

HFAC4 and THE CORE PROGRAMME – notes by David Hall.

[We need to consider the programme from the parents' point of view - "what should I expect to receive as part of this core programme".

*The first part of this paper is a proposal for the core programme. After the divider **** there is a reflective section asking commentators for their views.*

General principles:

1. There will be a universal or core programme available to all, plus additional services targeted to those who need them.
2. The professional qualification of the person(s) delivering this programme is less important than the quality of their training, audit and self-monitoring.
3. The content of the universal programme should be justified as far as possible by evidence of effectiveness
4. Nevertheless, parental views where known should be given due weight
5. The delivery of care should be based on what people need and what skills and resources are needed to meet those needs – rather than being based on traditional professional roles. If new skill combinations are needed, developing these must be the aim.

The **need** for a universal programme of preventive health care for all children is based on the following considerations:

- Some procedures, tests and items of information or primary prevention have a sufficiently sound evidence base and magnitude of benefit that they should be available to all children and families.
- Some families need more input or support than others in order to achieve equity of outcome but the identification of children and families needing additional services or support is only achievable if a core programme is universally available.
- There is no individual factor or set of risk factors that would allow sufficiently precise targeting of services to families with problems, and therefore it is necessary to establish the needs of each family.
- Services that are provided only to selected families have a high risk of becoming stigmatising and therefore of being rejected by the families
- It is not feasible or cost effective to provide high levels of health professional input to every pre-school child.
- Targeting more resources to more needy areas is the best way of addressing these dilemmas
- Public health work involving community wide initiatives may be the best way to help many families, but they rely on involving and recruiting individuals – it makes no sense to be selective in efforts designed to involve a whole community. Individual care and public health work are not options to choose between – they are inseparable.

Vulnerable children

One important duty of the child health programme is to identify, assess and manage children who are vulnerable in various ways and to support their families. These categories include:

- Disabled
- Having special educational needs
- Abused or neglected
- Looked After by the local authority
- Being fostered or awaiting adoption
- Homeless, refugees, asylum seekers and travellers.

Statutory duties are placed on the NHS to provide for these children. This is a responsibility that will have to be clearly allocated with the advent of PCTs. The aims of the core programme are firstly to prevent children developing these problems where they are preventable – and to identify then and refer them to the right service where they are not. Professor Polnay has been leading a group reviewing these issues.

The objectives of the universal or core programme are:

- To identify families who may benefit from additional support or services beyond the core programme and negotiate whatever is needed
- To ensure that all parents and children have access to and understanding of, all relevant health care messages that are evidence based and shown to be beneficial.
- To arrange and deliver immunisations.
- To carry out the agreed screening procedures.
- To enable parents with worries about their child to locate the help they need promptly and efficiently.
- To support the local community in creating an environment at home and at school in which the child can be safe, grow and thrive physically and emotionally.

Many families need more input than is specified in the core programme, and the package of care required by each should be negotiated individually

Details of the core programme

The objectives of **antenatal care** are: the identification and prevention of pregnancy complications; informing the parents about the birth and the options available, where appropriate; carrying out agreed screening and monitoring procedures; providing information about early baby care issues, in particular the benefits and technique of breast feeding; developing a relationship that will facilitate future professional and community support for the family; making a preliminary assessment of the likely needs of the family for advice, support and other services after the baby is born.

Immediately after the birth: initial examination of the infant for visible and obvious anomalies or signs of illness. This is most commonly done by the midwife and the parent(s) together.

Within 72 hours of birth: the parents should be interviewed and the baby examined. The consensus is that the target should be to complete this (a) within 24 hours of birth (b) before discharge from hospital. There is no firm evidence to support this view and staffing problems sometimes make this standard difficult to achieve, but this should be the goal. In practice, delay up to 72 hours sometimes occurs; provided that no concerns have been identified by the midwife or expressed by the parents, this may be considered acceptable in the short term. With training for staff and service planning we ought to strive to reduce this to 24 hours and we ought to specify the date by which we want to achieve this.

The aims of the newborn examination(s) and follow-up in the first days of life are: to review any problems arising or suspected from antenatal screening, the family history or the events of labour; to discuss matters such as baby care, feeding, vitamin K, hepatitis B vaccine, and any other matters relevant to that infant; to identify parents who might have major problems with their infant (for example substance abuse or mental health problems); to explain about the problems that might not be observable in the first few days but could emerge later (see below) and to examine the baby for anomalies or signs of illness (see page xx for details).

Hearing screening: (page xxx) currently universal neonatal hearing screening (UNHS) is being piloted in 20 sites around the UK. If successful this will become a countrywide programme. The pilot sites include some where screening will be done in the community. For those districts where UNHS is not yet available, many units are instead offering high-risk screening. Local policy should determine how high risk babies are identified.

Further follow-up of mother and baby: the midwife normally visits the family on several occasions within the first 10 days of the baby's life (though legally she is responsible up to 28 days). There is no fixed frequency of visits – some mothers may be seen twice in one day whereas others only once every two or three days. In addition to monitoring the mother's health and well-being, these visits provide an opportunity to observe the baby's health, feeding and progress. Where appropriate the baby should be weighed (see page xxx). Support for establishing breast feeding is important and a contribution to this can be made by lay workers (who with appropriate training might also assist with monitoring the baby's progress). In particular the baby should be observed for breathing and feeding problems that might suggest heart disease (page xxx); exceptional sleepiness which could suggest

infection or metabolic disorder; and jaundice (see page xxx). There is however no evidence to support a second complete physical examination for every baby in the first two weeks of life.

At seven days the blood spot for PKU and hypothyroidism screening is collected. To this will be added in due course haemoglobinopathy screening and (probably) CF screening. Extended biochemical screening may also be added to the programme in due course.

It is usual for the health visitor to visit at around **ten days of age** and take over care from the midwife. There may be one or several more visits depending on need but this should be regarded as negotiable. Changes in the respective roles of midwife and health visitor might increase the efficiency of the service; for instance, the midwife might continue her role for longer than has usually been the case in the UK.

Review at 4 – 8 weeks: in the previous edition of the programme we described this as occurring at 6 to 8 weeks. This coincides with the first vaccine dose in the current UK schedule of immunisation and, for those mothers and GPs who so wish, it can be combined with the postnatal examination, at which physical health, contraception, depression etc can be discussed as appropriate. At 8 weeks of age, the baby should be showing a range of behaviours including smiling and visual following; heart murmurs may be more readily detectable; testes are more likely to be descended; and the commonly used scale for detecting maternal postnatal depression is standardised for this age. Weight, head circumference and a full physical examination are required.

There are on the other hand advantages in an earlier examination – there is a consensus that the outcomes for CDH and cataracts may be better if they are detected and treated before 6 weeks, and the same may also be true for jaundice due to biliary atresia. However, there is also much concern that if this examination were to be brought forward, perhaps to four weeks, parents who attended the health centre for this examination might be less likely to attend again for immunisation at 8 weeks. A decline in immunisation rates has potentially more serious public health consequences than a largely theoretical reduction in good outcomes for treatment of CDH and cataract and we are at this time reluctant to change to a routine four week check.

The problem could be overcome if midwives or health visitors examined the baby at home, having learned to carry out procedures traditionally only performed by doctors – in particular, auscultation of the heart and examination of the cardiovascular system, check of CDH and looking for the red reflex to exclude cataracts. While this is achievable, we anticipate that it will take considerable time and effort and suggest that its practicality should be examined and a training plan developed to put this in place over the next few years.

We recommend that the current approach be continued until such time as this can be done. In view of the concerns about delayed treatment of cataract, CDH and biliary atresia, we recommend that the examination still be described as taking place at 6 – 8 weeks, because in practice it is often delayed until 11 weeks or later for various reasons. The aim should be to complete this examination in all babies *by* 8 weeks of age. Any baby in whom there is suspicion of the problems listed, resulting from a check at 6-8 weeks, must be referred as a matter of urgency.

At age three and four months, the second and third doses of vaccine are given. The baby is weighed.

The 1996 programme included **three further contacts** – at 8 months, 18-24 months and 42-48 months. These remain as fixed points in the programme but as there are no formal screening or health promotion measures that must be provided at these ages, the nature of the contact is more flexible.

As a minimum, the aims are two-fold. The first is to ensure that the parents have no worries, the baby is growing normally and is in good health and that development and behaviour are within normal limits. The second is to summarise key data about each child for the public health dataset.

For many families these goals can be achieved without an additional face to face contact. Some families may already be receiving frequent support for various reasons, whether from the health visitor or other professionals or from a programme like SureStart. Some will be frequent attenders at the health centre and will be well known to the GP and the health visitor. Some parents, particularly those who have already had a previous child, may not feel that they need any further formal reviews.

Accordingly, we recommend that after the third dose of vaccine at four months, the health visitor should negotiate the nature of any further reviews with the parents. There will be some children about whom the primary care team may have insufficient recent knowledge to “sign off” the two or four year summaries and these children would need to be seen and reviewed.

Further doses of vaccine are given at 12-15 months (MMR) and at 3-4 years (booster). The baby should be weighed at the same time as the MMR vaccine is given and the parent invited to express any concerns. At 3 – 4 years, the opportunity may be taken to review the child if needed as specified in the previous paragraph. Our recommendations are that the height and weight should be measured at around the age of five, at school entry, but if staff shortages or other local problems prevent this from being done or if there is any earlier concern about the child’s growth or health, this should also be checked in the health centre at the same time as the vaccine and / or review .

Vision check Formal screening for vision defects should not be undertaken on a community wide basis before four years of age. Screening of the vision of all children should be undertaken by an orthoptist with the aim of achieving this by the age of five years. The role of photorefractive lenses should be re-considered.

School entry when the child starts formal schooling (around the age of five) the following should be done: height and weight; hearing test (under review); review of records by school nursing team to identify children who had not received pre-school health care, especially immunisations and vision check. Children not on the list of any primary health care team are a priority and the aim should be to secure their primary health care needs rather than merely to carry out a single health review. Meeting the child and parents, either as individuals or in a group setting, is important to establish a relationship with parents and to explain how the school health service can help each child.

After school entry, there are no formal universal routine procedures except for: immunisation programmes where indicated; vision check at age 11 (under review); information transfer procedures for the core dataset.

Health promotion All pre-school children and their families have access to a health promotion programme. This includes antenatal information and care; early support after childbirth with particular reference to breast feeding; information and guidance about issues where the evidence supports universal intervention – vitamin K, reducing the risk of SIDS, recognising and managing depression, handling babies including the risks of shaking; this information can be in the form of written material in the PCHR and the 0-5 book but may need to be explained as well (for mothers with low literacy and those whose first language is not English); information about local networks and services, and the question of confidentiality and data handling; free and straightforward access to a health visitor and other members of a primary health care team. All families can request and negotiate additional help, advice and support as needed.

In school, all children have access to a health team providing health support and health promotion programmes with the following elements:

- Information and guidance to teachers regarding any special health care needs or medication, with additional input from school nurses, specialist nurses or other health professionals as needed
- A health professional who is able and willing to listen to a child’s concerns in confidence and take appropriate action
- A Healthy Schools environment that addresses diet and exercise, bullying, emotional literacy, civic responsibility etc.
- Parental access to the team for information and discussion
- Guidance, preparation and support for the transfer from junior to secondary school
- For older children and teenagers, access to confidential health care in settings acceptable to the users and relevant to local conditions.

These Health Promotion measures apply equally to children in all mainstream schools, special schools, pupils out of school for any reason, and independent or private schools.

Records and data

The Personal Child Health Record (PCHR) is being reviewed by a group chaired by Dr Helen Bedford. Systematic evidence is being gathered about current practice. Proposals for updating the record and adopting a common policy will be put forward. For reasons of economy, equity and simplicity, the ideal is for all districts to use a similar format even though they may wish to add local information relevant to the area or to local problems.

The Child Health Informatics Consortium chaired by Professor Brent Taylor has compiled a core public health data set and the aim is to integrate this with the PCHR. The advent of electronic record systems will greatly simplify data capture and analysis.

