

**Australian Parliamentary Joint Standing Committee on the National Disability Insurance Scheme (NDIS)**

Witness Statement: Lincoln Hopper (Townsville Hearing - 6 April 2016)

Introduction

Thank you for the opportunity to again present evidence to the Joint Standing Committee. My evidence will seek to update, inform and give comment to the Committee on :

- Readiness for the NDIS (1. individual/participant, 2. organisational and 3. systems/sector);
- ILC design, outcomes, commissioning; and
- Unique NDIS challenges facing Queensland

With the timetable and process of full scheme roll-out here in Queensland now formally announced, the pervasive sense of doubt and uncertainty is now finally dissipating and Queenslanders can, with emerging confidence, begin to understand and participate in the NDIS.

There remain many challenges to participation in the scheme for the 3,700 Queenslanders living with multiple sclerosis (MS) and the collective 130,000 Queenslanders living with a progressive neurological disease (PND) including MS, Huntington's, Epilepsy, Motor Neurone, Alzheimer's, Parkinson's, Friedreich's Ataxia and Leukodystrophy. Successful implementation of the NDIS will require a careful and deliberate focus on the PND cohort. Expert and deeply trusted organisations operating in the specialised/cohort- focused PND arena are the foundation for a smooth roll-out and operation of the NDIS in Queensland for the PND group.

Readiness for the NDIS*Individual/participant readiness*

We believe there remains a persistent lack of NDIS readiness amongst many people living with PND in Queensland. NDIS awareness, understanding and engagement by this cohort is highly variable (somewhat understandably considering the unpredictable and complex nature of PND). Experience of NDIS trial sites estimate up to half of people living with PND are unaware of the relevance of the NDIS to them and if aware, are unclear and anxious regarding how the system works in practice, how to engage with it and what the consequences of this will be on their individual circumstances. For example, many people living with MS do not automatically perceive themselves as having "disability" rather they see their situation more as a "health or medical condition", particularly the newly diagnosed.

Pre-NDIS roll-out education for the PND cohort is therefore doubly crucial to the success of the scheme here in Queensland as there is a risk that people affected by PND who do not identify with a disability or do not actively manage their disease state may later present in crisis with significant impact for the individual, the family and the services system. Given the strength of existing relationships between the 35,000-strong PND cohort and specialised/cohort- focused not for profit agencies in Queensland, we suggest funding be set aside for a state-wide pre-NDIS education to

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increase the base level awareness, knowledge and understanding of the NDIS and the relevance to clients with PND in Queensland.

### *Organisational readiness*

Whilst many PND specialised/cohort- focused not for profit organisations are doing their best to “get ready”, the unique characteristics of the PND sector are an additional challenge. Many of the organisations in Queensland are relatively small in size (reflecting their customer base) and do not have access to discretionary spending to prepare for transition to the NDIS (e.g. business practices, outcomes frameworks, marketing etc). Most are not direct deliverers of IFP-type supports, but rather deliver ILC-type and early intervention activities (e.g. information, referral, service co-ordination and support, capacity building). Most are under-resourced and all rely on a level of philanthropy to operate.

A lack of practical NDIS transition funding and support on the ground for these organisations in Queensland has left many vulnerable to closure and with it, the loss of deep and trusted relationships with the sometimes difficult to engage PND cohort and decades of irreplaceable specialist knowledge and know-how of PND. If lost, this will have a dramatic impact on NDIS participant outcomes and potentially long term scheme sustainability as PND customers present in crisis due to a lack of specialised early intervention and support.

Not helped by the previous lack of a trial site or gazetted roll-out plan in Queensland, great uncertainty has added to the overall lack of organisational readiness and organisations in Queensland being “further from the start-line” than otherwise would have been the case. Organisations desperately need assistance now to successfully make the transition to the NDIS.

### *Systems/Sector readiness*

People living with PND are often regular users of services across multiple jurisdictions including health, housing, education, employment, community, disability and aged care. Disconnections between/across systems creates serious gaps and confusion for people living with PND with regards to information, funding and service provision and a resulting lack of “ownership” of the person from each system.

