HSP Research Foundation
A better deal for HSPers, their children and their grandchildren

Hereditary Spastic Paraplegia
Taking Steps Toward a Cure

Feedback on NDIS Independent Assessments

Independent assessments in the case of rare diseases must be, in general, uninformed assessments. The knowledge of, and expertise with, a rare disease such as Hereditary Spastic Paraplegia (HSP) is extremely thin on the ground nationwide anyway. There have been repeated, multiple problems with eligible people with HSP having perfectly adequate applications to the NDIS rejected, let alone the problems for members of our community in NDIS planning and implementation once accepted into the scheme. Many are significantly better off, but any claim that the scheme to date has been well-conceptualised, well-planned and well-implemented are spurious.

What has been poorly understood to date with this disease across the breadth of the NDIS in dealing with it is a failure to:

- understand the implications of a genetic disease
- understand the implications of a progressive condition
- understand what is in the reports on individual cases from neurologists, let alone the implications of what is in those reports.

A move to independent assessments will exacerbate this problem, widen the gap between people with HSP (and those with rare diseases in general) and access to the scheme that is supposed to be in their best interests.

When someone with HSP presents to an allied health professional such as a physiotherapist, even one with neurological training, in the absence of clinical management guidelines, the therapist can only see and work with what is in front of them – a biomechanical appraisal with limited understanding of the associated impairments or any sense of the degree of variability in symptoms and their impact experienced by individuals with the condition. Conversely,

when someone with HSP presents to a neurologist or neurogeneticist, there is a quantum level difference in understanding of the context of what the neurologist is seeing before them. There is understanding of the progressive neurodegeneration that is happening; there is understanding of the variability in the type and severity of symptoms experienced; and there is understanding of both the visible and invisible impacts of the disease. This difference between an allied health professional and a neurologist is profound, and it is a good parallel between the accuracy and completeness of an assessment by one's own medical specialist and the improbability of achieving that by an independent assessor who axiomatically cannot be as well-qualified to comment.

It is not like the NDIS has a great track record leading into this huge structural change in how assessments will be done. There is nothing to provide confidence to those of us whose remit is to care for the needs and interests of rare disease communities in this planned move to independent assessments. At least with the inclusion of HSP on the Lists, there was confirmation based on expert appraisal within the NDIS of the eligibility for inclusion in the scheme. It should be enough that HSP is on the NDIS Lists. It should be enough that an applicant's neurologist documents the diagnosis of HSP, the functional impairments caused, the permanent/chronic state of the disease, being genetic, the complete lack of any effective treatments, and the certainty of disease progression with time.

Now, on the contrary, it is with loathing and dread that this ill-conceived and unnecessary shift in policy, process and practice, based on questionable underlying motives, is approached. Does anyone seriously believe the NDIS exhortations that this is all about the best interests of participants, which is the recurring theme and impression anyone would get from reading the NDIS' "promotional material" on this change. There is nothing to support the conclusion that there is a likelihood of things being better for people with HSP, and with rare diseases in general, resulting from the shift to independent assessments.

Yours Sincerely

Frank McKeown
President