

HIGHLAND AUTISM INFORMATION PACK

A pack for parents and carers of children with autism



CONTENTS

	Page
Introduction	
Welcome from parents	3-4
All About Autism	
What is autism?	6
How is the diagnosis made?	6
Social Interaction	7
Social Communication	8
Routines and Repetition (Social Imagination)	9
Sensory Differences	10-12
How Can I Help?	
Social interaction and Social Communication	14-15
Sensory	16-17
Behaviour	18-20
Selective Eating	21-23
Anxiety	24-25
Repetitive behaviour	25
Special interests	26
Sleep	27
Toileting	28
Play	29
Body awareness (behaviour and boundaries)	30
Telling family, friends and my child	31-33
The Pines Highland Autism Support Centre	34
Where do I go from here?	
The Highland Practice Model	36-37
Education	38-39
Services for children with disabilities & families	40-41
Psychological Service	42
Websites for Autism	43-44
Local Support Groups	45
Other useful services and links	46-50
'Holland' – two descriptive accounts	51-52

Acknowledgements

Thanks to all the contributors of the Autism Guide to Parents produced by the Welsh Health Board for permission for us to adapt their guide for the Highland region.

Thanks to all those who help develop the pack in Highland and in particular:

The parents at The Pines information sessions for the introduction, guidance and feedback;

The many individuals who offered feedback and suggested amendments, including the NAS and ARGH! who helped to edit some of the original text;

The teams at The Pines Autism Centre, Inverness;

Karen Kelbie, Information and Support Officer at CHIP+, for co-ordination and nipping everyone's ankles to ensure we finished the job!;

The Occupational Therapy (Children & Young People Service) for the sensory information;

Dave Rex (Specialist Dietician for health Promoting Schools and Autism) for the diet and selective eating information.

This Information Pack could not cover every aspect of autism but tries to guide families towards the different sources of information and support available in Highland and beyond. It was developed in partnership with parents of children and young people with autism who are an amazing support to each other.

When using this Pack remember you do not need to be alone.

Please note throughout the booklet we talk generically about a “child or children with autism”. We are including young people in this statement and understand autism is a condition which is a spectrum including Asperger syndrome. We have generically used “he” or “him” throughout this pack but this equally applies to “she” or “her”.



Front cover picture by Moir Ferguson Age 10½

Design by Louise Kerr. Updated July 2017.

INTRODUCTION

BY VICKY, TRACEY, RHONDA AND KAREN (PINES AUTISM PARENTS' GROUP)

So your child has received a diagnosis of autism and you may be feeling many emotions: angry, sad, lost, and relieved, to name a few. It may be an unexpected shock or it may come as a relief after years of trying to discover why your child has seemed different.

*'.....relieved that someone could see he was different too
and I was not imagining it.'*

But remember one thing, your child is still the same wonderful, awesome person they were yesterday, **it's just that now there is a name for why they behave and react in a certain way**. Diagnosis is a key to accessing help and support for your child and your whole family.

You may have extra professionals in your life now. You can learn enough to get what you need from them and call upon the experience of the parents who've been through this already. Coming along to the Pines Information sessions and meeting parents like us, you will realise that there are many of us in your position and we are keen to help. If it is difficult for you to come to The Pines, there may be support groups nearer to you. Please phone The Pines for information.

THERE ARE TWO IMPORTANT THINGS TO REMEMBER:

It's not our fault

The exact causes of autism are still not known, but it is known for certain that it has nothing whatsoever to do with the way we have brought up our children. Autism affects children from all countries and cultures.

'It was hard but also a relief. We could finally say we weren't bad parents.'

You are not alone

The National Autistic Society's information states that more than one in every hundred people is affected by autism.

OTHER THINGS THAT MAY HELP AT THIS TIME

- When you feel ready, consider contacting or joining a group or organisation.

'The Pines Information sessions have been great, meeting other parents who understand what you are talking about without having to go into all the details every time.'

'Coming to The Pines has genuinely changed our lives.'

'Friends of Autism Highland is a parent support group started up on Facebook.'

- Talk to someone you trust about how you are feeling.
- Your extended family can be affected too and may need help/support.
- Write down all the questions you can think of and take them with you to appointments.

You may decide to look on the internet for information and there is an abundance out there but first please take a look at the websites of the the National Autistic Society and CHIP+ (Children in the Highlands Information Point). You can rely on them as trusted sources of information on just about anything from benefits to situations that may arise in everyday life. In this pack you will find tips and hints to help you, as well as words from parents and carers like us – and like you (contact details for both organisations can be found near the back of the booklet).

Lastly, after you have had a chance to look at the information in this booklet, at the end of this pack you may like to read two accounts of moving to 'Holland' written by parents of children with disabilities, although their accounts could describe autism too. Many of us have found these helpful.

ALL ABOUT AUTISM



WHAT IS AUTISM?

There could be 30 children in a room together all diagnosed with autism, yet they may seem very different from each other. This is why autism is called **‘the autistic spectrum’**. It affects people in many different ways and to very different degrees. Autism also affects children of **any** level of intelligence. Some may have profound learning disabilities; some may be of average ability; some may be of high academic intelligence. However, what these children have in common are differences in the way they communicate socially and relate to other people and also the world around them.

HOW IS THE DIAGNOSIS MADE?

For a child to be given a diagnosis of autism, s/he must show differences in these four areas:

SOCIAL INTERACTION	SOCIAL COMMUNICATION
ROUTINES AND REPETITION (SOCIAL IMAGINATION)	SENSORY ISSUES

Although children with autism will have differences in all four areas, each child will have these differences in varying degrees. This explains why children with autism can seem so unlike each other even though they share the same diagnosis.

Experiencing these differences creates a lot of anxiety and stress, which may show itself in your child’s behaviour. **We will talk more about this later in the booklet and offer ways that you can give support.**

Let’s go on to look at each of these areas in more detail.

SOCIAL INTERACTION

When they are born, most babies seem ready to become sociable and develop communication skills. Most young children just seem to know that other people are important to turn to for comfort, to share moments of pleasure with, to look to for guidance and to learn from. Many children/young people with autism do not seem to have this inbuilt need to be sociable in the way that is defined by those who are not autistic, possibly because their brains have developed differently from those who do not have autism.

HERE ARE SOME COMMON EXAMPLES OF DIFFERENCES IN SOCIAL INTERACTION:

- Some may seem less interested in people but prefer to focus on things in the environment instead. Some may show little awareness of the needs and feelings of others.
- Others may have a strong desire for social contact. They may be desperate for friends but **just don't know how to go about making and keeping them**. They never seem to get it quite right.
- Some may prefer **not** to make eye contact with other people.
- Some may prefer individual activities rather than be part of a group. Their preference may be for spending time alone rather than with others.
- Some may feel more comfortable with adults rather than children, or others their own age.
- Some may have poor understanding of social rules, e.g. not knowing when to take turns in conversations or games.
- Some may insist on sticking to rules and become agitated if a rule is broken e.g. always driving the car at 30mph or less in a defined speed zone or telling the teacher which child in the class was speaking after she had asked for silence. This can make some extraordinarily honest.

SOCIAL COMMUNICATION

Some children with autism may not be eager to communicate. They may not be ready to learn things that other children learn naturally and therefore they may not pick up language in the same way. Some may find it hard to make sense of the things that happen around them.

Many children/young people with autism find trying to make sense of words very confusing. Also, they may find it hard to understand all the non-verbal parts of language that are used in daily communication: body language, gestures, tone of voice, facial expressions. This may make it hard for them to learn what is expected of them, and to recognise when someone is happy or upset and what that means.

HERE ARE SOME COMMON EXAMPLES OF DIFFERENCES WITH SOCIAL COMMUNICATION:

- Some may echo words or phrases that other people say (either straight away, or later).
- Some may take your words literally rather than understand the meaning you intended:
'The teacher told the class to get into a circle so my son found a circle on the hall floor and went and stood in it.'
- Some may speak in a flat tone of voice or speak too loudly or quietly.
- Some may talk at length about something with no awareness of how the listener is feeling.
- Some may not understand jokes.

REPETITION AND ROUTINE (SOCIAL IMAGINATION)

Imagination helps us to understand the world and predict and see things from other people's points of view. Many children with autism are unable to do this to any great extent.

Differences in social imagination show in a variety of ways. When a child with autism plays with a toy car, he may just focus on moving it to and fro repeatedly, while other children may be imagining their cars in more complex stories. **It doesn't mean that children with autism do not have imagination**, but rather it is developed in different ways to other children.

Differences with social imagination can make the world a very uncertain place for children with autism. Therefore, in order to reduce anxiety, often many prefer to have order and routine.

HERE ARE SOME COMMON EXAMPLES OF DIFFERENCES WITH SOCIAL IMAGINATION:

- Some may become distressed if a familiar routine is changed e.g. taking a new route to school.
- Some may resist any new experience because not knowing what to expect is just too scary, e.g. refusing to come and say hello to a visiting adult.
- Some may need to know when an activity will finish and then will expect it to finish at the exact time specified.
- Some may develop rituals and repetitive behaviour e.g. insisting on sitting in the same chair, watching the same DVD over and over.
- Some may become distressed by unfamiliar events, people or unexpected changes, e.g. the teacher changing her hair colour!
- Some may find it hard to work out what other people are going to do or what their intentions are.
- Some may not understand or connect the consequences that their own actions have for other people.

