

Secretariat (ph 02 62773083)
(fax 02 62775829)
Parliamentary Joint Standing Committee on the
National Disability Insurance Scheme (PJSCNDIS)
PO Box 6100
CANBERRA ACT 600.

Dear [Name] - With many thanks for forwarding my ^{the} trade
participant feedback to the PJSCNDIS Committee.
Re: feedback submission (in writing/by mail as fax or/A on
18/3/16 due to state Telstra outage glitch) due to my
inability to attend the Newcastle City Hall hearing of
the Parliamentary Joint Standing Committee on the National
Disability Insurance Scheme (NDIS), as advert^{ed} ⁱⁿ the
Newcastle Herald, 24/2/16, page 29, + as per our phone
discussions with yourself at the Secretariat of the said
Committee, your advice + contact details for the
enclosed submission for the Committee to consider.
Apologies again for the need for the written format due to
my disabilities following a stroke in 2009.

Thank you, for submitting the information ~~on~~ on my behalf
with apologies for the length (due to handwriting form
possibly) + please don't hesitate to contact for
further clarification if required by yourself or another
reader. Best wishes + many thanks. Regards -
KAREN
MA.

To Whom It May Concern
per favour

/Secretariat

(ph 0262773083 / fax 0262775879)
Secretariat, kindly is to forward my submission/feedback)

PARLIAMENTARY JOINT STANDING COMMITTEE on the
NATIONAL DISABILITY INSURANCE SCHEME (NDIS)
PO BOX 6100
CANBERRA ACT 6000

Dear Sirs/Mesdames

Re: TRIAL NDIS SITE (HUNTER) participant feedback
(with my ^{submission} apologies for my disability needs to handwrite
my responses), in lieu of my inability to attend the recent
hearings held at Newcastle City Hall on Monday 7/3/16,
as per invitation notice in "The Newcastle Herald",
24/2/16, page 29. On contacting the Secretariat for the above
committee,

advised the ^{above} mailing + fax
addresses to forward my responses as a NDIS Hunter trial
site participant (I am a Lake Macquarie City Council
resident), living approx 5 km from the NDIS Charlestown
Hilltop Plaza admin office. Thank you for considering my submission +
feedback.

cont med

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NDIS + PERSONAL UNIQUE

BASIC BACKGROUND (CTD): As a NDIS participant since Hunter and Incention,

I am a 59 year old female, ^{medically retired} mother, wife, sister, daughter with 2 grown adult children (adult living overseas) + a son who works in the small family optical business with my husband of 30+ years who works 6 1/2 days per week + after hours with business management + paperwork. My hb also unfortunately has a recurring chronic pain condition which in its debilitating extreme presentation may prevent him physically speaking & eating. It is usually managed by significant pain medication at worst can require neurosurgical intervention procedures which if unable to work, occasionally hospitalisation for those interventions - our income ceases.

I attend self funded hydro/physiotherapy once weekly consuming our health fund allocation fully - in pursuit of maintenance, decreasing spasticity ^{+ contracture} in my left arm + to address personal goals with physical challenges (eg balance, terrain difficulty) swimming/surf simulations

I have a unique viewpoint as an NDIS participant/respondent as I have tertiary qualifications + 20 years postgrad working experience in The Hunter region ^{Sydney} since my studies completed in 1979 with Bachelor of Applied Sciences in Occupational Therapy - I have working experience in both private + public sectors and large acute + tertiary community based settings with a wide range of diagnoses + working with all ages with mild to very high degrees of physical + psychiatric ^{physical + psychiatric} fields. I survived a ^{residual} major stroke in 2009 with significant residual disabilities to my left side (in particular no active return of any functional use on my L side, arm hand + have slowed walking need to be cautious with balance + foot placement on my L leg even though ambulant. If distance/time/speed are critical I have a ^{manual} commuter wheel chair

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BACKGROUND/CONTEXT Ltd:

However it requires someone ^(usually my husband) to push the wheel chair + be able to erect + collapse it. It is useful for some faster access eg. airport/travelling + when parking is not close by to the venue I need to access/attend. Time is a factor.

