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Submission on consultation draft list of NDIS Supports for s10 of NDIS Act

25 August 2024

About Australian X & Y Spectrum Support (AXYS)

Australian X & Y Spectrum Support is the peak body for individuals living with a sex chromosome variation in Australia; in particular Klinefelter Syndrome (XXY), Jacobs Syndrome (XYY), Trisomy X (XXX), and associated variants. We are individuals, parents, families, health professionals and allies who are continuously working hard to support, empower and inform.

AXYS works to increase awareness and to inform the health and education sectors, and broader community on what X and Y sex chromosome variants are, and the impact it has on individuals and families. We participate in research, and engage relevant stakeholders on policy development on how they can better support, guide and implement appropriate tools and provide holistic models of care.

We aim to ensure that everyone living with an X & Y chromosome variant has the opportunity to reach their fullest potential living a happy life with minimal impacts from possible health related issues. Sex Chromosome Variations lie on a spectrum. While some individuals have minimal impact from their diagnosis, most have mild to moderate disability. Some individuals experience severe disability. Disability within our community includes musculoskeletal issues, neurological impairment, swallowing impairment, motor weakness, poor balance, motor incoordination, speech and language difficulties, cognitive impairment, poor executive functioning, intellectual disability, specific learning disabilities, sensory differences, and increased neurodevelopmental prevalence. Collectively the impairments in those with Sex Chromosome Variants are multi-systemic and multi-faceted.

Klinefelter Syndrome affects 1:450 male births, Jacobs Syndrome 1:1100 male births and Trisomy X 1:1000 female births. There are more than 15,000 Australians living with a Sex Chromosome Variation.

Australian X & Y Spectrum is a member of a consortium of organisations that represent people with Down syndrome and similar Chromosomal Variations. This consortium is recognised by the Australian Government as a Disability Representative Organisation (DRO). The Consortium provides systemic advocacy for Australians with Down syndrome and similar Chromosomal Variations.

As individuals with innate variations of their sexual characteristics, AXYS represents one cohort of Intersex persons. The Commonwealth has made pledges around the “I” in the 10 Year National Action Plan for LGBTIQA+ Health and Wellbeing. As persons with chromosomal variations, members of our community can experience disability arising from a gene expression or imbalance across 3 or more sex chromosomes.

These lists are contrary to the Government’s commitment in supporting the health outcomes and wellbeing of intersex individuals with disability in decreasing their health disparities.

DSS Consultation Period

Australia X & Y Spectrum Support has attempted to complete a submission on the draft list of NDIS Supports that has been requested by the Department of Social Services (DSS) with a 14- and 21-day timeframe. Initially the DSS did not release the easy read version at the commencement of the enquiry which significantly affected our community and minimised our communities' opportunity to respond. In addition, the easy read version oversimplified complex concepts, was misleading in places and lacked concrete examples. In addition to the late release of this easy read format, many members of our community have been prevented from providing feedback as the time allocated is too limited to understand such a complex, convoluted and critical list; a list that will affect our lives.

In response to the limited time provided by the department AXYS has formally lodged a Disability Discrimination complaint with the Department of Social Services requesting further extension. The limited consultation time disadvantages those with intellectual disability or those with specific learning disabilities such as dyslexia and dysgraphia from reading, understanding and providing a response. AXYS again reiterates its request that the Department provide further extension on the consultation to these crucial lists. Prior NDIS-related consultations requested by the Department were afforded a minimum of 8 weeks. If that was acceptable then, how is 2-3 weeks acceptable now? It is worth noting that the Department has been afforded 28-days to respond to our complaint, which is frustratingly more than our community has been given to respond to this enquiry.

AXYS respectfully requests the Department comply with the Disability Discrimination Act and provide reasonable time for constituents with disability to read, understand and respond to this enquiry.

It is absolutely crucial that people living with Sex Chromosome Variations with individual budgets continue to receive access to evidence-based clinician-recommended therapies, and safe and supportive individualised innovative supports to assist that individual meet their individual needs to participate in life commensurate with people who do not live with disability. AXYS is a strong supporter of the Scheme and the positive outcome it strives to deliver for many. AXYS is invested in assisting with the development of genuinely co-designed lists that meet the nuances of individual needs so that individuals with Sex Chromosome Variations can meet their fullest potential and live happy fulfilling lives.

These lists do not move us toward a NDIS that make can make a positive impact on an individual's unique experience of disability and their life. AXYS requests further consultation extension for the disability community to meaningfully participate in co-design to ensure a sustainable Scheme that assists those with significant permanent lifelong disability.

Regional and rural disability support service access

AXYS notes a concern that the suggested 'not' list contains many mainstream supports that a significant number of our regional and rural members depend on due to limited support worker numbers working in their area. One of our members has highlighted they use mainstream services rather than support workers because there are insufficient support workers available in their area. The immediate implementation of these draft lists would cut this individuals entire support ecosystem off, posing a serious risk of harm or death, as they would be unable to employ support workers to fill the gap.