For debate:

We suggest that the evidence is quite sufficient for us to de-emphasise developmental screening in any formal way. However, the question is how far we ought to go in suggesting that (a) contacts at 8m, 2y and 4y need not necessarily be face to face. Should we aim to see everyone at these ages?

The reality is that coverage has never been anywhere near 100% in the UK, though it has in Scandinavia. To expect that we could now achieve 100%, when we did not do so in the era when the central role of individual routine checks was the doctrine is wishful thinking – especially as some areas are reporting 40% of HV vacancies unfilled and there are areas where general practice vacancies are not far short of that figure. Furthermore the evidence is weak as to the benefits of routine checks for either physical disorders or developmental problems.

On the other hand, some may find it hard to swallow a programme which offers no universal health check of any kind to children after 8 weeks of age. We are already out on a limb compared to most Westernised countries who have far more checks than we do. I would happily defend our reduced programme compared to, say, the USA – but can we defend a programme in which we offer no universal health check whatsoever after the age of 8 weeks? Some may feel intuitively that this is unwise; others will point to the lack of evidence of benefit and the possibility of doing harm by unsolicited advice.

If we ask primary health care teams to complete a public health report form, brief though it is, essentially saying that *as far as they know* the child is well physically and developmentally, will they be happy to do so without being sure that they have seen the child in a setting where they would have some hope of identifying any problems?

What might be the benefits to be gained from a universal contact at 8m, 2y and 4y?

The first at 8m would be done in the health centre in most cases. It would offer a chance to weigh the baby if the mother wished – while we remain sceptical in general about weighing on a regular basis, and think we have much more to learn about failure to thrive, a weight at 8m would certainly be welcomed by many HVs and parents. The Coventry consensus struggled with the pros and cons of weighing in the light of the debate about FTT. The notion of weights at immunisation visits and at 8m seemed acceptable to most people.

At 2y we have always said that it ought to be an HV review, preferably at home, and the main issues here are developmental, behavioural and educational. Although we doubt the value of formal developmental screening for all children, it is generally agreed by clinicians that many parents use this review as a way of discussing their concerns and then they decide to act and get a referral – in such cases their concerns are often well founded. Given the accumulating evidence of benefits from pre-school language and literacy, the contact would also be valuable for informing parents. However, it would be quite reasonable to be somewhat discriminating in this review – *offer it* to all parents but expect that many would turn down the offer.

At 3.5 to 4 years, the precise age being not very important, the justification for a review might be first that in the absence of any formal school health examinations (which have been discontinued in most

places) this is an opportunity to identify any previously missed physical disorders such as undescended testes, heart murmurs or other more unusual problems. It is quite clear that such procedures are most unlikely to pass scrutiny as screening tests. Neither the screening “test” (physical examination), the yield, the importance of the conditions, or the benefits from finding and treating them, would meet current rigorous standards for screening. Secondly, most children with developmental problems would have been identified in playgroup or pre-school by this age, but a few parents may have unresolved worries or have been missed for one reason or another. And some may have had difficulty facing up to their fears. As formal schooling gets nearer they may be forced to accept that the child might have special needs. Again, there is no place here for any formal screening – just careful listening and observation.

A strictly logical analysis could therefore easily dispose of the case for any such review. Yet some people feel uneasy about this. It is after all the GPs who will have to deliver this if it is recommended - and they will carry the can if we decide against it and parents then complain that things have been missed. There is also the real concern that if one offers a review that purports to identify any previously missed problems, but cannot guarantee to find them all, one is actually just deceiving the parents and might be even more likely to receive complaints if something is missed.

Based more on a perception of what parents might say if we asked them (even if they were in possession of all the facts) one might argue that it would be wise to offer a health and development review to parents at this age. If they choose not to accept it that is fine – it is not like a screening programme where you should not even embark on it unless you believe that it justifies striving for 100% coverage. Parents can be told that it is a review and a chance for them to raise any concerns – but still warned that nothing is infallible and that they should always return if new concerns emerge, rather than assuming the child is guaranteed perfect.

Since what little evidence we have is that the *measurable benefits* are slim for any such procedure, it becomes a highly pragmatic decision.

The working party has come to its own tentative conclusions but is keen to hear a range of views!

David Hall, 14.06.01