Exercise & Sports Science Australia submission

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Health Care for People with Cognitive Disability

20 March 2020

E info@essa.org.au P 07 3171 3335 F 07 3318 7666 ABN 14 053 849 460
A Locked Bag 4102, Ascot QLD 4007 www.essa.org.au

1.0 About Exercise & Sports Science Australia

Exercise & Sports Science Australia (ESSA) is the peak professional association for exercise and sports professionals in Australia, representing over 8,000 members, including university qualified Accredited Exercise Physiologists (AEP), Accredited Sports Scientists (ASpS), Accredited High-Performance Managers (AHPM) and Accredited Exercise Scientists (AES).

2.0 AEPs and the National Disability Insurance Scheme

AEPs are recognised allied health professionals who provide clinical exercise interventions aimed at primary and secondary prevention; managing sub-acute and chronic disease or injury; and assist in restoring optimal physical function, health and wellness.

There is compelling evidence that clinical exercise interventions, as delivered by AEPs, provide a range of physical, mental and psychosocial benefits to people with a disability. Exercise interventions prescribed by AEPs can:

- improve cardiovascular fitness[i]
- improve muscular strength and balance[ii]
- decrease symptoms of depression, anxiety[iii] and pain[iv] and
- when completed in a group setting, foster social connections and feelings of belonging[v].

AEPs develop a range of exercise-based activities that empower National Disability Insurance Scheme (NDIS) participants and support them to achieve goals in the areas of daily living, social inclusion and functional well-being.

AEPs can currently register under the 'Exercise Physiology and Personal Well Being Activities' and 'Therapeutic Supports' registration groups and can deliver supports under the 'Improved Health and Wellbeing' and 'Improved Daily Living' categories of participant plans.

3.0 Summary of Recommendations

Recommendation 1: Increase the number of sessions available to people with cognitive disability under the Chronic Disease Management plans.

Recommendation 2: Increase access to legal services to assist people with cognitive disability to address legal issues impacting access to health care.

Recommendation 3: Introduce a system navigator service to support people with cognitive disability to access health care.

Recommendation 4: Health professionals receive in depth, practical training on how to effectively communicate with people with a cognitive disability and/or communication disorder.

Recommendation 5: Health care and NDIS funding models acknowledge the increased time required to effectively communicate with people with cognitive disability or communication disorders.

Recommendation 6: Increased education on substitute decision making for people with disability, and their formal decision makers including family and friends and health professionals.

Recommendation 7: The NDIA adopt strategies to ensure participants receive a quality planning experience which is supported by appropriately skilled and experienced NDIA staff.

Recommendation 8: NDIS planners to have access to clinical oversight to ensure that objective outcome measures presented in clinical reports are understood and do not negatively impact on a participant's access to therapy.

Recommendation 9: NDIS plan reviews are made subject to quality measures and feature meaningful engagement with both participants and relevant providers.

Recommendation 10: Processes be put in place to ensure the NDIA provides timely access to wide range of aids, equipment and supplies that support people with cognitive disability to access health and therapy services.

Recommendation 11: The NDIA ensure appropriate funding is allocated to ongoing access to therapy supports delivered by qualified allied health professionals.

Recommendation 12: The NDIA, NDIS Commission and organisations employing support workers put quality measures in place to ensure support workers are held accountable for when aiding with maintenance therapy.

Recommendation 13: Training and guidance materials are introduced to support allied health professionals achieve an appropriate balance between duty of care, client safety and restrictive practice.

4.0 ESSA's response to the issues paper on Health care for people with cognitive disability

ESSA welcomes the opportunity to provide feedback in response to the Royal Commission's issues paper on *Health care for people with cognitive disability*. ESSA's submission is based on feedback received from AEPs delivering NDIS funded exercise physiology supports to people with cognitive disability. The submission only responds to questions that are relevant to the experiences of AEPs.

