

DUCHENNE & BECKER
MUSCULAR DYSTROPHY
A GUIDE FOR NDIS PLANNING



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CORE SUPPORTS

WHAT ARE CORE SUPPORTS?

Core supports are those supports that are central to an individual's life and lifestyle; these supports include:

- Personal care: such as showering, toileting, dressing, and grooming
- Daily living tasks: meal preparation, doing dishes, doing laundry, walking dogs, general tidying up
- Domestic tasks: cleaning bathrooms, vacuuming, and mopping, spring cleaning, making beds, maintenance of gardens and lawns, jobs completed by a handyman
- Social participation: assistance from a support worker or similar at a social or community event, attendance at and participation in group activities for people with disabilities, attendance at and participation in camps, retreats or getaways for people with disabilities, or attendance at accommodation or holiday programs specifically designed for people with disabilities, food shopping, attending appointments
- Consumables: items which, by their very nature, are used once or a number of times and then discarded, such as PEG feeds and lines, BiPap masks and tubing, continence aids, batteries and tyres for equipment, etc

Once individuals reach a certain age, core supports are likely to be included in their NDIS plan every single year, as these supports are recognised as being essential to them achieving their goals and living as independently as possible.

Core supports is arguably the most flexible of all support categories through NDIS, as they can be used for almost any support, so long as it can be demonstrated that the support assists the individual to achieve their NDIS plan goals, and the support is either a task or activity the individual would complete without support if they did not have a disability (such as showering, meal preparation or participation in a social event), or items (such as PEG feed) which would not be required were it not for the person's disability.

WHAT ISN'T COVERED?

Despite the flexibility of the core supports category, there are some exclusions to the support that will be funded; typically, fees for membership (such as for gyms or mainstream sporting clubs) or admission (such as to movies, concerts or events that do not have a disability focus or are not run by disability organisations) will not be covered by core supports; costs for materials used for completion of daily living or domestic tasks (such as the vacuum cleaner used by a support worker or cleaner, or the plants and soil planted by a gardener) will also not be covered; finally, 'cost of living' expenses are also not covered, which typically represent those costs a person without a disability would reasonably be expected to pay to achieve the same outcome (such as flights for an interstate holiday or ingredients for preparing a meal)

WHAT DOES FLEXIBILITY ACTUALLY MEAN?

Within the core supports category on an NDIS plan, there are further subcategories, to which funding is allocated in specific amounts, based upon the information gathered at planning and review meetings; the subcategories within core supports are as follows:

- Assistance with Daily Living (ADL): funding allocated for supports for personal care, daily living tasks and domestic tasks
- Social, Community and Civic Participation (SCCP): funding allocated for social participation
- Consumables: funding allocation for consumables and Low Risk Assistive Technology (refer to the Assistive Technology chapter)
- Transport: funding allocated at one of three distinct levels for assistance with transport requirements, with levels determined by hours of work, study, or volunteer involvement per fortnight

Depending upon how an NDIS plan is built, the funding allocated within each of the core subcategories above is able to be pooled and used as ONE large pool of funding, from which the individual may access the supports and services they require (in line with the NDIS rules) to achieve their goals.

In practical terms, this means that if an individual has \$10,000 allocated to their SCCP subcategory and \$10,000 allocated to their ADL subcategory, but they wish to spend \$15,000 on social participation throughout the year, they can make the choice to use some of the funding available within their ADL budget for this purpose (with the understanding they will only have \$5,000 remaining for personal care and domestic tasks).

In some cases, this flexibility extends to an individual's transport funding also, however this is dependent upon the wording in the NDIS plan. Specifically, the NDIS plan must not state that core supports funding is flexible across THREE categories; where the plan nominates only three categories for flexibility, this means the transport category is to be treated as a separate and distinct pool of funding.

CORE SUPPORTS STAGES



Stage 1 Pre-symptomatic (Birth – 2 years)

At this stage, core supports are highly unlikely to be funded on an individual's NDIS plan, due to the expectations of children of this age and the nature of their dependency.

