Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan

A Cross Party Group on Neurological Conditions Inquiry Report

Chair's foreword

I express my thanks and gratitude to all those who contributed to this inquiry, and shared their professional and personal experiences with us. This report has been informed by the expertise of people with neurological conditions, carers, Royal Colleges, the NHS and the third sector.

The introduction of the Neurological Conditions Delivery Plan (NCDP) in 2011 brought a much-needed focus on improving services and support for people with neurological conditions in Wales. Building on the recommendations of the 2007 Independent Review of adult neurosciences in Wales, led by Mr James Steers, the plan promised a co-ordinated, all-Wales approach to raising standards.

Nevertheless, this Cross Party Group inquiry heard evidence that progress has been slow, and that people with neurological conditions are still experiencing unacceptable levels of hardship. Contributors described difficulties related to delayed diagnosis, lack of follow up support, barriers to accessing treatment and medication, low levels of availability of community services and poor experiences of end of life care.

It is undoubtedly true that the NCDP has begun to build the foundations for change. The Neurological Conditions Delivery Group (NCIG) told this inquiry of their achievements in creating a network to support service improvement, despite starting from a very low baseline in terms of coordination across Wales. This report celebrates the good practice that has been developed as a result of the strategic focus, funding and dedicated hard work that has been delivered through the NCDP.

However, the most prominent theme running throughout the evidence submitted to this inquiry was that of the long journey still to travel. It is clear that the focus on improving services and support for people with neurological conditions must be sustained if we are to make real change to people's lives. It is also evident that people with neurological conditions and carers must be partners in this process, helping to shape the future of services and to hold the system to account.

Mark Isherwood AM, Chair Cross Party Group on Neurological Conditions

1. Introduction

1.1 About neurological conditions in Wales

There are more than 250 recognised neurological conditions. In Wales, approximately 100,000 people are living with a neurological condition that has a significant impact on their lives.

Many neurological conditions are life threatening and the majority significantly affect quality of life.

Too often, people with neurological conditions in Wales report substantial barriers to accessing the treatment, services and support that they need from health and care services.

1.2 About the Neurological Conditions Delivery Plan

In 2011, the Welsh Government published a number of Health Delivery Plans[1]. One of these was the Neurological Conditions Delivery Plan (NCDP).

The NCDP provides a focus for improvements in the delivery of services and support for people with neurological conditions across Wales, both at local and national level. Each chapter of the plan looks at a different area. These chapters are:

- Raising awareness of neurological conditions
- Timely diagnosis of neurological conditions
- Fast, effective, safe care and rehabilitation
- Living with a neurological condition
- Children and young people
- Targeting research
- Implementing the plan

1.3 About this inquiry

While the NCDP has served as a useful catalyst to progress and the development of good practice, in 2019 people with neurological conditions, clinicians and charities raised concerns that it had not yet resulted in the degree of change which should be expected. They questioned whether the implementation of the plan had been effective in ensuring that treatment and care sufficiently meets the needs of all people living with neurological conditions in Wales.

Consequently, the National Assembly for Wales Cross Party Group on Neurological Conditions took action to conduct this short inquiry.

Its purpose was to gather evidence and to present the Health and Social Care Committee and the Welsh Government with recommendations for action to:

- Improve the implementation of the current NCDP; and
- Deliver a long term strategic approach to raising standards in treatment, services and support for people with neurological conditions in Wales.

Both written and oral evidence was submitted to this inquiry by a wide range of stakeholders, including:

- Individuals living with neurological conditions and carers;
- Charities representing people affected by neurological conditions;

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[1] Welsh Government website – Together for Health Plans

- Specialist clinicians;
- Royal Colleges;
- The Wales Neurological Alliance; and
- The Neurological Conditions Implementation Group.

Three oral evidence sessions were held. Two sessions were located in Cardiff, South Wales, and one in Wrexham, North Wales. A full list of contributors is provided in Appendix A.

2. Methodology

This report includes an overview of evidence submitted in relation to each of the chapters of the NCDP. It looks specifically at input regarding the outcome indicators included within the 2017 NCDP document[2].

As the purpose of this inquiry was to establish issues that are relevant to neurological conditions in general, specific points about individual conditions have not been made in this report.

Evidence was submitted in a range of different ways; in written form, at oral evidence sessions and over the telephone. Some of the information provided included good practice examples and data based on the results of research. However, the majority of evidence was based on the views and experiences of a wide range of stakeholders. The intention of this report is to faithfully present the evidence that was submitted to this inquiry. As a result, the report is not intended to be read as a scientific study and further research to verify the points made has not be undertaken.

3. Raising awareness

3.1 Outcomes indicators within this chapter of the NCDP

- Delivery of Patient Experience and Outcome Measures as a tool for indicating awareness levels
- Delivery of comprehensive education frameworks
- Delivery of Neurological Service User Forums
- Delivery of Once for Wales portal

3.2 What are the issues

'I think there is clearly a training need for GPs and practice nurses. They are not specialists, and neurology is a very small part of their training. It is very complex, but there is very little understanding of the symptoms and how it impacts on people's lives. The lack of empathy and some of the language that is used is very distressing… to be dismissed or to be told you are imagining it when you are in such debilitating pain and you are feeling so vulnerable and stressed and anxious.' [Individual with a neurological condition]

Evidence was provided to this inquiry which demonstrated low levels of awareness of neurological conditions within health and social care services. This

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[2] Neurological Conditions Delivery Plan: High standard of care for everyone with a neurological condition, Welsh Government, 2017

was evident prior to diagnosis, while people live with neurological conditions, and during end of life care. In some cases, individuals had experienced retrograde attitudes to the validity of particular neurological conditions which had prevented them from accessing treatment and support.

3.3 What has been achieved?

The majority of evidence that was submitted with regard to progress in raising awareness under the NCDP related to activity rather than outcomes or impact.