At a systemic level there is a need to establish cross-sector collaboration so people can be supported while they build the confidence and skills to understand the way these many sectors will respond and work with them. This is a significant change for people requiring support and expecting people to be able to navigate and represent themselves will not be possible for some people in the first instance. Barriers, restrictions and eligibility criteria around each of these service systems need to be identified and removed to allow people where possible, to independently explore and navigate access.

Policy and funding that encourages systemic pathways of co-operation to stop the silos, duplication and fragmentation will streamline the experience of many and will alleviate the intense frustration experienced by those seeking services. This will limit the time expended by providers and importantly, deliver better productivity, financial and social outcomes to the entire NDIS.

### ILC design

Building the capacity of people living with PND to navigate across service sectors and within their community is vital and will reduce the need for intensive crisis-centred information, advice, support and complex case management. We estimate up to 80% of the PND community could be appropriately supported by accessing ILC alone, with timely access to information, services and support strategies at an individual, organisational and system level vital to the functioning and the long term sustainability of the NDIS. This will only be true if ILC is:

- adequately funded;
- delivered by PND specialist/cohort specific community organisations who have deep and trusted relationships with the PND cohort; and
- implemented prior to NDIS IFP (Tier 3) roll-out in each Queensland region.

PND specialised/cohort- focused community organisations have, over many decades, developed significant bodies of expert knowledge and experience and deep relationships that will be needed by the NDIA and allied community providers to ensure the best outcomes for people affected by PND. We therefore believe these PND specific organisations are best positioned to support the readiness of this cohort and to promote readiness of the sector, based on the strong track record of trusted relationships, genuine collaboration and information sharing and partnership with the health and community sectors due to the multiple and overlapping needs of people affected by PND.

There are some obvious benefits of PND specialised/cohort- focused organisations providing this role, which include:

- retention of specialist knowledge and expertise of PND-focused organisations and preservation of the important relationship of individuals, families and carers and staff within these PND organisations;
- improves the availability, timeliness and convenience of locality-based solutions;
- provides timely support to the majority of PND customers;
- can improve the capacity of the sector to address PND by training the broader workforce in the specificity of the individual progressive neurological diseases across the health, disability and aged care sectors; and
- provides a cost effective and financially sustainable approach through cross sector collaboration

The value of volunteerism must not be overlooked as important feature of ILC in building both community and individual capacity. Effective management of volunteers is critical (just the same as in paid human resource management) and organisations will need to be appropriately funded to ensure value is delivered to-and-from volunteers participating in ILC delivery.

### ILC commissioning

#### *Local Area Co-ordinators;*

We endorse the ILC Commissioning Framework Consultation Draft five priority investment areas.

Given the centrality of the Local Area Coordinator (LAC) role in ILC and being the “...*single biggest investment the Agency will make in delivering ILC outcomes*” (pg 13 of the Consultation Draft), the LAC will clearly be critical to the estimated 80% of the PND cohort who will be accessing ILC-only supports. As the pivot-point in the ILC-IFP continuum, the unpredictable and unique needs of the PND cohort would be best and most effectively served through a Queensland-wide PND

specialised/cohort- focused LAC response. A generalist LAC applied to the PND cohort simply will not work, as evidenced through the co-design process workshops where questions of LAC skillset were raised. If a lack of contracting size/efficiency were an argument against a cohort-focused LAC, we suggest the scale of the PND cohort (130,000 Queenslanders) is more than adequate to justify the LAC specific response for this cohort.

#### *Measuring ILC outcomes;*

Recognition of the local context needs to be incorporated into the measurement of funded outcomes. For example, a measure of: *“The percentage of assisted families who report they are able to gain access to desired services, programs and activities in their community”* (pg 34 of the Consultation Draft), clearly needs to take into account the actual level of availability of services in that community. Market failure in some parts of Queensland has resulted in some communities having no services to access and therefore would affect the ability of an ILC provider to satisfactorily deliver against this outcome.

Outcome measures taking into account quality of life are the ultimate “best” measure as seen from the end-customers own perspective. Standardised, validated and benchmark-able quality of life instruments already used in the disability arena (such as the AQoL8-D) would be worth considering amongst other measures proposed to assess the outcomes of ILC.