At this stage, it is expected that parents complete the vast majority of personal care and daily living tasks for their child, regardless of whether they have a disability or not. Similarly, it is also expected, at this stage, that parents organise, coordinate and facilitate social participation on behalf of their child (again, regardless of whether they have a disability or not). Finally, at this stage there is no expectation of the child to participate in or complete domestic tasks, regardless of whether they have a disability or not.

For these reasons, core supports are unlikely to be funded on an NDIS plan for a young person at this stage. Where there is a need for some level of core supports (such as funding for assistance with domestic tasks), it is important for the young person's family to present information about why these supports are needed, with reference to the individual's disability support needs and how these exceed a typical dependence relationship, even for a child with a disability.

Stage 2 Early ambulatory (3 years - 5 years)

Heading into childcare and kindy (or preschool) years, the need for core supports starts to emerge as the physical impacts of DMD start to be seen on a more regular basis.

For children without DMD and disability, this would be the age where they start to become more independent in personal care (especially bathing and toileting) and some daily living tasks. For children with DMD, they may require a greater level of support than their peers without DMD, which obviously demands more time and energy of parents and caregivers.

At this stage, funding may be required for assistance with domestic tasks, including cleaning and garden maintenance, to ensure parents and caregivers can continue to support their children with personal care and daily living tasks, without experiencing fatigue or injury.

From the age of about 4-5 years, children without DMD and disability would typically start to attend playdates or outings during the daytime with friends from childcare, kindy or school, and potentially even stay overnight at extended family member's or close friend's houses. For children with DMD, these age-appropriate social activities can become more

difficult and may require specific support, to ensure the young person is still engaging with their community and developing socially.

At this stage, funding may be required for social groups for children with disabilities, to help the young person to engage socially in an environment that is suitable to their physical support needs and provides opportunities to connect with children with similar experiences and support needs.

Stage 3 Late ambulatory (6 years - 9 years)

At this stage, children without DMD and disability would be having regular playdates and may spend nights away from home with school friends. For children with DMD, this becomes increasingly difficult as their physical support needs increase and their reliance on their parents does not decrease, in the way it would for a child without DMD or disability.

At this stage, assistance with domestic and daily tasks becomes increasingly important, as parents may find it difficult to manage the competing demands of their child with DMD with siblings, work, sporting activities, household responsibilities and life generally. Having support for domestic and daily tasks at this time is also important as it starts to familiarise the young person with support workers and carers, so these people are known and trusted when the times comes that additional support is required for personal care and more intimate daily living tasks.

Social participation is also very important at this stage, as this may be where the young person becomes aware of the difference between their body and the bodies of their school friends or peers without DMD or disability. At this stage, connection with other children with DMD or disability can help the young person's social development, as well as hoping to establish a sense of belonging within a community of people with shared experiences.

At this stage, children with DMD may also benefit from connection with a mentor, who is essentially a support worker but with a focus on more of a guide or buddy role, rather than a caring role. By engaging a mentor at this stage for smaller social activities (i.e. support at home whilst parents attend to sporting or other commitments with other children), the young person can start to build trusting relationships that will be needed as they become more socially active in their communities.

Finally, at this stage it may be beneficial for the young person and their family to investigate options for overnight stays away from the family home, such as at a camp for young people with disabilities. These supports are sometimes necessary to ensure parents and caregivers are able to sustain their caring roles for as long as possible, so it is best to start looking into (and potentially accessing) these supports early, before support needs start to take a toll on parents and caregivers physically, mentally and emotionally.

CORE SUPPORTS STAGES

Stage 4 Early non-ambulatory (10 years - 13 years)

By this time, most children without DMD and disability will be starting to take greater steps toward personal and social independence. For children with DMD, these steps toward greater independence are still achievable, but may require specific support systems and networks (i.e. other than parents, caregivers, and family) to be in place.