Presently I live onehanded with all functional daily living tasks + I drive onehanded with a modified auto car + manage as best I can as maximally independently as possible with some essential aids, techniques. It can be naturally very frustrating + tedious + tiring to live this 'new normal' after stroke + although I am a tenacious + highly autonomous person who thrives on a challenge, I never expected to be dealing with this situation, however I have good friends + a very supportive hb + family (my family of origin is Sydney-based + some members live overseas). I have had always a self coordinating self managing rehabilitation ^{process} after my stroke recovery + the NDIS inputs thus far + hopefully to be continuing will have added to the quality of my living including day to day tasks' medium + in my ongoing quest to live the best I can with a filled sense of well being + quality of living.

I trust this personal context + particular precedes to me as a participant with a cane on list NDIS contact thus far gives a context for the lived NDIS experiences + can improve the quality/issues I've encountered + can help optimize the NDIS process further as the scheme is implemented further.

I am happy to be contacted to clarify my points + I writing deciphering if needed.

UNPAID (VOLUNTARY) POST STROKE OCCUPATIONS:

As a stroke survivor, I use my unique position in an advocacy capacity to share my unique viewpoint re the needs, aspects in several community entities in a voluntary capacity by invitation + EO1 - Namely by attendance in person with ^{bi monthly} input to the Agency of Disability Advisory Panel of my local shire, Lake Macquarie City Council. I also attend ^{and expanding meetings as required.} teleconference over person NSW Health's Agency for Clinical Innovation's Rehabilitation Network ^{Education} & CPD Working Party of same monthly. I also participate in my local area health district (Hunter New England's Community Stroke Team's activity programmes as of interest or relevance when suitable.

More recently, I have, by invitation been a research subject for PhD studies ^{of the Hunter Medical Research Institute (HMRI) -} where I fit the criteria + if I have time available - this is actually why I was unable to attend the recent Hunter session on 7/3/16 in Newcastle CBD, as I was committed to test conditions for 730am - 430pm. I have been a regular 'test case' for University of Newcastle Medical School Prac exams for 3rd year students in recent years, annually when required. I am not keen on public speaking but have also been invited to present in a forum style panel for final year occupational therapy students also at UON on invitation.

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MY NDIS EXPERIENCES/CONTACT TO DATE:

These are jotted for NDIS contexts and as the source informing this feedback from ^{my} the ^{NDIS} experiences in this submission, forwarded with these writings (unfortunately, empty due to the sizing of handwriting and detail).

- I attended as many preliminary community information forums, expos which were held in the Hunter area in the prelude period before the Hunter NDIS commenced in July 2013. with local newspapers also advertising the 1800 info line, which I was uncertain if I was eligible/suitable for the scheme + how it would/could apply to myself (so far at that time, self managing with the support of my husband + GP + self funded hydro/physiotherapy for maintenance + to address my personal improvement (goals as needed in my living activities at the time).

- I was advised initially to do the 'online check' to see if I was eligible + to attend the Hill Top office pop up + sign authority forms (release of information of my treating drs etc + involved my care). As it evolved I was regarded as eligible to be a participant, essentially as I was under 65 years of age + had a permanent disability condition. I attended the office + NDIS was interviewed by ? duty officer who provided case planning questionnaire forms - I was to take away + return with for discussion at an appointment made to discuss my goals + possible NDIS supports which could be applied. I followed up within the following week or so, from memory. The forms were useful to prompt thinking + discussion + pertained to my well being sense + quality of life - it felt positive

continued

page 5 NDIS EXPERIENCES etc:

being able to be catered for. I did question (as a taxpayer) about the issue of when does such a goal become a personal choice + it was advised that there were any significant financial discrepancies, I could pay the difference for choices. As it was, the

bathtub modification was only an issue to be implemented, as that process was never advised.

^ I only effected really by my assertive tendencies to inquire/ask/check on when was this task to start as I understood the goal/supported project was 'approved verbally in principle' + all inquiries were often when I had had several near-miss falls/slips using our bathroom. Eventually by

incidental contact as noted, I learnt of the procedure that the Modification Service had to attend the job/site + a contractor had to quote on the job providing that information to Mod S. Service who in turn presented the information

cell based on the OT ^{elaborate} assessment when a design and modifications required to standards was sufficient to Mod S service + NDIS for approval (of aeds/project) + the funding required to fulfil the job + goal.