#### *Competitive Sourcing;*

We endorse the use of allocating funds on a competitive basis, however need to highlight the many smaller/niche PND focused organisations facing the disadvantage of having little or no resources/capability to prepare the required quality funding request (unlike large, national, well-resourced organisations).

We also question the utility of the main annual funding round process, with respect to:

- the annual disruption of awarding/renewal/removal of contracts (with associated loss of productivity, disruption to customers and loss of community cohesion and social capital);
- loss of connectivity with customers (revolving door of funded organisations)
- the potential “locking out” of innovative solutions outside of the funding rounds;

Funding allocation decision making should explicitly evaluate the actual cost/benefit of not awarding (at least initially) ILC contracts to incumbent PND cohort focused providers (or consortia if scale is required). This would, at a minimum, provide continuity of service and connectivity with the PND cohort during the critical NDIS transition and also provide time for the smaller/niche organisations to build a robust grant application (and thereby by levelling the “playing field” with larger, better resourced competitors).

Additional weighting should be given to scaled-up collaboration/consortia-based solutions put forward for funding in recognition of the complex needs of the PND cohort as well as the opportunity to support and preserve the expertise and know-how in the market of niche organisations which would otherwise miss out on funding due to their lack of individual scale.

### *Co-investment;*

Whilst not explicit, we suggest co-investment will also come from the sector itself. As a real-life example, please refer to Attachment *SPARK neurocare*, an innovative service delivery response funded by seven not for profit organisations in Queensland.

It may be due to a definitional issue, however we are doubtful that social impact investment (definition: generating a social impact alongside a financial return) will be secured for ILC activities due to the relatively low levels of funds being allocated (\$132m) and the commensurately low potential return to impact investors from these funds. Co-investment via philanthropy is however a resounding “yes!” as is investing for social outcomes, but impact investing, for reasons stated above is doubtful.

We suggest the level of co-investment for activities should be taken into account when competitive ILC proposals are assessed, via the Sourcing Principle of “Efficient” (pg 21 of the Consultation Draft), due to the additional value created/ efficiency dividend delivered at no additional cost to the NDIA.

### Unique NDIS challenges facing Queensland

#### *Over 65s and the NDIS roll-out in Queensland*

The announced roll-out of the NDIS in Queensland (19% of the population in year 1, 19% in year 2 and 62% in year 3) will significantly disadvantage large numbers of people aged 63+ who will likely be ineligible for the scheme by the time it arrives in their community. Many communities in the “back-end” of the roll-out have significant populations of people in this age demographic. The end result of being outside the scheme for the PND cohort is devastating for them, their families and the community.

#### *Mainstream service market failure in Queensland*

Regions of Queensland already suffer from a lack of mainstream services, let alone specialised/cohort- focused services. The roll-out of the NDIS will be significantly hampered in such areas of the state. The NDIA therefore needs to identify such areas of market failure in Queensland and implement innovative solutions to ensure all participants of the NDIS have equitable access to reasonable and necessary supports regardless of where they live in Queensland.

#### *Queensland geography*

Of significant concern is the potential for future ILC service providers to displace current local PND cohort staff in regional communities through FIFO (fly-in-fly-out) operations of new providers. Additional recognition in funding allocation decisions must be given to organisations offering permanent on-the-ground ILC presence in regional and remote areas of the state.

Please do not hesitate to contact me for any further information.

Lincoln Hopper  
CEO MS Queensland and Chair of The NeuroCare Network



## Who is SPARK neurocare?

We are an innovative non-profit organisation delivering **coordinated care services** to people living with a progressive neurological disease. We're dedicated to enabling better outcomes for them, their families and their carers.

We **understand progressive neurological disease**. We have the knowledge, networks and expertise in service delivery to ensure people living with progressive neurological disease can access the services and supports they need and deserve.

We are supported by a collective of not for profit organisations who are **experts** in delivering such specialised support and care.

We **open in Townsville in May 2016**. When fully established across Queensland, we will provide coordinated care to more than 7,450 people living with progressive neurological disease each year.