At this age, children without DMD and disability would be expected to complete the majority of their personal care independently and would contribute to a number of daily living tasks, such as making their own breakfast, making their lunch for school (e.g. sandwich, fruit, chips and muesli bar), washing up their own plate and cutlery, packing their school bag, putting dirty clothes out to be washed and putting clean washing away in their bedroom. Similarly, children without DMD and disability may be contributing to domestic tasks as part of the family, such as dusting, emptying rubbish bins and putting council bins out for collection, helping with recycling efforts, helping maintain gardens and mowing lawns.

For children with DMD, independence in personal care may look very different, in that their independence comes from having a team of people they know and trust to assist them, and having the confidence to take ownership of these processes, so that the process is completed at their pace, with their permission and in the way they feel most comfortable. Consistent with age-appropriate norms, children with DMD may want their parents to step away from the personal care role, which can be difficult for many parents and caregivers, but can also provide some relief after many years of physical effort.

At this age, children without DMD will start engaging in more social interactions without parental supervision, such as spending time with friends in public places (such as a shopping centre, the beach or the movies), going to a local park or riding bikes or skateboards around the neighbourhood. For children with DMD, this is where the right team can facilitate the same social independence, whilst still ensuring that support needs for personal care and meal-times can be met in the community.

Mentors can be an invaluable component of a support team, as they are typically matched to the young person's interest, personality and energies, to ensure that their presence at social activities is as a guiding and supportive hand, not as a parental replacement.

Camps, getaways, and retreats are also important ways for a young person with DMD to take steps toward personal and social independence. Accessible accommodation may also be necessary for family holidays or getaways, to ensure essential equipment (such as power wheelchairs, hoists and slings and shower chairs) can be used for mobility and transfers. Where such accommodation is required for a family holiday, NDIS can be used to fund the costs that are in excess of standard accommodation charges (i.e. if the standard hotel room is \$300 per night and an accessible room is \$350 per night, the \$50 difference would be claimable).

At this stage, many schools will host camps and retreats for students. Core supports through an NDIS package can be used to fund additional support for personal care and activities of daily living at a school camp, to ensure the young person has the same opportunities for participation as their school friends.

Stage 5 Late non-ambulatory (14 years+)

From this stage onwards, steps toward personal and social independence will only increase, as the young person gets nearer to adulthood.

By the age of about 16 years, the young person would ideally have a team of support people who are able to assist with personal care, daily living tasks and domestic tasks on a daily basis. Similarly, this team would also feature supports for accessing their local community for social activities, but also for essential services like food shopping and attending appointments.

Throughout their schooling years, support for attendance at and participation in school camps or retreats may continue to be funded using NDIS supports, but after this time consideration may need to be given to a specific NDIS goal for going on holiday, to ensure adequate supports can be funded, such as holiday programs (i.e. packages that include accommodation and support for personal care, daily living tasks and social participation) or short-term accommodation.

For holidays taken by an individual (i.e. not with their family members), short-term accommodation funding may be accessed, which will allow the participant to utilise their NDIS funding for an accessible room (featuring ramps and / lifts, wider doorways, level entry bathroom, etc.) for their holiday, as a standard hotel room will not meet their support needs.

As much as possible, supports at this stage should be planned with a view to the young person's future, such as where they will live as an adult and what work, study or volunteer opportunities they may wish to pursue. By planning with these future considerations in mind, individuals and families can start preparing and working toward these end goals in a proactive manner, reducing the need for reactive strategies when parents and caregivers experience burn out or individuals finish school and their day-to-day support needs change dramatically.

HEALTH SUPPORTS

WHAT ARE **DISABILITY-RELATED HEALTH SUPPORTS?**

Over the past few years, NDIS has come to realise that many individuals and families living with disability have health support needs that have arisen as a result of their disability.

A classic example of this is podiatry (namely, maintenance of feet, toes, toenails and lower legs), which was historically viewed as a health support, most suitably funded and accessed through a GP Access Plan or Chronic Disease Management Plan (through Medicare).