SENSORY DIFFERENCES

OCCUPATIONAL THERAPY (CHILDREN AND YOUNG PEOPLE SERVICE)

THE SEVEN SENSES ARE:

- sight
- hearing
- touch
- smell
- taste
- balance – part of the vestibular system that also plays a role in posture and levels of alertness.
- body awareness (proprioception) – uses sensors both around joints and from inside muscles that contribute to body awareness. Heavy activities that stimulate body awareness that use muscles and joints such as heavy pushing and pulling can be very useful in helping regulate most people's sensory system.

In children with autism, the brain processes sensory information differently. Sometimes these differences can cause pain, distress, anxiety fear or confusion. An individual's responses to sensations or activities that the majority of people find enjoyable or at least non-problematic e.g. hair brushing, may cause an adverse reaction such as discomfort, which may then lead to screaming.

There are many children who do not show outward signs of discomfort while in the school environment. When in class, these children may focus on managing the discomfort by actively working to tolerate/block out sensations they experience as adverse. They manage to get through the school day but then release their feelings once back home.

Sensory systems may over respond to sensations. For many people the noise of finger nails on a chalk board is highly unpleasant – there is no real danger from the noise but the sensory system responds adversely and can even go into a protective response e.g. the person covers their ears. It is common for the sensory systems of children with autism to be over responsive to sensations that do not cause any problems for the majority of people. e.g. the sound of a pencil on paper. However, the feelings they experience are just as real as if it was finger nails on chalk board.

Hypersensitivity is when individuals demonstrate or experience discomfort with sensations that are okay for the majority of people. When sensory systems are over responding, activities such as rocking, taking slow deep breaths, dimming lights and listening to soft music are likely to be helpful.

Some individuals find that they can look or listen but find it uncomfortable to look and listen at the same time.

Sensory systems sometimes under respond to sensations (people may experience this when in deep thought and have stopped attending to a situation. They may only realise they had not been taking in information around them once their attention was regained). Children with autism can be under responsive to sensory information e.g. they may not readily respond to their name being called.

Most people's **sensory** systems fluctuate in terms of their level of responsiveness within a day (over responsive, optimum and under responsive) e.g. they may be more responsive in the morning than late afternoon. This is also true of the sensory systems of children with autism but often their extremes of responses are wider than most other people.

It is important to consider that a child may be able to tolerate a sensation on one day but can have an adverse reaction to the same sensations on a different day, e.g. going into a noisy hall or school canteen. Their tolerance can also be reduced by stress or anxiety coming from something else.

HERE ARE JUST A FEW EXAMPLES OF SENSORY DIFFERENCES EXPERIENCED BY SOME CHILDREN WITH AUTISM:

- It is challenging to automatically filter sensations that for the majority of people are experienced as background noise e.g. a humming noise from the light is given equal attention to the sound of someone speaking.
- Individuals may continue to be aware of or be uncomfortable with sensations that the majority of people typically become accustomed to, such as the feel of clothing against the skin.
- Processing of information may be delayed. Sometimes a child will respond to a verbal request a couple of minutes after it has been given so allow time for this.
- Sometimes the senses become distorted which may mean that some children with autism may see, hear, taste or feel things differently from people who do not have autism.
- There can be difficulty using senses at the same time e.g. some have said they can listen or they can look but they feel very uncomfortable and not skilled at doing both together.

SENSORY DIFFERENCES CAN MAKE SOME ROUTINE ACTIVITIES CHALLENGING

A haircut involves lots of sensations: touch, possibility of small hairs landing on skin round neck and shoulders, noise of scissors/shaver, temperature changes during and after washing, person cutting hair being in very close proximity, music and noise from conversation.

Noise sensitivity: noises that are okay to the majority of people may be challenging to those with autism e.g. the sound of a washing machine in the background could be distressing. Preparing for and showing how long the noise will last can be helpful. A full information leaflet about managing noise sensitivity is available from Occupational Therapy. It is designed for key professionals and parents to work through together.

Introduce regular and organised sensations, particularly ones which stimulate muscles and joints to work in a sustained way for example:

- walking with a heavy back pack (no more than 10% of child's weight and firmly adjusted).
- squashing plastic bottles for recycling with hands and/or feet.
- carrying wet washing out to line or building with heavy rocks in garden or on beach.

Some children like the pressure from tight clothes as the sensations produced by tight clothes are regulating to the sensory system. Firm consistent heavy pressure is often helpful e.g. having a heavy cushion over the knees when sitting, or firm hugs from parents.

HOW CAN I HELP?

Before we look at ways that you can help and support, it is important to know that some children with autism may have other conditions too. Some of these conditions are:

**ATTENTION DEFICIT
HYPERACTIVITY**

ANXIETY

DEPRESSION

DYSLEXIA

DYSPRAXIA

EPILEPSY

**OBSessional
COMPULSION**

TOURETTE'S

It is important to seek an assessment of any other conditions as this affects the sort of support that will best meet your child's needs.



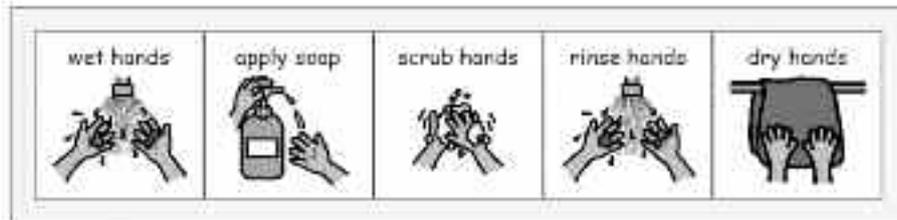
SOCIAL INTERACTION AND SOCIAL COMMUNICATION HOW CAN I HELP?

In order to make it easier for a child with autism to understand what we want him to know, we should try to adapt the way we communicate.

HERE ARE SOME WAYS THAT MAY HELP:

- Say your child's name to focus attention. Many children with autism may not realise that they are being spoken to directly, especially if there are others in the room.
- Keep instructions or requests short and simple. Long questions, detailed explanations, complicated instructions can cause confusion.
- Reduce your words. 'John, sit down,' will be simpler to understand than 'John, be a good boy and go and sit down over there, please.'
- Check for understanding. Although your child may seem to have been listening, don't assume that he has understood what you said. Always check.
- Allow thinking time. Don't rephrase what you just said. Children with autism often need more time to process and understand what you are saying. If you then try to say it in a completely different way, this will make things even more confusing for them as it will seem like a whole new instruction.
- Try and use facts to explain things. If you are trying to explain why a child needs to eat their dinner, we might say it is like putting fuel in a car, and if the car doesn't have enough fuel it will break down. Children who have autism would find it hard to understand this sort of explanation as it is not logical for the child with autism to link with the original idea.
- Do not rely on your tone of voice or facial expression to convey a message. A child with autism may not be able to understand these subtle ways of communicating. So if your child's hair looks messy, say it looks messy, rather than saying it looks lovely while making a funny face!
- Do not force your child to make eye contact. Children with autism can be very uncomfortable if made to look into a person's eyes or find it hard to look and listen at the same time.

- A child with autism may not appear to be listening or understanding what is being said to them, but this assumption may be wrong.
- Many children with autism respond to visual prompts. These may be pictures, photographs, drawings or writing.



Monday		
9.15	Registration	
9.30	Group 	Work at desk 
10.35	Morning break	
10.50	Work at desk	
12.00	Lunch	
12.50	Cooking	
1.50	Afternoon break	
2.00	Cooking	
3.00	Home	

SENSORY DIFFERENCES HOW CAN I HELP?

OCCUPATIONAL THERAPY (CHILDREN AND YOUNG PEOPLE SERVICE)

BELOW ARE SOME WAYS THAT MAY HELP YOUR CHILD:

- Sharing information about your child's **reaction to others** (but not within his/her hearing).
- Pace out activities so they do not become over-whelming, e.g. plan in quiet rest time – use a timetable which indicates when the quiet time will be.
- If your child does not make eye contact, that is ok (it may be uncomfortable to make eye contact) continue activity without pushing for eye contact.
- Strong heavy sucking (liken to baby sucking thumb) can be calming. Use these during or after situations the child has found challenging e.g. using a straw to drink a smoothy.
- Give firm consistent sensory information within regular activities e.g. after washing, towel dry in firm way.
- For children who find noise from multiple voices difficult, plan in some regular quiet time. Try playing background music to see if it helps. Further information and ideas are available on the noise sensitivity leaflet from the OT.
- For children who become visually over stimulated, decrease visual complexity and challenges by wearing plain rather than patterned clothes. Also consider the visual demands on the environment such as the walls. Try to keep these well organised and minimal.
- Many children benefit by the use of a den, sometimes called “**escape and regulate space**”. This is an area into which the child can retreat for a short time from sensations that are challenging to them. It could be a tent, bean bag, comfy chair.
- Provide children with ‘**fidget**’ items on outings that are challenging for them. Having access to a ‘fidget’ can help when waiting in a queue.
- Give information about what will happen next in written format (pictures or words) to which your child can refer at a later point.