Question2B. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

- **The high cost of health care**

In Australia, people living with a disability have lower incomes and are more likely to live in poverty than people without a disability[vi]. It has been suggested that the social and economic disadvantage that people with disabilities experience has a significant impact on their health outcomes.[vi]

AEPs observed that people with a cognitive disability and their carers will often seek out bulk billed health services to assist with affordability. AEPs have noted that appointment times for health services offering bulk billing are often limited and see some people waiting for extended periods of time for an appointment to become available.

These observations reflect experiences amongst other health services, with the Australian Institute of Health and Welfare (AIHW) indicating that:

- 1 in 5 (19%) people with a disability delayed or did not see a GP because of the cost
- 1 in 4 (27%) people with a disability did not see a medical specialist when they needed to, mainly because of the cost

- 1 in 4 (24%) people with a disability delayed going or did not go to hospital because of the cost
- 2 in 3 (64%) people with a disability delayed seeing or did not see a dental professional, because of the cost.[vii]

ESSA acknowledges that people with a cognitive disability and chronic conditions can access rebates for allied health services via Medicare Chronic Disease Management (CDM) Plans. However, we note that the number of sessions accessible through a CDM plans is inadequate in meeting ongoing needs. Eligible patients can only claim a maximum of five allied health services per calendar year under MBS items 10950-10970. [viii]

AEPs working with people with a cognitive disability and a chronic condition report that their clients often need to see three or more allied health professionals to manage a chronic condition. If these individuals were to spread their maximum five CDM services across the required allied health practitioners (e.g. speech therapist, dietician and exercise physiologist), the ability to make significant changes to the health and wellbeing is limited to potentially only one session per practitioner.

Recommendation 1: Increase the number of sessions available to people with cognitive disability under the Chronic Disease Management plans.

- **The link between justice and health**

Building on commentary relating to the high cost of health care, ESSA acknowledges that there is strong link between access to justice and access to health care. Health Justice Australia describes how many Australians on a low-income experience three or more legal problems a year and those legal problems can often contribute to – or even cause – their health problems.[ix] For example, accumulated fines or debt can cause stress and act as a barrier to meeting health costs associated with valuable allied health interventions such as exercise physiology[ix].

Health Justice Australia note that people are more likely to talk about these types of legal issues with a trusted health professional than a lawyer, highlighting the need for a close association between legal and health services.[ix]

ESSA suggests that health justice partnerships could play an important role in supporting NDIS participants to address a range of health-related issues including NDIS appeals for cases where allied health service provision has been denied or reduced within NDIS plans.

AEPs note that people with cognitive disabilities often receive plans that are inadequate in meeting their needs. In these types of scenarios, the participant only has access to a generalist legal aid lawyer with limited knowledge of disability, the NDIS scheme and the complex interface between disability and health.

Recommendation 2: Increase access to legal services to assist people with cognitive disability in addressing legal issues impacting on access to health care.

- **Support to access health care services**

AEPs working with people with a cognitive disability have observed that individuals with cognitive disability often do not have the capacity to appropriately monitor, recognise and respond to changes in their health conditions. Further to this, many require support to identify and action practical tasks associated with accessing health services. These tasks include:

- arranging health appointments
- managing a diary
- transporting independently to appointments
- managing the payment of health-related expenses
- communicating their medical history
- providing informed consent for treatment.

In order to receive good quality healthcare, people with a cognitive disability are often required to rely on the support of carers, family members and friends to manage their healthcare. The quality of the health care received is strongly influenced by the health literacy of their supporters. Research suggests health literacy programs specifically targeted at supporters, such as carers, family members and friends would be valuable in supporting the health needs of people with a cognitive disability.[x]

For those without the support of family members and friends, there are very few services available to support them to navigate the complexities of the Australian Health Care system. AIWH data highlights this concern by documenting the following:

- 1 in 6 (17%) people with a disability who needed help with health-care activities had their need for health-care assistance only partly met or not met at all
- 1 in 8 (13%) people with a disability who needed help with health-care activities had no source of assistance (either formal or informal)[vii].