NDIS now recognises the difficulty to maintain one's own feet, toes, toenails and lower legs as being related to certain types of disability, especially those which impact an individual's capacity to walk independently, thereby creating a need for a wheeled mobility device (such as a wheelchair), or where contractures in an individual's hips, knees and ankles and scoliosis of their spine prevents them from being able to bend down to reach their feet (or lift their feet up) for regular maintenance.

Recognising the broader impact of an individual's disability on their life and lifestyle, NDIS have now broadened their categories of support to include those health supports that may still be accessed via mainstream health or medical system, but can now be funded and paid for within an NDIS plan.

WHAT **SUPPORTS ARE COVERED?**

As with therapeutic supports, NDIS will fund those health supports that are 'evidence-based' (i.e. have been observed and documented through peer-reviewed journal articles, specialist recommendations and therapist reports) and have a direct link to the person's disability; this direct link is usually made through a recommendation from a clinician, practitioner or specialist, advising of the need for the health support and recommending a certain level or type of intervention; in the case of DMD, health supports typically include services for podiatry, dietitian, nutritionist and community nursing, as well as consumable items, such as PEG feeds, supplements, lines and equipment, BiPap masks and tubing, and materials for wound and continence care.

WHAT **SUPPORTS ARE NOT COVERED?**

NDIS will not fund GP consultations, surgical interventions, medication or intervention by specialist surgeons or doctors that is covered by Medicare or able to be accessed or most suitably funded by other clinical programs (such as Rehabilitation Specialists, Orthopaedic Surgeons, Neurologists, etc); NDIS will also refuse to fund anything that poses a risk to a participant's safety (such as oral supplementation if an individual has been advised not to consume anything orally due to risks of choking or aspiration) or exceeds the recommendation of the overseeing clinician, practitioner or specialist (such as additional BiPap masks and tubing).

HOW DO I DEMONSTRATE A DIRECT LINK BETWEEN THE DISABILITY AND THE NEED FOR HEALTH SUPPORTS?

When first requesting a health support, the direct link between the disability and the support is best achieved via a letter or report from the clinician, practitioner or specialist, advising of the need for the health support and recommending a certain level or type of intervention; where possible, it is best to include costs for the health support and recommendations for intensity (i.e. how often podiatry services should be administered each year) or usage (i.e. how many BiPap masks and tubing required each year, including some backups).

Stage 1 Pre-symptomatic (Birth - 2 years) &
Stage 2 Early ambulatory (3 years - 5 years)

At these stages, health supports are typically not required. Where a podiatrist's services are needed (i.e. for footwear or AFOs), this is a therapeutic support and should be presented as such, to ensure its inclusion in therapy budgets.

Stage 3 Late ambulatory (6 years - 9 years)

At this stage, changes to capacity for walking and transferring, as well as the introduction of medications (such as steroids), are likely to impact the individual's weight. It may be necessary to seek the guidance of a nutritionist and / or dietitian to seek advice and guidance about healthy options that will maximise energy and help the young person feel satiated but will prevent sudden or rapid weight gain.

Stage 4 Early non-ambulatory (10 years - 13 years)

At this stage, the changes to mobility and transfers, as well as the possible need for non-invasive ventilation will require annual health supports to be included within each NDIS plan, to ensure individuals and families are not having to fund these costly supports.

As the young person spends more time using their power or manual wheelchair, their feet and lower legs may require more attention from a podiatrist to ensure they are healthy and maintained.

Where the recommendation is made for BiPap, this should include an annual allocation for masks and tubing, to ensure the BiPap can be administered comfortably and regularly.

Management of health and wellbeing, specifically in terms of weight and nutrition, continues to be a focus at this stage, especially as the young person enters their teenage years and puberty. Regular consultation with a nutritionist and / or dietitian can assist families and individual's themselves to be aware of and familiar with healthy food options, to ensure they feel satisfied but do not experience rapid weight gain (which may lead to safety issues for transfers and mobility).