AXYS calls on the department to reconsider the blanket approach to areas that have thin disability support markets, and on individuals with complex support needs.

Universal Designed Assistive Technologies

Many supports identified in the 'NOT NDIS Supports', and the requirements to be a 'NDIS Support' do not align with Article 4 of the Convention of the Rights of Persons with Disability. Article 4 promotes the use of universally designed assistive technologies to support disabled persons.

The rationale of universal design according to the United Nations, is that universally designed supports promote availability, access and reduce cost, rather than generally relying on support specifically designed for disabled persons, unless there is no alternative.

Article 4; State parties shall:

> *"undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines"*

Integrity of health professionals' therapeutic recommendations

Some of the proposed therapeutic practice supports, and assistive technology bans undermine the integrity of allied and medical health practitioners' integrity and dismisses their formal qualifications that meet national standards that are governed by national regulatory bodies.

The exclusion of many evidence-based supports (Neurofeedback, Gaming Therapy, kitchen appliances, sensory aids etc) on principle, as opposed to its outcome or evidence-base will increase the costs of the scheme, place participants in danger of loss of supports increasing harm, including physical, psychological, financial, social isolation and death.

Language concerns

AXYS is concerned the Department has not released a '*definition'* list with the release of these documents. This leaves some supports ambiguous and may lead to misunderstanding. For example, "***specialist***" is used to describe types of assistive technology, but there is no explanation of whether this includes universally designed goods that meet the needs of individual participants, or whether they are specifically modified assistive technologies.

In addition, members of the wider disability community have repeatedly requested the definition of "**carve out**". There is no clarification provided by the Department as to whether these supports will be the responsibility or the State and Territories, or whether they are caveats to the allowed or banned supports such as disability-related health supports.

The level of misunderstanding in the disability community raises concern that the community poorly understand the material which has been provided. Given the lack of consultation time allocated to the disabled community, the lack of guidance and clear definitions AXYS believe the Department are engaging in obfuscation and are being disingenuous in this consultation.

AXYS reiterates its request for a further extension, and clear and intelligible definitions and descriptions to support the disabled community to make informed responses to the enquiry. We recommend a pause to these lists until proper co-design with permanent lists occur.

Supports that are 'NDIS Supports'

<u>Assistance Animals</u>

There are several issues with the phrasing of this.

Firstly, there is no formal national accreditation scheme for assistance animals in Australia. Governments have previously consulted on a national accreditation scheme, or principles regarding Assistance Dogs and Assistance Dogs in Training but this has not yet come to fruition.

This may mean people of different states that do not have accreditation standards would not be able to access assistance animals when deemed necessary by health professionals. For example, while QLD has formal qualification through the Public Access Test, NSW requires an animal to be able to perform the same duties without formal accreditation. People is NSW would be discriminated against simply because of where they reside.

This policy will significantly decrease access to a vital assistance animal service through the form of an assistance dog that is acquired and trained by the participant with or without an accredited, or a qualified professional dog trainer. This is a growing necessity given many organisations that supply ready-trained assistance animals have closed their books due to the demand.

The phrasing implies the removal of the ability to acquire an animal to be purposely trained to be an assistance animal either by oneself, or directly with the trainer, or with the assistance of a trainer.

The AAT found numerous times (TYKL, SCHW, TJYS, CYHY & MMBX) that the acquisition and training of an assistance dogs is effective and beneficial, increases access to assistive technology and is value for money.

Freedom of Information requests for agency data on assistance animal types yields no data as to the type of assistance they provide. There are differing training standards for medical alert and response, mobility (brace and stability), guide dog, psychiatric service dog etc. This regulatory policy must reflect the different roles assistance animals may provide.

In the case of mobility assistance animals, many of these need to be purpose-bred for the clients' needs and therefore they are not readily-available and trained. They require to specifically matched according to height and weight and gait pattern of the client.

The policy must include exceptions for those who require purpose—bred and acquired animals to be trained. Providers cannot afford to train for such niche purposes without guaranteed funding.

This over-prescriptive inclusion criteria is unlawful under the Disability Discrimination Act.

<u>Accommodation/Tenancy assistance</u>

AXYS is also concerned about the carve-out for 'mortgage repayments' and how that specifically relates to community members receiving self-provided Specialist Disability Accommodation. This has been allowed by the Agency to date. This allows a participant to build their own SDA residence and they indirectly use their SDA to facilitate a loan.

AXYS is concerned that this measure may inadvertently impact those in self-provided SDA and prevent them from continuing to indirectly pay their mortgage. This could result in default and homelessness. It is of note that the SDA Payments would only cover the additional housing needs to meet that participants specific needs and the participant and or family members would be contributing the non-disability related housing costs.