The aged care system has been trialling the concept of a system navigator to support older people to understand and access aged care services.[xi] This trial service offers information and practical support such as filling out paperwork. The Counsel Assisting the Royal Commission into Aged Care Quality and Safety have also proposed a care finder service.[xii] The Counsel Assisting has suggested that the role of the care finder service would be to ensure that the complexities of the broader aged care system do not manifest into an obstacle for the older person and their carers and family. [xii] The proposed care finder service features a case management function to assist the older person to engage with relevant services and steps along their journey through the aged care service system.[xii]

ESSA suggests that people with a cognitive disability would benefit from accessing a similar system navigator function focused on health services. Ideally this type of service would have strong links to health justice partnerships.

Recommendation 3: Introduce a system navigator service to support people with cognitive disability to access health care.

- **Communicating with health professionals**

Communication is an essential element in the delivery of quality health services. People with cognitive disabilities have varying communication abilities. Some can verbalise their basic needs, whilst others may use communication aids or visual or behavioural cues to indicate their wants, needs or feelings.[xiii] The extent to which they can express their needs and wants and the extent to which they can understand and respond to the communication of others will impact their overall health care experience.[xiii]

AEPs working with people with a cognitive disability have suggested that health professionals, across the board, require increased training on overcoming communication barriers. Most health professionals receive very little training through their tertiary training, on how to communicate effectively and respectfully with people with a cognitive disability or communication disorders. Effective communication is essential to the process of obtaining informed consent, documenting medical histories, conducting accurate health assessments, prescribing safe and appropriate interventions and measuring the success of said interventions.

Health professionals that are not appropriately equipped to communicate with people with a cognitive disability are at risk of bias influencing their assessment and treatment of conditions. Further to this, they are not supporting the individual to exercise a basic human right, that is, to be informed and involved in decisions regarding their health care.

ESSA recommends that health professionals receive in depth, practical training on communicating with people with a cognitive disability and/or communication disorder. Communication strategies should be considered for inclusion in the core curriculum for all health professionals. Training should include on the job mentoring and coaching, where possible.

ESSA suggests that the health and disability service systems could better support the improved communication between health professionals and people with a cognitive disability

and/or communication disorder by ensuring funding models make provision for the extra time needed to engage in quality communication.

Recommendation 4: Health professionals receive in depth, practical training on communicating with people with a cognitive disability and/or communication disorder.

Recommendation 5: Health care and NDIS funding models acknowledge the increased time required to effectively communicate with people with Cognitive Disability or communication disorders.

- **Substitute decision making**

AEPs working with people with a cognitive disability have described how disputes relating to substitute decision making arrangements can delay access to health care. These circumstances often occur where an individual has two or more people appointed to act jointly on a decision (i.e. each party must agree on the decision). AEPs report that in circumstances where two jointly appointed decision makers cannot agree on the best course of action for a health problem, the health of the individual may be compromised whilst an independent third party is engaged to resolve the dispute.

AEPs note that substitute decision making arrangements can also impact on access to health care during the phase where an individual with cognitive disability transitions from childhood to adulthood. Throughout this transitional phase a parent or sibling will often apply for guardianship, a process that can be lengthy. During this time, it is difficult for the individual to access health supports, particularly when they do not have the capacity to provide consent.

ESSA suggests that further education on substitute decision making should be made available for people with disability, their formal decision makers, family, friends and health professionals.

Education for people with disability, their formal decision makers, family and friends could focus on organising guardianship arrangements prior to the transition from childhood to

adulthood, respecting the rights of people with cognitive disability when acting as a substitute decision maker, making joint decisions and resolving disputes in a timely manner.

Education for health professionals may include working with substitute decision makers, understanding the rights of individuals with cognitive disability, encouraging supported decision making where possible and options for obtaining consent when there is no formal decision maker in place.

Recommendation 6: Increased education on substitute decision making for people with disability, formal decision makers, family and friends and health professionals.

Question 3B. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

- **NDIA Planners**

ESSA suggests the quality of an NDIS planning experience can be life changing for individuals with a cognitive disability and their family/carers. A positive planning experience can improve the quality of life of both participants and their family/carers. Whilst a negative planning experience can be distressing for all involved and lead unnecessary to gaps in care.

