Submission to the SEN Green Paper on behalf of He-special

June 30th, 2011

He-special.org.uk (www.he-special.org.uk) is a long standing website and email list offering support for parents and carers who are, or are thinking of, electively home educating children with a wide range of special educational needs and disabilities, including genetic conditions such as Down Syndrome, congenital conditions such as Cerebral Palsy, Autistic Spectrum Conditions, acquired brain injury, Hypermobility Syndrome, and specific and general learning difficulties such as dyslexia, dyspraxia, speech and language disorders, and delayed development. This list is not exhaustive. It should also be noted that many children that have more than one condition.

This submission is based on the experiences of several parents. As there is only one thing that brings these families together, that is that they home educate, their needs are all different and, at times, views can be opposing.

Not every question has been answered, and we believe that there were additional questions that should have been asked so have added additional material.

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Question 1: How can we strengthen the identification of SEN and impairments in the early years, and support for children with them?

First and foremost is that the parents must be involved and must be taken seriously. All parents will have a clearer understanding of their child and their needs than a professional who may have only assessed the child briefly in an environment unfamiliar to the child. This can be a particular problem for children with 'hidden disabilities', such as developmental disorders, and others that result in behavioural problems. Currently there is a tendency to assume that the child's problem is due to parenting issues, or that they are just a little slow at developing, and the important years are lost. Parents must be an equal part of the team.

There is also a tendency to rely too much on a label and not enough on the actual child, as well as disregarding some diagnoses and concentrating on just one, despite overlapping issues. Some of our members have had other needs of their children ignored just because there are no services available for the core diagnosis. For example, this can happen when the core diagnosis is an Autistic Spectrum Condition (ASC) and the child has co-morbid conditions. It can also happen when the parents of children with conditions such as Down Syndrome are told that there is no point in providing services as they will never achieve anything anyway. Many children with congenital or genetic disorders, such as Down Syndrome or Fragile X, also have an ASC but parents find that the first or most obvious diagnosis takes dominance and it is difficult to get health or education professionals to address the other difficulties.

For Elective Home Educators (EHEers) there is also the reality that these children may well not be found in early years settings as the parents have decided to home educate either before the birth of their children or soon after, or have been home educating their older children. For them, identification of needs will be done through health services not the education service. This means that there must be support for the parents outside of traditional early years settings. There should not be an assumption that all young children are in childcare and there should be a way for parents to seek assessment and support services outside of a school setting.

For some families, it can take years to get an appropriate diagnosis and services, if available at all, are withheld until they have a diagnosis. Sometimes, parents go through the process of diagnosis only to find that there are no services available. For any new system to work, it must be centred on the child and their needs, not on whether or not they have a diagnosis as many families are left without a formal diagnosis for several years. For children with SEND, those needs often start from birth, with problems with breastfeeding and sleep. Despite lack of an early diagnosis, there should be support for those families if required, but families should not be forced to accept support if they make an informed choice to make their own arrangements.

There is an issue with services not being available. The services available are different from area to area, which is not just frustrating for families who miss out on something that is available to others in a different part of the country, but also makes it difficult when people move. There should be a national minimum acceptable level of services.

There is also currently a problem in change of staff from midwife to health visitor to school nursing service, where a child is passed off to become 'someone else's problem' and there is no continuity of care. This can be avoided by having a key worker, which could be a member of the health or social or educational service, but equally could be a parent if they so wished. This is particularly useful for EHEers as they see their children in all situations, both in social and educational areas. EHEers may not have all the answers but they should be respected as knowing their child best and should be trusted where possible to keep track of their child's progress; they should also be able to request further involvement where necessary.

Question 2: Do you agree with our proposal to replace the statement of SEN and learning difficulty assessment for children and young people with a single statutory assessment process and an ‘Education, Health and Care Plan’, bringing together all services across education, health and social care?

Yes, in principle, but some of our members feel that they don't have a clear enough idea of how this would work and the success or failure will be in the detail.

There must be safeguards for home educated children, who are less likely to either have or need a statement but may still have health or social care needs. There will also be situations where some children have no requirement for health or social care and some children that have need of health services but not educational services.

Many home educating families find that there is a lack of trust and co-operation between services. Even within the same department, different members of staff can have different ideas and can insist on re-doing assessments for their own base line. Children's Services has yet to master working together and there is still a strong 'them and us' attitude between services and parents.