**THINGS THAT
MAY HELP ME**

Not making me give eye contact

*Only one person at a time
talking to me*

Neutral odours

Plain clothes, dull or neutral colours

Uplighters, red or green bulbs

A quiet environment

Quiet personal care

One thing at a time

Knowing what will happen next

Consistency

**THINGS THAT
MAY CHALLENGE ME**

Direct eye contact

*More than one person talking to me,
hearing other people's conversations*

Perfume, aftershaves or other smells

Patterned clothes, bright, vivid colours

Strip lights, bright light, sunshine

Kettles, traffic sounds, phones, noise

Toilet flushing, running water, hairdryer

Being bombarded by lots of information

Unpredictability and chaos

*Different people responding to me in
different ways*

UNDERSTANDING BEHAVIOUR HOW CAN I HELP?

Some children with autism may seem to have different behaviour that challenges those around them more frequently than children without autism. This is because they see the world differently and this can be overwhelming for them to deal with. Sometimes, the only clue we have that something is wrong is from their behaviour.

‘Our son chooses to challenge every boundary. It is hard to say ‘no’ to everything so we pick things that matter and get them right first – the rest can wait.’

Meltdowns or shutdowns usually occur in three stages: **rumble, rage and recovery**.

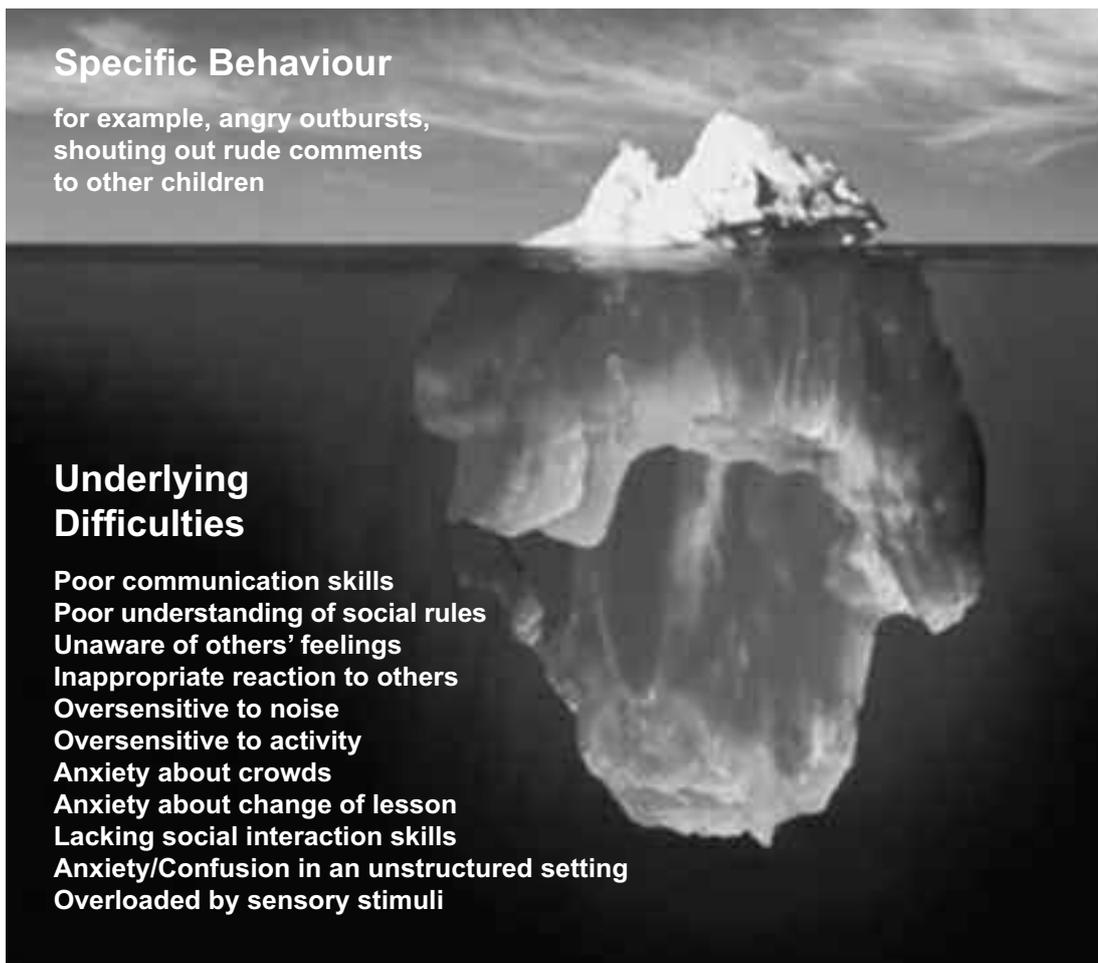
- **Rumble** – This is the start of the behaviour. It is often called the ‘trigger’ or antecedent. It is important because the child is building up to the rage phase and there are often ways to defuse the situation. These behaviours may initially appear to be minor (fidgeting, foot tapping, making faces, etc) but once identified, they will help you work out the best way to intervene and develop ways to help your child from reaching the rage phase.
- **Rage** – This is the ‘acting out’ or meltdown. This is a natural biological response where your child has reached maximum stress level causing him to go into instinctive ‘fight or flight’ stress response. The child has little control at this stage as this behaviour is regulated by hormones. Common behaviours often include screaming, hitting, biting, destroying property, etc but the child can also become withdrawn. It is important to stay calm and make sure that your child is safe, as well as those around him.
- **Recovery** – This is the stage when the behaviour has passed. The child may be tired and sleepy, may apologise, may deny the behaviour happened at all, or may not remember anything about it.

WHEN YOUR CHILD’S BEHAVIOUR CHALLENGES YOU, IT IS IMPORTANT TO THINK:

Why did he behave like this? What may have caused it? Sometimes it is easy to see what has triggered the behaviour. It can be simply because someone has said ‘no.’ It may be more complicated e.g. related to sensory issues or the need for a predictable routine. It may be that he has misunderstood but is unable to communicate this in a verbal or rational way. Often it may be something in the environment that we have not considered.

A meltdown is probably an instinctive response to extreme and overwhelming stress which leaves the child incapable of returning to a level of calm at that time.

Think of this behaviour as an iceberg. When we see an iceberg, we see just the tip of it that is above the water. The largest part is under the water and cannot be seen. The behaviour that we observe is the tip of the iceberg. The many causes for the behaviour have been unseen or misunderstood by us.



It is important to work out the **function** of the behaviour. What does the child get from doing it?

e.g. I scream and shout = Mum or Dad take me out of the shop. To a bystander, this may look as if the child is '**spoilt**'. However, there may be many logical reasons for this behaviour that we have failed to understand: adverse sensory experiences – too hot, strange smells, too bright; the shop was too busy; too many strangers. A child with autism may not be able to express this in a way that would be expected from a child who does not have autism.

Try to monitor and record behaviours over one to two weeks to see if any patterns occur. It is important to consider each child as an individual when deciding on how to give or remove rewards for good behaviour.

Remember that:

- if you **reward** a behaviour you will see more of it.
- if you **ignore** a behaviour you will see less of it.

To help learn new behaviour it is important that your response is clear and consistent. **YOU MUST RESPOND IN THE SAME WAY EACH TIME.**

‘Once boundaries are established they work really well but it does take time and effort to get them up and running.’

HERE ARE SOME WAYS OF SUPPORTING YOUR CHILD:

- Be positive and praise good behaviour. Make sure the praise is given quickly and clearly so that your child knows what you are praising them for. However, also be aware that some children with autism dislike praise as it draws attention to them and the emotion maybe overwhelming.
- Don't try to change too much too soon. Tackle only one thing at a time. Start with whatever will be easiest to change first.
- Consider the way you communicate with your child (see previous section on communication).
- Depending on your child's stage of development, you may be able to help him to understand and change behaviours by explaining about other people's thoughts and feelings. Social Stories are useful (more advice is available by contacting The Pines).
- Use calendars and other visual information to help them understand the concept of time.
- Plan ahead for activities and changes to routine (see previous section on Repetition and Routine (social imagination)).

DEALING WITH FREQUENT BEHAVIOUR THAT CHALLENGES CAN BE STRESSFUL AND OVERWHELMING.

‘Boundaries = wars. I have to come around the side of her, not at her.’

- Whenever possible, try to make time for yourself in order to help you relax and regain energy. You may need support and encouragement during these difficult times.

SELECTIVE EATING IN CHILDREN WITH AUTISM

DAVE REX – SPECIALIST DIETICIAN FOR HEALTH PROMOTING SCHOOLS AND AUTISM

Children with ASD sometimes have very specific food preferences. This can have an impact on their development, mental wellbeing and physical health. It can also cause significant practical and social difficulties for family and child.