In retrospect I ^{could} have been more assertive to obtain a copy of my plan (after those initial conversations were documented) + had it gone through one on one + to understand the timeline/progression + how implementation would occur. I had decided not to manage the case's funds being it at 'arm's length' for the plan to organise/coordinate especially with arrangements for NDIS in the earliest days evolving literally as it grew.

only saw it at 1st annual review

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I would recommend plan copies are given as standard once approved + gone over for timing + preparatory advice + remaining implementation steps + if needed advice of participants like, times to contact etc etc. Would be helpful + cost effective + clearer communication for new participants it may be initially a bit more time consuming but it would be efficient for ongoing familiarity + how to engage / troubleshoot any issues / the system if required. A reduced the other frontline interaction stresses on reception / call centre staff - so that issues / queries are dealt with directly + effectively + actually where the desk / call centre staff are not in position by their comments to cross off problems requiring actions / decisions / app'its or the like?

Initial guidelines would help map the path + assist expectations + streamline communications as required by case planning assistance / manager at this point. For me my whole journey in health depts also, I have been managing my own case the whole time + in my case in house with my GP / physio's + with the NDIS my initial care planner.
• Case ^{below} planner (esp. issues.)

It would have been helpful to have the Case Plan / manager roles defined / delineated at the outset + also include goal management, follow up + monitoring. FAQs? + troubleshooting / communication matters WHO / HOW / WHERE / WHAT etc ie responsibilities / contact details + types of issues to be addressed (this could have included more modifications. Greater transparency of processes + paths)

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page 7 CASE PLAN ANNUAL REVIEWS =

I only chanced upon the network) annual review when advised. The 1st year was very informal (a few key chat on phone + follow up on site @ home visit with a service provider coordinated also on site to confirm services/achievements (deduct goals / safety access in initial case) + what needed (Chris etc) working out + suitable + it was to be requested to continue or (this became integrated to domestic help / subsequently).

The following year a new case planner was advised. She was taking over 6 months after 1st review (without any notification to participant which felt disappointing, but disrespectful + no handover? apart from case notes perhaps?)

The bonus was "fresh eyes" picking up on loose ends + unfulfilled provisions of small aids for ^{kidde} dependence / cleaning + cooking etc + bathroom modification (under way by then)

However the difficult aspect was lack of continuity when 2nd referral review occurred where there was no history or site visit for an understanding of needs + level of continuing of some service provider support + although 1/2 hr per week additional would have assisted the garden support, it was declined firmly with a comment that I would be lucky to retain my ^{present} 1 hr per week so "noway" for the additional - as I understand - + was not requested even - this all felt non-empathic.

CONTINUED.

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CASE PLANNER/MANAGER ROLE + CONTINUITY? ^{? INVOLVEMENT?}

Case monitoring periodically is not systematic - perhaps would be useful especially newish parts of a part (+ would have helped in the early trial site evolution) - I personally know an capable to direct myself + steer through uncharted waters + always to questions inquire + clarify ANY matter - especially where ^{necessary + reasonable}

My original planer ^{took the time to visit me in} _{made}

my environs to fully comprehend my needs, requests for assistance + it helped to tweak ^{+ select + match} recommended providers to assist + have capacity to provide appropriate help in an empathic way + to prioritise what how + sequence the inputs for NDIS plan approved funds could then be released out + hours/time allocated could be sorted accordingly. In the early phases of plan implementation it requires a close monitor + link to the situation/person needs keeping the processes on track - Similarly, if any hitches, difficulties or unforeseen issues/occurrences either participant, service, super systems or other upheavals which have ^{+ can} occurred from time to time, unexpected things - options + links/communications were critical then to smooth operations to go on.

