location each time you participate in an exposure-based task, this may help to demonstrate what they can expect.

We should focus on one way of communicating a situation to your child, as including multiple ways may be overwhelming. Are there any of these options that particularly stand out to you? It may be helpful to think back to the Reinforcement Inventory that you completed and consider which of the methods might incorporate your child's interests. When using these strategies, it may take lots of repetition for the strategies to become helpful for your child. It is important to use these strategies in good time before the task, rather than rushing, to allow your child space to process the information that has been communicated to them.

## Developing your behaviour warning card

In week 6 you will have written down a description of what happens start to finish when your child shows anxiety, including some of the challenging behaviours. Using this information and the information you gave about avoidance behaviours your child shows in week 2, create a 'warning card' using the template in the appendix. Using this, agree a point/behaviour that when your child reaches you will remove the trigger. Ideally, this may be the second to last behaviour your child shows.

Sometimes when doing the exposure tasks, your child may go straight to the worst behaviour or crisis point. Don't panic and remember what works best for your child in this situation. Remove all triggers and your child from the situation. Give them time to calm down, using whatever resources help with this. This does not mean the intervention isn't working, it's likely just a bad day. Remember to reward yourself and try again another day.

It is important that you stop the task whenever your child becomes too distressed. The steps on the ladder are completely flexible and you can stay on a step for as long as you feel your child needs to or even move back down a step. Every child is individual, and some steps may be harder than others. Staying on or moving down a step is not a failure. Patience, persistence and taking it at your child's pace are key for an effective strategy.

## Overcoming Barriers

*Some other final important things to consider before you get started*

Along the way, you are likely to face some challenges that may stop you from being able to do some of the parts of the programme, or may mean that you cannot implement them as well as you would want to. That is ok! It is important to acknowledge that this is not an easy process. However, perseverance is important and trying to stick with it where you can. Today, we will go through some potential barriers and things that may be important to consider and pre-empt as you work through the programme. Thinking about some of these things beforehand might help you to deal with them or plan around them to make it easier for you to keep going!

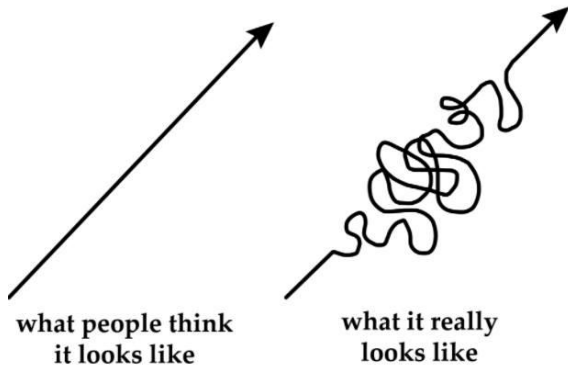
**Here are some potential things to consider:**

### 1. It will take time

The things you do are unlikely to result in immediate change. You will probably not meet your long-term goals by the end of this programme. Small manageable steps are ok which will help you to reach your goals in the longer term. To reach your goals, remember that persistence is important, and that you and your child are doing your best and that is ok. If you feel like you are making very slow progress, look at your ladder, and see how far you have come! If you feel it is taking too long though, speak to the therapist and we can change the goals to make them smaller if you think that will help. We can also reconsider which strategies you have found most useful, and which ones you have not. Equally, if you are making good progress, make sure you continue! It might be tempting to take your foot off the pedal a bit, but to have the best long-term effects, it is important to carry on.

Do not rush ahead either, or your child might become overwhelmed. Stick to your plan and we can continue to review your plan each week according to your progress. Every parent and every child is different and will move at different rates. That is ok.

If you need some reassurance, listen to the videos from other parents who have used these sorts of strategies before with their child.



Remember that progress, though we may want it to, does not usually move in a straight line; there will be times where progress slows down, stops, or even takes steps backwards, and this is ok.

## 2. Challenging behaviour and extinction (behaviour) bursts

If anxiety is associated with challenging behaviour in your child, as you go through the programme, you may notice these behaviours get worse before they better. These increases in behaviour can occur when parents/carers change the way they are responding to their child. This is because your child is trying to show you their anxiety in the way they know how or are using strategies to escape a situation that have worked previously; so they are trying harder to escape. This is called a behaviour burst and is a normal part of behaviour change. We have designed the programme to identify warning signs so that challenging behaviours do not occur all the time as part of the programme, but if they increase when you are doing the programme, do not be put off. Over time, they will reduce, especially if you reward brave behaviour consistently and quickly! Keep in touch, tell us about behaviour, and tell us if it is getting too much.