## What does SPARK neurocare offer?

- advice, information and resources
- referrals to appropriate physiotherapy, occupational therapy, speech therapy and other allied health services
- assistance with preparing for the NDIS
- linkage to appropriate local service providers
- referrals to wellness programs and other useful educational events
- assistance in managing service provider relationships

## What is coordinated care?

SPARK's highly trained Regional Service Coordinators (RSCs) **provide information, support, referral and advocacy** based on their specialist knowledge and strong networks of locally based health and community services in the area. They work one-on-one alongside their clients and their family and carers to minimise the impact of the disease on their life.



Our service is **tailored to meet each unique situation** - some people need minimal contact while others require increasing information and support at different points of life depending on how their disease affects them; as their lifestyle changes and as their informal support network evolves over time. We're **here to help** with effective, best practice services that enhance and support self-management, choice and wellbeing.

## Reasons to choose SPARK neurocare

**Respect** – we believe each person deserves dignity and the best possible opportunity to lead a life of quality

**Flexibility** – clients decide what support they want and when they want it.

**Local knowledge** – we'll connect clients with local care solutions which are relevant, appropriate and individualised.

**Approachable** – clients, along with their family and carers, can discuss their individual needs and situation and we'll help them access the services most helpful.

**We listen** – we understand people living with progressive neurological diseases and their condition and will work with them to get the best out of life.

## Further information

Call Karen Quaille, Director of Services, MS Queensland, on 07 3840 0840

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## SPARK neurocare brought to you by





# THE NeuroCare Network

## Who is the NeuroCare Network?

We are an **innovative alliance** of not-for-profit organisations focused on ensuring people living with a progressive neurological disease receive the support and services they need, **leading the way** during this time of immense change for the disability sector.

We are **community-based specialists** in progressive neurological disease, dedicated to improving quality of life for Queenslanders living with progressive neurological disease.

We **understand progressive neurological disease**. We have the knowledge, networks and expertise in service delivery to ensure people living with progressive neurological disease can access the services and supports they need and deserve.

## Why a NeuroCare Network?

A significant proportion of the 130,000 people living with progressive neurological disease in Queensland are **unable to access** the necessary information, support and care they need to manage their lives.

The **complexity of the current system of care** in the community, health and disability sectors makes identifying and accessing appropriate service providers a significant challenge.

Key efficiencies are obtained by the NeuroCare Network organisations **working together** strategically and operationally. Each has unique specialist knowledge and experience and collectively they draw on significant human and materials resources.

## What does the NeuroCare Network do?

We draw on the strengths of our members and our **collective expertise** to deliver better outcomes for people living with progressive neurological disease and their families and carers.

We offer a **community-based care response network** through the SPARK team. Initially offering local coordinated information, support, referral and advocacy in Townsville, SPARK commences in May 2016.

We work to **overcome barriers to accessing services and supports**, speaking with one voice in advocating for better comprehensive care for people living with progressive neurological disease.

We engage with the Queensland and Commonwealth Governments on matters of **policy relating to disability**, and on the impact of such policy on individuals living with progressive neurological disease.



## What are the benefits of the NeuroCare Network?

We **empower people** living with progressive neurological disease by advocating on their behalf with leading service delivery providers to broker effective, best practice services that enhance and support self-management, choice and wellbeing.

We deliver **solutions of care** that are relevant, appropriate, individualised and localised.

We offer leadership and vision for people living with progressive neurological disease in Queensland through increasing the readiness and capacity for **participation in the NDIS** by clients, their families and their carers as well as service providers and practitioners.

### Further information

Project Manager The NeuroCare Network,

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## The NeuroCare Network partners

**FIGHT ALZHEIMER'S  
SAVE AUSTRALIA**

**mnd**   
Queensland

 **epilepsy**  
queensland inc

 **MND and Me**  
FOUNDATION

 **FAN**  
Friedreich Ataxia Network

 **MS** MS Queensland

 **HUNTINGTONS**  
queensland

 **MUSCULAR DYSTROPHY**  
QUEENSLAND

 **Leukodystrophy Resource and  
Research Organisation Inc.**

 **parkinson's**  
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