AEPs working in the NDIS have expressed concern about the inconsistences in planning decisions, noting that some participants receive a generous plan with adequate funding for therapy, whilst others with similar conditions and circumstances receive very little funding. These types of concerns are reflected in the recent Tune Review of the *National Disability Insurance Scheme Act 2013*.[xiv]

ESSA considers it essential that planners have qualifications and/or experience in health, human services or disability. ESSA suggests that a lack of relevant qualifications and experience in these areas significantly impacts on the ability of planners to understand and address the complex needs of participants, particularly when it comes to the complex interface between health and disability (refer to Case Study A).

Case Study A

A NDIA planner recently denied a participant funding for both exercise physiology and a dietician stating:

> *"The request for exercise physiology and a dietician will be declined. These supports are more fittingly provided by Health as they are not disability-related supports. The need for a dietician and exercise physiology is related to medication-related weight gain, not to her traumatic brain injury nor her schizophrenia."*

In this scenario, the participant's health and wellbeing related goals were directly attributable to the primary diagnosis and included strategies to address motivation and the impact of antipsychotic induced weight gain.

Recommendation 7: The NDIA adopt strategies to ensure participants receive a quality planning experience which is supported by appropriately skilled and experienced NDIA staff.

- **Subjective Outcome Measures**

AEPs working in health and across compensable schemes, including the NDIS, routinely use validated subjective outcome measures to assess the impact a treatment is having on the individual's function or quality of life. AEPs note that subjective data is often useful in demonstrating the effectiveness of a treatment when completing an NDIS report. AEP feedback suggests that NDIA planners often don't have a clinical background and respond better to subjective measures/statements compared to objective outcome measures which feature healthcare language specific to the AEP and physiotherapy professions.

AEPs working with people with cognitive disability have noted that many of their clients are non-verbal and cannot engage in the assessment process associated with subjective outcome measures. AEPs have expressed concern that the absence of subjective outcome measures can negatively impact on individuals with a cognitive disability as it becomes harder to justify and have NDIS plan reviewers understand the effectiveness of treatment and the need for future funding.

Recommendation 8: NDIS planners to have access to clinical oversight to ensure that objective outcome measures presented in clinical reports are understood and do not negatively impact on a participant access to therapy.

- **Plan reviews not considering allied health reports**

ESSA members have reported that some funding review meetings are being requested early and the review process is rushed. For example, one AEP was asked to prepare a report to help inform a participant's plan review. The AEP was given two weeks to prepare the report, however, the plan review process was finalised before the two weeks expired and before the AEP report was submitted. As a result, the planner did not review the supporting documentation prepared by the AEP and made a clinical decision that they were not qualified to make. The outcome of this practice was reduced therapy funding for the participant.

ESSA suggests that this practice not only impacts the quality of the plan provided to the participant, it is also a misuse of valuable NDIS funding (i.e. the NDIS is funding the preparation of professional reports that are not being considered as part of the overall plan review process).

Recommendation 9: NDIS plan reviews are made subject to quality measures and feature meaningful engagement with both participants and relevant providers.

- **Managing incontinence**

AEPs have reported that many of the individuals they work with are affected by incontinence. For those with an intellectual disability, it may be difficult to learn or remember how to manage their own bladder or bowel control or to communicate their toileting needs. Furthermore, those with an acquired brain injury may not be able to sense when they need to empty their bladder or bowel.

Incontinence, when not managed appropriately can impact on an individual's access to therapy services. Access to hydrotherapy is of particular concern for people experiencing incontinence. AEPs have reported occasions were exercise physiology sessions have ceased early due to incontinence issues that have not been managed appropriately. In some of these circumstances the ability of the NDIS to respond to continence needs in a timely manner significantly impacts access to therapy (refer to Case Study B).

Case Study B

A 17-year-old girl with low muscle tone cerebral palsy and complete incontinence had been completing hydrotherapy as a part of her exercise therapy. When management of the hydrotherapy facility learned the participant was incontinent, they stipulated she must wear an adult continence bather specifically designed to contain faecal matter without any leakage.