Co-production activity between NCIG, third sector organisations and individuals with neurological conditions was welcomed. In particular, contributors cited the joint working between NCIG and the Wales Neurological Alliance (WNA) to create a Patient Reported Experience Measure (PREM) as a positive step.

Discreet educational activity was cited by NCIG. They stated that:

- A Neurological Education Framework is being developed to support the training and development needs of staff working with people with a neurological condition.
- A Neurological Service User Forum is being established to inform awareness raising needs and future service improvements.
- Six people from a variety of professional backgrounds from across Wales have been funded to complete a clinical leadership programme delivered by Swansea University.
- Betsi Cadwaladr University Health Board (BCUHB) has hosted a number of highly successful Neurosciences Conferences and Study Days

Written evidence submitted by Vaughan Gething AC/AM, Minister for Health and Social Care provided an update on recent positive activity, saying:

'The Patient Reported Outcomes Measure (PROM) has been signed off by NCIG and work is ongoing with the value based healthcare team and Cedar (A combined NHS/Academic research organisation which sits within both Cardiff and Vale University Health Board and Cardiff University) to place the tool on a national platform. The PREM is being developed further in response to evaluation by the Wales Neurological Alliance.'

3.4 What challenges remain?

From the perspective of people with neurological symptoms, significant challenges still exist in relation to lack of awareness. They felt that the activity which has occurred in relation to the plan has yet to make an impact.

Many contributors were concerned by the lack of progress in relation to specific outcome measures within the NCDP for this chapter, e.g. the timetable for implementation of the PROM and PREM, the comprehensive education frameworks and LHB Neurological Service User Forums.

4. Timely diagnosis

4.1 Outcomes indicators within this chapter of the NCDP

- Improvements in waiting times for urgent, non-urgent and follow-up appointments
- Access to outpatient diagnostics

- Creation and auditing of referral protocols

4.2 What are the issues?

4.2.1 Delays

'There was a four month wait for my initial NHS appointment and I was in absolute agony – I had trigeminal neuralgia, which is excruciating electric shocks through your face.' [Individual with neurological symptoms]

Many individuals who gave evidence described negative experiences when seeking diagnosis. These negative experiences included long delays that have occurred during the time in which the NCDP has been operational. Many cited delays caused by lack of awareness or understanding of neurological conditions within the NHS, as mentioned above. Some contributors described having to find money to pay for private appointments when desperate for help:

Some people with neurological conditions wait months or years for a diagnosis. One third sector organisation told this inquiry '*Our members report an average of diagnosis of between two and 20 years... Mis-diagnosis is a major problem, and 98 per cent of patients who do get diagnosed within two years, have been seen on a private basis*'.

4.2.2 Lack of support for people with neurological symptoms waiting for diagnosis

One individual had waited for 13 months at the time of this inquiry and had not yet received a diagnosis. She made the point that support services for people with undiagnosed neurological conditions are not available, but would make a huge contribution to the lives of those affected. She said *'I have found that there are absolutely no support services available for people who are awaiting diagnosis… at a time when you need support the most because it is so scary and daunting and stressful.'*

4.2.3 Poor experiences of diagnosis

Examples were given of distressing experiences of diagnosis, e.g. being informed of a diagnosis in an insensitive way. One contributor said '*There are too many examples of cruel diagnosis*'.

In their written evidence, one third sector organisation told this inquiry '*We are aware of several people being given a diagnosis insensitively, over the telephone with little or no follow up information about the condition*'.

4.2.4 Impact of delay on services

Clinicians were clear that delays to diagnosis have a detrimental effect on NHS and social care services. One clinician said '*When neurological conditions are not diagnosed, these patients are visiting lots of clinics, which ties up services, and they end up more disabled! We need to diagnose and treat them.*'

4.3 What has been achieved?

4.3.2 Good practice examples

- Contributors welcomed the requirement within the refreshed version of the NCDP that LHBs and primary care networks should raise awareness of neurological symptoms with GPs, and ensure that people are referred to

secondary and tertiary care in line with national guidance and referral protocols.
- Cardiff & Vale University Health Board (CVUHB) has developed a call system for epilepsy specialist nurses (ESNs) to support Emergency Unit staff when a person presents with suspected epilepsy.

4.4 What challenges remain?

Contributors questioned whether awareness raising by LHBs and primary care networks had yet made a discernible impact on the diagnosis experiences of people with neurological conditions. They felt that the implementation of PREM for neurological conditions is likely to be very helpful in understanding changes as they occur, and reiterated the importance of gathering this data.

Management data in relation to the outcome indicators for this chapter was not provided, so it has not been possible to determine the extent to which these outcomes have been achieved. When giving oral evidence to this inquiry, Michelle Price, Clinical Lead for Neurological Conditions, told us '*One barrier or difficulty I think is the lack of data and measurement we have. I think until we start getting there it will be really hard to evidence improvement*.'

5. Fast, safe, effective care and treatment

5.1 Outcomes indicators within this chapter of the NCDP

- Access to treatment
- Emergency admissions
- Access to neuroradiology
- Unscheduled hospital admissions and length of stay
- Clinical audits against NICE guidelines

5.2 What are the issues?

5.2.1 Lack of consultants and nursing staff within neurological services in Wales

Access to neurologists and specialist nurses for people with neurological conditions was the most prevalent theme of evidence submitted in relation to this chapter. One third sector organisation pointed out that in 2015 Public Health Wales stated '*there is a significant shortage of consultant neurologists in Wales and some areas within Wales are not only poorly served by the number of consultants per head of population but have a non-existent specialist nurse input*.' [3]

One individual living in Powys explained the real life impact of this, saying '*From my point of view accessing services has been very difficult. I am in mid-Wales, North Powys. There is absolutely no specialist that covers our area. I was referred to Wolverhampton to see a neurologist there. So that for me is two and a half hour drive… I've got two young children so I have to coordinate school pick-ups and stuff because it is essentially a whole day to go to the neurologist*.'

