

Consultation
Transforming Your Care
Vision to Action



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

www.nirdp.org.uk
info@nirdp.org.uk

Transforming Your Care Vision to Action

Consultation Response from the Northern Ireland Rare Disease Partnership

January 2013



TYC Programme Team
Health and Social Care Board
12-22 Linenhall Street
Belfast BT2 8BS

Email: tycconsultation@hscni.net
Telephone: 028 9055 3790
Textphone: 18001 02890 553790
Fax: 028 9055 3625

14 January 2013

**Response to the Consultation on Transforming Your Care
Vision to Action
Northern Ireland Rare Disease Partnership**

Dear TYC Programme Team,

The Northern Ireland Rare Disease Partnership, (NIRD DP) is pleased to have an opportunity to respond to this consultation on Transforming Your Care – Vision to Action.

NIRD DP attach great importance to engaging constructively with policy makers and with service providers at all levels. We are anxious to contribute our knowledge and experience to discussions. We want to explore ways in which people living and working with rare diseases can work in partnership with the health and social care system to ensure the best possible care is accessible to those with rare conditions; making the most efficient and effective use of resources available to meet physical; educational; emotional and leisure needs at the correct time and correct place.

NIRD DP strongly believe promoting equality, and protecting the vulnerable, are fundamental core values within our society. We are firmly committed to the belief that those who have rare diseases, and those who care for them, are entitled to protection under the principles set out in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Convention on the



Rights of the Child (UNCRC). These Treaties are part of the body of international law, which the Northern Ireland Executive and its public authorities are bound to respect. We are interested in how principles established in both Treaties may be interpreted in relation to those who have rare diseases and their carers. We also believe that those who have rare diseases, and those who care for them, are entitled to equality of opportunity in accordance with the Northern Ireland Act 1998: Section 75. We therefore believe it imperative that robust efforts are made to promote equality of access and opportunity to health and social care, to education, employment and social activities both for those who live with rare diseases and for those who care for them.

In our view it is crucial that the opportunity created by Transforming Your Care to take rare disease issues into account is seized, so that the new policy framework:

- Embraces and enriches all relevant existing policies and strategies.
- Evolves with contemporary knowledge; experience; and improvement in technology; so improving provision of treatment and meaningful support within the community; and
- Develops an inclusive approach and an open mind to a mixed economy of care provision.

Summaries of our views on improving equality of opportunity within health and social policy; and recognising challenges faced in delivery of effective public health policy, are outlined in the following consultation responses submitted to the Department of Health, Social Services & Public Safety.

"Response to the Consultation on Outcomes of DHSSPS Equality Screening Exercises"

To: Legislation, Equality and Human Rights Branch; 10 December 2012.

"A Response to the Consultation on Fit and Well – Changing Lives (A 10-Year Public Health Strategic Framework)".

To: Health Development Policy Branch; 23 October 2012.

We are very keen to build on our existing work with the Health and Social Care Board and Public Health Agency. For example, through piloting care pathways for rare disease and, with continued collaboration, ensuring realisation of the full potential for creating sustainable person centred care.



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

Consultation
Transforming Your Care
Vision to Action

www.nirdp.org.uk
info@nirdp.org.uk

NIRDP hope that this Paper will be useful in the policy formulation process, at this key juncture in the reforms of health and social care in Northern Ireland, and in the UK generally.

We hope that this response will be the start of a more detailed series of conversations on the integration of rare diseases and their management within pathways of care as part of the implementation of Transforming Your Care.

Yours sincerely,

Christine Collins
Chair
Northern Ireland Rare Disease Partnership
Address: 6 Ava Crescent, Belfast. BT7 3DU
Tel: 07843256442
Email: info@nirdp.org.uk



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

Consultation
Transforming Your Care
Vision to Action

www.nirdp.org.uk
info@nirdp.org.uk

Transforming Your Care Vision to Action

Contents	Page
The Northern Ireland Rare Disease Partnership	6
Transforming Your Care	8
Northern Ireland Rare Disease Partnership Response	12



The Northern Ireland Rare Disease Partnership

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. Our membership includes people with over 30 different rare conditions ranging from the very rare to relatively well-recognised conditions such as Motor Neurone Disease, Spina Bifida, or Muscular Dystrophy. While each individual's condition is rare, these are not minority issues.