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COMMUNICATION ACCESS ISSUES/SUGGESTIONS:

Case planner changes (especially unexpectedly) suddenly needs to be addressed? perhaps a ^{face to face discussion/} handover to new planner needs to be occurring. (It in my case the need to new planner to be able to read original planner, matter of continuity of my ^{+ comprehension} services, ^{plan listed} scrutiny I understand but an understanding why continuity needed was also necessary - fortunately my plan was contactable & possibly in another role) NDIS by ^{so was trackable} that time. Although I believe I've had seniorish + experienced planners it is still courteous + professional ^{+ explicit} transitions to new planners smoothly enabled + also ^{+ support} plan to continue ^{seamlessly +} constructively onward.

It is like? riding a horse + changing reins ^{could be disastrous/tricky} in ^{midstream}. Additionally a mere phone call discussion or pop out to advise the situation would make it less alarming/suprising/unsettling + a fresh contact system ^{number} put in place for ensuring continuity including phone numbers etc.

Keep it simple is suitable + (x2) time efficient also.

A recent voice messg left on my landline was a frustrating experience when I followed up calling the 1800 number + with no contact name + a vague ^{request to} pls make a phone plan review appointment (unseasonably - also

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Unexpectedly in February when the usual
ambassador is July! ? was also disorienting
as with a number deflecting to SA/VIC call
centres where phone staff were polite but
unable to assist + advised they were not
permitted to give me the 'Newcastle' office
switch number. This seemed very accessibly
NOT! These several staff also were somewhat
stressed as they had no backup or reserves
to draw upon! + admitted they didn't know
either what was happening - not feeling empowered
or able to problem solve the situation? more
training for specific help might be needed?
These call center staff as a frontline service are
in a box seat to record areas of FAQst
what backup is needed the situations they
would be commonly / often asked + could be
excellent survey feedback + so create user
helpful guideline designs + simultaneously
develop disability sensitivity skills + how to
navigate the NDIS system with such insights.
These are potentially a trained frontline
workforce.

In the mētie of being unable to reach my own
BSO + Care planner (end take over ones), I ended
up driving to my local office having had good
responses previously at the reception + was
advised ^{to my relief} yes there was a new switch number
+ given a business card with the new number
hand written with the new number. The
exceptional receptionist ran the Newcastle
city office + ascertained

fig. ps stuff not sure what BSO means?

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Who I should speak to and that this person would be able to make required appointment for? new idy procedure being tried out? for a phone plan review? + This receptionist also efficiently defused my stress + offered to advise the BSO of my situation. I was somewhat terse + frustrated + apologized directly to this receptionist at the front desk until Hilltop office + explained my frustration. As a result she suggested I try the 'new' number which would put me into the realm to reach the phone plan appointments officer. My BSO rang me first up the next day Friday + advised she would (+ could? unless we had not been successful) to reach the phone plan contact directly so that person could get involved this seemed thorough + taking my case to the new arena. My fault is reentered hangover stretched where the app't office called me at 5 to 5pm on the same day to make that app't. April 2016 as not an emergency ^{Shelley's} ^{task for BS team to review} ^{to review 180 gen. numbers} ^{had a direct line up yet} need to pop you to the Hilltop office as was unable to reach anyone able to help - I had mislaid my recently acquired plan copy + review guides + needed these reprinted - which was ably offered by same receptionist as my day of being locked out of communication notes.

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final page 12.

I trust despite the awkward handwriting & length
of jottings - that the experiences from my
unique viewpoint - dealing with an acquired
disabled state at age 52, sustaining a severe
R sided stroke with resultant left sided deficits -
& massive functional implications & challenges
to regain a new sense of 'normal' - helps
in the appreciation of the humanity aspects
of participants & their needs as they re-visit
their lives & the trivial minutiae that
involves. to enhance their quality of life
resuming the maximum activity & actualising
as possible.

Please do not hesitate to contact if
any discussion or clarification is needed
or deciphering of my handwriting - again my
apologies for the medium of my handwritten
version as the Dragon Naturally Speaking
training was not able to be fulfilled as
 hoped (it is a fickle program plus technical
issues of computers, etc. - Similarly Siri on
Ipad is not reliable and too tedious to
need to correct every letter often to be
truly useful.

Yours faithfully -

KAREN MA .