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[3] Public Health Wales (2015) Neurological Conditions Needs Assessment Cardiff, Welsh Government

Recruitment was identified as a key challenge, one clinician said: '*Recruiting specialist nurses in certain areas is incredibly difficult'.*

One third sector organisation told this inquiry that they had received '*anecdotal evidence that the neurosurgery department and overall care teams at University Hospital Wales, Cardiff are heavily reliant on the goodwill of staff… Not only this, but we have also heard neurology community teams are also significantly under-resourced meaning some patients are unable to receive neuro-rehabilitative care in a community setting*.'

In addition, many contributors recognised the value that generalist neurological nurses can bring. They felt that due to the similarity of some neurological symptoms, input from generalist neurological nurses on chronic disease management might resolve some of the workforce challenges.

5.2.2 Lack of publicly available patient pathways

Individuals with neurological conditions expressed frustration at the lack of clearly expressed patient pathways for specific neurological conditions, as well as for routes to diagnosis. They felt that health and care services should be able to articulate what patients should expect from their journey through services, what the access points are and how their care and treatment should be coordinated.

One individual with a neurological condition who lives within the Hywel Dda LHB area, told this inquiry '*I struggle to know who to turn to regarding my treatment. There is no lead health board or neurologist that is in charge of my care. I get treated under four different health boards*.'

5.2.3 Limited focus on follow up

Some felt that there has been a lack of focus on addressing delays to post diagnosis follow up appointments. One third sector organisation told this inquiry '*timely follow up is becoming more and more difficult, resulting in less time to assess people effectively, discuss treatment options and manage risk*'. They went on to say that without this information, individuals don't know about treatment, services and support or how to access them.

5.2.4 Access to medications

Third sector organisations raised concerns about low levels of take up of some treatments, and delays in making medications available following NICE approval.

One individual talked about limited access to emerging treatment for their neurological condition, saying: '*New drugs have just been given the OK in Scotland but nowhere else. And there is an 11 month wait now to be seen at the headache clinic*. *But once you get on the right treatment you can be back to normal*.'

Others talked about the problems they experience when they have unscheduled hospital appointments. In particular, they provided examples of issues caused by changes to drug regimes when individuals with certain neurological conditions are admitted to acute care.

Third sector contributors stressed that the requirements on specialist services to manage the monitoring and follow up of emerging treatments and medications is already putting extreme pressure on teams that are already stretched almost to breaking point.

5.2.5 End of life care

Written evidence by some third sector organisations described a number of very poor experiences related to end of life care, particularly in terms of lack of knowledge of neurological conditions. They described one real life example of this, saying '*As she neared the end of her life, there was no privacy… There was no understanding of her condition on the ward and no input from the specialist team. They did not keep up to date records and there was little or no communication. We occasionally would see the doctor and he would speak to us but they just didn't give her the care that she needed*.'

5.3 What has been achieved?

5.3.1 Good practice examples

Contributors highlighted positive developments such as the creation of new posts, good practice guidelines and treatment innovations.

- Abertawe Bro Morgannwg University Health Board (ABMUHB) has worked with technology firm, DrDoctor, to ensure they get the most valuable data for both the patient and the clinician. This has resulted in plans to introduce multi- professional clinics for patients with highly complex needs, so that they don't have to travel to multiple appointments and reduce duplication of work.
- Partnership between BCUHB and the Motor Neurone Disease Association to the recruitment of care coordinators as first point of contact, liaising with consultants at the Walton Centre in Liverpool.
- Patients are involved in Disease Specific Advisory Groups (DSAGs) in BCUHB, regularly attending meetings and conferences.
- Cwm Taf University Health Board (CTUHB) Community Neurorehabilitation Service has set up a co-production committee to advise on service developments.
- CTUHB has also ensured that service users have had an active part in developing media resources and 'starring' in educational videos which will be available to clinicians and the public via inter and intranet sites.
- A UK wide study which is currently evaluating the effectiveness of short term integrated palliative care (SPIC) for progressive long-term neurological conditions over six sites across the UK including one in Cardiff and the Vales University Health Board (CVUHB).

5.4 What challenges remain?

Specific issues related to the progress of the implementation of the NCDP were raised by contributors. These included:

- Lack of consistency across Wales in terms of improvements, and in terms of applying good practice more broadly.
- Complexity of aligning neurological services with those delivered outside of neurology, e.g. by care of older people teams.
- Gaps in the evidence base on most effective models of palliative care which inhibit progress in this area.

Despite the best efforts of LHBs to create a support system for people with neurological conditions, contributors to this inquiry felt that the lack of specialist neurologist presence in Mid and North Wales has a significantly detrimental impact on their physical, mental and emotional wellbeing, and their ability to practically manage their conditions.

The refreshed NCDP published in 2017 stated that:

'Overall, the numbers of all kinds of neurological clinical specialists, be they doctors, healthcare scientists, nurses or therapists, remain low and this needs to be addressed.

However, it is important neurological services are organised in a way that is responsive to patients needs and make best use of existing resources. While increased resources are important, it is clear these resources need to be used differently to the way they are at present.'

LHBs and NCIG members were rightly keen to stress that there are flexible ways in which gaps in service provision can be filled, and that it is important to work with people with neurological conditions and third sector organisations to discern the exact needs of certain populations.

However, individuals with neurological conditions, third sector organisations and clinicians were absolutely clear this must be done alongside a push for sufficient neurology consultants and nurses to meet the needs of the Welsh population. In addition, that a review of current commissioning arrangements is likely to be necessary in order to achieve this.

As the NCDP acknowledges, numbers are currently not sufficient. This places expensive pressure on primary and acute care, and creates significant hardship for people with neurological conditions. Many contributors felt that this is one of the highest priority challenges to be addressed by Welsh Government as we move to the next stage of strategic improvement of neurological services.

6. Living with a neurological condition

6.2. Outcomes indicators within this chapter of the NCDP

- Access to services
- Compliance against NICE guidelines
- Availability of annual reviews

6.2 What are the issues?

6.2.1 Low levels of availability of community services

Many poor experiences were described by contributors, in particular in relation to a lack of availability of community based services such as physiotherapy, speech and language therapy, occupational therapy, continence advice and support, services that help people to be physically active, mental health services and emotional support.

One contributor told this inquiry *'Charities are picking up the slack where there is a lack of service provision. There have been pockets of investment but no consistency across Wales'.*

6.2.2 People moved out of hospital but left without support

Several contributors described incidents in which individuals were encouraged by medical staff to leave hospital rather than '*bed blocking*', but had subsequently received very little support in the community. One clinician said, '*I work front line. There is a lack of community support. People are promised the earth to unblock beds, then support in the community isn't made available*.'

One individual with a neurological condition described the impact that this has, saying '*I am meant to get home physiotherapy appointments… this doesn't always happen... I have to manage my own care and take letters, once they eventually arrive, to other appointment so my medical staff know what is going on elsewhere*.'

6.2.3 Lack of psychological services

In addition, lack of psychological support for people with neurological conditions was noted. The Royal College of Speech and Language Therapists pointed out the specific issues that this can cause saying, '*Neuropsychiatric services are significantly under-resourced in Wales, which leads to inequity and paucity of service provision. Cognitive communication deficits are prevalent within the neuropsychiatric population and are observed to impact upon an individual's ability to participate socially or to self-manage and access psychological talking therapies.*'

6.2.4 Low engagement levels from social care

Despite the focus on health and social care integration within the Social Services and Wellbeing Act (2014), many contributors reported difficulties in engaging social care staff. This was reported at both a national and local level.

One third sector organisation stated in their written evidence to this inquiry, '*From the outset NCIG has lacked Local Authority Social Service representation despite repeated appeals from NCIG members, the Chair and Welsh Government officials. Considering the emphasis within the Social Services and Well-Being (Wales) Act 2014 of working across sectors in collaboration, this lack of involvement hinders both cross sector service development and holistic care planning opportunities*'.

Another third sector organisation described a possible reason for this problem, saying '*At the moment the onus is on health to provide support for people with neurological conditions. In many cases these conditions can't be treated but only managed… Because there is often not a cure, health services, particularly therapists adopt other wellbeing approaches that could be better, and more cost effectively, delivered by social services, the third sector or the local community*.'

6.2.5 Questions raised about the impact of NCDP funding

Some questions were raised about whether NCIG funding had delivered the required impact. Many contributors mentioned the lack of outcomes and impact monitoring in relation to the funding. One third sector organisation told this inquiry that they felt funding in North Wales could have been better spent '*by investing in current services and third sector organisations who specialise in delivering services and outcomes to people living with neurological conditions*'.

6.3 What has been achieved?

The focus on providing financial investment to support the development of neuro-rehabilitation through the NCDP was welcomed by many of those who submitted evidence.

6.3.2 Positive progress

NCIG stated that they have created a task and finish group to focus on the work of the community rehabilitation services, and to better understand current pathways, patient flows and the value-added care. The group is currently looking at evaluative measures and interventions to offer recommendations for best practice and a consistent approach across Wales.

Figure 1 below sets out the funding provided by NCIG to NHS organisations and Third Sector partners across Wales to support NCDP priorities through the delivery of neuro-rehabilitation services

Project	Organisation	Funding	Description
Early Supported Neurology Discharge Team (ESD) / Community Neurorehabilitation	Abertawe Bro Morgannwg University Health Board	£152,000	To further develop the existing community neurological rehabilitation services.
Community neuro-rehab service (CNRS)	Aneurin Bevan University Health Board	£206,000	To support the expansion of the community neuro-rehabilitation service to support acquired brain injury.
Establishment of a level 2 neuro-rehab unit in N Wales	Betsi Cadwaladr University Health Board	£100,000	To undertake a feasibility study about the development of an inpatient neurological rehabilitation service in Llandudno Hospital.
Community neuro-rehab service	Cardiff and the Vale University Health Board	£174,000	The development of an integrated community neurological rehabilitation service.
Multidisciplinary Community Neuro-rehab Team	Cwm Taf University Health Board	£117,000	To further develop the community neurological and stroke rehabilitation service.
Stratified, integrated community neuro-stroke rehab	Hywel Dda University Health Board	£145,000	Investment in the specialist community neurology rehabilitation service.
Community neuro-rehab service	Powys Teaching Health Board	£96,000	Support to increase the numbers of patients attending community neurological clinics.
Specialist physiotherapy service for adult patients with neuromuscular (NM) conditions and Family Care Advisor	Wales Neuromuscular Network	£120,000	Specialist physiotherapy service for adult patients with neuromuscular (NM) conditions For NM patients and their families, the Family Care Advisor role is critical in coordinating their care across organisational boundaries.

WHSSC Paediatric Services	Welsh Health Specialised Services Committee	£150k	Supporting children and young people with a neurological condition.

6.3.3 Good practice

- ABMUHB has developed links with community providers who helped to integrate patients into the community following brain injury. This has included the development of roles to tackle the social isolation, preventing re-admissions to the health service and supporting patients to return to work. Community partnerships that have formed part of this initiative include: Down to Earth, Surfability, Active Wood, Cae Tan Agriculture Project, Mi Space Construction, Swans Community Trust, Headway, the Stroke Association and Swansea Hacker Space.
- ABMUHB and Hywel Dda University Health Board (HDdUHB) have a shared psychological resource, and their use of a co-productive approach has been mirrored. The services have worked with the same Third Sector organisations plus the Botanical Gardens and Farm Projects in Pembrokeshire; representing the needs of their rural population.
- Significant improvements in access to community rehabilitation for people with head injuries in Aneurin Bevan University Health Board were cited.
- Similar community partnerships have been developed by Cardiff and Vale University Health Board (CVUHB) with the third sector, to develop and support the provision of the following activities: Let's Get Moving, Walking Football, Swimming, Golf and Sailing programmes
- CVUHB has also introduced the 'step model' of psychological interventions within their neurological services to bring the right skills to the person's need and taking on board the principles of prudent health care.

6.4 What challenges remain?

Although investment in neurological rehabilitation was welcomed, a large number of contributors were concerned that there is no available evaluation of the services that were funded. During one of the oral evidence sessions, one contributor said *'There has been no evaluation of the money that has been given for neuro rehab by NCIG so how do we know what progress has been made?'*.

Consequently, while most contributors welcomed the focus on increasing support for rehabilitation in the community, the poor experiences that were reported to this inquiry show that sustained focus and continued investment is likely to be necessary.

The Clinical Lead for Neurological Conditions described the complex range of NICE guidance that exists in relation to neurological condition. This presents a challenge for NCIG with regards to tracking compliance, and suggests that resource and capacity to needs to be considered in terms of ensuring guidelines are adhered too.

7. Children and young people

7.1 Outcomes indicators within this chapter of the NCDP

- Unscheduled hospital appointments

- Urgent and non-urgent appointments
- Follow up and access to services
- Access to diagnostics

7.2 What are the issues?

7.2.1 Lack of psychological support for children and young people

Evidence was provided that the psychological needs of children and young people with specific neurological conditions are not being met due to lack of access to neuropsychology and neuropsychiatry through paediatric services.

One third sector organisation described the results of a Freedom of Information Act request they had made to LHBs in relation to condition specific psychology and psychiatry support for children and young people with neurological conditions. Only three LHBs responded. None of these said that they provided neuropsychology through paediatric services for children and young people, and only one provided neuropsychiatry through paediatric services.

7.2.2 Access to treatments

Issues with access to specific treatments were raised. One organisation highlighted the fact that there is currently no UK centre that has capacity to deliver prolonged video electroencephalogram (EEG) services for Welsh children.

7.2.3 Transition to adult services

Room for much greater improvement in transition of children with severe neuro-disability was noted, including the identification of an adult service which can meet their needs. The Royal College of Physicians told this inquiry '*One of the issues for us is about transition from paediatric to adult services. Specifically, for neurology there are some transition, but with more children surviving into adulthood, there is a big gulf in the support network that these patients can access when they enter adult neurology, so a lot of them stay in paediatric services*.'

Examples were provided of young people who had lost contact with the system at the point of transition, and were then only referred back in to support services when it was '*too late*'.

7.3 What has been achieved?

7.3.2 Good practice examples

The Royal College of Paediatrics and Child Health noted several service improvements in their evidence to this inquiry, including the introduction of:

- A neurorehabilitation multi-disciplinary team (MDT), commissioned by WHSSC, has been established at the Children's Hospital for Wales (CHfW) within CBUHB. This provides a service to children from all health boards in South Wales who are inpatients recovering from a brain injury.
- A named clinician and a co-ordinator with responsibility for improving pathways for paediatric stroke in all the South Wales health boards are now in place.
- Improvements in waiting times for neuroimaging under general anaesthetic at the CHfW from 18 months to 8 weeks.

- A named paediatrician with an interest in transition of CYP with severe neurological impairment is now operational at CHfW.

7.4 What challenges remain?

It is concerning that NCIG did not provide any information in their evidence about implementation of the plan in relation to children and young people.

Evidence submitted to this inquiry highlighted specific concerns about deficits in children's services. They also highlighted significant concerns that neurological conditions affecting children, progressive and non-progressive, are often not followed up when children reach 18.

It is clear that much more work needs to be done to ensure that improvements in services for children with neurological conditions have an equal level of focus in the implementation of the NCDP. It is also apparent that attention should be given to improving transition to adult services.

8. Targeted research

8.1 Outcomes indicators within this chapter of the NCDP

- Increase in relevant research studies and clinical trials
- People with neurological conditions entered into trials
- External grant funding for neurological research
- Academic and industry collaboration

8.2 What are the issues?

8.2.1 Links between the NCDP and the research community

Questions were raised by some about whether the plan is sufficiently linked in to the neurosciences research community, and therefore whether it is making any impact in this area.

Contributors were concerned that there is not currently an active or reciprocal engagement between NCIG and the neurosciences research community, and that important areas of collaboration are likely to remain untapped. Submissions suggested that this is compounded by a lack of detail in reporting on progress towards achieving outcome indicators in this chapter of the NCDP.

Others highlighted the fact that the research agenda has benefited significantly from investment by the third sector.

8.2.2 Involvement of patients in research

The importance of involving the third sector in recruitment to research was stressed. Calls were made for action to deliver commitments regarding patient involvement, building on good practice examples such as the Patient Involvement Network.

Contributors of oral evidence in Cardiff also mentioned that they felt that progress had not been driven by the NCDP, and some attendees commented that they had not heard the plan mentioned in meetings with researchers.

8.3 What has been achieved?

8.3.2 Good practice examples

- Two Portfolio Studies relating to the collection of Patient Reported Outcome Measures (PROMs) in stroke and neurological conditions.
- Investment by Welsh Government, through Health and Care Research Wales, in the Wales wide BRAIN Unit.

8.4 What challenges remain?

Contributors were clear that research is a necessary priority for the plan. Based on evidence received by this inquiry it is clear that consideration needs to be given to the ways in which the NCDP could be best linked in to the research community.

Priorities highlighted by contributors were largely related to the involvement of individuals with neurological conditions in research design, and to close contact with academic establishments and third sector organisations that are commissioning research.

9. Implementing the plan

9.1 What are the issues?

Many of the organisations and individuals who submitted evidence to the inquiry focussed on opportunities, concerns and challenges related to the way in which the plan has been implemented. Some felt that it is very unlikely that the outcomes and performance measures in each chapter of the NCDP will be met by 2020.

9.1.1 Role of NCIG

The role of NCIG is clearing defined with the NCDP. **Figure 2** is the list of actions contained within the NCDP that defines the role of NCIG.

1. The Neurological Conditions Implementation Group will work in a co-ordinated way, at an all Wales level, to support Health Boards and partners to deliver the actions within this plan and achieve the desired outcomes.

2. The Neurological Conditions Implementation Group will agree a focus for delivery and priorities each year to provide clear guidance to Health Boards to support the production of their IMTPs; ensuring neurological conditions are fully embedded within their plans.

3. The Neurological Conditions Implementation Group will facilitate the sharing and implementation of best practice.

4. The Neurological Conditions Implementation Group will identify constraints and develop national solutions to common issues where a strategic approach is needed.

5. The Neurological Conditions Implementation Group will review and critically assess Health Board delivery plan actions in light of progress and new developments.

6. The Neurological Conditions Implementation Group will review appropriate outcome and performance measures annually.

7. The Neurological Conditions Implementation Group will allocate, monitor and report on the use of £1m annual funding from Welsh Government in line with the delivery against clearly stated priorities.

8. The Neurological Conditions Implementation Group will produce an annual statement highlighting progress made throughout the year.

9. Health Boards are required to monitor their performance against the Neurological Conditions Delivery Plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.

10. Health Boards to incorporate feedback from local Neurological Service User Forums into the work of their Neurological Delivery Group.

11. The Welsh Government will continue to maintain oversight of delivery and assurance framework and produce a national statement of achievement annually. It will also support and enable liaison between the Implementation Group and Welsh Ministers.

Contributors noted that when the NCDP was first introduced, there was little or no co-ordination across neurological services at an all-Wales level. Networks for conditions such as cancer, cardiac and renal services were well established at that stage, but this was not the case for neurological services.

As a result, the task that NCIG faced was complex and difficult. The Clinical Lead for Neurological Conditions explained during her oral evidence, '*We were coming from such a very low baseline… We felt it was important to allow organisations to bid against what was the next step in their journey*.'

Despite the scale of the change programme that NCIG has been tasked with, the vast majority of NCIG members do not have ring-fenced time within their roles. As a result, many contributors felt that the already difficult task that NCIG has had to undertake has been hampered by a lack of consistent membership from LHBs. This in turn has led to differences in progress with implementation across LHBs.

In the view of contributors to this inquiry, those LHBs with consistent representation at NCIG, a designated LHB neurological lead and a specific LHB Neurological Steering Group or lead appear to be making greater progress.

As previously stated, work with NCIG is expected to be undertaken on a 'voluntary' basis by LHB representatives. Consequently, contributors have observed that they experience challenges in terms of time capacity, ownership at the right level and ability to work strategically rather than focus on potential vested interests for their own LHB.

This is further exacerbated as local NCDPs do not appear to be effectively embedded. When giving oral evidence, the Chair of NCIG told this inquiry '*The link between the national discussions, and the regional discussions just hadn't been there. They are there now. But I was quite surprised. So, I think there is a* *challenge around communication, and making sure that we have the right people around the table and that those links locally are actually working*.'

Several contributors also noted that relevant parts of the NHS often seem unaware of the NCDP. This makes it more difficult to create improvement across service boundaries, e.g. with care of older people teams.

9.1.2 Clinical Lead for Neurological Services

The appointment of a Clinical Lead for Neurological Services in 2018 was warmly welcomed. However, a note of caution was sounded by many as the role only has one day per week ring-fenced time, and the appointment was made relatively late in the implementation process. One third sector organisation told this inquiry '*Prioritising a clinical lead for neurology from the outset would have emphasised the seriousness of intent for the Delivery Plan to effect real change. Given that this has worked well for other condition-specific plans, there would have been greater opportunity to lead and direct change under this plan. However, it is still very early days since the appointment to evaluate*.'

9.1.3 Inconsistent roll out of good practice

Contributors were particularly concerned that pockets of good practice which are being developed as a result of the NCDP are not being effectively replicated across the country. One explained their view of what was happening on the ground, saying '*There are some specific examples of local improvements… but these successes do not seem to be replicated at the all-Wales level'*.

9.1.4 Lack of management data and monitoring

While information on the projects that NCIG has funded was provided to this inquiry, no monitoring information in terms of outcomes achieved or impact of this work was supplied. This also seems to be the case in terms of publicly available information about this funding. Many contributors stated that this funding was much needed and very welcome, but were baffled as to why information on what this spending has achieved is not available. Consequently, they feel it is difficult to ascertain whether the monies allocated to plan have changed the lives of people with neurological conditions sufficiently, bearing in mind the lack of tangible evidence of their impact.

Third sector organisations, individuals with neurological conditions, royal colleges and NCIG were all concerned by the lack of robust and consistent local, regional and all-Wales data in relation to services and support for people with neurological conditions. When giving oral evidence, the National Clinical Lead for Neurological Conditions told this inquiry '*We don't have that data to drive our priorities at the moment. I think we need to get to that point but to date we don't have a resource within the NCIG to pull that together*.'

Many contributors were disappointed by the way that information on progress towards the delivery of the refreshed NCDP at a national level is presented. One contributor '*The Wales Delivery Plan Annual Statement of Progress lacks detail on progress against all outcomes and is selective in highlighting pockets of good practice against a particular condition or service, or in a particular geographic area. Whilst it is good to hear about such progress, the selectivity of a few examples highlights the patchy progress of the Delivery Plan.*'

9.1.5 Funding concerns

Several of the submissions of written evidence suggested that progress with implementation of the NCDP has been slow because neurological services in Wales are '*chronically underfunded and have problems attracting and retaining staff*'.

Examples were provided of the uncertainty caused when there are changes in funding for partnership working between NHS and voluntary sector. It is suggested that, for the NHS to work effectively with charities and other organisations to deliver person-centred services there needs to be funding arrangements which support organisations who provide those services to do so on a stable basis.

9.1.6 Limited progress in co-production with people affected by neurological conditions

Contributors questioned the extent to which the plan had enabled genuine co-production and participation with people with neurological conditions and carers. They expressed disappointment with the lack of discernible progress in setting up a Neurological Conditions Service User Forum in every LHB. One third sector organisation told this inquiry '*Neurological Service User Forums have not been established across Wales as intended by the plan. It is not evident whether Health Boards or NCIG have drawn on feedback from service user forums'*.

9.1.7 Partnership working with third sector

Third sector involvement in NCIG was perceived as positive. However, concerns were shared that third sector involvement generally is patchy, inconsistent and not equitable across Wales or by condition.

In addition, it was noted that many smaller charities do not have the resources to send representatives to strategic planning groups or to work in partnership across all LHBs.

One submission suggested that there is a reluctance by NHS staff to refer to community-based organisations. It went on to raise concerns specific to the value placed on third sector collaboration by BCUHB in North Wales.

9.2 What has been achieved?

9.2.1 Positive progress

Outcome indicators and assurance measures for this chapter are not stated within the NCDP 2017 itself, but the following statements of expectation are included:

- *Health boards are required to monitor their performance against the Neurological Conditions Delivery Plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.*
- *The Welsh Government will continue to maintain oversight of delivery and assurance framework and produce a national statement of achievement annually. It will also support and enable liaison between the Implementation Group and Welsh Ministers.*

The Chair of NCIG described the significance of the plan, and the leap forward in improving treatment, care and support for people with neurological conditions that it represents, saying '*This has been the first opportunity to get people around the table on an all Wales basis from a clinical, managerial, third sector, patient voice perspective. Being able to share conversations and be able to move things forward in a comprehensive way across Wales*.'

Many contributors welcomed the recent appointment of a Clinical Lead role for neurological conditions. They welcomed the fact that the Clinical Lead has begun defining the areas of required intervention, and identifying clinical pathways, underpinning clinical services and the underpinning principles.

In his written evidence, Vaughan Gething AC/AM, Health and Social Care Minister told this inquiry that '*Having a dedicated clinician with protected time to take forward the actions within the neurological conditions delivery plan is a significant step forward for neurological conditions in Wales and we have already begun to see the benefits that having such a post can bring*.'

The Chair of NCIG also highlighted the prioritisation of key areas of work by NCIG for example, the focus on community rehabilitation as a priority area for action. She told this inquiry, '*We recognised that there were vast gaps in service provision, different organisations in different patches were at different points. So, we took a pragmatic approach. Michelle was involved in writing a 'Blueprint' of what a good neurological rehabilitation service should include, and then we invited everybody to bid against that blueprint with a view of wherever their baseline was it was the next step towards that ideal place.'*

Several contributors agreed there have been common aims between NCIG and other areas of NHS improvement, for example with the team working on the development of PREMs in Wales, there have been positive results in addressing duplication and ensuring common solutions.

9.3 What challenges remain?

9.3.1 Maintaining the work of NCIG

Contributors to this inquiry were very clear that it would be extremely detrimental to lose the focus on service improvement and networked approach that the NCDP has introduced. There are so many challenges that need to resolved, it is clear that this focus should be sustained.

The Chair of NCIG explained that it has taken a long time to establish a network and ways of working which have enabled good practice to develop. She told this inquiry that this should continue and be further strengthened '*I think there has to be a national forum on neurological conditions. I think the membership of that needs to maintain the membership that we have currently [within NCIG]. There may be other partners we need to think about, but we need representation from all of the organisations, including third sector, clinical and operational management and social care, multidisciplinary and multiagency*.'

9.3.2 Accountability for delivery

The NCIG Chair and Clinical Lead for Neurological Conditions told this inquiry that they didn't believe there was a mandate to hold LHBs to account for critical elements of implementation like workforce development strategy. The NCIG Chair said '*I don't think NCIG can hold organisations to account, I don't think that it the role of NCIG. I think from the perspective of the priorities and the* *annual reports of progress, I think NCIG can and has been the monitor of what is going on'*.

If this is indeed not the role of NCIG, then it could be suggested that this accountability should be provided by another means in order to effectively incentivise service change.

9.3.3 Information and communication

Many contributors felt that communication about delivery to stakeholders and the wider public needs to be improved. The newly appointed NCIG Co-ordinator told this inquiry that establishing a national communication platform is critically important. She also explained that communication has been a challenge common to this kind of delivery plan, saying '*they have all had that issue in terms of cascading that information in a two way format and getting that information down to the people who are actually on the ground'*.

9.3.4 Lack of management data

The NCDP lead in BCUHB gave evidence which stated that they do collect and analyse management data in terms of re-admission rates, waiting time, length of stay in hospital, etc. This demonstrates that it is possible to cut through the complexity in terms of numbers of conditions and associated pathways in order to collect data. However, all-Wales data of this kind was not provided as evidence to this inquiry.

The Clinical Lead for Neurological Conditions told this inquiry, '*I think we need to get to that point but to date we don't have a resource within the NCIG to pull that together. I think going forward it looks like they are starting for the next iteration of the national clinical plan I think data and having the resource that pulls out data to evaluate, because it should be one of the universities is able to do a proper, it's a whole skill set that you need*.'

9.3.5 Weakened reporting requirements

Many contributors were concerned that since 2017, robust and visible reporting has not required of LHBs. Consequently, they told this inquiry that they do not feel able to assess whether there has been any real progress. One third sector organisation stated '*Since the Health Secretary removed the requirement for individual LHBs to publish annual neurological delivery plans and annual reports it has been more difficult to consistently consider progress generally or at an individual LHB level.'*

It was noted that to date LHB Integrated Medium-Term Plans (IMTPs) have not been effective at driving change on NCDP priorities. The point was made that they often do not have neurological specific sections, and that any neurological service references can be dispersed under different IMTP sections.

10. Successes and challenges

10.1 Successes

'*The plan provided a real opportunity to shine a spotlight on neurological conditions, raise awareness and address key issues, common to neurological conditions, that necessitated improvement*.' [Third sector organisation]

Contributors were clear that the greatest success of the NCDP is that it has created a focus on the needs of people with neurological conditions in Wales. It has thrown a spotlight on the factors that have been missing in terms of strategic delivery of services for neurological conditions – e.g. networks such as those that exist for cancer, cardiac and other conditions. It has provided an opportunity and structure for individuals and third sector organisation to share their concerns and poor experiences. As a result, it has allowed those involved in implementation to begin to take action to address unmet need and to find solutions to challenges.

10.2 Challenges

'*Five years on from the plan's inception there remain real challenges and little evidence of positive change… across all of the thematic areas of the plan*.' [Third sector organisation]

NCIG has worked hard to establish a baseline, and is beginning to promote good practice and marshal pragmatic improvement activity. Contributors to this report were clear that it is vital that a group such as NCIG should continue to exist and be embedded more permanently, in order to deliver a better networked approach to promoting ongoing improvement and efficiency across Wales.

However, a great many contributors cited the lack of management data related to the outcome indicators of the plan and the delivery of diagnosis, treatment, services and support for people with neurological conditions as a significant problem. They felt that it would be impossible to track improvements over time without a properly resourced mechanism to gather and publish this kind of data.

In addition, many individuals with neurological conditions and third sector organisations raised concerns about whether patients and carers have been genuinely given the opportunity to take part in service improvement.

Contributors mentioned the context of the delivery of the NCDP in terms of austerity and increasingly limit resources. Many mentioned specific cuts to neurological services that have had a negative impact on access to treatment, services and support. This has increased travel time and costs for individuals with neurological conditions, which has a very negative physical, emotional and financial impact on people and can result in them not accessing that treatment and care they need at all.

In part due to the low starting baseline, the NCIG has yet to deliver anything like the scale of change that is required to ensure that people with neurological conditions across the whole of Wales have safe, timely and equitable access to treatment, services and support. While the current approach has begun to yield positive results, it will not be possible to create the step-change which is needed without wider strategic commitment from across the NHS, from Welsh Government and from local authorities at a senior level.

This includes action to manage the disconnects that occur when care for people with neurological conditions falls under different sections of NHS services (e.g.

older people’s services, acute, community, general practice, social care etc.), and the wide disparity of commissioning arrangements across Wales. Steps must also be taken to address what contributors to this inquiry described as the ‘*chronic underfunding*’ of neurological services, and the significant challenges of ‘*attracting and retaining staff*’ in order to address unmet need.

11. Recommendations

11.1 Recommendations for the current NCDP

In order to deliver the objectives of the current plan and respond to the concerns raised during this inquiry, we recommend that **NCIG and LHBs** should be asked to commit to the following:

1. Deliver specific commitments related to the outcome indicators within the NCDP by the end of 2020, and that regular information on progress is publicly available. This should include the delivery of:
    - Comprehensive education frameworks
    - LHB Neurological Conditions Service User Groups
    - The Patient Reported Outcome Measure
    - The Patient Reported Experience Measure
    - A one stop shop information portal
2. Ensure that the Annual Statement of Progress reports delivery against the actual outcome indicators included within the NCDP, using any management data available.
3. Ensure that information on outputs and activity related to the NCDP is publicly available.

11.2 Recommendations for the next stage of neurological services improvement

We urge **Welsh Government** to take the following action when the NCDP comes to an end in 2020:

1. End the '*chronic underfunding*' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.
2. Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.
3. Commit to a workforce development and commissioning strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with neurological conditions in a timely manner and an appropriate place.
4. Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.
5. Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.[4]
6. Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current

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[4] *This recommendation has been made in response to statements from NCIG that they do not feel it is their role to hold LHBs to account, and to address questions about conflicts of interest when those involved in the delivery of the plan also have responsibility for accountability.*

NCIG model. This should include funded posts for a Clinical Lead and a coordinator.

7. Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.
8. Ensure all LHBs publish Progress Reports against the outcomes of this plan which are easily accessible on LHB and Welsh Government websites, in the context of this simplified outcomes framework.
9. Mandate that each LHB should have:
    - A Neurological Steering Group with cross sector representation;
    - A Neurological Conditions Service User Forum, or other mechanism to support service user participation;
    - A named neurological lead; and
    - Full attendance by the lead or deputy at each NCIG meeting.
10. Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.

Appendix A – List of organisations who submitted evidence

Betsi Cadwaladr University Health Board

The Brain Tumour Charity

Dystonia Society

Epilepsy Action

Headway Cardiff and South East Wales

Motor Neurone Disease Association

MS Society Cymru

The Neuro Therapy Centre

Neurological Conditions Implementation Group

Royal College of Nursing

Royal College of Paediatrics and Child Health

Royal College of Physicians

Royal College of Speech and Language Therapies

Stroke Association

Parkinsons UK

Wales Neurological Alliance

Oral and written evidence was also submitted by a wide range of individuals with neurological conditions and carers, to whom we are extremely grateful.