HOW TO ASSESS WHETHER OR NOT THE DIET IS ADEQUATE

We need 40 nutrients in our diet. For children over 2 years of age, the easiest way to assess whether or not we are likely to be getting these, is to compare a child's food choices with the **“Eatwell Plate”** (www.food.gov.uk/scotland/scotnut/eatwellplate/). Ideally, there should be some foods consumed regularly within each of the 4 essential “food groups”. In addition, there are specific advantages to including oily fish, “wholegrain based” starchy foods, and green vegetables. These contain essential omega 3 fats, dietary fibre and magnesium (respectively), each of which benefit physical and mental wellbeing. Remember that most children in the UK have a diet that does not provide all the nutrients in the right amounts! This means that their diet can be adequate for survival, but still not the best for optimum health and mental wellbeing.

UNDERSTANDING SELECTIVE EATING IN CHILDREN WITH AUTISM

Children with autism may be more likely to stick with what they are most familiar with. This can be because they become obsessed with a particular food or routine. They may also avoid new foods because they find all new experiences difficult to cope with. They may also refuse some meals because they want something that they feel in control of. For a child who finds communication difficult, refusing to eat something can be a way of communicating stress or anxiety about something else. Also, many children with autism experience taste, smell or texture differently. This can be a further reason for finding some foods difficult to accept.

HOW TO INFLUENCE FOOD CHOICES

- 1 Having nutritious foods within sight, and making healthy choices yourself, is usually the best approach in the long term. This is usually more effective than persuasion, coaxing or any active encouragement. It is important to appear not to care what choices are made. This is sometimes easier said than done!
- 2 Some of the most preferred and least nutritious choices sometimes have to be unavailable to make it possible for new foods to be accepted.
- 3 Providing a choice between two different foods or meals can be helpful. It still allows a child to feel in control, even when neither choice is their favourite. Ensure that the choices are realistic though.
- 4 Try having a “Self service” meal. This is where everyone helps themselves to whatever they prefer from serving dishes placed in the middle of a table. This is less pressure than putting food on their plate.
- 5 Sometimes, telling a child what meal is coming next can help. For examples, including pictures of specific meals on a “visual timetable” can help.
- 6 Involve children in food preparation. The more a child is involved in choosing, preparing and cooking ingredients, the more they have invested in it and the more attached they become to the meal that is prepared. Don’t actively encourage them to taste it though!
- 7 It is often best to get a selective eater to take a school meal rather than a packed lunch. The modelling of other pupils, different setting and limited menu often leads to “breakthroughs” with new foods that have been hard to achieve at home.
- 8 Some older children with autism can be motivated to make more nutritious choices simply through education about nutrition. This should always be done in a very “Matter of fact” way or it soon becomes nagging and persuasion.

SPECIAL DIETS AND NUTRITIONAL SUPPLEMENTS FOR CHILDREN WITH ASD

There are many “Special diets” and supplements promoted for children with ASD. Below is a guide to the safest, most effective and practical options. Most of the interventions listed below have some risks attached and are most safely and effectively implemented with the support of a State Registered Dietitian.

Intervention	Why	Risks	Other Comments
Milk (casein) exclusion	Produces morphine like substance: can effect mood, sleep or health. Often referred to as “intolerance”. Not the same as an allergy.	Milk products are a major calcium source. They also provide iodine (also found in eggs and fish) and protein (found in meat, fish, eggs, beans, nuts and pulses)	Sometimes soya products or goat & sheep milk / cheese tolerated. Other calcium fortified milk substitutes are made from rice, oats, or nuts.
Gluten exclusion	As above	Some “wholewheat” foods provide valuable fibre. Without fibre, there are risks of constipation and poor blood sugar control. Make sure of enough fibre elsewhere in diet.	May need to avoid barley and rye. Oats maybe OK if labelled as gluten free.
Food additive exclusion	Some have been shown to worsen mood and concentration	None	No need to avoid all E numbers. “ Food additive sheet ” is available. Specific colourings, preservatives and sweeteners are the main problem
Other exclusions	Various substances like phenols, salicylates and amines can cause physical or behavioural intolerance	Could take too many foods out of the diet just in case of intolerance. Foods containing these substances are very nutritious.	Most common causes of reaction are oranges, tomatoes tea & bananas. Sometimes also children also apples, berries, and peppers.
Healthy, well balanced diet	Use the “ Eatwell Plate ” as a guide. What’s good for the body is good for the brain.	Easier said than done for some children! Requires patience and modelling. See “ Guidance on managing selective eating ”	Green vegetables, high fibre starchy foods, some oily fish, some beans and pulses, a little red meat and very little added sugar or high sugar foods.
Vitamin & mineral supplement	Some have key roles in brain and poor intakes are common. Eg: Iron, Zinc, Magnesium and folic acid.	All nutrients have a “safe upper limit” beyond which they can be dangerous. Nutrients in food are better absorbed.	Useful “safety net” especially for a child with a poor diet. An information sheet is available: “ Supplements needed depending on diet ”.
Omega 3 supplement	May improve mood, sleep, attention or health in general.	Very few except for very high doses. May lead to increased risk of bruising	250 to 1000 mg per day, depending on diet and age of child. Children with raised red bumps on arms, high levels of thirst, dull hair and weak nails may be showing signs of omega 3 deficiency.
Vitamin D supplement	Important for healthy bones. May improve mood. May reduce a wide range of health risks.	Few risks unless on very high dose. If aiming to increase vitamin D levels through sun exposure, care to avoid burning. However, spend some time without sunscreen in sun.	Opinion varies on ideal vitamin D dose. Blood vitamin D levels in Scotland are often low.

ANXIETY

Feeling very anxious much of the time is very common in children with autism. However, your child may not be able to tell you why he is feeling anxious. Instead it may show in these ways:

- tantrums and aggressive behaviour
- becoming withdrawn and not wanting any interaction with others
- experiencing pain
- becoming distressed
- feeling tired a lot of the time
- changing patterns of sleep

There may be many causes of anxiety which makes it difficult for parents to know what to do or how to react. Making sense of the world around them and not understanding social rules are very common reasons for feeling anxious and stressed. Other reasons can include:

- meeting strangers
- being given too many choices
- not being able to communicate what they need
- changes in routine
- new activities or places
- experiencing unpleasant sensations, eg, noisy environments
- transitions from one activity to another (no matter how small)
- trauma – remembering unpleasant events, eg, visit to doctor, dentist, hairdresser – which, if asked to repeat, makes them anxious.

Sometimes, children with autism can be anxious about more than one thing at a time. This may cause overload, which could then lead to extreme anxiety behaviours (meltdowns).

HOW CAN I HELP REDUCE ANXIETY?

Some children with autism may appear to control situations or take part in things only on their terms. This might be because being in control helps reduce their anxiety levels. It is important to remember this when deciding how to manage your child's behaviour.

- **Try to stay calm yourself** – Your own anxiety, anger or frustration may make things worse.
- **Keep a diary of the behaviour** – You may begin to see what has triggered the anxiety. It is sure to be something from one of the four categories of autism discussed earlier.
- **Make routines and stick to them** – If you do need to change a routine, give your child as much warning as possible. Explain what will happen instead.
- **Allow breaks between activities** – e.g. getting dressed then having breakfast.
- **Give one instruction at a time.**
- **Allow time to process information.**
- **'Fiddle toys' may help** – e.g. stress balls, plasticine.
- **Identify a 'safe' place that your child can go to when anxious** – Make sure other people are aware of and respect this.
- **Provide a 'Time Out' card** – Teach your child how to use this when he needs to remove himself from a situation.
- **Use an 'Anxiety Scale'** – Older children can be helped to identify the level of anxiety.
- **Be tolerant** – Try to accept your child's way of calming himself, no matter how difficult or annoying this may be to you.
- **Use Social Stories to help understand social rules.**

REPETITIVE BEHAVIOURS

Some behaviour is very obvious e.g. head banging, while others are not so easy to notice, e.g. blinking or eye rolling.

Although the reason for these behaviours is not completely clear, we know that children with autism experience a lot of chaos and anxiety, so repetitive behaviour is a way of bringing predictability to what is, for them, an unpredictable and frightening world.

Some children learn ways of monitoring this behaviour. Some of the tips about managing anxiety will help. However, it is important to understand that, whatever the behaviour it is something your child needs to do in order to find peace.

SPECIAL INTERESTS

All children have favourite things, games, toys, films but some children with autism seem to develop interests in a way that makes it seem as though they are obsessed. They may retreat into their own little world for hours and hours, or they might want to talk non-stop about their interest, which makes it difficult for them to develop friendships.

Special interests, like repetitive behaviours may be for the following reasons:

- To reduce anxiety
- To keep a sense of calm
- To feel happy
- To avoid having to do another activity

Special interests can be anything at all. However, there are some that are common:

- Dr Who
- Thomas the Tank
- Cartoon Characters
- Drawing
- Types of cars

Although special interests can interfere with learning or daily living activities, they can also be used to motivate and used as an incentive for your child. They can tell you a lot about what your child enjoys; what he may be naturally good at and where his strengths and abilities lie.

HOW CAN I HELP MANAGE MY CHILD'S SPECIAL INTEREST?