## 3. Finding time

Everyone has lots of things to do on a day-to-day basis, especially as a parent of a child with ID. You may find that you become distracted by other things going on in the house. It may help to make yourself a timetable for the week, and plan the times at which you are going to engage with this programme. It could even be that these are things that you can plan into your day-to-day life (e.g. going a slightly different way to school). However, make sure you also plan in time for rewards! Making sure that you reward yourself (see below) might also help you to find time to stick to the programme.

It can be difficult to find time for other children in your family at the best of times. You may find that even harder if you are committing to this programme. However, it is also important to try and find time for other children if you can. If it is possible, and it is safe, you could include other children in the exposure tasks and rewards. If it is not possible, or you think that won't work, speak to your other children beforehand. They might find it unfair that they are not receiving as many rewards as their sibling. Be open and honest about the need to spend time on this programme with your autistic child. If you can, build some time into your timetable to spend some time with your other child and involve them in the planning. You could brainstorm ideas or give them a choice of what they might like to do with one or both parents (play a game, read a book, go for a walk). You could also start a rewards-based system for them based on something they can engage in (e.g. homework).

We have included an example of a timetable below:

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
5pm: Exposure-task. Show a video of walking around Sainsbury's Reward: biscuit		8pm: Reading time with sibling	5pm: Exposure-task. Show a video of walking around Sainsbury's Reward: biscuit			5pm: Exposure-task. Show a video of walking around Sainsbury's Reward: biscuit

#### 4. Regulating and understanding your emotions

In the earlier weeks, we talked about how your behaviour and emotions may play a role in your child's anxiety and how being mindful and responding to your child's behaviour may help to reduce their anxiety. You may find yourself thinking 'I'm trying to be mindful, but I just can't help reacting!'. Don't worry, just like setting events will affect your child's behaviour, they will affect yours too. Just keep practicing being mindful and responding when you can and if you have a bad day just remember that it's ok and start afresh the next time.

You may also find it hard to recognise your emotions and what you are feeling in the moment. In this case, you may find it helpful to focus on observable behaviours you do when in situations that are anxiety-provoking for your child. For example, when you go to the park, do you find yourself constantly on the lookout for dogs? If so, when you recognise you are doing this, try and change the behaviour for some of the mindful strategies in Week 4. For example, listen out for the sounds of birds or count your steps.

#### 5. Working together

In some families, parents and/or other family members have differing ideas on the best ways to manage anxiety. If this is the case, it can mean that aspects of the programme are not being delivered consistently. For example, a family member is not praising or rewarding brave behaviour quickly. This programme will have the best outcomes if it is being delivered consistently.

Share information that you have learned in this programme with as many people who are involved in your child's care as you can (e.g. other parents, grandparents, teachers). At the very least, encourage them to notice and praise brave behaviours that are on the fear ladder that you have developed as part of the programme. If it is helpful, we can talk to other primary caregivers (other parents) as part of this programme.

## 6. The wrong day

Lots of parents of children with a moderate to profound ID who may also be autistic ~~autistic children~~ say that sometimes, no matter what they do, their child just has days where they will feel more anxious or irritable than others. This is completely usual; of course we all have days like that. It could be that your child is not feeling well, or is generally not in the mood. If that is the case, and you get a sense that 'today is not a good day', you might choose not to engage in the programme. That's ok. You know your child and family best, and the time needs to be right. If possible, try not to leave it too long before returning to the programme (try the next day or a few days later).

## 7. Remember 'Awareness- Reassurance- Toolkit'

1. How am I coming across to my child. Try to stay positive and reassuring
2. Remember you are not failing. Anxieties and fears are normal but there are many ways you can help your child to overcome them. Remind yourself you are doing a great job.
3. Picture your tool kit in your head and start thinking about your step by step plan to help your child overcome the anxiety.

## 8. Reward yourself

Build in regular rewards and downtime for yourself. This doesn't need to be anything big, a yoga session, a walk, build time into your Timetable for some you time. Remember you are doing a great job, and this will take time.