<u>Assistance with Daily Life Tasks in a group of Shared Living Arrangement</u>

AXYS is deeply concerned about the phrasing that respite or short-term accommodation would force persons with disabilities into group settings. The phrasing implies that respite cannot be provided outside of a group or shared living arrangements. This is deeply concerning in limiting choice and control and safe participation of participants in community and social activities to increase their capacity. Community participation does not mean segregation from the wider community, but active participation in the wider community.

AXYS calls on the department to publish a supplementary policy for self-directed, self-

managed, and sole participants short term accommodation, and those requiring 1:1 or 2:1 support.

The Department has listed each component of self-managed short-term accommodation as individual supports that cannot be claimed. What is the difference between a provider providing these as a package, and a self-managed participant claiming each support individually to create the same collective support at substantially lower cost?

The AAT has previously ruled that the Agency should be assessing how these supports assist the participant to overcome their impairment as a collective in how effective and beneficial they are to that individual to meet their specific disability-related needs.

The Agency agreed to this assessment process by agreeing to recommendation 2 of the ANAO report Decision-making Controls for NDIS Participant Plans[1].

Assistive products for recreation

Many AXYS members experience physical disability including but not limited to disproportionate limb and torso development, and motor coordination difficulties. This results in customisation requirements to wearable equipment, including protective equipment for sport participation, and equipment to assist with guided motor planning. In addition, sensory differences necessitate needs above the basic sporting and recreational equipment.

A mother from our community reported how she is required to buy mainstream aftermarket equipment for her son to participate with siblings in recreational activities. AXYS is concerned this phrasing reinforces the need for recreational aids to be specifically adapted, rather than relying on aftermarket or mainstream options that are required specifically due to a participant's disability-related impairment needs.

AXYS is deeply concerned the Department has categorised **wheelchair accessible tents** as housing. Recreational camping should be available to all Australians regardless of whether they are a wheelchair user or not. The exclusion of this would also prohibit those with mobility needs who require flat entrances and maneuverability space inside a tent. Recreational camping cannot be said to be housing.

Exclusion of electricity generators, solar panels and batteries explicitly for camping for those who require electricity due to their disability would deny those with severe disabilities from participating in camping activities. AXYS believe that electricity generators, solar panels, batteries, inverters and food storage should be allowed for dysphagia and other disability-related supports that require electricity in remote locations as the AAT found (RHRD).

AXYS recommends that recreational equipment need not be specifically designed to assist an individual, rather they be allowed if the product is directly related to their support need.

1. https://www.anao.gov.au/work/performance-audit/decision-making-controls-ndis-participant-plans

Assistive products for Household Tasks

Many AXYS members experience physical disability including but not limited to disproportionate limb and torso development, motor coordination difficulties, swallowing difficulties, balance and motor weakness difficulties. In addition, sensory differences and poor executive functioning necessitates needs above basic household items applications.

As above AXYS is concerned that the use of the term "*specialist*" is too prescriptive and will prevent a participant from accessing a mainstream item that is cheap and outcome-focused, which will result in loss of independence and increased support needs.

AXYS recommends that equipment for household tasks need not be specifically designed to assist an individual, rather they be allowed if the product is directly related to their support need, and that universally designed products be promoted that assist a participant overcome their impairment.

Management of Funding for Supports

AXYS is concerned of the removal or omission of support for Participants to self-direct or self-manage their own support services. The Agency currently enables self-managed participants to claim supports to assist them self-manage their plans and to meet indirect costs associated with self-management.

AXYS calls on the Department to expand this to include those who self-manage their plans to be able to claim for supports that assist them to self-manage, increase their capacity to self-manage and for any incidental costs related to managing funding under their plan. Given the new measures placed on participants, the Department must provide supports to assist participants who wish to optimise their independence by doing this task themselves.

This should also include legal costs associated with self-employment contracts and meeting other legal obligations in relation to administering their own NDIS supports.

Supports that are not 'NDIS Supports'

Day-to-day living costs

AXYS is concerned that 'Disability-related Health Supports' are not explicitly mentioned in this section. Several of our members have swallowing issues including dysphagia and require texture modified foods, and fluids including carbonation and food to practice swallowing with, or additional food specifications above typical consumer convenience standards.

International best practice would require 'water aerators' or carbonation devices for these individuals to prepare a texture modified diet. This has been listed as a "*lifestyle*" product. For these individuals this can be a life and death decision[2,3] and a designation of it being a '*lifestyle'* choice is offensive.

The phrasing for Groceries is problematic. The Department have phrased it assuming all Australian disability residents have access to the same services regardless of location.

Although the Department specifically excludes pre-modified groceries, they do not provide flexibility should a participant require to prepare their texture-modified foods/fluids at home from scratch. This is concerning to an adult member who lives in a regional area where no dysphagia-specific providers service where he lives.

Another member is allergic to a thickener in the pre-prepared foods and therefore cannot safely access these providers. Both are required to purchase specific ingredients at their local supermarket or other retailers to prepare their texture modified diets at home. These participants purchase these products as the use of these specific items changes the rheology of foods essential for safe swallowing.

AXYS recommend that disability-related health supports be explicitly included as a carve out in the Supports that are not 'NDIS Supports' Day-to-day living costs. AXYS recommend that 'carve outs' be identified prior to the specified items so that participants understand that these supports can still be obtained if these additional specifications are met, such as:

> *"Additional living costs that are incurred by a participant solely and directly as a result of their disability support needs".*

<u>Lifestyle related</u>

Sexual intimacy

AXYS is concerned with the language used by the department to characterise our community members living with disability-related sexual dysfunction as a "*lifestyle choice*". AXYS represents those with Klinefelter Syndrome who have higher levels of sexual dysfunction than the typical male counterparts.

Research has shown that these individuals continue to experience sexual dysfunction despite medical intervention in relation to their subjective experience of sexual pleasure and experience of orgasm. Medical pharmalogical intervention (hormone replacement therapy) successfully assists with the treatment of erectile dysfunction, however approximately 10% experience persistent 'muted orgasm'[4].

2. Turkington L, Ward EC, Farrell A, Porter L, Wall LR. Impact of carbonation on neurogenic dysphagia and an exploration of the clinical predictors of a response to carbonation. Int J Lang Commun Disord. 2019

3. Shapira-Galitz Y, Levy A, Madgar O, Shpunt D, Zhang Y, Wang B, Wolf M, Drendel M. Effects of carbonation of liquids on penetration-aspiration and residue management. Eur Arch Otorhinolaryngol. 2021

An orgasm is the euphoric subjective experience that people experience as they climax[4]. Male ejaculation follows, but this is not actually an orgasm; it is an entirely separate function[4]. Studies have shown concordant orgasm in intimate partners increases an individual's perceptions of the quality of their relationships[5]. Increasing the quality of relationship in consenting adults in intimate relationships will increase the sustainability of informal supports[6, 7].

Assistive technologies that have been designed for spinal injured veterans that has shown promising results as a maintenance support to assist those with enduring orgasmic sensation difficulties in increasing their capacity to experience orgasm, which in turn increases the quality and sustainability of their relationship.

AXYS requests that the Department include sexual assistive technologies that are prescribed by a clinician to maintain the functioning of that body part be provided as a disability-related health support to increase quality of life and relationship satisfaction.

AXYS only believe these supports should be provided to consenting adults with whom all other reasonable treatment options have been exhausted.

AXYS members' partners have reported their spouse/partner as unwilling to engage in mutually consenting intimacy as they describe it as "*dull*" for their partners, who in turn ignore them and decreases their relationship quality leading to estrangement, resentment and separation. Several adult members have described relationship breakdown as a result of an inability to experience orgasm and disengagement from sexual intimacy.

AXYS members require specialised assistive technology for sexual activity. These are not standard *'sex toys'* nor are they seeking '*sex work'*. These are specialised assistive technologies that have undergone clinical trials to assess their efficacy and are specifically designed for people with disabilities.

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4. Skakkebæk A, Moore PJ, Chang S, Fedder J, Gravholt CH. Quality of life in men with Klinefelter syndrome: the impact of genotype, health, socioeconomics, and sexual function. Genet Med. 2018

5. Klapilová K, Brody S, Krejčová L, Husárová B, Binter J. Sexual satisfaction, sexual compatibility, and relationship adjustment in couples: the role of sexual behaviors, orgasm, and men's discernment of women's intercourse orgasm. J Sex Med. 2015

6. Matthys O, Dierickx S, Van Goethem V, Deliens L, Lapeire L, De Pauw A, Hudson P, Vulsteke C, Geboes K, De Waele S, Spoormans I, Di Leo S, Guberti M, Schmidt US, Scott D, Harding R, Witkamp E, Connolly M; DIAdIC team; De Vleminck A, Cohen J. Sexual satisfaction and its predictors in patients with advanced cancer and their family caregivers in six European countries: Baseline data from the DIAdIC study. Psychooncology. 2024

7. Péloquin, K., Brassard, A., Delisle, G., & Bédard, M.-M. (2013). Integrating the attachment, caregiving, and sexual systems into the understanding of sexual satisfaction. Canadian Journal of Behavioural Science, 2013

AXYS members are entitled to specialised equipment to assist them in maximising the quality of their intimate relationships and sustaining their informal supports.

AXYS recommend "*assistive product for consensual sexual intimacy*" be included as a NDIS Support carve out.

Clothing related

Footwear

AXYS are concerned access to mainstream high-end advanced footwear would be excluded under the umbrella term of "standard".

AXYS members have a high prevalence of motor coordination difficulties, joint hypermobility, muscle weakness and poor balance[8]. Footwear that provides increased joint stability and assists with foot placement is crucial for increasing personal mobility and independence.

Footwear that provides addition a support and assists with mobility that are either custom prescription or their design includes advanced engineering should be allowed if they are required as a result of someone's individualised disability-related support needs.

An AXYS parent has stated they purchase shoes from Spendless Shoes and Kmart for their other children, but due to motor difficulties they must purchase from Athletes Foot or Skechers. These retailers do not sell just "standard" footwear simply because an average Australian could purchase them. They sell footwear that uses advanced engineering to provide additional supports that are essential for safer mobility in those with disability and therefore should be recognised beyond a "*mainstream*" retailer.

Clothing

Individuals with Klinefelter's Syndrome typically present with congenital malformation of their torso and limbs resulting is disproportionate growth. Subsequently this results in clothing designed for typical male counterparts (46XY) not being suitable. As a result, many adolescents and adults struggle to find clothing (including uniforms and personal protective equipment) that fits and subsequently are required to either purchase standard clothing and have it amended, or purchase custom-made clothing.

Many members and parents have reported social exclusion without clothing assistance as a result of peer perceptions (stereotypes) about their attire. Parents have reported their children unable to participate in sports because standard unforms or equipment does not fit.

8. Verri A, Cremante A, Clerici F, Destefani V, Radicioni A. Klinefelter's syndrome and psychoneurologic function. Mol Hum Reprod. 2010

AXYS recommend an acknowledgement that individuals with physical impairments can require assistance in acquiring mainstream/standard clothing and there are circumstances in which these supports address their '*disability-related needs*'.

AXYS recommend the removal of '*standard*' and refer to supports as to their specific nature, that being a disability-related need.

Travel related

Short Term Accommodation/Respite

As addressed on page 7 of this submission AXYS is concerned that the individual listing of supports that collectively constitute Short-Term Accommodation appear to be excluded.

AXYS calls on the department to publish a supplementary policy for self-directed, self-managed, and sole participants short term accommodation.

Vehicle Modifications/Motor Vehicles

AXYS has several members in regional and rural Australia. It is alarming that all-terrain vehicles are being excluded when this would otherwise be classed as a Personal Mobility aid for someone who lives on farmland. This would be unfair denial and discrimination of a specific and more appropriate personal mobility aid for those who live in regional and rural Australia.

All-terrain vehicles for those with disability are significantly more advanced and come with additional features that basic all-terrain vehicles do not. If a person in a metropolitan area required a motorised scooter, they would be able to acquire it under the Personal Mobility Aid NDIS Support category. However, a mobility scooter would likely not be able to be operated in regional and rural areas due to uneven terrain. Therefore, an all-terrain vehicle for someone with disability should be classed as the regional and rural equivalent of a mobility scooter.

AXYS recommend the purchase of all-terrain vehicles to be removed from Vehicle Modifications carve out and Travel-related 'not NDIS Support' list and be more appropriately included under Personal Mobility Aids explicitly for those in regional and rural Australia.

Petrol

AXYS are deeply concerned of this exclusion that appears to be based on principle rather than any assessment of whether this meets the disability-related needs of participants.

Prior to the NDIS individuals who could not use public transport accessed funding through the Mobility Allowance. The Mobility Allowance provided funding for transport needs that

arose due to an individual's inability to use public transport including increased car operating costs (fuel and maintenance), tolls and parking.

AXYS is acutely aware of allied health shortages in regional Australia. Many regional members express dismay at needing to travel hundreds of kilometres each way over several hours to access required face-to-face disability-related therapies. Although the Agency has a policy framework of 30-60 minute maximum travel time this is unrealistic for those in regional Australia, especially our members who have complex disability support needs and require more highly competent professionals. The need to travel to these providers should be covered. It is unreasonable for the Agency to enforce these radius limits when these health professionals are governed by national regulations that require they not provide services if they do not believe they are competent.

AXYS are deeply concerned this will further limit access to timely intervention for our members in regional and rural Australia. If a participant can pay a provider costs per kilometre which includes a calculation of fuel costs, why can participants not claim their own travel expenses for accessing disability-related therapies when they drive their own vehicle? People in regional Australia do not have the luxury of having numerous providers in a central geographical location and must have the ability to afford to have face-to-face therapeutic services when required.

AXYS recommend the Department uphold the AAT decisions to fund fuel costs for participants who drive their own vehicle to and from therapy or other NDIS support services, and for those who are funded transport allowance, at the rate determined by the ATO for that financial year (Castledine, Ewin).

<u>Income replacement</u>

AXYS is concerned the inclusion of '*loan repayments or buy now pay later payments'* would inadvertently ban a manner in which payments are made, without assessing what support is purchased through these means. Many self-managed participants rely on loans and buy now pay later services to acquire goods while waiting for reimbursement.

AXYS recommend the Department remove the term "*repayments*", and include the term "fees" to specify that late fees, interest payments cannot be claimed. The Department should rephrase to "*Loan and Buy now pay later fees"*. This will provide clarity to community members.

Not value for money/not effective or beneficial

AXYS is deeply concerned at the Departments dismissal of evidence-based therapies, and adjunct therapies, in addition to its overreach in determining the appropriate therapy approaches and modalities for participants. The Department should have no place in determining what therapies should be used for specific participants; this should only be opined by their treating health professionals.

Medical and Allied health professionals including, Otolaryngologists, Occupational Therapists, and Psychologists are regulated under The National Law, and are required to provide safe and ethical services and have a strong clinical basis for the recommendation of aids and services to participants.

The suggested exclusion of Neurofeedback, if applied to "*therapeutic supports*" is a transgression of Clinical Psychologists right to choose the therapeutic modality they wish to use in providing supports to persons with a disability.

Neurofeedback

Neurofeedback is a behavioural brain training technique in which the trainee receives moment-to-moment feedback of electroencephalogram (EEG) rhythms. These are the natural fluctuations of electrical activity between parts of the brain. Professionals detect EEG rhythms by using a computer and sensors on the scalp. There are 3 different feedback systems, chosen according to individual needs.

While usually delivered in the clinic, Neurofeedback can be clinically supervised through home-based systems which is helpful for those in regional and remote locations. Neurofeedback is an individualised intervention. Protocols, modality, session duration, frequency and therapeutic dose are determined by the Clinician according to the individual's presentation symptoms and stated priorities. Starting protocols are adjusted according to trainee response.

Like all individualised therapies, randomised controlled trials which are traditionally considered the gold standard for "evidence-based medicine" is a poor method for evaluating efficacy of neurofeedback. Alternative methodologies such as single case study series and related experimental designs are more appropriate. Neurofeedback has an established evidence-base of efficacy in individuals with neurodevelopmental disorders[9,10,11,12,13].

9. Arns, M., de Ridder, S., Strehl, U., Breteler, M., & Coenen, A. (2009). Efficacy of neurofeedback treatment in ADHD: The effects on inattention, impulsivity and hyperactivity: A meta-analysis. Clinical EEG and Neuroscience,

10. Coben, R., Wright, E. K., Decker, S. L., & Morgan, T. (2015). The impact of coherence neurofeedback on reading delays in learning disabled children: A Randomized controlled study. *NeuroRegulation*,

AXYS is concerned that the department does not recognise that neurofeedback is regulated by AHPRA and that the Australian Psychological Society (APS) offer it as a professional development module. APS states[14]:

> *"Clinical EEG Neurofeedback is emerging as an evidence-based approach to helping clients with a range of difficulties including emotional dysregulation, the effects of trauma, difficulties with attention and cognitive function. This activity has been assessed against the APS Standards for CPD activities and approved for its education quality."*

Under the Health Practitioner Regulation National Law Act, which governs the operations of the Australian Health Practitioner Regulation Agency (AHPRA) and the National Boards for Health Profession, all registered psychologists must undertake Continuing Professional Development (CPD).

AXYS notes the BGAP (Brain, Genes & Puberty) study currently being conducted by Stanford Medicine is investigating Klinefelter Syndrome and male adolescent neurodevelopment[15]. They have identified Neurofeedback as a potential therapeutic outcome of their study.

AXYS recommend that Neurofeedback be removed from Not value for money/not effective or beneficial. There is sound evidence-based clinical research supporting that Neurofeedback is effective and beneficial for specific individuals, including AXYS members.

<u>Hair therapy, hair and beauty services including nail salons</u>

AXYS is concerned about the inclusion of a mainstream provider for self-care activities related to an individual's impairments. Especially as those with Trisomy X, Jacobs Syndrome, and Klinefelter Syndrome all have fine motor difficulties[8,16,17].

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8. Verri A, Cremante A, Clerici F, Destefani V, Radicioni A. Klinefelter's syndrome and psychoneurologic function. Mol Hum Reprod. 2010

11. Micoulaud-Franchi, J-A., Geoffroy, P. A., Fond, G., Lopez, R., Bioulac, S., Philip, P. (2014). EEG neurofeedback treatments in children with ADHD: An update meta-analysis of randomized controlled trials. Frontiers in Human Neuroscience,

12. Perl, Moshe & Perl, David (2019). EEG amplitude neurofeedback: A review of the research. APJNT Asia Pacific Journal of Neurotherapy, Vol.1. No. 1.

13. Steiner, N. J., Frenette, E. C., Rene K. M., Brennan, R. T., & Perrin, E. C. (2014). In-school neurofeedback training for ADHD: Sustained improvements from a randomized control trial. Pediatrics,

14. https://psychology.org.au/event/24468

15. https://med.stanford.edu/bgapstudy/findings/_jcr_content/main/panel_builder_1579741960/panel_0/download/file.res/-AXYS_3.28.pdf

16. Ross JL, Zeger MP, Kushner H, Zinn AR, Roeltgen DP. An extra X or Y chromosome: contrasting the cognitive and motor phenotypes in childhood in boys with 47,XYY syndrome or 47,XXY Klinefelter syndrome. Dev Disabil Res Rev. 2009

17. Otter M, Schrander-Stumpel CT, Curfs LM. Triple X syndrome: a review of the literature. Eur J Hum Genet. 2010.

Fine motor impairments impact the ability for an individual to shave, and wash their hair. In addition to balance difficulties and other musculoskeletal issues, most of our community have sensory differences which result in these tasks requiring assistance for a participant to complete. Using a hair or beauty service including hairdresser or barbers is a low-cost solution for these individuals.

Fair Work Australia requires support workers work for minimum of 2-hour shift. Rather than a low-cost service of $20 for a shave, or $35 for a hair wash once a week or fortnight costs to participants would be from $130.94 each time this support is required. This would exponentially explode costs in self-care activities. In addition, our members in regional Australia haver highlighted thin disability markets with an absence of adequate number of support workers to wash their hair or assist with shaving.

AXYS recommend that the nature of the support be assessed rather than what it is. This will address the individual needs of the participant and assist them in meeting their impairment needs for the lowest-possible cost.

Meal Preparation (Food & Beverage related)

AXYS is concerned about the blanket approach to this topic and the exclusion of food services and takeaway food.

Firstly, participants have **never** been able to claim the full outright cost of foods except in extremely narrow and limited cases. These exceptions are for participants while on Short Term Accommodation, and for those with Dysphagia for meeting texture modified requirements both at home and in public, and to participate in swallow therapy. There have been no other instances in which food and beverage costs are funded.

There are legitimate reasons in which participants require funding for food. The Agency explicitly funds those with Dysphagia the additional costs related to meeting a texture modified diet, or the acquisition of pre-modified foods for PEG feeding. In addition, additional funding for those with dysphagia to practice eating food under the direct supervision of a speech pathologist has been funded. An AXYS member has been audited by the NDIA for foods-related costs used for swallowing therapy. The Agency determined these claims to be in accordance with meeting their disability-related health support needs.

AXYS continues to support the current agency operational guideline that meal preparation services can be claimed at a ratio of 30:70[18]. This accurately reflects the cost component of the food for the participant and the service fee. It is more cost effective for a participant to purchase a meal through a local Indian restaurant than hire a support worker for 2-hours.

18. https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/nutrition-supports-including-meal-preparation/what-types-nutrition-supports-do-we-fund/how-can-i-use-my-meal-preparation-support-flexibly

Comparatively it would be much cheaper to fund the service portion (70%) than to hire a support worker during the week, and especially during penalty rate hours on evenings or weekends.

The identification of food services and takeaway is highly concerning. Especially in relation to the aforementioned support worker shortages and Fair Work requirements. As previously noted, an AXYS member resides in a regional town and there are less than 30 support workers for several hundred participants. To deny access to a service provider who can provide a meal service could result in significant harm including starvation and death.

AXYS supports the extension of the 30:70 ratio for participants while are on short term accommodation unless they have established texture-modification requirements. It is reasonable to expect individuals should purchase their own ingredients for meal preparation regardless of whether they are at home or away.

AXYS recommend that for participants funded meal preparation they not be banned from accessing meal preparation services from mainstream food and takeaway service providers, but that funding and participants contribution continue in line with the Agencies operational guideline of a 30:70 ratio split. AXYS recommend a carve out for those with Dysphagia who are established to require a texture modified diet and to purchase foods for swallow therapy. These individuals have additional food and beverage costs to ensure safe swallowing.

Gaming Therapy

AXYS is alarmed at the umbrella approach the Department are forwarding in relation to the role gaming has in assisting those with disability. Especially the exclusion of Gaming Therapy. Gaming is a loaded term that includes games for recreation, as well as Serious Games. Serious Games are games purposely designed to facilitate skill development in those with disability. Gaming is considered a recreational activity, from novice to professional. Gaming can also be considered employment for highly skilled esport athletes.

Exclusion of Gaming in general will also remove access to "Serious Games" including Exergaming and Exerlearning which has been found repeatedly to increase motor functioning in those with physical and neuromuscular disabilities, and cognitive flexibility in those with neurodevelopmental disabilities. In addition, serious and mainstream gaming has been found in several peer reviewed journals to increase Social Capital, and increase psychological well-being.

A 2018 Australian study from Southern Cross University found Australian gamers reported Online Multiplayer Gaming facilitated socialisation during gameplay **AND** outside of the game (ie in the community away from the game)[19].

19. Bradley, R., Donnelly, J., & Hurley, J. Online Multiplayer Gaming: mates, motives and mood. 2018. Frontiers Psychology.

In relation to the demographic of who designed this list AXYS asks the Department to assess for biases. Peer-reviewed research[20] has reported:

> *"Beliefs about the harmfulness of video games were predicted by respondents' age, female gender and negative beliefs about youth."*

Gaming therapy itself is an evidence-based clinician lead adjunct therapy[21]. That is, it is a therapy used together with the primary treatment to assist the primary treatment. The banning of this adjunct therapy is a transgression of Clinical Psychologists, Speech Pathologists and Occupational Therapists right to choose the therapeutic modality they wish to use in providing supports to that specific person with a disability.

The banning of gaming in general removes the assessment of what the games does to address the disability-related needs of individuals.

AXYS request the Department to be aware of the biases toward '*Gaming*' and not ban Gaming-related support services for those with disability. The evidence clearly indicates it is an effective and beneficial support in decreasing impairment in both physical, cognitive and social contexts, and increases socialisation outside of the gaming environment. In the context of neurodevelopmental disorders, the research indicates there are carry-over effects into other domains of life (positive effect of adaptive functioning).

AXYS recommends that recreational gaming and gaming therapy be revised and appropriately re-categorised as an innovative community participation support and as a evidence-based therapeutic support.

AXYS recommend that the Department respect the role of nationally recognised and accredited allied health professionals' clinical expertise and opinion of the best-practice therapeutic intervention for their individual client's needs.

Not NDIS Support List

AXYS recommend that the only '*Not NDIS support list*' should include the obvious: illegal, gambling, alcohol, cryptocurrency and non-evidence based pseudo-scientific practices (crystal therapy).

AXYS recommend that this process be paused, so that a reasonable extension be granted so that the disabled community can be genuinely engaged for the co-design of lists.

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20. Ferguson, C. 2015. Clinicians' attitudes toward video games vary as a function of age, gender and negative beliefs about youth: A sociology of media research approach, Computers in Human Behavior

21. Bul KC, Kato PM, Van der Oord S, Danckaerts M, Vreeke LJ, Willems A, van Oers HJ, Van Den Heuvel R, Birnie D, Van Amelsvoort TA, Franken IH, Maras A. Behavioral Outcome Effects of Serious Gaming as an Adjunct to Treatment for Children With Attention-Deficit/Hyperactivity Disorder: A Randomized Controlled Trial. J Med Internet Res. 2016

Grandfathering Provision

AXYS recommend the Department implement a Grandfather provision for participants whose plans have been funded supports that appear in the now 'not NDIS Support List'. It is unfair to limit access to support that have been explicitly funded as a reasonable and necessary support and included in a participants plan.

Permission 'Carve Out'

AXYS are concerned about the permission carve-out because the NDIA are known for inconsistent decisions[1] and the volume of permission requests could be overwhelming. Many 'household' items, and mainstream retail and hospitality services save support worker costs when the Fair Work Act is considered in decision making.

Contradictions within Draft NDIS Support Lists

AXYS is deeply concerned by the convoluted and at time contradictory drafted supports categories, carve outs and multiple instances where the same support can be both a support and not a support. There has been no guidance as to what takes precedence. The categories overlap appearing contradictory, leading to misunderstanding.

Conclusion

Australian X & Y Spectrum (AXYS), and the wider disability community has not been awarded reasonable time to be able to comprehensively understand these lists, nor have we had the time to survey our community members concerns, or to comprehensively respond to the Departments request for feedback.

The time allotted to our community by the Department shows utter disregard the experts with lived experience, nor the additional the needs of people living with Intellectual Disability or Specific Learning Disabilities. AXYS recommend that these support lists consultation period be extended to another 3 -weeks to make it consistent with previous DSS NDIS-related consultations, and to comply what is reasonable under the Disability Discrimination Act.

Overall AXYS does not support these current lists as they are inexplicably difficult to understand, they are misleading, confusing and contradict and establish an over-prescriptive rules that will increase cost, decrease participant choice and control.

AXYS is deeply concerned that blanket exclusion of items without reference to the specific needs they address for participants will limit choice and control, prevent access to vital and life-sustaining disability-related supports, and introduce inefficiencies.

AXYS endorses the Justice and Equity Centre submission to Department of Social Services: Consultation on Draft Lists of NDIS supports dated 16 August 2024.