For some individuals at this stage, dysphagia, or difficulty swallowing, may also become an issue. For severe cases of dysphagia, a PEG tube may be recommended by a speech pathologist. Where this is the case, the PEG feeds, lines and equipment required to ensure the young person receives sufficient nutrition can be funded through the NDIS plan, along with the required training of any support workers or carers by a community nurse, to ensure the safe and correct use of the PEG.

Stage 5 Late non-ambulatory (14 years+)

By this stage, the young person will likely be able to play a more active role in planning their supports, as well as following through with the recommendations from their therapists, specialists and supports. This is particularly relevant for health-related supports, as the young person may have specific priorities or preferences for supports.

Supports at this stage are about maintaining the individual's functional capacity (i.e. the capacity to complete daily tasks or activities independently or with the aid of equipment or formal supports) for as long as possible, and health supports services to compliment the assistance being provided through therapies and assistive technology.

Non-invasive ventilation continues to be important as the young person moves into adulthood, but at this stage the young person may be able to provide greater feedback about the masks they are using and when they are using them, to ensure they can continue to be as active and social as they want, without a BiPap mask impeding this.

Similarly, maintenance of feet and legs continues to be important, but the individual may have specific preferences for who completes this support and how often.

Weight and nutrition continue to be important for ensuring safety during transfers and repositioning, but decisions to maintain or discontinue specific medications or therapeutic supports may change the focus of a nutritionist or dietitian's intervention.

The young person may also be of an age where they can make some decisions, with consideration for all factors involved, as to how best to balance the management of dysphagia with the desire to maximise opportunities for social engagement and interaction with peers.

Health supports will continue to be funded throughout a participant's lifetime, through their NDIS plan, with regular reports (i.e. at least annual) and recommendations for intensity and usage.

THERAPEUTIC SUPPORTS

WHAT THERAPIES ARE COVERED?

NDIS will fund those therapeutic supports that are ‘evidence-based’ (ie have been observed and documented through peer-reviewed journal articles, specialist recommendations and therapist reports) and proven beneficial for specific conditions; in the case of DMD, these typically include physiotherapy, hydrotherapy, occupational therapy, exercise physiology and (depending on the planner’s knowledge and experience) behaviour support; NDIS will also fund those health-related therapeutic supports that are required as a result of the participant’s primary disability, but for more information refer to the Health Supports Chapter.

WHAT THERAPIES ARE NOT COVERED?

Typically, NDIS will not fund any therapies that are harmful to the participant, are not evidence-based (i.e. have not been proven to be beneficial through the evidentiary examples listed above), duplicate supports available through other systems or funding schemes (such as Medicare) or are not related to the participant’s disability; examples of supports that would not be funded would include chiropractic interventions or relaxation massage (i.e. not remedial).

HOW DO I CONVINCING NDIS OF THE NEED FOR THERAPY?

On principle, NDIS is designed as a system for implementing support early to reduce the need for support later; using this same principle, therapists can demonstrate (through annual progress reports, AT assessments and standardised assessments) how individual therapies, AT or low risk aids can build a participant’s capacity for independence and reduce their need for other supports (such as support workers or therapeutic support in the future); where possible, therapists should make predictions about how a participant is likely to be impacted if they do NOT receive the recommended therapeutic intervention, so that this information can be factored into decision-making.

Stage 1 Pre-symptomatic (Birth - 2 years)

At this stage, therapeutic intervention is likely to be minimal, with a focus on building (or maintaining) strength in the legs, arms, and core.

At this stage, hydrotherapy and physiotherapy will be the predominant interventions, with some input from an OT re low risk equipment or adaptive aids. There may also be input from a podiatrist or PT regarding footwear or AFOs.

Allocation should be made annually for standardised testing by a PT, such as the North Star, Six Minute Walk Test, and other useful measures. Typically, this testing would require about 5 hours of support.

Stage 2 Early ambulatory (3 years - 5 years)

Heading into childcare and kindy (or preschool) years, regular (i.e. weekly or fortnightly) hydrotherapy and physiotherapy will likely continue, but now the input from the OT and PT will increase, as assessments are completed and recommendations made for AT and low risk aids within the education and community environments.