## Going forward...

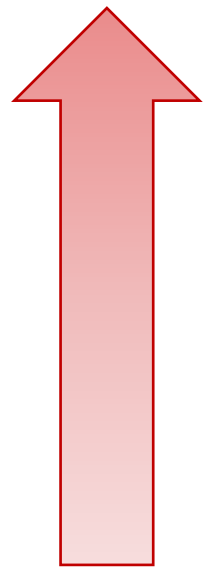
You have now built your toolkit and are ready to start it with your child! We will keep checking in via telephone to check how you are doing and give you any support you need. Make sure you refer back to this manual any time you need and remain positive! You may not see differences right away, but with perseverance and consistency you will be able to achieve your goals.

## APPENDIX P

### Behaviour Warning Card

#### Behaviour Warning Card

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



Using the card above, write down a list of behaviours your child shows when they are distressed. Work up the list from least distressed behaviours to most distressed behaviours. Once you have completed this, discuss with your therapist at which distress behaviour you should stop at when completing the exposure-based tasks.

## APPENDIX Q

### Week 16 – Parent/Carer Handout

#### Fading

Up until this point, you have needed to reward every instance of the target behaviour your child shows immediately and consistently. However, in some situations, it is not feasible to continue rewarding at this intensity forever. When you feel that your child's anxiety levels are more manageable and that they are showing less avoidance, we would start to think about fading out the reward schedule. It is important to note, that this may cause an initial increase in anxiety-related behaviour ('behaviour bursts') in your child, but this is expected so keep persevering!

Fading can be applied in different ways:

- Reducing the frequency of the reward e.g. only giving the reward every other time the task is practiced
- Reducing the time spent engaging in the reward e.g. reducing reward from 5 minutes gradually down to 30 seconds

One of the main strategies to fade out the reward is to delay the time between when the target behaviour occurs and when you present the reward. For example, instead of rewarding straight away, wait 2 seconds before giving the reward to your child and then slowly extend this delay (e.g. to 4 seconds, 6 seconds etc.). As we mentioned before, the re-emergence of anxiety behaviours are likely to occur during the fading procedure, especially as the delay time gets longer. To try and minimise this you may find it useful to introduce a cue to your child to indicate that the reward is coming. This could be something like a picture of the reward or a timer. **Additionally, you can also give some other reinforcement such as praise during the delayed period.** It is also important to remember to try and ignore the anxiety behaviour as best you can.

Fading is important if you wish to use your current reward for a new/different goal. Unless the reward is faded out for the current goal, it may be less reinforcing for the new goal, as your child already has other ways of accessing the rewarding item.

#### Generalisation

When achieving any goal, the best outcome is when the achievement can be generalised to other environments. If a child is able to achieve a goal, but only in certain circumstances or with a certain caregiver present, this may not be helpful in the long term. As your child builds confidence in working on the 'Facing Your Fears' ladder, try to ensure that, if applicable, other caregivers are involved in practicing the steps.

Discriminative Stimuli are signals which help an individual predict how they should respond. It is possible that only completing tasks with a certain caregiver/in a certain location, may lead your child to use these cues to respond with low-anxiety. This may mean that if new signals/cues are present (different location/different caregiver), your child may respond with higher levels of anxiety.

## Thinking about the future

We have focused on one specific goal for this intervention, however you may have many situations you would like to work on, where your child shows anxiety and avoidance/escape behaviours. When you pick a new goal in the future, remember that the goal should be something intended to improve the wellbeing of your child, even if it is not a priority for other people.

What other situations could the intervention be helpful for in the future?

.....

.....

.....

How could the intervention be applied to these goals?

.....

.....

.....

Remember to use the resources from weeks 2-9 when developing a new 'facing your fears' ladder. The rewards and toolkits may be different depending on the goal.

Weeks 2-4: Understanding anxiety and how to support your own wellbeing when caring for [children with a moderate to profound ID who may also be autistic](#)~~an autistic child with anxiety and complex needs:~~

Week 5: Overview of available toolkit resources for your child

Week 7-9: Developing a hierarchy, additional toolkit resources, communication strategies

Coming to the end of the intervention might bring up lots of different emotions for you (overwhelmed, worried etc.). If you are working with other services, you may find it helpful to share the LADDERS resources with them, so that they can support you in the future with other goals, using a LADDERS framework. If you are not working with other services, you could share the LADDERS resources with other individuals who care for your child/know your child well, so they can help to think and plan for future goals with you, using the LADDERS resources. The parent/carer wellbeing resources may also be useful for remembering the importance of not judging when events do not go to plan, staying focused in the moment, and providing reassurance that you are doing the best that you can.