- Be patient and tolerant – allow for the autism.
- Show your child that you know how important their interest is to them.
- **Don't criticise** or **tease** your child's special interest.
- If it is interfering with other activities, offer them specific times for them to spend on their interest but it is important that you keep to this agreement, unless you have given warning.
- Look for ways to expand the special interest.
- Special interests can be a way of making friends.
- Use the special interest as a way of engaging with your child. You may have to learn more about it!
- If you have to travel, if possible try to take their special interest with you so they have an instant comforter if anxious or bored.
- Although the special interest may seem pointless or silly to you, it might be the most precious thing in the world to your child. It is also serving an important purpose which may not be obvious straight away.

SLEEP

Many children with autism may have different sleep patterns from those of others in the family. This means the whole household may have difficulty sleeping which can make everyone tired and irritable. A child may have problems getting to sleep or he may wake from time to time throughout the night. The child may catch up on sleep during the day or may seem to need much less sleep than others in the family.

Many children show behavioural problems during the day because of tiredness and lack of sleep.

Often sleep problems can be sorted with behavioural interventions. Sometimes even a small amount of change can make a big difference but often, it is easier to 'give in' at night so that everyone can get back to sleep.

Children with autism often prefer predictable routines so it is a good idea to make one at bedtime. Busy environments can also cause difficulties in settling to sleep, especially for those with sensory issues. Many children are excitable during the late evening because they are over-tired.

Children who need external pacifiers such as a dummy, TV or cuddles from a parent are likely to wake in the night. They will find it difficult to resettle without the pacifier.

HOW CAN I HELP?

- Set up a regular night time routine and **stick to it**. Start '**winding down**' **at least an hour** before bedtime. Baths, stories, milky drinks may help children to relax.
- TV, computer games, physical play should be avoided for at least an hour before bed.
- Make the bedroom as calm a place as possible. TV off, computer off, dim lights and reduce the noise level.
- Encourage your child to settle alone in their own bed. If you usually cuddle your child to sleep, gradually change this. Each night withdraw yourself a little more, sit next to the bed, then away from the bed, in the doorway, on the landing, etc. Repeat these steps if the child wakes in the night.
- Set clear rules: '**you must stay in your own bed,**' '**no TV after 7pm**'.
- If you allow your child to sleep in your bed with you, it may make more problems long term.
- Encourage your child by using a reward chart.

TOILETING

Toilet training for children with autism may take longer than children who do not have autism.

The National Autistic Society (NAS) has a lot of information on its website: www.autism.org.uk

ERIC – Education and Resources for Improving Childhood Continence is another helpful site: www.ericshop.org.uk or www.enuresis.org.uk

Some children with autism may be prone to constipation or diarrhoea. They may experience one or both at the same time.

HOW CAN I HELP?

- Make sure that everyone involved with your child knows the approach that you are using so that you are all consistent.
- Keep to the same routine.
- If your child does not like change, it may be easier not to train using a potty as this will mean more change from potty to toilet.
- Watch your child to see when they wee and poo so that you can try and work out when you are likely to need to take them to the toilet.
- Have a visual sequence beside the toilet to help your child understand what to do.
- Some children may find bowel movements frightening so it may be useful to explain this.
- Some children may like the feel of a full nappy and not want to change.
- Some children enjoy the feel of smearing (touching their faeces), therefore other acceptable activities need to be provided.
- Check if anything in the toilet/bathroom may be affecting sensory issues e.g. water flushing.
- If your child does not like the texture of toilet paper, think of alternatives to use.
- Avoid using baby language as this may be difficult to change later.
- Use the same toileting routine when out of the home.

If difficulties persist, contact your GP or another health professional involved in the care of your child to give advice.

PLAY

Children with autism often do not develop play in the same way as other children of their age. Play can be difficult for them. If you encourage and help your child to play it can have many benefits:

- Develops language.
- Helps understanding of social situations.
- Encourages questioning.

If you reward your child during and after the play session it will mean they may want to take part again. Gradually involve other family members, but to begin, it is better to do smaller steps, one to one.

HOW CAN I HELP?

- Take away other distractions before you begin to play with your child, eg, turn off the TV, phones, etc. Do not allow yourself to be distracted. Keep the child's focus on being with you.
- Don't play if you are tired, stressed or anxious. Five minutes of good, energetic play is better than an hour of feeling as if you have to play. It should feel like fun, not a struggle. Stop if it becomes a chore.
- If your child does a repetitive behaviour you could try doing it with them to show you want to be with them more than doing what you were doing. Gradually, you can start to expand on this making it into two way play rather than solitary play.
- Be prepared that your child may react negatively to this. Remember that play may be difficult and you may need to keep trying before your child learns that it is fun.
- **Don't ask lots of questions during play.** Make statements e.g. 'That's a great tower you're making' or describe how you are feeling instead.
- Join in their chosen activity. Really try and experience what they are doing.
- Praise them at regular intervals. Remember, play may be difficult for them.
- Start with what your child likes to do. Then use your imagination and develop it.
- Play with anything that uses your imagination e.g. boxes, paper, feathers, bubbles, blocks, stickers, wigs, musical instruments, scarves...
- **Don't put out lots of different toys.** Put a **few** toys on a high shelf to help encourage the child to make a request.
- Allow your child to play in a way that is natural to him e.g. if your son asks to play with dolls allow him the opportunity to learn through this experience.

BODY AWARENESS (BEHAVIOUR AND BOUNDARIES)

Children with autism must be taught about body awareness, sexual issues and relationships. This is very important as people with autism often experience difficulties in reading social situations and may not realise that their behaviour is inappropriate. Explanations must be given in a clear, calm way that they are able to understand, even if you find it difficult.

People with autism can be confused by body language, facial expressions and tone of voice which leads to bewilderment, misunderstanding and upset. They may also be confused or worried about changes that are happening to their bodies and their feelings.

HOW CAN I HELP?

- Teach socially appropriate behaviour before puberty begins.
- If your child has 'inappropriate' behaviour make sure you know the purpose – it may be different to what you think.
- Comment on the inappropriate behaviour as it happens. Explain why it is and also how the situation/matter could have been handled.
- Be calm, clear and consistent. Repeated messages will help learning.
- Ensure your child has understood. Ask them to tell you in their own words.
- Find out from the school what topics will be covered during PSHE lessons. Talk to the teacher if you are not sure about anything. Try to work together.
- Make sure you are aware of what your child is watching on TV or film for any sexual content. Check your child's understanding of what he is seeing.

MORE INFORMATION CAN BE FOUND HERE:

- **National Autistic Society** – www.autism.org.uk/about/communication/sex-education.aspx
- **National Health Service** – www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sex-and-young-people-hub.aspx
- **Family Planning Association** – www.fpa.org.uk

HOW TO TELL FAMILY, FRIENDS AND MY CHILD

Once you have had time to consider your child's differences, you will need to decide how to tell your other children, family members and friends. At some point, you will want to tell your child, too.

SIBLINGS

- They may often find it difficult to understand why their brother/sister behaves in certain ways. They may feel rejected if he/she does not want to play with them.
- They may feel as if you are not giving them as much attention, or you do not love them as much.
- These feelings may show in their behaviour to gain more attention, rather than being voiced.

'My child finally understands her sister has a reason for being the way she is but has no support for how to deal with her sister's behaviour.'

'My boys have an older sibling who won't accept that they have autism. He thinks it's down to us giving them their own way.'

'His big brother finds it hard sometimes but he is so good with him too and tries hard to understand and avoids things that upset him. He is very supportive.'

HOW CAN I HELP?

- Give siblings as much information as possible about autism, depending on their age and level of understanding.
- Talk about their feelings. Tell them it is okay to feel angry, sad, etc.
- Give them the opportunity to discuss feelings with someone they trust. (They may not want to worry you).
- Tell them that having to spend more time with their sibling does not mean you love them less.
- Encourage them to interact with their sibling.
- Help them understand the difficulties and the strengths of their sibling.
- Tell them they are an important member of the family.
- Give them their own space and privacy without interruptions.

- Give them a safe place to keep important things.
- Make individual time with your children. Explain that this is their time just with you.
- Think together about activities which can be done as a family and one to one with you.
- Praise their positive behaviour. Look for lots of little things to praise.
- Explain that other people may not understand autism and may react differently.

EXTENDED FAMILY AND FRIENDS

It is important that family and friends have an understanding of autism so they can help support your child appropriately.

At first, you may decide only to tell those closest to you. The decision to tell family and friends is individual to you and your personal circumstances. Different people react in different ways. Some members of the family or friends who do not know your child very well may give unhelpful suggestions or make misguided comments. Try not to take this to heart.

‘Older relatives tend to be less accepting. They may see it as a bad reflection on their family or they may suspect you are fault. You just have to keep telling them till it sinks in.’

‘It took outside friends and family lots of time to accept my child is autistic. It needed severe symptoms that appeared at puberty before they accepted it.’

HOW CAN I HELP?

- Give them some basic information about autism and explain how it specifically affects your child and their behaviour.
- Provide them with appropriate information about typical signs/behaviours of autism so they can begin to understand.
- Encourage them to talk to you if they want to know more or if they do not understand your child.
- Accept help and support from family and friends when it’s offered. They may be grateful for some practical ways that they can do this.
- Tell them how best to connect with your child, i.e like and dislikes, best way to communicate.

WHEN SHOULD I TELL MY CHILD?

