CAMPAIGN FOR A
FAIR SOCIETY

A Consultation Response

from

The Campaign for a Fair Society

to

Support and Aspiration: a new approach to SEN and disability

Prepared by

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28th June 2011

Introduction

We welcome the fact that the Government is taking a new approach to SEN and disability. However we urge the government to take time to consider how the changes will be implemented; to align the proposed changes with other areas of legislation and policy that impact on the lives of disabled children and their families; and to consider how the changes will really impact on the life chances of disabled children and young people.

We are particularly pleased that the government is considering simplifying and joining together complex assessment and review processes. We are also glad that the government is considering an ambitious programme of reform around individual budgets in education, health and social care.

We believe that a high quality education system should equip young people with the self-confidence, belief and the skills to take part in the world at all stages of their lives, our focus in this submission is on preparing the ground for an education system that equips disabled children and young people with the skills and tools they need to succeed in life. We give examples of innovative practice that is improving outcomes for disabled children and their families; provide additional recommendations to support such practice or address deep-rooted barriers to this new approach; and we ask questions that extend the scope of the Green Paper.

Please contact Pippa Murray for additional information about the work we describe.

Our submission covers:

- Section One: A Positive Perspective
- Section Two: A Curriculum for Citizenship
- Section Three: Preparing for Adult Life
- Section Four: The Economic Climate
- Section Five: Questions for Reflection

1. A Positive Perspective

Disabled children and their families have been made many promises of change for the better over the past ten years or so, and yet many of them continue to experience discrimination and disadvantage. A radical new approach to SEN and disability opens an opportunity to allow a considered response to the fundamental questions:

- What are we educating our children for?' - and
- How can we help all children be the best that they can be?

We take the perspective that education is a human right and that the poor outcomes for young people with SEN and disabilities as they enter into adulthood are symptomatic of a system that discriminates against disabled children and young people. Our response to the Green Paper is framed within a perspective that assumes disabled children and young people have the right to the same opportunities as their non-disabled peers.

We take the view that education is about:

- providing all children with opportunities to develop their talents and interests;
- giving all children confidence in their methods of communication;
- inspiring all young people to be the best that they can be;
- giving all young people the skills they need to make the most of their lives; and
- enabling all children to participate and contribute to life in their local communities

The problems with special education and the poor outcomes experienced by disabled young people extend beyond the five main areas addressed in the proposed Green Paper. To raise aspirations and achieve the direction of travel laid out in the Green Paper we need to address the institutionalised discrimination that lies at the heart of our education system; to place all developments within the context of the Equalities Act; and to look beyond education and support to wider social issues.

Institutionalised discrimination

We can identify at least 3 aspects of institutionalised discrimination in the current system:

Negative view of disability - Current education and support for disabled children is based on a medical model of disability that views impairment as a problem. The medical model does not acknowledge the gifts of disability and it keeps aspirations low. A social model of disability provides an alternative perspective which allows for impairment to be seen as a natural part of our human condition and recognises the gifts disabled children have to offer the whole of our society (including our education system).

Narrow tokens of success - The rigid focus on academic progression as a means of demonstrating success in the education system works against many disabled students (particularly those with learning difficulties and/or communication impairments). For example, disabled young people attending mainstream schools who are unable to enter for GCSE and A level exams are denied the opportunity of moving into sixth form. We take the view that a more appropriate measurement of the success of our education system is the impact it has on the lives of our children and young people as they become adults.

Incentives for segregation - Our current system is riddled with ambivalence and confusion, rather than a bias, towards inclusion. Our experience - backed up by conversations with hundreds of parents across the country and learning across the world - is that inclusive education is only successful if educators have the will, understanding and expertise to adapt the curriculum successfully; to support each child appropriately and facilitate relationships between disabled and non-disabled children. There is no evidence that this has been done at any scale way in different parts of the country. We put forward the view that we do not yet know what inclusive education looks like, or the benefits it would bring to our whole education system.

The central aim of the proposed Green Paper is to raise aspirations and prepare disabled children to take their rightful place in our society. However, disabled children will only be able to take their rightful place in local communities if they feel they belong there. And the non-disabled community will only learn how to support disabled children if they live and work alongside them. At present there is a low level of confidence in mainstream schools around including students with complex impairments and high support needs that makes it very difficult for these children to be included in mainstream schools, even if that is what they and their parents would choose. In addition to this, many mainstream schools are reluctant to accept disabled children because they pull the school down with respect to our simplistic measures of achievement.

Each of these factors undermines any possibility that parents can pursue a placement within a mainstream school without ambivalence and confusion, and so it denies genuine parental choice. The Green Paper proposes that parents of children with statements of SEN will be able to express a preference for any state-funded school (including mainstream & special schools, Academies & Free Schools) and have their preference met unless:

- the school says it cannot meet the needs of the child,
- the placement of their child in a particular school is incompatible with the efficient education of other children,
- or it is an inefficient use of resources.

These three clauses place power and control firmly in the hands of schools and local authorities and will mean that disabled children will never fully belong in mainstream schools, for they are vulnerable to being excluded at any time. The three caveats not only deny families genuine choice and control, but also influence the way that all children understand disability. They make it seem normal that some children are rightfully excluded from local community options.

Our recommendations:

In order to give disabled children higher aspirations, and to allow all children the opportunity to learn about disability, we would like to see a pathfinder site exploring a wholesale move towards inclusive education.

In order to remove the bias against inclusion and to give families genuine choice and control about the type of school their child goes to, we recommend the three caveats be removed.

Family Leadership

The Green Paper is all about changing systems, services and professional practice. We need to place disabled children, young people and their families at the heart of these changes if we are to find the best possible solutions to the problems they face. A central theme of all the consultations carried out with disabled children since the Quality Protects Programme of the late ‘90s is that they have the same aspirations for their childhood and adult life as their non-disabled peers. They want to have fun, follow their interests, pursue their dreams, have a job they enjoy, have friends, get married and have children.

Disabled children, young people and their families have the biggest investment in the proposed changes to our education system. They have the most to gain and the most to lose. It is absolutely imperative that these changes are informed by the experience of disabled adults and the aspirations of disabled children and young people.

Our Recommendation:

All pathfinders include a strand of work developing the voice of disabled children and young people alongside **Family Leadership** (www.centreforwelfarereform.org) This work will explore families' experience of the changes being implemented, and place their ideas for making things better at the centre of future developments locally and nationally. In order to build on current learning, we recommend the inclusion of **Calderdale**, which is leading the way in the development of Family Leadership, as one of the pathway areas.

2. A New Pedagogy for Learning

The success of our education system depends on equal measure on the structures we put in place and the content of the education being delivered. Disabled children need an education that inspires and motivates them as well as equipping them to take their rightful place in society. This means giving them the confidence and skills to become employees and employers. However, at the minute, only a very small minority of young people coming through the special education system go on to succeed in the workplace. This is not solely due to barriers they meet in the workplace, but also to the lack of aspiration and vision within the education system.

In their attempt to improve outcomes in adulthood, **Ellen Tinkham School** (Exeter) has developed a radical new approach to the content and delivery of the curriculum. After trying out different tools supporting a personalised approach, **Ellen Tinkham School** has come up with a model for self direction that enables systemic change.

The **Self-Direction Model** is specifically designed to transform learning for disabled children and young people in order to give them higher expectations and aspirations. The model allows children, young people and their families to take control of their lives and learning.

Although designed for education, the Self-Direction Model can be adapted for use within health and social care as it provides a new DNA-code that enables organisations to offer genuine personalised education and support alongside systemic advocacy. In relation to proposals within the Green Paper, the **Self-Direction Model** holds the capacity to provide on going holistic assessment and review and to bring together one plan for health, education and support.

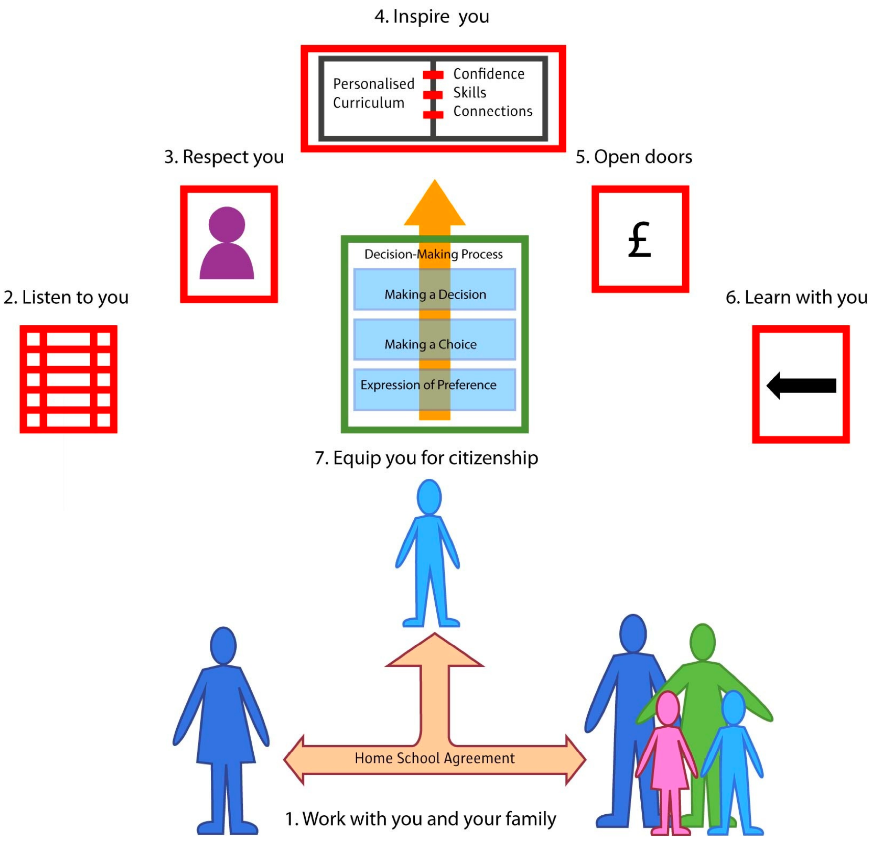
Most importantly, the **Self-Direction Model** has the potential to transform lives.

The Self Direction Model

The Self-Direction Model = Core Promise + Engagement in Learning + Personal Advocacy + Systemic Advocacy

Core Promise - The Self-Direction model uses a Core Promise to young people and families as the basis of service design and development. The Core Promise is a set of rights described within a series of seven person centred elements (see Figure 1 below.) Taken as a whole, the Core Promise provides an accurate reflection of and respect for the individual student, their dreams, aspirations and specific needs. The elements of the Core Promise comprise a set of principles that link into a range of tools forming a person centred methodology. The Core Promise provides each individual with a:

- planning process
- communication process
- personal profile
- home school agreement (outcomes & targets)
- decision-making process
- resource allocation



Each element of the Core Promise also ensures that the whole school is accountable to its children and families:

Engagement in Learning - The curriculum at **Ellen Tinkham** depends on methods and tools used to involve and motivate individuals in the learning process thereby facilitating excellent personalised approaches.

Personal Advocacy - Communication skills lie at the heart of the curriculum. Personal advocacy collects processes, tools and methods to empower individuals and to gather the information required to inform personalisation.

Systemic Advocacy - The culture of an organisation limits or extends the possibility for transformation. Systemic Advocacy provides ways to honour the requirement to check the accuracy and integrity of person centred information at every level. It requires the service to use person centred data to drive design and development and provides the means to do so.

These four strands make up the **Self-Direction Model**. The model has the capacity to ensure inspirational learning that will impact positively on the life chances of individual children.

A **Learning Impact Measure** is incorporated to demonstrate individual progress. Empowering learners to have ownership of their target setting and evaluation also means the measure can be used to monitor how well the school is responding to individual needs.

The **Learning Impact Measure** responds to the breadth of learning, not just the linear progression of learning (for example, moving upwards on a P-scale). In doing this, the **Self-Direction Model** ensures all children and young people are given opportunities to put their voice across, to be included and to aim high.

Our recommendations:

Ensure that learning from **Ellen Tinkham** informs the work undertaken by the pilots proposed in the Green Paper.

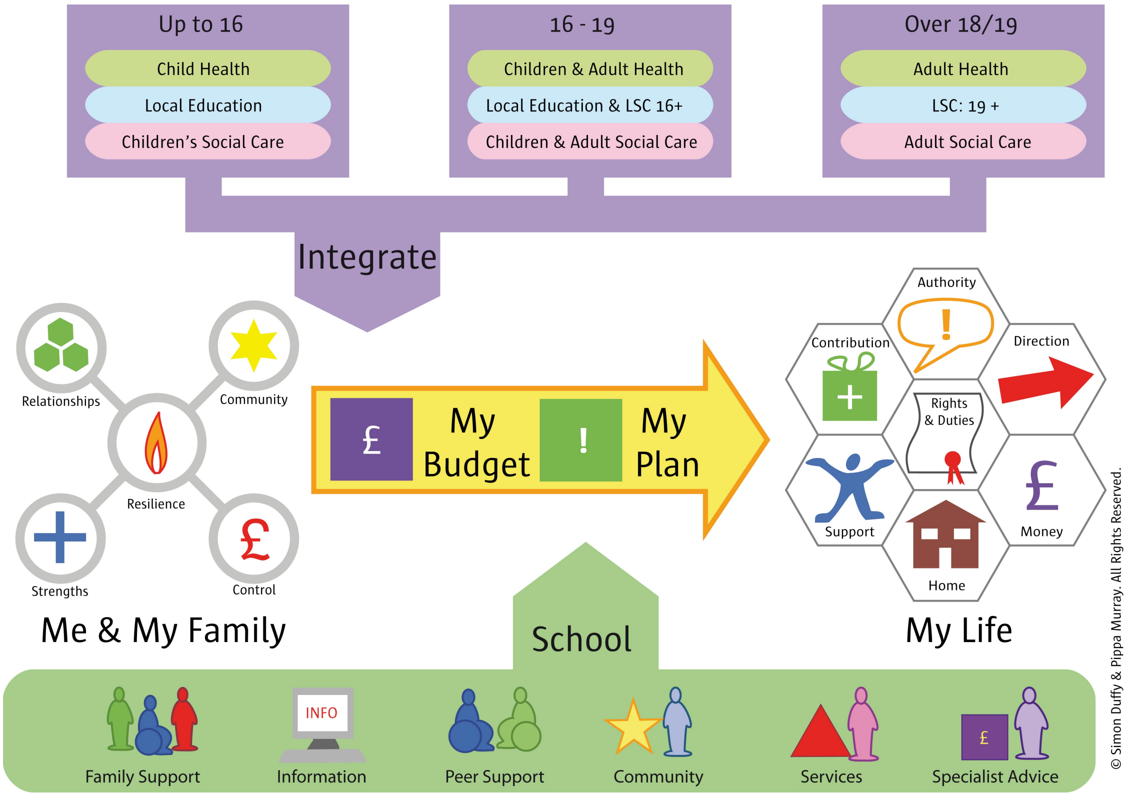
Ensure that **Devon** is one of the pathfinders in order to assess if the Self-Direction Model at **Ellen Tinkham School** makes a new assessment & review process both more efficient and more empowering for parents.

3. Preparing for Adulthood

In spite of the priority placed on transition in the past few years, many disabled young people and their families continue to face bleak futures. One of the most successful programmes leading to vastly improved outcomes for young disabled people as they leave school is the model of **Personalised Transition**. Started in **Talbot Special School** in Sheffield in 2008, this model depends on the development of four key areas:

1. A Curriculum for Citizenship
2. Family Leadership
3. Integrated Individual Budgets
4. Expert Co-ordinated Support

The improved outcomes for young people are leading to the development of this model across the country. The success of **Personalised Transition** depends on schools - mainstream and special - delivering an education that equips disabled young people to take their rightful place in their local communities and society as a whole (see Figure 2).



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In many areas, schools are acting as the main catalyst for change by developing radical new ways of delivering education. This includes transformation of the content and delivery of curriculum; placing student voice at the centre of the development of the school; finding new ways to engage with parents; working closely with colleagues in allied professions; releasing funding from the school budget to develop bespoke programmes for individual students; co-ordinating packages of support made up of funding from health and social care; developing new ways of giving parents the information they need; and providing young people with the opportunity to become positive role models throughout the school community and beyond.

Further information about the development of the Personalised Transition across the Yorkshire and Humber region will be published later this summer. (See www.centreforwelfarereform.org)

Our recommendations:

Ensure that learning from the areas that have started developing **Personalised Transition** informs the work undertaken by the pilots proposed in the Green Paper. In order to build on developments already underway, ensure that some of the areas undertaking this work (e.g. Sheffield, Rotherham, Lowestoft & Brighton) are pathfinders.

Further and Higher Education

The current funding system for post-16 provision is so complicated that even those people whose job it is to administer it, find it impossible to describe. Funding for post-16 education needs to addressed at Government departmental level as a matter of urgency.

In spite of the fact that there is a legislative framework to support learners who require additional support and a duty to provide learning opportunities for young people with learning difficulties up to the age of 25, colleges tend to adopt ad hoc responses to meeting the needs and aspirations of disabled students. It is still the case that FE is a no go area for young people unable to easily demonstrate progression; and many disabled young people with communication impairments struggle to access Higher Education as they cannot easily communicate their understanding.

Where young people with learning difficulties do success in accessing their local college, they often have a severely limited choice of courses to choose from e.g. basic skills or independent living skills. This lack of access is a severe case of discrimination and a denial of equal opportunities which compounds the low aspirations and reality facing all disabled adults.

On an individual level the funding arrangements mean that often more than one agency is providing funding for post-16 provision. Although local authorities have responsibilities for young people up to the age of 18, 19 or 24, funding for educational provision is either through the local authority or the Young People's Learning Agency. Those aged over 24 who remain in learning may be eligible for funding for their learning costs from the Skills Funding Agency. Health and Social care funding may also be part of the overall cost of support.

The current experiments using the Learning for Living and Work Framework seems to be focussed on the Resource Allocation System. We think this is over complicated and should be simplified.

The following piece demonstrates the negative effect present policy and practice has:

One family tells their story here:

Our daughter, Nadia, has complex disabilities. She has cerebral palsy and uses a motorised wheelchair. She is deaf with a cochlear implant. Her primary receptive language is BSL and her primary expressive language is through an AAC device. Nadia has come through mainstream schooling, is now nineteen and attends her local College. She works harder than anyone I have ever met (of any age) and is absolutely dedicated to achieving something in her life. She wants to go to University to study disability and different needs within education.

Nadia does not have learning disabilities, however she does not easily achieve good exam results. This is because she is confronted with a system which demands her to condense her astonishing range of ability, energy and dedication into units of English academia, within narrow parameters.

Nadia has been brought up to have high expectations of herself, and to achieve positive outcomes whilst contributing to society. She has a maturity and sense of responsibility that far outweighs many students who get the necessary grades to get into university. She is a young woman with strong values and knows what she wants to make a difference to people's lives in the future.

She also has an excellent knowledge of disability, inclusion, discrimination, human rights and education; she simply doesn't always know how to express this knowledge in English. English is not Nadia's language, however this is the medium through which she is judged on just about everything she does. As a deaf person her first language is sign and yet there are even restrictions regarding the interpretation of exam questions into sign language.

Nadia has the most comprehensive CV, including many awards that she personally has won; over 100 hours of voluntary work and many hours of paid work experience, achieved whilst running workshops and talking at conferences primarily about her life experiences.

As an Augmentative Communication Aid user, Nadia's second language is the communication system she has learned through using her Dynavox (communication device). Very few young and deaf people around the world use a communication aid with the confidence and competence with which Nadia does. The system is complex and takes years of hard work and motivation to use and to become successful with. Yet once again examination boards and entry requirements make very little allowance for these different communication systems.

The result is a continual struggle to manage the levels of academic English required – essentially the one and only standard that overrides everything else. Where are the measures for maturity, dedication, resilience to adversity and hard work – as well as the skills of alternative communication, being multi-lingual and more general people skills?

We are not suggesting that it's straightforward, but we are saying that a great deal more thought and imagination needs to go into the process of including people with disabilities into further education, higher education and beyond. Just consider that absolutely no imagination went into the creation of a random age for the category of "mature student" and yet even this makes a real difference to the lives of people who are dedicated and hard-working, but who will never achieve 'A' grades in exams.

We as a family together with Nadia have worked incredibly hard to ensure that she has a meaningful adult life with the same opportunities as her peers and siblings. We are now all wondering whether this was worth it and that she is heading to a bleak future with poor outcomes.

Unless we change the system, society will continue to dump extraordinary people like Nadia – who have battled the challenges whilst going through mainstream childhood – back into a segregated and disenfranchised adult life.

Andy & Katie Clarke, Nadia's Parents

This individual experience is being played out in different ways by young people and their families across the country. The barriers facing young disabled people as they try to enter into Further and Higher Education are seemingly impenetrable and have to be addressed.

Although it is good to see that central government and the YPLA have expressed some enthusiasm for increased individualisation and personalisation in FE, progress is slow. Work that began in Essex and Sheffield in 2006, has already demonstrated that it is possible for education funding to be provided to young people and their families as an individual budget. However, the slow pace by which national guidance is evolving may discourage local practitioners from exploring more creative and personalised solutions. This may even lead to families feeling forced to press for more institutional and distant solutions. This would be the worst possible outcome.

The problem here is not money. In fact the current system is highly inefficient and simply encourages the undue use of expensive out of area educational placements. Ongoing efforts to move the current system of funding for disabled people onto a genuinely individual basis in order to put people in control of their own lives and to drive up quality and standards. Many local areas do not feel the law or policy supports them in changing in local practice, in particular the new YPLA has removed access to the individual budgets which were so successful in contributing to young people's personalised education and support (see Cowan, 2010). **Such a retrograde step need to be addressed as a matter of urgency**. Every year young people are deprived of choice and control and their educational opportunities are damaged.

The introduction of individual budgets from birth could be one way of addressing the different funding streams for specialist resources. For instance the recent policy paper **A Fair Start** (Murray, 2011) sets out the case for a fully integrated model.

However, the introduction of individual budgets is not enough. The NHS needs to carry out their responsibilities for ensuring there are enough allied health professionals, for example Occupational Therapists, Physiotherapists, Speech and Language Therapists etc in their local area to meet the need. And local authorities need to support the growth and development of agencies to give new opportunities to disabled young people. For example, Post 16 providers, general FE Colleges, local specialist colleges, training providers offering apprenticeships and internships, social and community based projects, social enterprises and local businesses are key to the ability of local communities to raise aspirations, participation and success.

Our Recommendations:

Central government should provide more clarity about funding arrangements and individual budgets to support Further Education.

Pathfinders to include work on gathering evidence of what is actually happening regarding to access to local colleges, progression routes etc and the impact this has on the life chances of disabled young people

Pathfinders to include intensive work with local colleges to facilitate the inclusion of all learners in courses of their choice.

4. Present Economic Climate

This Green Paper is being introduced at a time when severe cuts to public expenditure are being enforced. These cuts will inevitably impact on the lives of disabled children and their families and on the capacity of support services to respond to their needs. This will affect the plans for the single assessment and care plan outlined in the Green Paper.

We agree it will be interesting to explore the possibility of agencies in the voluntary sector carrying out assessments and helping families put a joint plan together. But we are worried about the growing trend - nationally and locally - of contracts going to large providers in the voluntary sector on the basis that they are able to provide cheaper services. Providing high class support to families takes time and costs money. Quality is an area that cannot be compromised and it is often a false economy to go with the cheapest bidder. Work with disabled families depends on agencies being able to develop relationships of trust. Agencies with strong roots in their local communities are more likely to achieve this than large national organisations delivering centralised services.

There is a real danger that parents will equate the proposed changes with cuts. This would hinder the potential for innovations and could, inadvertently, contribute to a lack of enthusiasm for and uptake of individual budgets.

The Green Paper proposes a range of encouraging initiatives related to the training and development of teachers and other staff working with children in schools. Such initiatives include initial teacher training, core training for teachers and teaching assistants, and opportunities for more advanced and specialist training for staff working with children with more complex needs. Recent news that the Government will no longer be funding new Master's-level training jeopardises the professional development programme required to ensure the success of the proposed changes within the Green Paper.

5. Questions for Reflection

We end this submission by posing a number of pertinent questions. We are concerned that unless such questions are addressed, the Green Paper will not achieve the outcomes it aspires to.

1. How do we continue to raise aspirations and develop a broad understanding of the needs of disabled young people at a time of diminishing opportunities for much of the population?

2. If SEN statements are to be abolished, how will the legislation be changed to underpin the 'Education, Health and Care Plan' especially as there is currently a gap between policy and the law in both children's and adult social care?

3. If the 'Education, Health and Care Plan' is the only way of getting an individual budget won't this create a barrier for some families? What about disabled young people whose needs have been met without a statement?

4. Will there be different eligibility criteria applied by local areas as with Continuing Health Care and eligibility to children's and adult social care to the Education, Health and Care Plan?

5. If the voluntary or community sector are involved in coordinating the 'Education, Health and Care Plan' will Local Authorities or Health Boards accept assessments and agree funding without doing their own assessment?

6. How will the new arrangements within the NHS affect the reforms set out in the Green Paper? Will the new commissioning board take over some of the responsibilities for commissioning health services locally, or will they have responsibility for highly specialised services such as augmentative or alternative communication?

Background Information

Further reading

For more information about the Self-Direction Model contact Jacqueline Warne, Headteacher at Ellen Tinkham School: jacqui.warne@exeter-ellen-tinkham.devon.sch.uk

A full report about the work at Ellen Tinkham school will be published in the late autumn of 2011. Contact Pippa Murray for more information: pippa@ibkinitiatives.com

A Fair Start by Dr Pippa Murray and **Personalised Transition** by Alison Cowan are available to download from The Centre for Welfare Reform: www.centreforwelfarereform.org

A full range of information about Personalised Transition can be found here: http://bit.ly/personalised-transition-project

About this submission

This submission was written by Pippa Murray of ibk Initiatives with help from Katie Clarke and Jane Shepherd. Contact Pippa Murray for more information: pippa@ibkinitiatives.com

It is written on behalf of The Campaign for a Fair Society (www.campaignforafairsociety.org) which is a membership organisation in the UK (with independent steering groups in Scotland, Wales and England) and which is supported by over a thousand individual members and which has the support of many organisations:

Access Dorset
Action for Advocacy
Advance Housing and Support
Altrum
Aldingbourne Trust
Alzheimer Scotland
Ambrey Associates
Archibald Foundation
Association for Supported Living
Baroness Jane Campbell
Brandon Trust
C-Change
Cartrefi Cymru
Care Co-ops Community Service
The Centre for Welfare Reform
Choice Support
Circles Network
CCPS - Coalition of Care and Support Providers in Scotland
Contact a Family - for families with disabled children
Creative Support Ltd
David Towell

Direct Inclusive Collaborative Enterprise (DICE) CIC
Down's Syndrome Association
Down's Syndrome Scotland
Edinburgh Development Group
ENABLE Scotland
Generate Opportunities Ltd
Give me a chance
Glasgow Centre for Inclusive Living
Glasgow Disability Alliance
Enough Is Enough
The Foundation for Families
Havencare (Plymouth) Ltd
Heavy Load
Professor the Baroness Hollins
Housing Options
ibk initiatives
Inclusion Glasgow
Inclusion Scotland
Inspiring Inclusion
Isle of Wight Carers Forum - Adults with a Learning Disability
Jackie Downer MBE
KeyRing
L'Arche Communities
Learning Disability Alliance Scotland
LivesthroughFriends
Lives Unlimited
Long Term Conditions Alliance Scotland (LTCAS)
Lothian Centre for Inclusive Living
MCCH Society Ltd
Neighbourhood Networks
North West Training and Development Team
Parkwood Extra Care
PAMIS
Pathways Associates CIC
Personalisation Forum Group
Personalisation Plus Ltd
Professor Jim Mansell, Tizard Centre
Paradigm
Partners in Advocacy
Peaks and Dales Advocacy
People First (Scotland)
Wendy Perez, See Me As Me
Progress Care Housing Association (member of Progress Housing Group)

REBOUND DONCASTER
Renfrewshire Access
Richmond Mencap
Roberts Care & Training
Self Direct
Sense Scotland
Sheila Jones Trust
Skills for People
Southdown Housing Association
Stay Up Late
Support for Ordinary Living
UPDATE, Disability Information Scotland
United Response
Values Into Action Scotland
VoiceAbility
Jan Walmsley Associates
West Lancs Peer Support Group