- 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 (or about the population of Derry/Londonderry.)

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. RDUK was developed in response to the unmet healthcare needs of the millions of people living with a rare disease, who currently struggle to get access to integrated care and support. 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. Additionally we are working with the Public Health Agency to develop a survey and engagement process to identify the experience of care in the community for those living with a rare disease; and 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.



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

Consultation
Transforming Your Care
Vision to Action

www.nirdp.org.uk
info@nirdp.org.uk

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.

We believe that we are “Stronger Together”; and our aims are to advocate, educate and innovate for all those living or working with rare disease.



Transforming Your Care

Format of NIRDP response

Rather than provide answers to the specific questions asked in the consultation document this response comments on the proposals set out in the TYC report, complimentary strategies and the TYC consultation document, with particular emphasis on the implications and opportunities for NIRDP, those diagnosed with rare diseases, those who directly care for them and those within HSC who provide professional support.

Transforming Your Care – the essential elements of change

We have set out below our understanding of the key changes to health and social care envisaged by TYC.

The desired outcomes from TYC are:

- Increased support for people to stay healthy, make good health decisions and where possible manage their own conditions. How TYC will do this is set out in a complementary strategy *Fit and Well – Changing Lives* a draft public health strategy which will shape and influence this outcome.
- More services to be provided locally with opportunities to access specialist hospitals if necessary.
- More people cared for at home, where it is safe and appropriate to do so. People would also have more choice and greater control over the types of service they can access.
- Investment in new technology will help people stay at home or receive care locally rather than in hospital – tele-monitoring. The 'Connected Health' initiative is already developing this strand of TYC.
- The development of Integrated Care Partnerships: doctors, nurses, community and social workers, Allied Health Professionals, the independent sector and the voluntary and community sector will work in partnership to keep people healthy and prevent them accessing hospital services when this can be avoided. These will not be formal partnerships but will require new forms of partnership working, commissioning arrangements and service level agreements.



In October 2012 DHSSPS asked the Health and Social Care Board to lead a formal consultation on TYC. The consultation document focuses on four areas:

- The health and wellbeing of the population, with an emphasis on illness prevention.
- The development of Integrated Care Partnerships and integrated care pathways
- The development of care networks with an investment in Health and Care Centres operating a 'hub and spoke' approach
- The development of primary and community care services, with an emphasis on elderly care, Long Term Conditions, (LTC) mental health and dementia services and those with learning difficulties. In addition, palliative and end of life care in a community setting where possible, (already well developed as a care pathway).

While these represent new ways of working, existing problems of over demand and a need for greater productivity in the acute network of hospitals continue to be addressed. The efficiency programme already underway, Quality Improvement, Cost Reduction (QICR) – broadly equivalent to QIPP in the NHS – will continue to reduce cost and increase productivity without compromising patient safety. Part of TYC's aim is to reduce acute bed provision by 180 across the acute network, including the likely reduction of the number of A&E services across NI.

Integrated care partnerships (ICP)

One of the major proposals in the TYC report is the development of ICPs. Seventeen are planned. They have been described in the TYC consultation as "*a collaborative network for local health and social care professionals, working as part of a multi-disciplinary team to come together to work in a more integrated way*". It also places emphasis on the independent sector and the voluntary and community sector (VCS) as delivery partners.

One of the challenges for ICPs is that while most people intuitively understand the concept there appears to be no operating model on which ICPs will be based. ICPs are the binding around TYC's vision of how service provision will be delivered in the planned 'shift left'. However the policy is still unclear and the HSC system is waiting to see how ICPs will be formed, the service level agreements underpinning them and the commissioning arrangements for the Independent sector and VCS.



It is anticipated that the initial focus for ICPs will be improving key aspects of the way services are organised for the frail and elderly and for services for specific LTCs such as COPD and diabetes.

We understand the main emphasis of ICPs will be on proactively identifying patients most at risk of unexpected hospital admission and putting plans in place to prevent this. This will probably be organised around pathways of care for the elderly or for those with LTCs and mental health issues.

One of the measures of success will be the reduction of 180 acute hospital beds in the next 3-5 years as a direct result of prevention strategies. Also funding is based on a shift of 5% of current resource spent in hospitals to primary and community care services at a time when demand for hospital services is increasing. A significant behavioural shift in the mindset of patients and clients who regard their A&E as an Out Of Hours (OOH) GP service will also be required.