This particular type of bathing suit is not routinely available in the size required by the participant and as such the participant's mother applied to the NDIS for funding under consumables for custom made bathers. Due to the lengthy and complicated NDIS process of applying for consumables funding, it has been seven months and the participant has still not received funding required to order the bathers. Consequently, the participant been without hydrotherapy for over seven months and has received no communication about when she may receive approval for the purchase of the bathers.

Recommendation 10: Processes be put in place to ensure the NDIA provides timely access to a wide range of aids, equipment and supplies that support people with cognitive disability to access health and therapy services.

- **Support workers assisting with the provision of therapy**

ESSA has concerns about NDIS cost cutting measures that occur at both the planning and review stages. In particular, ESSA is concerned about the growing trend in NDIA planners encouraging the use of unqualified support workers for the delivery of maintenance therapy. AEPs have flagged several concerns associated with this practice including

- Organisations employing the support workers sometimes refuse to allow their employees to engage in therapy supports citing duty of care concerns. Therapy budgets won't allow for ongoing use of qualified therapists.
- Some participants receive supports from more than one therapist which increases the amount of maintenance therapy expected to be delivered by support workers (refer to Case Study C)
- Participants don't always receive the same support worker day to day or week to week, making it difficult to train a consistent team off support workers to deliver therapy support (refer to Case Study C).
- Support workers who are trained by therapists often don't follow through on actively supporting participants to engage in maintenance therapy including physical therapy.
- Group home staff sign off on records to confirm that home exercise services have been provided but these records conflict with the advice of participants

ESSA notes that these practices impact on both the quality of care delivered and the level of care delivered. ESSA acknowledges that assistance with therapy related activities have not historically been included in the training and job description of support workers but suggests that this needs to change if the NDIA is to continue to promote their involvement in therapy.

ESSA maintains that access to therapy services, involving allied health professionals is a basic human right and people with a cognitive disability should not be denied this right.

Case Study C

A 17-year-old female had been receiving a range of therapies including exercise physiology, occupational therapy, physiotherapy and speech pathology. As part of the review process, funding was reduced across all therapies and the therapists were asked to train the participant's support workers in the delivery therapy supports. The AEP noted that the participant received support from over 20 different care workers a week and concerns had been raised about the risks associated with training such a large number of care workers in such a diverse range of therapy supports. The participant's mother was appealing the decision and expressed fear that her daughter may need to consider residential aged care if her body deteriorates any further.

Recommendation 11: The NDIA ensure appropriate funding is allocated to ongoing access to Therapy supports delivered by qualified allied health professionals.

Recommendation 12: The NDIA, NDIS Commission and organisations employing support workers put quality measures in place to ensure support workers are held accountable for when aiding with maintenance therapy.

- **Restrictive practice**

Following the establishment of the NDIS Quality and Safeguarding Commission, increased measures were introduced to regulate the use of restrictive practices. ESSA acknowledges that the regulation of restrictive practice is essential in protecting the rights and freedom of movement of individuals with a disability.

AEPs have provided feedback on the challenges faced when working with people with a cognitive disability who do not have capacity to understand a range of safety concerns such

as pool safety and the risks associated with misuse of equipment in the gym (refer to case study D).

ESSA suggests further training and guidance materials should be introduced to support allied health professionals, who may have previously had little involvement or knowledge of restrictive practices, to understand and implement appropriate measures to ensure an appropriate balance between duty of care, client safety and restrictive practice.

Case Study D

An 18-year-old female with a severe cognitive disability (intellectual age is 2 years old) has no comprehension of road safety, food/chemical safety, safe use of therapy equipment) Within the gym/therapy setting the participant climbs all over and handles gym equipment inappropriately.

Recommendation 13: Training and guidance materials are introduced to support allied health professionals achieve an appropriate balance between duty of care, client safety and restrictive practice.

5.0 Contact ESSA

Thank you for the opportunity to provide feedback into the issues paper on Health care for people with a cognitive disability.