There is no set time for when to tell your child about their autism. It will depend on many factors such as their level of understanding, ability to process information and emotional strength.

Some parents tell their child when young so that they gradually become aware of their difference without it becoming a big issue. Others prefer to wait until the child is older so they may understand better. Some may leave it until the child begins to ask questions about themselves.

There is no right or wrong decision. You are the best person to gauge this although you may find it helpful to discuss it with someone who has knowledge of autism.

'I didn't tell my son till he was 9. We watched a programme together, and then a week later discussed it. Later again, I told him he was like the kids in the programme and told him all the positive things about his autism. We now discuss all aspects of his autism. It's an on-going process. He is now 11.'

'She didn't accept at first and now hopes that the diagnosis will explain how she is – not just bad.'

HOW CAN I HELP?

- Be confident about the strengths and abilities of your child and their sense of being.
- Be as positive as possible when talking about autism to your child.
- Give lots of time for them to process the information.
- Gives lots of reassurance. Encourage them to ask questions.
- Give the information in ways that suits them best e.g., DVDs, books, websites, etc.
- There are different programmes available to use with children. For more information contact The Pines for advice.

THE PINES

HIGHLAND AUTISM SUPPORT CENTRE

The Pines is a multi-functional facility which promotes accepting and positive attitudes towards children and young people who may be affected by autism and their families and aims to ensure that they feel supported no matter where they live in Highland.

The facility hosts a range of professionals and agencies. This includes The Highland Council, the National Autistic Society Scotland and CHIP+ who work across Highland with local colleagues, including NHS Highland and in partnership with parent carers.

The facility provides a low stimulus environment for therapeutic work with children including a small gym, life skills kitchen, library and chill-out room. Family members are also welcome to make use of these facilities. There is a medium sized training and conference facility. Training is delivered here and across Highland to a broad range of agencies, professionals, parents and carers as well as children and young people. We have the largest library on autism in the Highlands which is open every day from 10 am to 4 pm. Fill out a library membership form and come see our collection of DVDs, books and sensory items. We also work with High Life Highland to provide eBooks on autism.

The conference and smaller case conference rooms are used by several agencies providing services to children and young people and their families. Read about our training schedules, services and therapies on the Highland Council website. This includes:

- Consultation and assessment in diagnosis, see Frequently Asked Questions (FAQ)
- Training schedules
- Information and advice, including regular Autism Information and New Parent Drop In Sessions which are facilitated by CHIP+ and the National Autistic Society Scotland (Highland Branch)
- Individual and group therapeutic sessions
- The library, as above

The Pines also leads on implementation of the 10 year Scottish Strategy for Autism which has supported the vision in Highland ***‘that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives’***.

Highland Council and NHS Highland are developing a joint Highland Strategy for Autism with partners including parents and carers using the same underpinning values as agreed in the Scottish Autism Strategy. Action Plans for Children’s Services can be viewed on the For Highland’s Children Website.

WHERE DO WE GO
FROM HERE?

SUPPORT AND SERVICES



THE HIGHLAND PRACTICE MODEL

Getting it right for every child (GIRFEC) is outlined in the Children and Young People Act 2014. It aims to improve outcomes for all children and young people by promoting a shared approach that builds solutions with and around children and families. It enables children to get the help they need when they need it; supports a positive shift in culture, systems and practice and involves agencies and services working together to make things better. In Highland, the Highland Practice Model has been developed in keeping with the principles of Getting it Right.

The desired national outcomes for children and young people, from the Curriculum for Excellence, are that all children should be:

- Confident Individuals
- Effective Contributors
- Successful Learners
- Responsible Citizens

To achieve this all children need to be **Safe, Healthy, Active, Nurtured, Achieving, Respected and Responsible and Included**. These are known as the 'wellbeing indicators' and are known as **S.H.A.N.A.R.I.**

The Highland Practice Model will ensure that children and their carers are central to the process of finding solutions and having their needs met. Everyone working with children is expected to use one consistent and equitable approach, actively sharing information to agreed protocols and working more effectively together to improve outcomes for children.

Everyone needs to be clear about their personal responsibility to do the right thing for each child. Parents and children, together with schools, professionals and others working with children will benefit from a collaborative approach which results in the development of a Child's Plan to meet all the child's needs.

The Highland Practice Model operates throughout the Highland area. It affects the working practices of all staff in Care & Learning along with Police, Children's Reporter and Voluntary Agencies who work with children and families, including services to adults who are also parents.

The current responsibility to act if a child is at risk of harm does not change. All staff should follow Child Protection Procedures.

However, there is now a wider responsibility to consider a child's wellbeing across the S.H.A.N.A.R.I. spectrum.

Each child will have a **Named Person** in Universal Services (health and education) who is the point of contact for the child, parents, professionals and the community. This will be the family health visitor for pre-school children and a designated person in school for school age children. Where a concern about wellbeing is raised and there is no risk of harm to the child, consent should be gained from the child and parent to share this information with the **Named Person**. In partnership with the parents, child and, with consent, the **Named Person**, organisations/carers will consider what additional support is needed to meet the child's agreed needs. If there is a risk of harm to a child, information will be shared without seeking consent.

Where a child's support needs require different agencies/services to collaborate and work together, a **Child's Plan** will be developed. At this stage a **Lead Professional** will be appointed to ensure the **Child's Plan** meets the identified needs and everyone is doing what they agreed.

It must be clear to all involved in the **Child's Plan** what the actions are to be taken. It will; also outline the desired outcomes and reviewing process for the child. This may be as simple as a particular strategy to ensure a child's inclusion in certain activities to something more specific such as administering medication or providing personal care.

The **Lead Professional** will ensure the active involvement of a child and family and ensure the **Child's Plan** is reviewed with progress and challenges noted. Partners contributing to the plan may be asked to contribute to this review.

In the long term, all child protection training will be delivered as part of a series of Highland Practice Model training modules and so should eventually reach all organisations working with children. Meantime groups will have differing needs for information and training depending on the level of support offered to children and families in need by their service.

More information about the Highland Practice Model can be found at:
<http://www.forhighlandschildren.org/5-practiceguidance/>

EDUCATION

(ADDITIONAL SUPPORT FOR LEARNING) (SCOTLAND) ACT 2004 & 2009

The Education (Additional Support for Learning) (Scotland) Act 2004 came into force on 14th November 2005. This was amended by The Education (Additional Support for Learning) (Scotland) Act 2009.

Systems have been improved and modernised for identifying and meeting the needs of **ALL** children and young people who may need support with their learning.

The Scottish Government produced a Code of Practice in 2004 to accompany the Act which was called Supporting Children's Learning. It explained the duties on the Highland Council and set out good practice. This was updated in 2010 to take account of The Education (Additional Support for Learning) (Scotland) Act 2009.

The 2004 Act introduced a new framework for supporting children and young people in education and introduced the term Additional Support Needs. The 2004 Act and the amendments resulting from the 2009 Act have extended the rights of parents and young people with regard to additional support needs.

The term Additional Support Needs applies to children or young people who, for whatever reason, require additional support, long or short term, in order to make the most of their education.

The Acts do not just cover education. They place a legal obligation on other agencies to help the Highland Council to support children and young people with Additional Support Needs.

Parents and young people can request an assessment of their needs at any time.

The Additional Support Needs of most children and young people will be identified, and provided for by the systems which all schools have in place (e.g. Normal Classroom Practice, Differentiation, Staged Approach, Individualised Educational Programme [IEP] / Child's Plan).

Some children and young people may require help from other services/agencies and this will also be co-ordinated through the Child's Plan in line with the Highland Practice Model (see Information Sheet 12).

A small number of children and young people will have additional support needs which are/arise from complex or multiple factors, have a significant adverse affect on their learning, will last for more than a year and require a significant level of support from more than one agency to benefit from education. Where this support needs to be coordinated a Co-ordinated Support Plan (CSP) may be considered as part of the Child's Plan.

The format of the Co-ordinated Support Plan is set by law. Parents can request that the Education Authority considers whether or not their child should have a Coordinated Support Plan, and that particular assessments be carried out as part of the process by writing to their local Area Additional Support Needs Manager. Co-ordinated Support Plans must be formally reviewed every 12 months.

Sometimes parents/young people are unhappy with a decision made by the education authority or perhaps about the support arrangements made for their child. If a local solution cannot be found there are rights for parents and young people to use mediation and dispute resolution services and to appeal to independent tribunals. Information regarding these appeal routes can be found from your school, CHIP+ or by requesting Information Sheet 10 (Working Together and Resolving Disagreements).

AREA ADDITIONAL SUPPORT NEEDS MANAGERS IN HIGHLAND

SOUTH (INVERNESS, NAIRN, BADENOCH & STRATHSPEY):

Area ASN Manager,
The Highland Council Headquarters,
Glenurquhart Road,
Inverness IV3 5NX
Tel: 01463 702074

NORTH (CAITHNESS, SUTHERLAND):

Area ASN Manager,
Caithness House,
Market Place,
Wick KW1 4AB
Tel: 01995 609604

MID, EASTER ROSS & BLACK ISLE:

Area ASN Manager,
Council Buildings,
Strathpeffer Road,
Dingwall IV15 9QN
Tel: 01349 868603

WEST, WESTER ROSS, SKYE, LOCHALSH & LOCHABER:

Area ASN Manager,
Fingal Centre,
Dunvegan Road
Portree IV51 9EE
Tel: 01478 613697

SERVICES FOR CHILDREN WITH DISABILITIES AND THEIR FAMILIES IN HIGHLAND

THE BIG PICTURE

Provision of services for children and young people with disabilities and their families were boosted by the integration of the Highland Council and NHS Highland into the Children's Health and Social Care Service in 2012.