There is also an underlying assumption that ICPs will benefit from electronic patient records management and sharing. This will also need to be developed.

Health and Care Centres

ICPs will operate as part of a network of services in each Trust area. The networks will be comprised of acute hospitals and potentially 35 hubs, providing a range of services under one roof which would normally be delivered in a hospital setting, including some x-ray and ultrasound investigations as well as outpatient clinics and potentially day procedures in selected hubs. This is in addition to GP services, AHP services and social care.

Further thought should be given to the range of services being provided by these hubs to maximise use and the return on investment. Related community services, especially for the frail and elderly, or those with mobility or learning difficulties should be considered. For example, benefit support with the introduction of Universal Credit working with DSD, the provision of on-line Council services and other transactional services which will embed hubs as truly community facilities.

Outlying GP practices within the network area will provide the spokes to the hubs. The intention is that through the hub and spoke configuration many services will be provided to elderly patients, those with LTCs and with multiple chronicity to avoid unnecessary hospital visits or admissions. The hospitals in the networks would provide clinical expertise within the network working with their ICP. The expectation is that hospital clinicians will also work within the hubs as part of the wider area network of care, for example to provide outpatient consultations.



This is an ambitious plan which will require detailed planning of the hub and spoke provision, the services provided within the hubs and networking arrangements with their acute hospitals. Only around 6 hubs exist or are in the development stage with additional Health and Care hubs being built following what is described as "*the usual business case processes and consultation*".

Integrated care pathways

As indicated above the emphasis will be on preventing hospital admissions through greater preventative interventions and community care. Those specifically mentioned are:

- Older people
- Long Term Conditions
- Palliative and End of Life care
- Mental Health
- Learning disability
- Physical disability and sensory Impairment
- Family and Child Care
- Maternity and Child Health
- Acute Hospital Care and configuration

The very significant change planned will place demands on the current workforce and its capacity and capability to deliver the changes required. It also requires building new partnerships and developing new procurement arrangements with providers; a greater use of technology both as part of the Connected Health agenda and for sharing patient records, where everyone will have an Electronic Care Record.



Northern Ireland Rare Disease Partnership Response

NIRDP accepts that there is a compelling case for change in the way current HSC services are configured and delivered. The current period of austerity in public spending and the growing demand for services, if not directly addressed, will at present forecasts result in a £660m per year funding gap in HSC by 2014/15. Without radical action HSC is facing a period of unplanned and haphazard change with the potential consequence of delivery failure.

The over-reliance of the acute hospital network for many services which could and should be delivered through primary and community care is not new. In 2002 *Developing Better Services (DHSSPS)* recognised that over 70% of people attending an acute hospital need not be there, but little has changed to reduce that percentage in the interim.

The demise of OOH GP services has only served to exacerbate the problem. GP services remain under considerable strain. The constraints of the reduction in OOH GP services must be addressed and will require, if not 24/7 cover a flexibility and willingness on the part of GPs to change work patterns to allow greater access to GP services over the course of a day.

While Northern Ireland operates an integrated health and social care system, the inability of the system to cope with the demand for social and community care services means that many people stay longer in hospital than is necessary. Unfortunately hospitals are not safe places. Outbreaks of infection are all too common. We recognise that a mixed economy of community care provision already exists, with charities, social enterprise and the voluntary and community sector delivering a range of local services, or alternatives within the established commissioning framework.

Unfortunately neither the TYC Report nor the consultation document move beyond the broad strategic direction of travel for change and it is very unclear how these changes will be implemented. For example much of the 'shift left' in services will be into Health and Care centres in Northern Ireland acting as a hub for a range of services, including GP clinics, outpatient and minor day procedures, allied health services and diagnostic services, which will avoid the need to attend at hospital. These centres will support a range of GP surgeries in a 'hub and spoke arrangement. In turn these will be part of a network of supporting hospital services.

It is unclear when these hubs will be developed beyond the initial pilots being undertaken and consequently how the 'shift left' of services essential for TYC is to succeed. We have concerns as to how the hubs will be funded and the speed with which they will be developed under the glacially slow "usual business case



process". We are also concerned about uptake from independent practitioners such as GPs or Allied Health Professionals and how they will be incentivised to use them. From a rare disease perspective we know that it is essential for any "shift left" in day to day care to be matched and balanced by a "shift right" to ensure that there is easy and speedy access to specialist centres; including centres outside Northern Ireland. It is absolutely crucial that those affected by rare disease have appropriate and timely access to centres which have the critical mass and resources to provide specialist diagnostic and assessment facilities; and where clinicians possess the training and skills necessary to draw up treatment plans which are indispensable for quality care and support.

We also have concerns about the development of Integrated Care Partnerships, which will replace the Primary Care Partnerships (PCP) already in existence. Beyond the TYC report and the consultation document we are unaware of any further policy development which provides the detail of how these partnerships will operate, or the incentives required to drive the necessary collaboration between partners in the ICPs.

In particular, while NIRDP welcomes the recognition that charities and the VCS play in providing support to the HSC system and the role of the voluntary and community sector as a delivery partner within ICPs is unclear.

While clarity on the above is desirable, NIRDP realises that changes of the scale set out in TYC will of necessity take time. The changes will also be conditional on additional funding being provided or sourced to implement the planned changes and start the planned infrastructure investment in health and care centres.

It would be relatively easy for the VCS in these circumstances to wait and see how the planned changes might take effect before establishing their role. NIRDP believes that if TYC is to succeed charities and the VCS must align their activities in ways that will complement and add value to the development of ICPs and pathways of integrated care.

We have set out below our initial thoughts on supporting rare diseases within the TYC operating model and in particular where NIRDP might deliver a range of services within an integrated care setting. We are aware that our vision of care must complement analysis of need within population plans and go beyond an offering in its own right. However we would also wish to challenge a commissioning model where we simply respond to such an analysis without considering different ways of service delivery.

Our experience is that such a commissioning model has largely failed the needs of those with rare diseases due in large part to the lack of information and opportunities for meaningful engagement, leading to a lack of awareness and understanding of need. Consequently this response also considers how services



might best be designed and procured to foster co-design and innovation in the type of services commissioned and the way these are delivered.

Supporting Rare Diseases

Currently, while many individuals do receive good health and social care, NIRDP believe that those affected by rare disease are often marginalised and disadvantaged due to a condition being rare and largely misunderstood. Integration of care within other groups is to be commended; however there needs to be a much greater recognition that rare disease creates different needs, experiences, issues and priorities in relation to policy and service delivery decisions. At present we feel that these aspects of rare disease are under-represented in health and social policy.

The comparative numbers of those with rare diseases (where ultimately there may be no cure) has in the main meant that care is left to family and friends, with very little professional direct support or understanding of the special requirements of those with a rare disease. As with all such circumstances there are examples of excellent clinical, social and community care which sadly, are the exception which proves the general rule. It is fair to say that the support groups and charities which make up the NIRDP had their genesis in necessity, providing care for family and loved ones on a mainly self-help basis with little opportunity for respite.

However with time the range of care provided and the understanding of the management of conditions has grown. Today, the organisations which make up NIRDP are well networked across the UK, Ireland and beyond. They are already delivering a range of services to members, as well as training and development on the management of rare diseases to health and care professionals. Their organisation and governance arrangements are both professional and robust and they are acknowledged as providing a constructive role in shaping healthcare policy for rare diseases.

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 manifestation of a rare disease in a patient or client. Health 2020's major report '**Forgotten Conditions: Misdiagnosis and unsupported, how patients are being let down**' affirms what those within the rare disease movement already know.

'A new report by influential think-tank 2020Health covers the growing problem of GPs missing or misdiagnosing rare diseases. The report 'Forgotten Condition: misdiagnosed and unsupported, how patients are being let down' criticises those professionals whose overwhelming focus is on treating a handful of major illnesses rather than developing systems for diagnosing than treating the



increasing number of rare disease. As a result, thousands of people suffer for years with misdiagnoses and inadequate treatment’.

We recognise that it is asking too much to expect a wide or detailed knowledge of all rare diseases which may present to a GP, or other health professional, once in their professional career, and certainly less frequently than more ‘mainstream’ conditions. It has been our experience that where opportunities to learn are provided by rare disease support groups, through workshops and seminars, those, particularly within social and community care, seize the opportunity and are keen to learn more to enable them to provide better quality care. They, furthermore, recognise patients and clients with rare diseases to be uniquely isolated and vulnerable. Clearly, a vast and largely untapped knowledge and experience base of rare disease care requirements exists at community level and can be accessed through NIRDP and its member organisations. We would encourage this engagement to take place as early as possible in the implementation phases of TYC.

Integrated care pathways

Rare diseases do not exist apart from other forms of illness or requirements of care. For example any one of the care pathways identified in TYC could have as a subset of care, a patient or client who has a rare disease. Indeed someone with a rare disease may require interventions on multiple pathways of care at the same time. This adds a further level of complexity to the design and delivery of care pathways in TYC. This scenario already exists, but we have a system of care which caters for mainstream conditions at the expense and exclusion of the understanding and proper treatment of rarer conditions.

Providing the equality of access to services and levels of quality care must lie at the heart of care pathway development. Allowing different care pathways to develop across Trusts will result in different approaches and the potential for inequalities in the delivery of care. We therefore advocate a **central design approach** to the development of integrated care pathways for rare diseases where the same template of care, best practice, quality and regulation apply across the healthcare system. We also recognise that such regional approaches must be capable of local adaption and sufficiently flexible through the work of Integrated Care Partnerships that local population needs come be met through local commissioning and procurement arrangements.

The implementation of TYC must strike this necessary balance of a centrally designed and managed series of integrated care pathways, locally adapted and delivered.

In the ‘shift left’ of services towards care in the home or community for the elderly or those with multiple chronicity or specialist needs, a more sophisticated mixed economy of care will be required. This must meet the needs of the



majority of conditions and their care requirements as well as the requirements of those with rare diseases or conditions which all too often fall out of the mainstream of care. That mixed economy of care already exists across the private, independent and voluntary and community sectors, including charities and social enterprises, but for TYC to really deliver on its vision of integrated care a much greater diversity in the types of care must be developed across that mixed economy to diminish existing health inequalities and promote inclusion.

Developing a new care model

Both TYC and the consultation documents have hinted (and no more) at the role of the voluntary and community sector (including charities and the social enterprise economy) in the delivery of services as part of Integrated Care Partnerships. This presents both challenges and opportunities. Already a sliding scale of non-statutory care exists both in the independent sector and the VCS. It is driven by a cost model where commissioning is on the basis of a standard cost of providing a service, for example in residential homes, day centres or domiciliary care. The size and capacity of organisations delivering care also ranges from well-established independent providers and social enterprises to small organisations whose existence is dependent on the vagaries of an annual injection of grant funding year on year.

It is clear that more of the services currently provided in support of care in the community by HSC could be provided by third parties. It is also true, as with rare diseases, that with the necessary encouragement and direct support, more charities and support groups would be prepared to develop and deliver specialised or 'niche' areas of healthcare which presently are sporadic in their cover or marginalised by the HSC system. To develop such a mixed economy of care will require a revision or invention of new policies and greater cross departmental working in areas such as:

- Capacity and capability development,
- Procurement (including commissioning for outcomes)
- Regulation and quality standards
- New outcome based measures of the Return on Investment (HSC specific)
- Developing delivery scale

There will be a continuing debate as to whether services should be offered to HSC by third party providers on the basis of perceived need or whether commissioning of third party services should flow from the development of Trust population plans and a needs analysis. That is a dialogue which has to date not



taken place to any meaningful degree and should be part of the design and development of integrated care pathways as part of the Implementation of TYC.

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 (p 15). 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' collapses and is further 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.

In conjunction with the Health and Social Care Board (Specialist Services and Long term Conditions Teams), the Regional Medical Genetics Service and Muscular Dystrophy Campaign, NIRDP is already undertaking the development of a care pathway (a Patient Journey) for Muscular Dystrophy. This has identified the importance of clear procedures to ensure early and accurate diagnosis.

It is NIRDP's experience that without much greater understanding of rare diseases, commissioners will not be in an informed position to know what type or level of support to procure. It is a cornerstone of partnership working.

NIRDP, as part of the emerging implementation phase of TYC, wishes to engage with HSCB and the Trusts to establish a new delivery model for the care and reablement of those with rare diseases in a way that complements and enhances the development of integrated care pathways.

We have provided a rough outline framework as to how this delivery model might look and the types of service which would be provided sub-regionally to raise awareness through education of the signs, symptoms and practical care issues of looking after those with a rare disease.



Integrated Care Partnerships (17)		
Multi-disciplinary teams working within VCS delivery partnerships	N I R D P	Older people
		Long Term Conditions
		Palliative and End of Life Care
		Mental Health
		Learning Disability
		Physical Disability and Sensory Impairment
		Family and Child Care
		Maternity and Child Health
		Acute Care in Hospitals

*The Northern Ireland Rare Disease Partnership has the most appropriate support network to meet challenges surrounding delivery of care to those who have rare diseases and their families.

Key components of the NIRDP contribution to this Framework would be:

- The provision of training and education, drawing on the specialist knowledge and experience of member organisations.
- Regional rare disease co-ordinators (ideally nurses with experience of rare disease, social workers or other Allied health professionals) who could form a network of support and knowledge for GP's and other practitioners; thus ensuring that care is appropriately managed and co ordinated. Examples of such coordinators, chiefly for single conditions, have been trialled and found to be very effective in preventing unnecessary hospital admissions elsewhere in the UK.

Benefits may be reaped through participation with Rare Disease Coordinators who:

- have received specialist training;
- developed core skills;
- accumulated personal experience of certain rare diseases;



- have access to named experts and an affiliation with a network of clinicians, nurses, social workers, patient organizations; individual patients etc.:
- through networking and collaboration with other Rare Disease Care Coordinators; professionals/organizations/patients/research projects etc. can help develop more efficient and cost effective protocols for investigation of rare diseases and care plans for patients; including up to date knowledge on the most effective treatments and resources available;
- have personal experience relating to general and individual problems that present for patients who have a rare disease and their carers ie physical, psychological, social, financial.
- play a role in maintaining registers of rare diseases within their catchment area.

Rare disease care co-ordinators are essential if those affected by rare disease are to be empowered.

Barriers to entry to a mixed economy of care

Commissioning and Procurement

The Voluntary and Community sector is a misnomer. It is not a sector as such, but an amalgam of many different organisations of different size and capacity, most with a common set of social values and a strong sense of community.

In general terms such organisations provide a diverse range of services, some organised as trading enterprises and others surviving on the basis of fragile funding arrangements, with every type of variation in between.

It is generally acknowledged that the VCS has a greater capacity for flexibility and innovation at the local level than the statutory sector, but this does not translate into current commissioning models. Primarily there is no mechanism to shape the way services are provided, or to discuss or contribute to the design of types of care which the VCS might deliver.

We understand that within the VCS there is an antipathy towards any commissioning model which is viewed as simply an extension of public sector service delivery in a model driven by cost. We have sympathy with this view insofar as it stifles any opportunity to identify and address need for marginalised groups in a partnership approach. As we have seen earlier the Health 2020 report clearly indicates that where GPs are largely ignorant of the signs and symptoms of rare disease misdiagnosis occurs. We do not believe that commissioning differs in this regard. **A much greater level of understanding must exist by commissioners of the complexities of care for marginalised groups sitting outside the mainstream of care before commissioning takes place.**



We would therefore advocate a network of **'touchstone' organisations** to discuss and help shape HSC commissioning conversations with the VCS. In terms of rare diseases NIRDP would welcome this role. We believe such conversations which take as their start point a discussion around outcomes without prescriptive solutions can lead to much greater innovation and flexibility in delivery models. Such conversations would be driven by the identification of need both by the VCS and by commissioners.

There is presently no mechanism for such structured conversations to take place, either to raise awareness or as a direct precursor to commissioning services.

Procurement

Many community and voluntary sector organisations struggle with the procurement process, which many see as over bureaucratic, prescriptive and cost driven. We believe that a commissioning dialogue as a prequel to procurement would provide the focus which would still meet procurement criteria, while allowing leeway to articulate delivery solutions which encouraged innovation. We would particularly encourage a greater emphasis on procuring for outcomes which allows innovation to flourish. To do so the procurement function must in turn develop much more sophisticated evaluation criteria to include such things as the Social Return on Investment (SRoI) to raise standards and drive better health and care outcomes. Moving to more sophisticated procurement arrangements should not be hampered by these challenges but embraced as part of culture of change which will be demanded by all participants in TYC.

Capacity and capability

We also believe that special emphasis should be given to **encourage and perhaps deliberately reward partnering solutions**. There is a wide disparity in the capability and capacity of organisations in the VCS and much of the VCS 'best practice' examples cited by HSC during the development of TYC are already at a level of scale or experience to undertake and participate in the transition to the 'shift left' model with relative ease.

If the VCS is to grow and provide the best spread of choice and experience in delivering support to HSC then other smaller charities and organisations need to be developed as well. We see opportunity for established providers to develop their offering by partnering with special interest charities such as NIRDP to increase the depth of their service offering, for example in domiciliary care provision.

NIRDP considers that its governance structures, policies and expertise are at a level where we would welcome a commissioning dialogue with HSC. We also recognise that other organisations who have delivery capacity struggle with the



governance arrangements, programme planning and financial management required to build confidence in commissioners.

We would therefore advocate that the policy interests of DSD, DETI and HSC in relation to TYC to develop delivery capacity in the VCS is helped by the development of **'incubation' support** to clusters of VCS organisations. This will provide the capability and capacity in partnership to give confidence to commissioners that both services and their management and governance meet the standards required of commissioners. Some incubation support already exists in the VCS, but we see a need to ramp up such provision with more support being drawn from (potentially) Local Government, Enterprise Agencies and the private sector.

Community at the heart of care

We would also like to see the development of services which are not just aimed at delivering support and care to individual patients or clients or within one care group, but also develop community inclusion through partnering. NIRDP has a special interest in supporting people with rare diseases, but we wish that to be done within the wider context of the integration of those with rare diseases into the fabric of the communities in which they live. We have outlined earlier how the effects of missed or misdiagnosis of a rare disease can impact on the entire fabric of a patient's social and economic life.

Understanding those with rare diseases or their changing pattern of need must flow through to other aspects of care and the provision of a range of services within the community. Leading as full and as normal a life as possible within a community rather than apart from it goes to the heart of our care strategy.

Regulation and quality standards

The greater inclusion of the VCS as part of the mixed economy of service delivery in HSC must never be to the detriment of care quality standards. NIRDP see this as a considerable barrier to entry into service delivery, not because we feel we are unable to meet standards of quality care, but because the quality standards and regulatory frameworks which underpin their measurement require greater clarity. Those standards should be commensurate with risk and be part of any commissioning dialogue referred to above.

Conclusion

We recognise that Transforming Your Care, while driven by necessity, would in any event be the right approach to managed change within our system of integrated health and social care. The emphasis on shifting services away from the acute network into a more managed and supporting system of community care is particularly important for the frail and elderly or those with long term



conditions. Equally, we recognise that the elements of very specialist care needed by many with rare conditions can only be met at highly specialist centres, or by developing innovative ways of bringing that very specialist care to the patients, in effective and efficient ways.

The member bodies of NIRDP have been supporting those with rare diseases in the community for many years, but with little support from HSC. As such rare diseases are marginalised and misunderstood by many HSC clinicians and healthcare professionals. The burden of care has fallen to family and friends to develop the support networks, expertise and research to cope with rare diseases. Consequently more knowledge of rare diseases and the forms of compassionate care required to manage these conditions resides outside the HSC system than in it.

TYC, and in particular the desire to develop integrated care pathways provides NIRDP and the HSC with the opportunity to mainstream knowledge of rare diseases across all pathways of care, through a programme of education and support services across all Trusts. NIRDP is willing to provide this service and be part of the ICP model.

We understand and are sensitive to the difficulties of commissioning sustainable quality services from the VCS. A new commissioning paradigm is required which must start with a dialogue around need where a greater understanding of conditions such as rare diseases will inform and drive a mixed economy of care which provides confidence to HSCB and Trusts as well as driving innovation in care delivery.

We realise that for HSC to get the benefit from such a model will require investment in supporting capacity building in the VCS and also actively driving and rewarding partnering approaches.

As a developing charity with long term sustainable objectives of care for those with rare diseases we believe that TYC provides both a unique challenge and a unique opportunity for the HSC system to engage with us to develop models of integrated care for rare diseases, working within the identified care pathways in TYC, as well as testing through dialogue how such services might be commissioned. We are willing and eager to commit to work with you now in a pilot to tease out those practical steps which might be replicated as good or best practice in the development of the VCS in effective integrated care partnerships.