If you have any further questions regarding the content of this submission, please contact our Policy and Practice Innovation Team on 07 3171 3335 or email anna.harrington@essa.org.au .

[i] Warburton, D., C. Nicol, and S. Bredin, Health benefits of physical activity: the evidence. CMAJ, 2006. 174(6).
[ii] Taylor, D., Physical activity is medicine for older adults. Postgraduate Medical Journal, 2014. 90(1059): p. 26-32.
[iii] Lederman, O., et al. Consensus statement on the role of accredited exercise physiologists within the treatment of mental health disorders: A guide for mental health professionals. 2015 [cited 2016 4 April]; Available from: https://www.essa.org.au/wp-content/uploads/2015/10/Consensus-statement-on-the-role-of-AccreditedExercise-Physiologists-within-the-treatment-of-mental-disorders-for-mental-health-professionals_v8.pdf .
[iv] Waller B, et al., Effect of Therapeutic Aquatic Exercise on Symptoms and Function Associated with Lower Limb Osteoarthritis: A Systematic Review with Meta-Analysis. Phys Therapy 2014. 94.
[v] Bauman A, et al., Updating the evidence for physical activity: Summative reviews of the epidemiological evidence, prevalence, and interventions to promote "Active Aging". The Gerontologist, 2016. 56(S2): p. S268–S280.
[vi] Victorian Health Promotion Foundation. Disability and health inequalities in Australia. [Internet]. 2012 Aug. [cited 2020 Mar 18]: Available from https://www.vichealth.vic.gov.au/-/media/ResourceCentre/PublicationsandResources/Health-Inequalities/VH_Disability-Summary_web.pdf?la=en&hash=3347870D3B7ADF0227C5B7B831E02A2ED27AE31E .
[vii] Australian Government, Australian Institute of Health and Welfare. Access to health services by Australians with disability. [Internet]. Australian Government, Canberra (AU). 2017 Dec 3. [cited 2020 Mar 18]. Available from https://www.aihw.gov.au/reports/disability/access-health-services-disability/contents/content .
[viii] Australian Government, Department of Health. Chronic Disease Management - Provider Information. [Internet]. Australian Government, Canberra (AU). 2016 Feb 9. [cited 2020 Mar 18]. Available from https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-factsheet-chronicdisease.htm .
[ix] Health Justice Australia. What is a health justice partnership? [Internet]. [place unknown]: Health Justice Partnership Australia; 2020. [cited 2020 Mar 18]. Available from https://www.healthjustice.org.au/hjp/what-is-a-health-justice-partnership/
[x] Geukes C, Bröder J, & Latteck ÄD. Health Literacy and People with Intellectual Disabilities: What We Know, What We Do Not Know, and What We Need: A Theoretical Discourse. (2019) *International journal of environmental research and public health*, *16*(3), 463. Available from https://doi.org/10.3390/ijerph16030463 .
[xi] Australian Government, Department of Health. Aged care system navigator measure. [Internet]. Australian Government, Department of Health, Canberra (AU) 2020 Jan 31. [cited 2020 mar 18]. Available from https://www.health.gov.au/initiatives-and-programs/aged-care-system-navigator-measure .
[xii] Royal Commission into Aged Care Quality and Safety. Royal Commission into Aged Care Quality and Safety Counsel Assisting's Submissions on Program Redesign. [Internet]. [place unknown]. 2020 Mar 14. [cited 2020 mar 18]. Available from https://agedcare.royalcommission.gov.au/hearings/Documents/submissions-by-counsel-assisting-4-march-2020.pdf .
[xiii] Chew KL, Iacono T, Tracy J. Overcoming communication barriers: working with patients with intellectual disabilities. Australian Family Physician. 2009; 38 (1). [cited 2020 Mar 18]. Available from https://www.racgp.org.au/afp/200901/200901chew.pdf .
[xiv] Tune D. Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS participant service guarantee [Internet]. 2020 December [cited 2020 Jan 23].Available from https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf .