

# **Inquiry into post Special Educational Need Provision in education, employment and training for those with Learning Disabilities**

## **Northern Ireland Rare Disease Partnership (NIRDP)**

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**March 2014**

## **Inquiry into post Special Educational Need Provision in education, employment and training for those with Learning Disabilities**

Committee for Employment and Learning  
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BY E-

21 March 2014

Dear Committee Clerk,

The Northern Ireland Rare Disease Partnership (NIRDP) is pleased to have an opportunity to respond to this Inquiry into post Special Educational Need Provision in education, employment and training for those with Learning Disabilities.

### **Introduction**

The Northern Ireland Rare Disease Partnership (NIRDP) is a unique partnership of those living with a rare disease; organisations representing them; health professionals; science and industry; health policy makers and academics. A disease is "rare" if it affects fewer than 5 people per 10,000. There are over 6,000 rare diseases, with others being defined all the time. One in 17 people is likely to be affected by a rare disease at some point in their lives; that is almost 106,000 people in Northern Ireland (approximately the population of Derry/Londonderry.) While each individual's condition is rare, these are not minority issues. Collectively, rare diseases are not "rare".

We work closely with Rare Disease UK (RDUK), the UK national multi-stakeholder alliance for people with rare diseases and all who support them. We have also developed constructive linkages with rare disease organisations in the Republic of Ireland and hope to further cultivate and strengthen these extremely productive and beneficial relationships with our sister groups.

As our first major piece of work, we surveyed (with the support and facilitation of the Patient and Client Council) the experience of diagnosis of those living with or suspected of having a rare disease in Northern Ireland. This Report demonstrated the need to improve the diagnostic process. We are now working with the Health and Social Care Board on developing a Care Pathway for Muscular Dystrophy as a template for Care Pathways for other rare diseases. We have worked with the Public Health Agency in developing a survey and

engagement process to identify the experience of care in the community for those living with a rare disease. We are working with the medical training authorities to trial a rare disease input to training for medical students and, in due course, other health and social care practitioners. NIRDP are also represented on the UK Rare Diseases Stakeholder Forum.

We are dedicated to working inclusively and constructively together to find practical ways of improving the quality of life, treatment and care for those living with rare disease across Northern Ireland. NIRDP believe that we are "Stronger Together"; and our aims are to advocate, educate and innovate for all those living or working with rare disease.

In this submission NIRDP sets forward the following proposals:

- (a) People with a learning difficulty, their carers and families often experience a range of barriers and inequalities in all areas of life including education, employment and training.
- (b) There is unease, and indeed fear, among parents regarding the provision of services for people with learning disabilities.
- (c) Existing barriers post SEN to education, employment and training are further compounded for those who have learning disabilities caused by rare disease.

We believe that each has relevance to the Terms of Reference in general. Therefore we have outlined general concerns and suggested recommendations (paragraphs 1-24); and concerns related to the additional impact of learning difficulties when caused by rare disease with suggested recommendations (paragraphs 25-51).

## **Proposal**

### **General Concerns**

1. NIRDP support the principle that people should have the opportunity to enjoy the best possible health outcomes and quality of life; and where barriers exist that they are reduced to the lowest levels. Those with a learning disability should have access to the same range of services as the general population. Individuals must be supported as appropriate to their needs; have the right to paid employment and training; involvement in their community; voluntary work; sport or leisure activity; or have an opportunity to meet people and make friends. However often people with a learning difficulty, their carers (often parents or siblings), and families experience a range of barriers and experience inequalities in all areas of life including education, employment and training. We are also aware of the anxiety caused during assessment of special educational needs and during transition of care; and in particular of the "cliff edge" facing young people as they move out of the education system into further education and the workplace

2. People with learning difficulties also suffer severe obstacles due to the impact of being “more likely to experience major illnesses, to develop them younger and die of them sooner than the population as a whole. UK reports indicate they have higher rates of obesity, respiratory disease, some cancers, osteoporosis, dementia and epilepsy. It is estimated that people with learning disability are 58 times more likely to die prematurely. However, even with such a dramatic health profile, the learning disabled population are less likely to get some of the evidence-based screening, checks and treatments they need, and continue to face real barriers in accessing services. Information on, and activities in, health promotion can be difficult to access. These factors contribute to preventable ill health, poor quality of life and potentially, premature death”. Source: Health Inequalities & People with Learning Disabilities in the UK: 2011 Public Health England  
<http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems>
3. We have concerns that the learning disabled population as a whole are less likely to get some of the evidence-based screening, checks and treatments they need, and will continue to face real barriers in accessing services. This could impact on the availability and quality of services provided due to (a) incorrect assessment of needs for provision of Day Opportunities; (b) incorrect assessment for placement regarding Day Opportunities and Day Services for People with Complex Care Needs and; (c) assessment of need for those who are allocated places in Day Services for People with Complex Care Needs. Correct assessment of need is essential for Objective 4 of Equal Lives: *“To enable people with a learning disability to lead full and meaning full lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships”*.
4. Increased vulnerability to major illnesses must also certainly cause additional barriers to education, employment and training for people with learning difficulties.
5. A “meaningful life” should not mean that adults with learning difficulties:  
Receive insufficient care and support, and may even be placed at risk due to an inadequate level of supervision.  
Are placed in situations that are difficult to cope with, have a damaging impact on identity, and that may lead to unnecessary instability and stress for the adult with learning difficulties, their family and home life.
6. We hope that the ethos behind Objective 4 is not misinterpreted; we certainly do not wish any adult with learning difficulties to be deemed “fit for work” on the back of the new Regional Learning Disability Day Opportunities Model if they are not capable of working.

7. We are very concerned that as a result of the new strategy, and drive to promote opportunities via the Regional Learning Disability Day Opportunities Model, current essential Day Centre places may be prematurely closed and permanently lost.
8. We believe the opinions of those with learning difficulties, those who care for them and their families should be heard and given serious consideration. **Parents' opinions have been provided in this submission as follows (paragraphs 9-20).**
9. We want to focus first on 'immediate' things that are happening right now to some parents who have children with severe learning disability.
10. Due to TYC parents are placed under enormous pressure to give up hope of day-centre provision. The drive towards TYC has left parents feeling really apprehensive about loss of day care or respite; they feel as if it is morally reprehensible for them to consider sending their young people to Day Centres; they feel as if the withdrawal/reduction of services has moved far too quickly. Whilst the principals behind TYC are welcome the reality for parents in this situation, where there is severe learning disability, is very different. Parents who want day centre provision have been made to feel like pariahs when the realities are deliberately obscured.
11. Several of our parents have reported cases of past abuse, and this is at the forefront of their minds - it is real and it has happened. So distressed parents have been told that their young adults will spend their days in leisure centres. How does this chime with safeguarding of vulnerable adults? How can a young adult who cannot feed or toilet himself, or speak be expected to attend a leisure centre? What training is there for the staff there? Who is trained to communicate with him? How will the leisure centre attendant be able to read from the young person's body language or from his eye movements what the young person wants? What safeguards are built in? How is the young adult supposed to travel to the leisure centre? This situation might seem absurd to many but that is what parents are talking about and that is what they think lies ahead for them.
12. Therefore if TYC is going to thunder ahead everyone needs to travel at the same speed and parents should not have to run the gauntlet between children's services and adult services who at times don't communicate properly.
13. It was also noted that some young people appeared to be assessed repeatedly despite transition plans being put in place much earlier. Assessments were also being carried out by people who had no previous contact with the young person, and the parent was unaware of why this assessment was taking place and when it was taking place. The impression the parent was left with was that the assessor seemed to be looking for reasons not to provide day care provision rather than looking at what could be provided.

14. It was also disturbing to note that despite so many previous reports, that we have all read from various quarters regarding transition, there was very little help available to the parents in these instances. TYC had to roll on and parents were left with very little choice only to fight very hard for Day Centre services with the help of MLA's.
15. The above illustrates what has been happening very recently to young people and parents who do not have the luxury of time to plan ahead for young people with severe learning disabilities.
16. Young people with less severe learning disabilities:
  - Possible avenues - circles of support.
  - Personalisation - cultural change is needed to make this happen.
  - Use of Direct Payments; brokerage schemes; registers of suitably trained personal assistants and management of DP's by CIL's- availability of suitable PA's is an ongoing problem that needs to be addressed.
  - Advocacy - are there enough self-advocacy routes to help young people work out what they want to do?
  - FE Colleges - courses: horticulture, art, personal skills development, life skills/ sport, drama, cooking; accredited courses that can be inspected and build on strengths/weaknesses. There should be an emphasis on building friendships.
  - Routes to work - are employers encouraged to take on workers with learning disabilities, will the support be there for them, and buddy schemes to ensure that workers have someone to talk to who will help both them and their employers to work together? Many people have never actually met a person with learning disability - such is the segregated society we live in.
  - Provision of Housing for those who can be independent which is all about choice - supported living, shared home, or self-contained with on-going support available when necessary.
17. The above is about choice, young people with LD should be able to exercise choice and helped to do so, there also needs to be an understanding that young people with LD should not be expected to choose, in their teens, how and where they want to live for the rest of their lives.
18. We need to understand the needs of parents too, faced with no provision, parents have to give up work and the toll of caring 24/7 is enormous. Emotionally and financially it is difficult. Whilst it is the immediate family, parents who do this work, the wider family and indeed the community sadly are not willing to help. Our parents have expressed this sentiment so many times.
19. Parents should not be blamed for being overprotective; they know full well the Winterbourne story and the most recent case of Conor Sparrowhawk- a young man with Autism who drowned in a bathtub in a residential home.
20. The rising number of diagnosis of Autism is alarming with 1 in 50 children now diagnosed. An estimated 70% of those who have Learning Disability also have Autism; and an estimated 40% of those who have Autism also

have learning disabilities. Provision for these young adults needs also to be planned.

## **Recommendations**

### **General**

21. We ask that in reaching its recommendations the Committee will consider inclusion of the following:
22. General evidence-based screening, checks and treatments that are timely and robust; with measures adopted to ensure no one slips through the net.
23. Processes that ensure assessment of need at all levels is carried out sensitively and by qualified assessors. Correct assessment of need is crucial if adults with learning difficulties are to receive the care that they are entitled to; that they are provided with opportunities to achieve their full potential in life; for realisation of the aims, principles and vision of TYC and Fit and Well; The Future of Adult Care and Support in Northern Ireland, and if the recommendations in the Bamford review and Equal Lives are to be fulfilled.
24. Greater support for the needs of people with learning difficulties, carers and their families is crucial and must be addressed. This involves:
  - Being given reliable information.
  - Being listened to, and personal knowledge and experience being respected.
  - Clinicians improving their knowledge of the condition and striving to work in partnership with both the individual who has learning difficulties, if possible, and their carers.
  - Psychological support, including during transition from child to adult services.

### **Proposal**

#### **Rare Disease Concerns**

25. What we fully need to consider is an additional impact on those affected by learning difficulties; the further obstacles and inequalities when learning difficulties are caused by rare disease. We need to remind ourselves that in terms of equality rare disease is not a subset of disability. Disability caused by rare disease can of course result in inequalities; but we should also fully examine the aggregate inequalities of societal disabilities that can be caused by the very fact a disease is rare. That when a disease is rare the established pathways that exist for supporting those with more common conditions simply do not exist. The further obstacles and inequalities of rare disease are broadly outlined below.

**26. The diagnostic and management impact:**

Lack of suspicion; misdiagnosis and non-diagnosis.

Reliability of testing techniques; no available testing.

Lack of available drug therapy and management.

Attending multiple clinics as rare disease is often complex and affects multiple systems.

Cost of drug therapy that is so often expensive and can be difficult to obtain.

Lack of knowledge and experience of a rare disease and of the skills required for the delivery of care and support in community care.

Lack of established Care Pathways and support systems.

**27. The social impact:**

The stigma and disadvantages of rare disease for children, adults and their families; for instance:

The isolation within peer groups at school.

The fear of employing an individual with a condition that is not well understood.

Difficulties in seeking financial help and services in a system where those carrying out assessments lack understanding of a condition and where many applicants who have a rare disease will certainly not fit any "boxes".

**28. Psychological impact:**

Experience of delays in diagnosis, misdiagnosis or no diagnosis.

Realisation that not much is known about a rare disease is terrifying and may be compounded by recognition that some service providers who are providing care are not experts and may also be giving poor advice.

Isolation: humans are social animals; they need to feel that they belong. However those affected by rare disease often feel very isolated due to a culmination of the factors we have outlined and their never having met anyone who has their condition. The sense of isolation, of "difference", of being an outcast caused by a rare disease means that throughout an entire life loneliness and social exclusion is acute- both for the individual affected and their family.

**29. NIRD strongly agree with the evidence for obstacles and inequalities that have been highlighted in the following abstract:**

"Rare disease patients experience particular obstacles in accessing high quality healthcare. These obstacles include but are not limited to: (i) lack of scientific knowledge of their disease, (ii) lack of access to correct diagnosis, (iii) delays in diagnosis, (iv) lack of appropriate multidisciplinary healthcare, (v) lack of quality information and support at the time of diagnosis, (vi) undue social consequences, (vii) inequities and difficulties in access to treatment, rehabilitation and care, (viii) dissatisfaction with and loss of confidence in medical and social services, (ix) denied treatment by

health professionals and (x) lack of availability of orphan drugs. Three surveys and their subsequent analysis, conducted by the European Organisation for Rare Diseases (EURORDIS), a non-governmental patient driven alliance of European patient organisations, demonstrate several of these obstacles by describing the experience of rare disease patients across 18 rare diseases and over 24 European countries as well as highlighting inequalities that exist between them". Source: Rare Diseases Social Epidemiology: Analysis of Inequalities; Anna Kole, François Faurisson MD; Advances in Experimental Medicine and Biology Volume 686, 2010, pp 223-250.

30. NIRD cannot provide written evidence for all of the obstacles and inequalities that impact on those affected by rare disease in this submission. This is because the research to produce such evidence has not yet been carried out. Rare conditions are all too often ignored and forgotten and although each condition may affect only a relatively few people there is a huge multiplier in the number of different conditions. It is only now that the public health impact of rare conditions is being realised and addressed systematically. We have however provided references (paragraphs 36-44 inclusive) to existing reports which corroborate our proposal. Findings relate to rare disease in general but general obstacles and inequalities will also impact on those with learning difficulties caused by rare disease. We can, for the purpose of enlarging on examples, focus on the impact of an incorrect diagnosis or non-diagnosis of rare disease and also the additional obstacles faced during transition of care as the latter has a special relevance to education, employment and training for those with learning disabilities.
31. **Diagnosis.** Health2020's report: "Forgotten Conditions: misdiagnosed and unsupported, how patients are being let down" criticises the overwhelming focus on treating a handful of major illnesses to the detriment of developing systems for diagnosing and treating the increasing number of rare diseases. As a result, thousands of people suffer for years with misdiagnoses and inadequate treatment, costing the system a fortune in nugatory expenditure of scarce resources. Our experience shows that very many care professionals at all levels of the HSC system are largely unaware of the signs, symptoms or behaviours which can provide proper diagnosis of the manifestations of rare diseases.
32. We suspect that many of those with learning difficulties may have undiagnosed rare diseases- for example, Fragile X. These individuals will experience particular difficulty post SEN, as without a recognised "label" the appropriate support will simply not be available, or difficult to access. Another aspect is adult onset conditions; where progressive neurological deterioration may result in cognitive deficits without any pre-existing SEN

“track record”. Again, lack of diagnosis or misdiagnosis (and consequent mistreatment) will bedevil an individual’s hopes of living a dignified and supported life.

33. The aims, and ultimately the vision of health and social care policy can only be feasible for those affected by rare disease if systems help to ensure correct and timely diagnosis. For example ‘A dynamic model for well-being’ has been provided in the Fit and Well Strategy consultation document (p15). As posited, the model describes how an individual’s external conditions such as their income, employment status, housing and social context act together with their personal resources such as health, resilience and optimism to allow them to function well in their interaction with the world and therefore experience positive emotions. When such an important ‘External Condition’ as ‘Health’ is compromised due to failure in making a correct diagnosis, and so provide appropriate treatment and support, all other determinants posited within ‘A dynamic model of well-being’ can undoubtedly collapse. Unless clear and constructive action is taken to address fundamental problems, such as appropriate and timely diagnosis of rare diseases, the Fit and Well Strategy will not alter, support or improve the lives of a significant, yet extremely disadvantaged, percentage of the population.
34. Without accurate diagnoses, and careful collection and collation of data into structured registries, the reliable information essential for efficient health and social care planning, and for education and employment, is simply not there. Appropriate medical treatment is not made available. Appropriate follow up care and support in the community is not made available. Additionally, diagnoses and data management alone cannot ensure appropriate care and support in the community if those delivering care at all levels are not equipped to deal with protocols necessary for rare disease; and especially in delivery of person centred care.
35. The complexities of rare disease impact adversely on effective and efficient planning and delivery of services, leading to preventable personal cost, inequalities, and waste of vital NHS and other resources. A much greater level of understanding must exist by commissioners, and service providers at all levels of delivery of care and support, of the complexities of care for marginalised groups sitting outside the mainstream of care.

36. **Transition of care to adult services:** "A prime example of the lack of holistic care is seen in the transition from paediatric to adult services. Patients with rare diseases often experience problems with medical, psychological, financial and social issues at this time, and too often support in these areas is not available for them to access". Source: Improving Lives, Optimising Resources; p64. (Rare Disease UK).
37. "However, it is not just problems with medical care that patients and families or carers often experience at transition. Patients and families have reported feelings of isolation and being 'cut off' following transition and then either not being offered, or having to fight for, necessary psychological support. We have also been informed of patients and families no longer being able to claim benefits following transition to adult services and not being offered any support or information in this regard". Source: Improving Lives, Optimising Resources; p64. (Rare Disease UK).

### **Evidence- Reports**

38. We recognise that the new UK Rare Disease Strategy is in its infancy and the Northern Ireland Rare Disease Implementation Plan is currently being drawn up. As such many of the points we make have not been given consideration in the past. The evidence we can provide to substantiate our proposal is in the form of existing reports and therefore has already been published. We ask that the challenges and obstacles of rare disease are acknowledged and applied, in this instance to learning difficulties caused by rare diseases; and to the difficulties of living with rare disease in a community, which is suspicious of the "unknown".  
Key reports include:
39. Rare Disease UK's (RDUK) report 'Improving Lives, Optimizing Resources: A Vision for the UK Rare Disease Strategy' outlines the current situation for people living with, or working in the field of, rare diseases in the UK and the actions that are needed to improve on this. Recommendations have been informed by over 1,000 contributions from organisations and individuals. 'Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy' may be accessed by following the link: <http://www.raredisease.org.uk/improving-lives-page.htm>  
The Royal College of General Practitioners have voiced their support for 'Improving Lives; Optimising Resources' recommendations.
40. 2020health Report "Forgotten Conditions: misdiagnosed and unsupported, how patients are being let down". This paper is a report on a roundtable held by 2020health on 12 June 2012 in Portcullis House, London, on "Forgotten Conditions". These are health conditions and diseases that due to their low prevalence mean patients often get neglected or overlooked.

"Forgotten Conditions" is available for download at 2020 Health's website [www.2020health.org/](http://www.2020health.org/)

41. EUCERD Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies; November 2012.

Available at: [www.eucerd.eu/%3Fpage\\_id%3D304](http://www.eucerd.eu/%3Fpage_id%3D304)

42. Another significant RDUK report '[Experiences of Rare Diseases: An Insight from Patients and Families](#)', published in December 2010, is based on a survey of almost 600 individuals or family members. 'Experiences of Rare Diseases: An Insight from Patients and Families' can be accessed by following the link:

<http://www.raredisease.org.uk/documents/RDUK-Family-Report.pdf>

43. The Patient Client Council's Report 'Experience of Diagnosis' (February 2012)

[http://www.patientclientcouncil.hscni.net/uploads/research/Experience\\_of\\_Diagnosis.pdf](http://www.patientclientcouncil.hscni.net/uploads/research/Experience_of_Diagnosis.pdf)) reflects the reality that even though there are over 6,000 different rare diseases, each with its own unique characteristics, those affected face common problems in getting the care, support and treatment they need.

- 29% of patients wait between 1 and 5 years for a correct diagnosis, and over 20% wait over 5 years;
- 34% of patients are misdiagnosed – 20% of whom received inappropriate treatment as a result;
- Patients have to attend multiple appointments with different health professionals to obtain a diagnosis and it is frequently a battle to do so;
- 57% of people caring for a person with a rare disease do so for more than 20 hours a day;
- Over 40% of patients described their experience of the health and social care service in Northern Ireland as "poor" or "very poor", and nearly a quarter described it as "average". Only a third of patients described their experience as "very good" or "excellent";
- Patients also reported feeling ignored by doctors; and that there is a lack of information and support for rare disease patients.

44. Contact a Family's Report "Counting the Costs" (May 2012) reveals that families with disabled children in Northern Ireland are going without essentials and spiraling into debt, even before the full impact of planned benefit cuts is felt:

<http://www.cafamily.org.uk/pdfs/Counting%20the%20costs%202012.pdf>

45. The UK and Ireland Huntington's Disease Alliance's Report, "Welfare Benefits" (June 2012) shows how families throughout the UK and Ireland are impacted by the effects of the disease itself; the need for partners and

“significant others” to give up work to take on extensive caring responsibilities; and the ignorance of the condition amongst staff responsible for social care and benefits. This study shows how a rare condition affects an entire family network; and how the very rarity of the condition adds to the disadvantage faced by individual, and their whole family and social network.

46. The RDUK Report, “Rare Disease Care Coordination: Delivering Value, Improving Services” sets out how having named care coordinators in post helps to ensure that patients and families receive the well-coordinated care they have a right to expect, and offers the NHS potential cost savings. <http://www.raredisease.org.uk/documents/RDUK-Care-Coordinator-Report.pdf>

## **Recommendations**

### **Learning difficulties caused by rare disease**

47. Rare disease reports show the compelling need to improve the quality of care for those who have rare diseases and their families. NIRDP applaud the Health Departments in all four nations’ joint efforts to build on this work at the strategic level. We also appreciate that effective implementation depends on frontline service delivery organisations and their staff. Co-ordinated efforts to implement the recommendations would certainly diminish inequalities that currently exist within the Northern Ireland health care system for this significant group of people: including those with learning difficulties caused by rare disease. We therefore ask that in reaching its recommendations the Committee will consider inclusion of the following:

48. **Health in All Policies.** If effectively implemented the Northern Ireland Rare Disease Implementation Plan will undoubtedly reduce the impact of existing inequalities faced by a significant group of people in accessing health care provision and support; and support across the wider social network of education, culture, employment and housing. However we are mindful that this can only happen if the new Implementation Plan is integrated into and supported by the normal procedures and operational systems of service delivery, across the spectrum of the public sector. NIRDP feel strongly that rare diseases, and the specific issues they raise, should be explicitly referenced in the narrative accompanying all relevant plans and strategies so that it is made clear proposals are fully inclusive of, and applicable to, all patients and carers, and not aimed simply at those affected by common conditions and diseases. We are very disappointed to note that in the “Equality, Good Relations & Human Rights Strategy & Action Plan – PROGRESS TEMPLATE”, and in many of the plans and

strategies we have encountered in the past, that there is no reference to specific action to remedy the challenges and inequalities of those affected by rare disease. We believe it imperative that robust efforts are made to promote equality of opportunity and to protect the rights of those who have rare diseases, and those who care for them. In our view it is crucial that the opportunity created by health and social policy to take rare disease issues into account is seized so that the new Northern Ireland Rare Disease Implementation Plan is allowed to:

Develop in partnership with all relevant existing policies and strategies.

Evolve with contemporary knowledge; experience; improvement in technology; provision of treatment and meaningful support within the community.

This should include all policies and guidelines relevant to learning difficulties, many of which are linked to rare disease.

49. **Equality.** NIRDP believe that human rights standards, equality legislation and equality plans, and screening of all relevant policies can play a vital role in fulfilling the vision of all major health and social policies for those affected by rare disease. We believe that the establishment of a multi-disciplinary Steering Group to assess the problem of rare disease inequality; and identify and support appropriate measures for inclusion in Commissioning Priorities and plans, in Inequalities Plans, and in screening relevant policies would not only be beneficial but is necessary to ensure the Northern Ireland Rare Disease Implementation Plan is robust and sustainable.

50. **A change in culture.** We need robust guidelines for rare disease but we also need to ensure effective implementation of these guidelines is safeguarded by changing culture throughout health and social care services; that is changing the way many service providers think about rare disease. We believe that this is a vital component in achieving excellence in the delivery of care and support for rare diseases.

51. Many of those who have a rare disease have complex needs, affecting many bodily and mental systems. Person centred care, linking those who have rare diseases, their families, main carers and all those delivering care and support in the community and within a wider network of treatment, is essential if the challenges and inequalities of rare disease are to be addressed. Care that is integrated within the main systems of provision while providing the degree of flexibility needed to ensure it is appropriate and delivered at the right time and the right place. Such flexible, integrated, person centred approaches are vital for the success of the visions of TYC; of Cohesion, Sharing and Integration, and all relevant health and social care and educational and economic frameworks for those

affected by rare disease. Including those with learning difficulties caused by rare disease.

Yours sincerely,

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## **Annex**

### **A UK-wide vision for rare diseases**

#### 1.1. All 4 UK countries will:

- promote equity of access – allowing everyone with a rare disease to follow a clear, well defined care pathway, providing high quality services for every individual through integrated personal care plans;
- offer a patient centred, coordinated approach to treatment services, specialist healthcare and social care support which takes into account the needs of patients, their families and others who provide essential support;
- deliver evidence-based diagnosis and treatment of rare diseases, developed through the best use of regional and national resources that are easily accessible by patients and professionals;
- support specialised clinical centres to provide expert, high quality clinical care and expertise to patients their families and carers and the patient's, multi-professional health care team;
- promote excellence in research and develop our understanding of and treatments for rare diseases;
- deliver rapid and effective translations of advances in the understanding of rare diseases into clinical care by creating appropriate infrastructure, care pathways and clinical competences;
- deliver effective interventions and support to patients and families quickly, equitably and sustainably;
- promote collaborative working between the NHS, research communities, academia and industry wherever possible to facilitate better understanding about rare diseases and how they can be best treated;

- support education and training programmes that enable health and social care professionals to better identify rare diseases to help deliver faster diagnosis and access to treatment pathways for patients;
- promote the UK as a first choice location for research into rare diseases as a leader, partner and collaborator.

The complete UK Rare Disease Strategy can be downloaded here <http://bit.ly/I8pV4I>