It will take a huge change in attitude to make this work and, if there is no legal protection as there currently is with statements, many children and their families will fall between the cracks of the system.

There are also concerns that a single assessment will not cut down on the number of people that children have to see. Presumably the child will still need a diagnosis before proceeding to the assessment and, as previously stated, many children fall at this point as a diagnosis is not forthcoming. Currently in many areas, if you don't have a diagnosis then the LA refuses to assess the child to see what help they need.

Some parents have found that low expectations of their children mean that referrals to services such as occupational therapy and physiotherapy are not forthcoming because they think the child is 'coping' or is doing 'well enough for their condition'. This will have to be addressed in any new system, to make sure that expectations are as high as possible for each individual child.

There is also a problem in assessments where therapists do not recommend anything that they know they cannot supply, whether because of financial or staffing constraints, regardless of whether or not it would be useful to the child. This can be a problem in particular for EHEers as the parents would often provide therapy themselves at home, if only they were informed of what to do, at very little extra cost to the family or the LA.

Parents must be able to take part fully in the new system if they so desire, and their input must be treated equally to that of other professionals. Professionals should be discouraged from the current common practice of holding preliminary meetings where everyone except the parent is there, rendering the main meeting pointless and doubling the overall cost. The parents should be included from the onset.

Question 3: How could the new single assessment process and 'Education, Health and Care Plan' better support children's needs, be a better process for families and represent a more cost-effective approach for services?

It could stop some duplication of multiple assessments, but that won't necessarily cut costs. Whether a child sees all the therapists one at a time or together, they still have to see them all and a single assessment could end up taking too long and tiring a child out.

There is nothing at the moment to stop multiple assessments if one professional takes notice of previous assessments. If a child is seeing a relevant specialist then other less knowledgeable professionals should not duplicate those particular assessments.

It won't be possible to train people up to be able to assess all aspects of a child's life, especially if they have multiple disabilities. Although it would be possible to have a single assessment where further assessments would be recommended, many children will still have to have multiple appointments to assess needs with various experts.

There will still be a requirement for experts in each area to diagnose the child, so the reality of a single assessment in many cases wouldn't actually cut down on the number of assessments or appointments a child would need.

Question 4: What processes or assessments should be incorporated within the proposed single assessment process and 'Education, Health and Care Plan'?

This would entirely depend on the child and their SEND. The assessments should not just be based on diagnosis, but also on parent's feedback. As previously mentioned, many children have multiple diagnoses and often people dwell on the one that they think is most important, ignoring the rest. Equally some children won't have any formal diagnosis at all.

Unasked Question: Sharing of information.

Currently if a child has never been to school, there is no reason in law for parents to inform the LA that they are home educating a child. These children are 'unknown' home educators, in that the LA EHE department does not involve themselves with them. Many families are happy with this situation and, despite being unknown by the LA, they still receive services from health and social care.

Some EHEers are concerned that a joint assessment will mean that they become 'known' by the EHE department resulting in an increase of intrusion into their lives. This would not be acceptable to many families and could dissuade them from seeking out other services, in order to avoid unwanted involvement with the EHE department.

Unasked Question: How will the Education, Health and Care Plan affect Elective Home Educators?

Currently where a child has a statement of SEN and is home educated, the statement continues to be annually reviewed even when the LA is not providing anything laid out in part 3. It is well established by the DfE that parents who Electively Home Educate do not have to deliver an education as set out in the statement, and there is no legal duty for the parent to do so. Except in rare instances where the LA does provide something in the statement, many EHEers find that statements are more trouble than they are worth.

Some EHEers feel that the statement is of no practical value while home educating, however they do not wish it to 'cease to be maintained' in case it is needed again in the future. Some of our members have suggested that, once the council has been satisfied that the child's needs are being met outside the system, the statement could be classed as being on hold, saving money and everyone's precious time, unless the council has reason to believe that the situation has changed or the parents wish to use it. This would relieve the LA from having to maintain the statement annually.

Because the LA is able to avoid providing some things in a statement for children when they are home educated, there is a concern that this problem will be exacerbated when the replacement for the statement also includes health and care plans. Any future changes to the current system of statements must take into consideration that some children will be Electively Home Educated and that there will need to be a funding path to allow for those children to be able to access all aspects of the Education, Health and Care Plan. There will need to be a mechanism to make sure that LAs can't refuse to meet the needs of the child just because they are electively home educated.

Question 6: What role should the voluntary and community sector play in the statutory assessment of children and young people with SEN or who are disabled? How could this help to give parents greater confidence in the statutory assessment process?

Some members feel that there should definitely be a separation between the assessor and the deliverer, but the voluntary sector shouldn't necessarily perform either of those roles. There is no doubt that the current system is abused by the LAs having control over both parts, and there is evidence of pressure from the LA upon health authorities to remove or change a diagnosis, or arbitrarily restrict how much therapy or support a child gets according to their primary diagnosis. It would work better if all health assessments were done through one agency, and all deliverance done through another, and the volunteer sector could do the support work, informing parents of procedures, what to do when it goes wrong and helping with appointments and assessments.

Other members disagree and feel that having an assessment and then someone else deliver means a new level of decision making that will slow things down. LAs will still have to manage their budget, there are still going to be cuts, and that means that parents will get assessments recommending things that there is not money to provide. This will either create a need for a meeting to resolve this, or budgets will run out and some people will get nothing. There is a worry that this would lead to more expense, longer waits and people being lost between two services, or being assessed for something and being told by the provider that they don't provide it.

There is also concern that the voluntary sector cannot guarantee support. Many charities are currently at crisis point because of the financial situation. Although there are some large national charities that people depend on, there is no guarantee that even they will be able to carry on supporting families. The voluntary and community sector is a postcode lottery so for them to have a serious role in the new set up they would have to be consistent throughout the country.

Question 7: How could the proposed single assessment process and ‘Education, Health and Care Plan’ improve continuity of social care support for disabled children?

Currently funding is split between between Social Services and the NHS. Many families are told they should access services through the other service but the other service refuses and sends the family back to the first service and in the end they get nothing. Having a plan that is controlled from outside the departments should stop this happening.

The single assessment rather than an initial and core assessment sounds good, but there is a danger that unless it is truly flexible it will result in Children's Services just combining the two assessments into a single much longer assessment. At the moment, separate teams usually do the core assessments under section 17 or section 47. If initial and core assessments are to be combined into one, then there will have to be a huge amount of training for all social workers to be conversant in both child protection and disability. This training would have to be done before the new system is rolled out. Just reading questions and putting answers down is not good enough for a section 17 assessment.

There is lack of training even within the disability teams in Social Care at the moment, so before any of this can be rolled out there will have to be substantial training for all those doing assessments for both safeguarding children and disability support.

Question 8: How could the arrangements for provision of health advice for existing statutory SEN assessments be improved?

More paediatricians, SEND specialist health visitors, and other trained staff are needed. Teachers must accept that they are not trained in medical problems and accept advice from medically trained personnel and parents.

Delays are also caused when GPs are involved as they often don't see the importance of being timely or maybe are just too busy or they have receptionists that don't pass information on. Health visitors often don't have time to meet with all families. The new arrangements for GP consortia to provide services is a worry as they too will have to have confidence that they understand a wide variety of disabilities and SEN, which at the moment they don't.

Health professionals should provide information about the implications of the child's disability, the impact of their motor skills on their day to day lives, the expected improvements, the equipment that could make life manageable as well as the equipment and therapy that might lead to improvement. The implications any medical conditions on behaviours and the need for rest should be conveyed so that that these things can be properly incorporated. Expertise should be fully shared with other professionals working with the child to allow information about how therapy can be built into daily life or play activities so that the child receives the correct support in between therapy sessions.

Question 9: How can we make the current SEN statutory assessment process faster and less burdensome for parents?

The only time limiting factors should be waiting for reports. Once the reports are in it should only take a single meeting. It currently takes far too long to do this; while the adults are messing about with time limits, children are suffering without support. They don't suddenly need support after an assessment, they clearly need support or the assessment would not have been suggested. Not only should these time scales be drastically reduced, support should be put in place in parallel to the assessments rather than waiting for the end of the time line.

Sometimes deadlines are used as a date to aim for, rather than the last possible date allowed. Assessments should be done as soon as possible, not allowed to drag on until the end date.

However some members feel that if time limits are shortened too much it could make it difficult for professionals to find a suitable time to visit a family and could lead to rushed assessments or deadlines missed when children are ill.

Question 10: What should be the key components of a locally published offer of available support for parents?

Whatever it is it needs to be available to parents who electively home educate so there needs to be flexibility in the system to make the information available to EHEers too, through the EHE departments of the LA, as well as though other agencies, both government and volunteer. Information about Elective Home Education should also be available to all parents, including parents of pre-school children.

Local Authorities should be tasked with keeping information updated on websites and making sure that all information available is as current as possible. The information should include state support available in and out of school, support groups for specific disabilities, accessible play areas, after school and holiday clubs, respite care services and universal services that are able to offer support to families with SEND and any other information of use to parents.

Support should be delivered on a timely basis so that the child receives it when they require it, not when they get to the top of the waiting list.

It could also be used to externally assess the Council's standard of provision.

Question 12: What do you think an optional personal budget for families should cover?

This should cover things that are not done more efficiently in group settings. For instance, if a child is in a school that provides physiotherapy then it is more cost efficient for that equipment to be supplied for the use of the group, whereas for a child who is home educated that same equipment would be better provided through a personal budget.

It should not be assumed that parents can use DLA or PIP to pay for these items as the DLA pot of money is not infinite.

There needs to be a huge range of support available for the parents to choose from. From past experience it can be hard to persuade some people that certain therapies or support is useful. If the range of support is too prescriptive it will become like a restricted shopping list rather than a way of meeting the individual needs of the child.

There may also be a problem that even though the money is available directly to the parents they may not be able to either arrange or fund it out of the money. For instance, currently it is not uncommon for people with direct funding from social services to find that they can't find anyone to work for them. Equipment is often very expensive because providers think that LAs will be paying for it therefore they can charge what they like. Some equipment, such as orthotics, is only available on a prescription, so personal budgets will still involve the parents working closely with therapists and teachers.

Intensive Applied Behaviour Analysis Programmes (ABA) and other programmes should be available to children both in school and those that are electively home educated, especially where an ABA or other programme has been started in a school, and subsequently the child is de-registered.

Question 13: In what ways do you think the option of a personal budget for services identified in the proposed ‘Education, Health and Care Plan’ will support parents to get a package of support for their child that meets their needs?

A support package has a huge number of different aspects and it should not be looked at in narrow terms of what is traditionally available from the council. Parents should have a choice of what works best for their family. This might be someone to come into the home to mind the children or someone to take a child out so that the parents can spend more time with other children. Having available activities for the child to be taken to is important. Some parents find that activities arranged for the children are completely unsuitable their child's specific disability. When they point this out, they are told that the council can only provide activities for which they can get outside funding. Some parents have found that even after they have secured services funding is withdrawn and so are the services.

Trained personnel are required to deliver services. Often children are de-registered from school because they have disabilities that are difficult for other people to manage and it is therefore inappropriate to expect the child to be away from the family. It can be difficult to get carers who can sign, or deal with medical needs.

Some home educators would also like to access the same sort of services that are available for children at school, such as field trips, text books, tutoring or sport. However other EHEers feel that they would not like this kind of support as they worry that there may be strings attached resulting in unwanted interference with family life, such as monitoring and testing of the child.

Parent forums: There seems to be an assumption about what parents want. Experience of forums is that if your face fits, you get on, but if your child isn't the stereotypical child then what you suggest will be overlooked at best, or you might be told you are not suitable for the forum. They can also be very difficult to get to and it can be difficult to arrange child care.

Short breaks and Respite Care

It seems to be assumed that all parents want short breaks from their children and that all children want to play football, swim or go shopping. Some parents and children don't want to be separated and would find short breaks totally useless. Some of the activities on offer are not appropriate for some children because of their disabilities. Parents have been told that other more appropriate activities are not available due to funding.

Some children would be too traumatised by having to stay somewhere other than the family home, even if only during the day. For these families, the offer of someone to come into the home would be more appreciated than the offer of a short break outside the home.

Parents and children need genuine choice, not a choice of a predetermined selection. Many of the services that EHEers would like would actually be cheaper to provide than short breaks.

Having said that, there are also EHEers that would appreciate respite care as they do have to spend far more time with their children than those that send them to school. Currently some EHEers are told that if they want a break from their children they should send them to school, which is an unacceptable attitude.

Question 14: Do you feel that the statutory guidance on inclusion and school choice, Inclusive Schooling, allows appropriately for parental preferences for either a mainstream or special school?

To truly have inclusive schooling we need to have a wider range of schools. No amount of statutory guidance will help if the appropriate school is not there in the first place.

In some areas, there is only one type of special school, such as ASD schools, or special schools that try to cater for all SEND. Parents find this unacceptable as their children's needs are not specifically met. There should be an increase in the types of school available.

In mainstream schools, attitudes need to change. SEND children are often seen as a nuisance or are used as an extra pair of hands in the class. There is nothing to encourage teachers to get involved with the child, and it can be left to untrained assistants who are not qualified to help teenagers.

Different guidelines, different funding and a bit of training is not going to make any difference. Proper disciplinary action against education staff who deliberately flout their duties or ignore the statement will be needed.

Special schools usually only cater for children of lower intelligence. There are children who are very bright but have an uneven profile, resulting in SEN, which is not catered for in special schools or mainstream schools. This is one of the reasons why families feel that they have no choice but to electively home educate.

Question 15: How can we improve information about school choice for parents of children with a statement of SEN, or new 'Education, Health and Care Plan'?

Information should also include information about EHE. It should be given to all parents of preschool children and be available at any time for all parents of school age children.

The information should include outcomes for SEND children from schools with details of levels of SEN to rule out minor problems, for instance how many MLD children left early and where they went – special, EHE or mainstream – how many have been held back a year to avoid SATS.

Question 18: How can we ensure that the expertise of special schools, and mainstream schools with excellent SEN practice, is harnessed and spread through Teaching Schools partnerships?

Although learning from each other can be effective, there is also a danger that incorrect or inappropriate information can be passed on. This is particularly noticeable with more complex disabilities as there are so many variations and teachers will tell a parent that they know what they are doing just because they have gone on a training day with someone who has had experience with just one or two other children.

Sometimes there are people who can been seen as experts locally but they are actually ignorant from a national or international point of view. There is a need for specialist staff who keep up with current research and disseminate it to all teachers.

Question 21: What is the best way to identify and develop the potential of teachers and staff to best support disabled children or children with a wide range of SEN?

It should be remembered that there needs to be an attitude towards SEND children which cannot be taught. Some staff feel that the children shouldn't even be at the school. There is no amount of teaching that will improve a person if they just don't 'get it'.

By the same token, there are some people that just don't need any training as they instinctively get SEND. Many families find that they end up EHEing because the teachers at schools, although they have been on training courses, do not have the attitude towards individual children.

Parents should be able to have a say in who works well with their child and who doesn't, and the head of the school should take notice of this. Someone who is wrong for working with SEND won't improve with more training.

This training should be extended to EHE officers in the LA; at the moment many of them have little understanding of SEND. SEND officers should also have training in EHE.

Question 24: How helpful is the current category of BESD in identifying the underlying needs of children with emotional and social difficulties?

Children with communication difficulties including ASD often get caught up in BESD. The category of BESD should be reserved for children with BESD – ASD should be excluded first. It is not uncommon for ASD children whose needs are not being met to present as if they have BESD. To treat them as being BESD will be to make things worse. This is one of the reasons why some families choose to home educate; their children are not BESD even though they show some of the same behaviours.

Question 25: Is the BESD label overused in terms of describing behaviour problems rather than leading to an assessment of underlying difficulties?

Yes, it can be overused when it is used to describe ASD children or as a quick answer without looking for deeper causes.

Question 28: What are the ways in which special Academies can work in partnership with other mainstream and special schools and Academies, and other services, in order to improve the quality of provision for pupils with SEN and disabilities?

Often parents who home educate find it difficult to tap into expertise especially when they come across a difficulty that they don't know how to handle. EHEers should be able to contact a special school or Academy through their EHE officer in order to get support or information about educational matters that affect their child. This should not require registration at the school nor should there be any comeback on the family if they find that the advice offered is not suitable and decide not to take it up.

Families who are unknown to the EHE department should be able to tap into expertise directly within the school, rather than having to go through the EHE department.

Question 29: What are the barriers to special Academies becoming centres of excellence and specialist expertise that serve a wider, regional community and how can these be overcome?

Getting the information to EHE families can be difficult especially when a child has been at a school that has failed them. The child and parent may mistrust any contact with schools or the LA. It might be better that the voluntary sector act as a go-between, informing the parents of what is available.

Question 30: What might the impact be of opening up the system to provide places for non-statemented children with SEN in special Free Schools?

Special free schools shouldn't need statements for the child, if the child is suitable for the school then they should get a place. It would be good to have a wider variety of special schools, particularly as many special schools are for low-functioning children only. There are children who have normal intelligence but have learning difficulties and there are few schools that cater for them. This is one of the reasons why some families choose to home educate.

Question 31: Do you agree with our proposed approach for demonstrating the progress of low attaining pupils in performance tables?

Indicators, not targets.

It is really important that indicators do not turn into targets. It would be a good idea to have indicators of how well schools are doing with their bottom 20% of pupils, but if those indicators are turned into targets by expecting the school's indicators to improve year on year then teachers and schools will end up manipulating the child's behaviour in order to meet the targets.

It is also important to understand that these indicators are for schools, not individual children, and therefore should never be applied to home educated children.

Question 32: What information would help parents, governors and others, including Ofsted, assess how effectively schools support disabled children and children with SEN?

Again it is indicators that are needed not targets. It is important to make sure that parents find out a lot more about the schools than just how much the schools have improved. They need to know that the schools take each child and meet their needs, not meet the needs of the system.

It is also important to look at the wider picture of how the children and the school interact and whether children settle and stay in the school or are moved on to other schools or into EHE.

Parents would have more confidence in assessments of the schools if they knew that other parents' opinion of the schools were available and part of the assessment.

Question 33: What more can education and training providers do to ensure that

disabled young people and young people with SEN are able to participate in education or training post-16?

It is important that EHEed children also get a chance to tap into post-16 services. It is not unusual to find HEed children going to college at age 16, and they need to have the information and support for assessments to enable them to get support. It is possible that these children, having been out of the system, will not have a statement.

It must also be recognised that some SEN children are very bright and more suited to academic work, but also that some children will never be in a position to be independent in training, education or life. The right courses and help or assistance should be available for all children regardless of level of achievement. For those who wish to sit formal exams but aren’t up to ‘normal’ ones the choice is very limited with fewer colleges providing alternative courses.

Question 34: When disabled young people and young people with SEN choose to move directly from school or college into the world of work, how can we make sure this is well planned and who is best placed to support them?

It is important that the person who knows the child best is involved. This may well be a parent. Just because a parent is involved does not mean that the child is not independent of the parent. The parent may well still know what's best for the adult child and may well need to be extensively involved in order to translate or help the young person's understanding of what is happening.

In many EHE families, there is a closeness between the parents and the children that is less commonly found in schooled teenagers. This is not an indication of lack of independence, and to expect the parent to stand down at this point can be detrimental to both the young person and the family. In some cases, it is the parent who is best placed to support the young person.

Question 35: Do you agree that supported internships would provide young people for whom an apprenticeship may not be a realistic aim with meaningful work opportunities? How might they work best?

Internships are generally considered to be something that the person does for free, like voluntary work. It is insulting to think that SEND young people would be expected to do this. Either they are in a paid position, or not, and if not, they they shouldn't be doing the work.

It is also important that any funding for positions for SEND young people continue. There have been cases of young people losing their jobs when funding finishes, even though they were good at their jobs.

Apprenticeships are meant to be a route to employment, not just funded labour for a company. However, if apprenticeships are to be made available then this information should be passed on through the EHE department and arrangements should be made available to those EHE families that wish to tap into this service and support.

Question 36: How can employers be encouraged to offer constructive work experience and job opportunities to disabled young people and young people with SEN?

Some of the barriers in health and safety and tax should be removed so that employers have a freer ability to take on SEND young people.

It must be possible to find ways to encourage take-up of SEND employment. Employers need to see it as a social responsibility, encouraged for example through tax incentives. Over time, SEND will become more accepted (just like the idea of inclusive education!) and not seen as such a problem. Lack of knowledge can result in fear of the unknown, so employers take the safe bet, which isn’t the SEND candidate.

Unasked Question: Where is the support for those that are disabled but wish to pursue an academic or research position?

There is an assumption that SEND young people are of low IQ. This isn't true. There are young people who are physically disabled but who are academically able. There needs to be support at university level from health care services for those who wish to pursue a more academic career.

Question 37: How do you think joint working across children’s and adult health services for young people aged 16 to 25 could be improved?

For a start, people could just listen and stop putting an artificial barrier of age in place. A person doesn't magically change because they are 24 hours older. A young person should move on only when it is necessary. For instance some children at age 14 would benefit from adult physiotherapy services, others at age 20 would benefit from a more juvenile style of physiotherapy. A GP should always be at the heart of the health care. Consultants such as cardiologists or neurologists should either be able to deal with all ages, or hand on when they feel that their expertise with younger people is at an end and that a different consultant is required. Age shouldn't come into it at all, as it isn't the system that is important but the person.

Many families that home educate find that, because they didn't have access to services when their children were younger, they have even less access to adult services. There may be a case for extra support and information to be available for those families that choose EHE when their children are older.

However, if these services are refused that should not be taken as an indication that the family is not meeting the needs of the young person or is wasting people's time. Some EHE families find that, once they enquire about services available, they are swept along regardless of whether there is any benefit from the services.

It should also be understood that some conditions are variable and young people may find that their requirements change over time. They should be able to stay registered for services and not lose them just because they don't need them at a specific time.

Question 43: What would be the most appropriate indicators to include in the NHS and public health outcomes frameworks in the future to allow us to measure

outcomes for children and young people with SEN or who are disabled?

First we need indicators not targets. Measuring outcomes of individual children is not helpful to those children.

Secondly, the best indicator would be to see how happy and satisfied with life the children are. Not all SEND children will grow up to be adults who are fully able to engage in the wider world, be economically productive or be independent. But it is hoped that they will grow up to be happy or at the very least content with themselves and their lives.

Many parents who home educate see that as the most important goal in life.

Question 44: What are the ways in which the bureaucratic burdens on frontline professionals, schools and services can be reduced?

For home educators it has to be understood that there is no need for much of the bureaucracy that schools have. Many LAs have a tendency to apply school ideas to home educators, requiring them to have timetables or follow a statement. If there are to be fewer bureaucratic burdens on frontline professionals, there should be even fewer on EHEers.

Sometimes therapists are required to do so much paperwork that they have less time to visit children. They can end up using prescriptive predefined tasks. Because they don't take the word of the parents about what the child can do, they end up spending time asking the child to fully demonstrate using predefined tasks that rarely engage the child, leading some children to refuse to cooperate. This can lead to a poor behaviour pattern in some children, leading to an assumption that they cannot perform at a particular level, thus leading to them being given inappropriate treatment or tasks that are below the child's level.

Question 45: In addition to community nursing, what are the other areas where greater collaboration between frontline professionals could have the greatest positive impact on children and young people with SEN or who are disabled and their families?

Greater collaboration is also important in physiotherapy, occupational therapy and speech therapy. All these services should be available in the home as well as in school. At the moment EHEers find it hard to access services as the LAs and NHS have no idea of how to facilitate these for children at home.

Question 47: How do you think SEN support services might be funded so that schools, Academies, Free Schools and other education providers have access to high quality SEN support services?

Regardless of how it is funded, some of that funding should be available for EHEed children too.

Any equipment that a child needs in school will also be needed at home if the child is de-registered, for instance special seating, writing slopes, various schemes such as handwriting, ABA or other specific programmes or software. There is not a predefined list of these things, but the individual child's needs should be looked at and it should be understood that equipment in school may need to be different from equipment at home, for instance an indoor wheelchair may be suitable for school use but while EHEing an outdoor wheelchair may be more appropriate.

Question 49: In addition to their role in the assessment process, what are the innovative ways in which educational psychologists are deployed locally to support children and young people with SEN or who are disabled and their families?

Educational psychologists should be able to be engaged by EHEers without the expectation that the children should be in school. Every county should have at least one educational psychologist who is experienced in EHE.

Currently EHEers are too often told that their child cannot be assessed as they are not in school. They often have to seek the services of private educational psychologists who don't seem to have that attitude.

Educational psychologists should also be used throughout the child's life, not just at an initial assessment.

Question 50: How do you envisage the role and service structures of educational psychologists evolving to meet local demands?

They should be independent of the LA and schools, so that they can give an independent view of the situation with the child and the family at the heart of it. This is particularly important for families that choose to home educate.

Many families when they resort to private assessments by educational psychologists are then told that private reports are not valid and the LA will often put the children through a further assessment. This is unnecessary as all educational psychologists should be equally honest in an assessment, regardless of who is paying the bill.

Question 51: What are the implications of changes to the role and deployment of educational psychologists for how their training is designed and managed?

They should be trained by people in universities rather than by LAs. Sadly, over the years there has been little academic rigour or evidence-based training for educational psychologists. This is an ideal opportunity to change that and bring educational psychologists back into the realm of academic excellence. Educational psychologists should have links and training with educational neuroscientists.