An Evidence Based, "Common Sense" Approach to the Evaluation of Dietary Interventions in ASD and ADHD – Dave Rex, Specialist Dietitian, NHS Highland.

The use of dietary approaches to help children with ASD or ADHD is both popular and controversial. Interventions such as gluten and casein free diets, exclusion of food additives, and supplementing the diet with vitamins, minerals and omega 3 fatty acids are common parent led interventions. But how do we decide whether the science supports their use? How do we decide whether such approaches safe, practical and likely to be effective? Should we expect clear guidance on nutrition from those who are more used to assessing the effectiveness of medical interventions? If not, what is the alternative?

We all have to eat something. For medical interventions, there is always a "do nothing" option. This is in sharp contrast to food where parents make decisions about what to feed their children whether the "evidence base" is complete or not. So how can we use the reductive logic of a "levels of evidence approach" in a way that also acknowledges the fundamental need to eat something; and the natural instinct of parents to do what they can to help their child?

This paper proposes 5 rules against which dietary interventions can be assessed. The use of these rules allows common sense to be applied to *food* and *diets*, while still recognising the value of an objective approach to assessing research on *single nutrients*.

For all parents, they make decisions about what food to shop for, prepare or cook several times a day. They are, when it comes to food, the "Consultant-in-Charge" steering a delicate course between financial, socio-cultural, practical and nutritional considerations every time they prepare a meal. Nutritional considerations begin to loom even larger after diagnosis, especially following a brief "Google search" for "Diet and ASD" or "ADHD". Dietary interventions are described with varying degrees of caution or evangelical fervour and certainty. A range of privately available supplements and tests are then just a tantalizing click away.

For health professionals working in the NHS, providing appropriate advice and support for children with ASD or ADHD is just as complex. They too must steer a delicate course between what the published evidence tells them, and what they feel the individual needs of the child in front of them might be. As if that's not enough, they must then balance all of this with the child's parent's perception of need. The parent will be able to draw on hundreds of

observations about what their child eats and whether or not this is affecting their health and wellbeing.

Both parent and health professional will often bring with them a degree of bias and prejudice about the likely impact of diet. The health professional might argue that they are better trained to evaluate the quality and relevance of scientific research papers. The parent might argue that they have more experience of how their child is affected by food. Sometimes they might even dare to suggest that they have read more of the research and are better informed than the health professional! The seeds of conflict can be quickly sown and if the relationship between the parents and health professionals break down, the child may be the one who suffers the most.

Traditional health professional/patient (or parent) relationships have been quite paternalistic in nature. The Health Professional has the expertise, decides what treatment is most appropriate, and prescribes this accordingly. The more progressive health professional accepts that patients and their parents or carers should be involved in decision making. It can be difficult to know where to stop however. If we are to ensure both the safety of the child, and the most effective use of limited resources, health professionals should not simply cave in to every demand. This would be a "consumerist" healthcare model which can be more dangerous and inequitable than a traditional one.

Rational, logical analysis has served health professionals and scientists well over the years. Health policy should be based on a rational assessment of all the evidence available. In order to do this, we have rules that govern what constitutes a good "level of evidence". For example, the incidence of strokes was once very high in Finland. Finnish is not extensively spoken in any other country. Analysis merely of the statistics might conclude than speaking Finnish is a cause of strokes. Common sense tells us that this is not very likely. If common sense is not enough, we can design a clinical trial to prove or disprove that speaking Finnish causes the incidence of strokes to rise. In this way, we can distinguish between a co-incidence (chance), a consistent correlation, and cause an effect (where speaking Finnish actually causes strokes). We used to think that, for example, eating cholesterol was a major cause of heart disease until clinical trials showed that this was not the case.

The "gold standard" for evidence comes from clinical trials that are "blinded" and "placebo controlled" with large subject numbers and treatment effects.

If several such clinical trials all point in the same direction, the intervention is likely to be recommended by groups such as NICE (National Institute for Clinical Excellence) or SIGN

(Scottish Intercollegiate Guideline Network). Indeed, guidelines on ASD and ADHD are published by such bodies and include, with varying degrees of rigour, an attempt to grapple with nutritional interventions.

Unfortunately, there are very few well designed trials on diet and ASD or ADHD. No wonder then that NICE and SIGN are hardly enthusiastic in their review of nutritional approaches. Let us leave aside for one moment, the specifics of ASD and ADHD. Commercial and practical constraints mean there are substantial barriers to nutrition research *per se*, with drugs trials being easier to fund and design than nutrient trials, and nutrient ones being easier than those involving real foods or whole diets. If we based our public health nutrition policy only on the analysis of blinded, placebo controlled trials, what would be recommending as the cornerstones of a healthy diet?

Real food already exists in nature. As such, it has very little patentable value and therefore research on its effect on health is not as attractive to would be funders when compared with drugs, supplements or "functional foods". It is also difficult to design a blinded study involving real food as the participant usually knows what they are eating! One can design a blinded placebo controlled trial of a specific substance, but what about whole foods? What about whole diets? The public health message becomes: "Don't bother with eating more fish, fruits and vegetables just eat more Benecol, and keep taking the drugs". The box below shows the 5 questions that, I believe, should be asked before a dietary intervention can be seriously considered:

5 questions to help evaluate the suitability of dietary intervention for ASD and ADHD

- 1. Are there *plausible mechanisms* through which the nutrient, food or diet might help?
- 2.Is there some evidence from clinical trials in favour of the nutrient, food or diet?
- 3.Is there evidence of marginal or excessive intakes at the population level?
- 4.Is the food, nutrient, or diet broadly consistent with "healthy eating" messages?
- 5. Are there *populations* who consume this nutrient, food or diet at this level, *without* obvious *harmful effects*?

For drugs and other medical interventions, only the first two questions are relevant. The other three questions can only be applied to diet. Some interventions will score more strongly on

some points more than others. In particular, question 3 is vital. There is evidence that, as a population, we eat far too much saturated, fat, added sugar and salt and not enough fruit, vegetables and oily fish. While the understanding of how this diet affects the brain is still in its infancy, we know if affects physical health. Is it plausible that the brain is not affected? Our default position – our assumption, unless there is clear evidence to the contrary, should be that we should strive to address this imbalance for each individual child with ASD or ADHD. The benefits may be physical, mental or cognitive; and noticeable in the short, medium or long term.

We should also briefly consider what we mean by "help children with ASD or ADHD". We are rightly suspicious of "therapists" who promise to "cure" Autism. Autism is not curable and many people with such a diagnosis would not want to be "cured" anyway. However, it is clear that children with an ASD or ADHD diagnosis are often more vulnerable to difficulties in mood, behaviour, learning and sleep. Those with a poor diet (more common in ASD) are also more vulnerable to long term diet related illness such as cancer, stroke, obesity and heart disease. Some researchers have suggested that metabolic differences mean a higher proportion of children with ASD or ADHD are more vulnerable to "oxidative stress". If this is true, it further adds to the importance of a good diet rich in "antioxidants" and nutrients that may be particularly prone to oxidation (such as omega 3 fats).

Applying these 5 questions, some specific dietary approaches stand out as being sensible, safe and possibly effective. These will, no doubt, change as further evidence accumulates. Those that I would currently recommend are shown at the end of this paper. These interventions should be considered as a menu of treatment options between health professional, parent and child. In doing so, we can have new health professional / parent relationship based on shared decision making, rather than the two extremes of paternalistic or consumerist models of healthcare.

There is considerable concern, by NHS health professionals about families seeking alternative sources of care and advice. However, if we can engage families in a sensible discussion about diet, health and wellbeing using these rules as a starting point, families would be less inclined to seek out these sources. There are some who will always be looking to go to the "next level", those who will leave "no stone unturned". However, my experience of working with families in Highland, tells me that the vast majority accept their child's diagnosis, and just want to ensure that their diet is as conducive to physical, mental and emotional good health as possible.

If the evidence about the impact of diet on brain function is rather weak and patchy, then we should be honest enough to say so. But families should feel encouraged and supported in their attempts to improve their child's diet. This is particularly important given that children with ASD or ADHD are often (but not always) at the poor end of an unhealthy modern food culture that is already less than healthy.

Health professionals should see the motivation of parents to find the right diet for their child as an opportunity, not a threat. It is obvious that parents of children who have a neuro-developmental diagnosis, will want to do everything they can to create the best possible conditions for good mood, behaviour and learning. Many will, therefore, have a healthy interest in diet and brain function. They will need support from well informed health professionals that can make general healthy eating guidelines relevant for their child. It is hoped that these rules provide a framework that enables health professionals to do just that.

A menu of dietary and nutritional recommendations for children with ASD and / or ADHD, with a view to safety, general healthy eating advice, and possible benefit in brain functioning

- Promotion of a "balanced diet" based on the 5 food groups as shown in the "Eatwell Plate"
- Eating regularly and not skipping breakfast
- Eating at least 5 potions of *fruit and vegetables* a day (for folate, magnesium, antioxidants in general and fibre)
- Reduction in soft drinks /confectionery containing specific artificial food colours / benzoate preservatives (added benefit of reducing empty calories)
- Consideration and possibly testing of *vitamin D* status with oral supplements for northerly latitudes, dark skin or indoor lifestyle
- Eating *oil rich fish* or taking omega 3 supplements
- For those with an inadequate diet, the use of a multi-purpose *vitamin and mineral supplement* where no ingredients exceed the reference nutrient intake
- Measurement of Ferritin stores and prescription of Iron supplements depending on results
- Ensuring the inclusion of *Iron and Zinc rich foods* or using supplements
- Consideration of *food intolerance*s to a range of foods through trial and error but only under the *supervision* of a State Registered Dietitian