This built on existing multi-disciplinary practice in particular with Allied Health Professionals in child health including occupational therapists, physiotherapists, speech and language therapists and dieticians. They joined the Council along with the children's community learning disability nurses who were already integrated into the Children's Disability Service in central Highland.

Such momentum in improved provision was further enhanced by the merging of Health and Social Care and Education Services into Care and Learning in 2014, including the creation of new **Family Teams in October 2014**, based around Associated School Groups.

How does this ensure we get it right for every child, including children, young people and families affected by disability?

Family Teams deliver universal and additional public health services, as well as social care and child protection services for children in the context of the Highland Practice Model. Teams are multi-disciplinary with an ethos of collaborative practice – within the team and with children, young people, parents and carers. The teams work in communities with partner services from the associated school group, the area and from across Highland.

Practice Leads (for early years, for school years and for care & protection services) work together within the team to provide a local integrated service to children & families. Practice Leads collaborate to support the work of the team, providing leadership and supervision to distinct but complementary areas of professional activity.

All children with disabilities are considered children first and their needs assessed in the context of their family, school and community in this way.

The Child Health and Disability Teams, who are an integrated and distinct part of the Family Teams network, deliver targeted services where the situation and/or the disabilities are more complex.

Further information about the disability teams can be found on the Council's website or on the The Pines website using the highlighted titles:

South Child Health and Disability (Family) Team, formerly the Children's Disability Team and the services they provide.

Mid Child Health and Disability Team is smaller and spanning the Mid and East Ross Family Teams.

North Area has a small Child Health and Disability Team, included in the Caithness and Sutherland Family Teams, offering a similar service.

West Area has no disability Team as such but has dedicated disability posts covering Lochaber, Skye, Lochalsh and Wester Ross Family Teams

NEW HEAD OF ADDITIONAL SUPPORT SERVICES

This new post is a welcome consequence of the creation of Care and Learning, and is in recognition of the Council's significant responsibility and commitment to children and young people with Additional Support Needs (ASN), including children with disabilities.

A major review of ASN provision was completed in May 2014 and a detailed update on progress provided in May 15. Both can be viewed on the Highland Council Web Site. The whole purpose of the review was about "improving peoples' experiences of services, whether it is as a pupil or a parent".

The significant recommendations from the work of an ASN Improvement Group provide principles which guide further actions. There are also an ongoing range of evaluations and audits which collect data on specific actions that can demonstrate improvements in service delivery.

BUILDING CAPACITY IN FAMILIES, SCHOOLS AND COMMUNITIES

Children and young people with disability need to be included in and nurtured by their families, their schools and their communities.

The **Self-Directed Support (S-DS)** legislation, enacted by the Scottish Government in 2014 has given the Council and NHS Highland a further means to support this and improve outcomes for children and young people with disabilities.

S-DS implementation in Highland is shifting resource to children, young people and families affected by disability who are eligible for Health and Social Care Services so that they have more control and choice about how to meet their needs.

Following 18 months of piloting Self-Directed Support, in partnership with families, the Council began processing assessments of all new requests for service and review of existing packages utilising the new S-DS process, from July 2014.

Some families may choose to use the resources allocated in different, new and creative ways. Others may wish to take a more measured approach and continue to make use of existing services. Others might have a mixture the two.

Families and services are on a journey together, learning to ensure that the resources available add value to what is already working well for families.

The Highland Council SDS Pamphlet for Children and Families provides more information.

PSYCHOLOGICAL SERVICE

We are a team of Educational Psychologists and Pre-School Home Visiting Teachers.

WHAT WE DO

Educational Psychologists help to find solutions to improve the learning, social and emotional wellbeing and environment for all children and young people.

The Pre-School Home Teaching Service is offered to the family of any child with additional support needs which may affect their development, learning or behaviour. We work to support your child within the home and early years settings. We work in collaboration with families and other agencies to identify goals and demonstrate play and learning strategies to ensure a holistic approach to continued learning.

Read the information leaflets on the Highland Council website about the Educational Psychology and Pre School Home Visiting Service.

OUR VISION

Our Psychological Service is solution focused and works for positive change. We strive to form attuned relationships with others through collaborative and inclusive working. We are child centred and seek to be evidenced based, reflective practitioners with a commitment to on-going innovative practice.

REQUEST FOR INVOLVEMENT

Following the staged approach, requests for involvement typically come through the Child's Plan. We can provide informal consultation at stage 2 of the Highland Practice model. However, more direct involvement is negotiated with the Educational Psychologist in a Solution Focused Meeting or Child's Plan Meeting.

A request for involvement to an educational psychologist does not always need to be from the school but can be anyone who knows the child or young person well, including the child or young person themselves. If you have any concerns about a child's development, learning or behaviour, please contact us. Please note that consent must be obtained from a parent or carer before discussing any child under the age of 16 with a psychologist.

AUTISM SPECIFIC ORGANISATIONS

ARGH (Autism Rights Group Highland) is an Autistic People's Organisation, run by and for Autistic adults. (18+)

We are a collective advocacy, lobbying and campaigning group and promote self advocacy and access to quality Independent advocacy for all Autistic people.

ARGH works locally and nationally including working in partnership with the Scottish Government as members of the Autism Strategy (Scotland) Governance Group. We are stakeholders for NICE guidelines relevant to autistic people. We also run a UK wide autism alert card scheme for adults and children.

ARGH is an organisation which will:

- Inform service providers about what autistic people really experience.
- Campaign for better services for autistic people in the highlands and beyond.
- Challenge stigma and discrimination through education about autistic strengths.

For more information on membership, alert cards or meeting and event details please see: www.arghighland.co.uk

Email: info@arghighland.co.uk or Phone: 01847 851743

ASD FRIENDLY

For everyone to share experiences of everyday life with children with autism.

www.ASDfriendly.org

AUTISM CONNECT

An online resource providing information about autism, news and events from around the world and access discussion forums and other web sites about autism.

www.autismconnect.org

AUTISM NETWORKS

A charitable body run by a group of like-minded parents, carers, professionals and people with autism.

www.autismnetworks.org.uk

AUTISM NETWORK SCOTLAND

Supports individuals on the autistic spectrum, their families and carers, and practitioners working in the field of autism. A hub of reliable and impartial information, signposting people to supports, resources and useful information.

www.autismnetworkscotland.org.uk

HIGHLAND ONE STOP SHOP

Autism Initiatives Highland One Stop Shop is a service for adults aged 16+ with an autism spectrum condition living with Highland region. We provide scheduled drop ins, free social groups and activities as well as 1:1 appointments on a wide range of issues such as employment, relationships, benefits, etc. You can be kept updated through our monthly newsletter and activity calendar. If you would like to know more or arrange a visit please contact us via the following routes:

Telephone: 01463 717649

Email: highlandoss@aiscotland.org.uk Web: www.highlandoss.org.uk

SCOTTISH AUTISM

An organisation dedicated to enriching the lives of people with autism. Sharing their knowledge and expertise with parents, carers and other professionals in order to support the development of skills and strategies needed to provide the best care and support for people with autism.

www.scottishautism.org.uk

THE NATIONAL AUTISTIC SOCIETY SCOTLAND (NAS SCOTLAND)

The NAS is the leading charity in Scotland for people with autism (including Asperger syndrome) and their families. It is committed to providing the best services and sharing it's knowledge and experience with the entire autism community. Across the country, the charity provide support, information and care at every stage of life. Whether you are affected by autism as a child, adult or as a family, the NAS services are here to help.

The National Autistic Society Scotland Highland Information Service

Based within The Pines the Highland Information service responds to enquires from parents, carers and young people. The information service also supports The Pines library resource. **Contact them directly on 01463 720056 or email highland.informationofficer@nas.org.uk**

Supporting People with Autism in Scotland

The NAS website is a world-leading online autism resource: **www.autism.org.uk**

Our helpline provides impartial and confidential advice: **0808 800 4104**

Parent to Parent Telephone Helpline: **0808 800 4106**

Education Rights Service: **0808 800 4102**

Welfare Rights Helpline: **0808 800 4104**

Autism Services Directory – an online source of information specific to your area.

Community Care Service Helpline: **0808 800 4104**

If you would like to receive regular information on autism and receive the membership magazine sign up now at www.autism.org.uk/membership or call us on: **0808 800 1050**.

Like the NAS on Facebook: **<https://www.facebook.com/autismscotland>**

LOCAL SUPPORT GROUPS

**FOR UP TO DATE INFORMATION OF SUPPORT GROUPS
IN YOUR LOCAL AREA, PLEASE CONTACT:**

CHIP+

Tel: 01463 71189 or Email: info@chipplus.org.uk

THE NATIONAL AUTISTIC SOCIETY HIGHLAND OFFICE

Tel: 01463 720056 or Email highland.informationofficer@nas.org.uk

THE PINES WEBSITE

www.pinesautismhighland.org.uk/Pines/frm247dynamiccontentshow.aspx?UniqueID=SUPPORTGROUPS

OTHER USEFUL SERVICES AND LINKS

ADDERS

ADDERS promote awareness of ADHD, providing information and free practical help to adults and children, and their families.

www.adders.org

ADVOCACY HIGHLAND

Advocacy Highland provide free & confidential independent advocacy advice in Highland region for individuals of all ages, including young people, who need to be supported to speak up about specific issues.

www.advocacy-highland.org.uk

ANSA (Additional Needs Support Association)

The group support parents and carers of all children with additional support needs and meet in the Royal Highland hotel in Tain on the first Wednesday of every month.

E-mail: ansa_highland@yahoo.co.uk

BENEFIT ENQUIRY LINE – DIRECT GOV

www.gov.uk/disability-benefits-helpline

CAPABILITY SCOTLAND

Capability Scotland campaigns with, and provides education, employment and care services for disabled children and adults across Scotland.

Watch our film. **www.capability-scotland.org.uk**

CHALLENGING BEHAVIOUR FOUNDATION

A charity for people with severe learning disabilities whose behaviour challenges, to improve understanding of challenging behaviour, empower families with information and support, and to help others to provide better services and more opportunities across the UK.

www.challengingbehaviourfoundation.org.uk

CHIP+

CHIP+ (Children in the Highlands Information Point) gives information, advice and support to the families of children and young people with Additional Support Needs, and to the professionals supporting them. Based in Inverness, it works throughout Highland to provide a friendly, reliable and confidential point of information on any issues of concern to families, from where to find funding for basic equipment, to help with challenging problems over education or health issues. Many families find CHIP+ particularly helpful

at challenging times in a child's life, such as on diagnosis or when approaching transitions of various kinds.

CHIP+ was started over 20 years ago by parent/carers in the Highlands and is a first point of call for families in the Highlands who need further information, or would like to discuss, their child's situation. CHIP+ provides a telephone helpline (or access to our staff in the Birnie Centre); a range of information packs for parent/carers and others; support for families at Child's Plan meetings where necessary; a free lending library (with books also available by post); a termly newsletter, and regular training events and workshops. Where appropriate CHIP+ acts as a first stop shop, providing information and signposting families or professionals to specialist support.

**Tel: 01463 711189/720054 Email: info@chipplus.org.uk
www.chipplus.org.uk**

CITIZENS ADVICE BUREAU – www.citizensadvice.org.uk

CONNECTING CARERS

CONNECTING CARERS

Connecting Carers is a voluntary organisation working throughout Highland providing information, advice, support, training and befriending services to unpaid carers. **www.connectingcarers.org.uk**

CONNECTING YOUNG CARERS

Connecting Young Carers can provide you with information and support you in your role as a young carer. By connecting to our growing network we hope you will be better informed, better supported and better connected to other young carers.

**[www.connectingcarers.org.uk/carers-services/
connecting-young-carers.aspx](http://www.connectingcarers.org.uk/carers-services/connecting-young-carers.aspx)**

CONTACT A FAMILY

Contact a Family is a national charity which exists to support the families of disabled children whatever their condition or disability.

www.cafamily.org.uk/scotland

DOWN'S SYNDROME SCOTLAND

Down's Syndrome Scotland work to help people with Down's Syndrome to reach their full potential by providing information, services & support to them, their families, carers & professionals.

www.dsscotland.org.uk

DYSLEXIA SCOTLAND

Dyslexia Scotland support people affected by dyslexia, and campaign on their behalf, in many different ways. Whether through the helpline, branch network or online.

www.dyslexiascotland.org.uk

EDUCATION LAW UNIT - GOVAN LAW CENTRE

The Education Law Unit works in partnership with schools, education authorities, parents' groups and charities across Scotland to make pupils' rights and parents' rights in education a reality.

www.edlaw.org.uk

EDUCATION SCOTLAND

This website includes information on Curriculum for Excellence, Additional Support needs, GLO & resources for parents on Education.

www.education.gov.scot

ENABLE

ENABLE Scotland works with families living with learning disabilities throughout Scotland. We support parents with children who have learning disabilities from birth all the way through to adulthood. We also provide parents who have learning disabilities with support. Whether you need to find a service or branch in your local area or just need some advice we can help.

www.enable.org.uk

ERIC

ERIC is a childhood continence Charity who give information and support on childhood bedwetting, daytime wetting, constipation and soiling to children, young people, parents and professionals. **www.eric.org.uk**

ENQUIRE

Enquire are the Scottish advice service for additional support for learning.

www.enquire.org.uk

F.A.C.E.S.

A support group for parents/carers of children and young people with additional support needs based in Badenoch & Strathspey area.

E-mail: facescharity@yahoo.co.uk www.facescharity.co.uk

FAMILY FUND

They provide grants to low-income families raising disabled & seriously ill children & young people. They can help with essential items such as washing machines, fridges & clothing but also consider grants for sensory toys, computers & much needed family breaks together.

www.familyfund.org

FOR SCOTLAND'S DISABLED CHILDREN

The Scottish Government has funded Children in Scotland to undertake participation work with parents of disabled children. For Scotland's Disabled Children aims to turn the good intentions of policy and legislation into better lives for families with disabled children in four key areas: Education, Short Breaks, Childcare & Education. **www.fsdc.org.uk**

GIRFEC

An up to date guide on GIRFEC available through the Scottish Government website. www.gov.scot/Topics/People/Young-People/gettingitright

HEALTH SCOTLAND

Looking for information about how to improve your health? Visit NHS Health Scotland's series of websites for the public that give information on a range of health and wellbeing topics.

www.healthscotland.com

HI-HOPE DIRECTORY

The Hi-Hope Handbook has information about choices, opportunities and services available in the Highlands to support transition from school to adulthood.

www.hi-hope.org

HIGHLAND CARERS ADVOCACY

Advocacy is a free service supporting carers to express their views and opinions, sometimes speaking on your behalf. This can be through attending meetings with you, helping you to write letters or make phone calls.

www.connectingcarers.org.uk/carers-services/highland-carers-advocacy.aspx

HIGHLAND CHILDREN'S FORUM

Highland Children's Forum is a registered charity created by the parents/carers of children with additional support needs. The Forum aims to ensure that the voices of these children are heard in the design and provision of services in Highland.

www.highlandchildrensforum.org

MINDROOM

We provide one-to-one support for families affected, offer help and advice for individuals and organisations who work with people with learning difficulties, and strive to increase knowledge and understanding among policymakers.

www.mindroom.org

NHS HIGHLAND – www.nhshighland.scot.nhs.uk

SENSE SCOTLAND

Non-profit organisation working with people who have impairments to vision and hearing with or without other disabilities.

www.sensescotland.org.uk

SIGN

The Scottish Intercollegiate Guidelines Network (SIGN) develops evidence based clinical practice guidelines for the National Health Service (NHS) in Scotland.

www.sign.ac.uk

SLEEP SCOTLAND

A charity providing support to families of children and young people with additional support needs and severe sleep problems.

www.sleepscotland.org

THE DYSPRAXIA FOUNDATION

The Dyspraxia Foundation is a country wide charity which exists to help and inform parents and children with the condition.

www.dyspraxiafoundation.org.uk

THE HIGHLAND COUNCIL – SUPPORT FOR LEARNERS

www.highland.gov.uk/info/886/schools_-_additional_support_needs/1/support_for_learners

HIGHLAND COUNCIL WELFARE SUPPORT TEAM

TEL 0800 090 1004

www.highland.gov.uk/directory_record/102970/benefit_advice/category/108/housing

THE SCOTTISH GOVERNMENT – www.gov.scot

THE CHILD'S PLAN

<http://www.forhighlandschildren.org/5-practiceguidance/>

TOURETTE SCOTLAND

A registered Charity dedicated to providing support & information to people living with Tourette Syndrome.

www.tourettescotland.org

TURN 2 US

Turn2us helps people in financial need gain access to welfare benefits, charitable grants & other financial help – online, by phone & face to face through their partner organisations.

www.turn2us.org.uk

YOUNG MINDS

Young Minds is a charity working with children, young people, their families & the professionals who support them for better mental health & wellbeing.

www.youngminds.org.uk

WELCOME TO HOLLAND

BY EMILY PERL KINGSLEY

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, 'Welcome to Holland.'

'Holland?!' you say. 'What do you mean, Holland?' I signed up for Italy. I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland had tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, 'Yes, that's where I was supposed to go. That's what I had planned.'

The pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

CELEBRATING HOLLAND – I’M HOME!

BY CATHY ANTHONY

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I’d planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger – the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But this too, has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than me and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn’t so bad.

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I’ve wondered what life would have been like if I’d landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveller and discovered that it doesn’t matter where you land. What’s more important is what you make of your journey and how you see and enjoy the very special, the very lovely things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn’t planned. Yet I am thankful, for this destination has been richer than I could have imagined.

NOTES

NOTES

NOTES

NOTES