At this time, an assessment and recommendations may also be provided for a manual wheelchair or specialised stroller, to assist with longer days or distances and when little ones get tired. This assessment and quoting process is likely to take about 10 hours.

AFOs will be required bi-annually at this stage, so allocation will need to be made within the therapy budget for reviews twice per year (usually about 3 hours each time).

There may also be the need for an assessment of the environment at home, to ensure personal care and other daily tasks are being completed as safely as possible. An OT or PT can assist with this assessment, which will usually require about 5-10 hours.

At this stage, it is also beneficial to start talking with an OT or PT about a scooter or power wheelchair, as well as portable ramps to assist with accessibility in the school environment.

Standardised testing should continue throughout this stage, with assessments completed annually and then moving to six monthly by about 4-5 years of age.

THERAPEUTIC SUPPORTS

Stage 3 Late ambulatory (6 years - 9 years)

At this stage, capacity for walking and transferring independently is likely to change. Furthermore, attendance at schooling will often impact the young person's capacity (or in some cases, tolerance) for therapy, so it is important to maintain a balance.

Hydrotherapy and physiotherapy continue to be the predominant therapy types, but at this stage it is important to balance fatigue with outcomes. As such, many families may choose to scale back therapies for the first six months of school, while their young child is adjusting to the new routine.

Another option may realign therapies with social outcomes, so that the young child feels as though their hydro and exercise sessions are more about fun and socialising (kind of like sneaking carrots and peas into the spaghetti sauce).

This may be achieved by having a PT or EP (depending on the type of therapy being delivered) write and train a support worker or TA in a program for stretches, exercises, water play (i.e. hydrotherapy) and physical manipulation (i.e. massage). This program can then be delivered by the support worker or TA on a weekly (sometimes twice- or thrice-weekly) basis, at a fraction of the cost for a PT or EP. When using this model, it is recommended to have (at least) quarterly check-ins with the therapist who has written the therapy program, to ensure it is still relevant and effective.

Input from an OT will become a regular feature at this stage, as annual assessments will need to be completed for AT (i.e. mobility and transfer equipment) and low risk aids. Hours of support from an OT for AT assessments will range from 10-30 hours, depending on the types of AT required, number of assessments to be completed and other factors.

With the commencement of schooling, behavioural changes may start to emerge, and therapeutic support may be required for these. Depending on the type of behaviour being experienced and its intensity, support may be required from a Developmental Educator (in South Australia), Behaviour Support Therapist (in other parts of Australia) or even a Psychologist. The hours required for this support will be specific to each child, their circumstances and the behaviours being experienced.

Standardised assessments should continue on a six-monthly basis at this stage, completed by a PT.

Stage 4 Early non-ambulatory (10 years - 13 years)

By this time therapy will take on a specific focus for maintain capacity for mobility and transfers as much as possible.

Hydrotherapy and physiotherapy continue to feature heavily within the therapy program, delivered either by the therapist themselves or using the support worker or TA model, as identified above.

OT input will also continue to be a regular feature for ongoing assessments completed for AT, low risk aids and potentially home modifications. Behaviour support may also continue at this stage, especially with the advent of puberty and high school.

At this stage, the need for non-invasive ventilation may emerge, which will mean input from a PT trained in respiratory management, specifically (sometimes referred to as a Chest PT). The hours of support required from the Chest PT will vary for each young person but may range from 3-10 hours per year.

Management of health and wellbeing, specifically in terms of weight and nutrition, may require support at this stage also. For specific information about the inclusion of these supports in NDIS plans, refer to the Health Supports Chapter.

As much as possible, standardised assessments should continue at this stage, however the type of assessment conducted may be different. Due to changes in functional capacity and mobility, a functional capacity assessment may be more relevant than the North Star, Six Minute Walk Test, or other measures. There are numerous types of functional capacity assessments available for OTs and PTs (or even behaviour support therapists) to complete, so it is best to have a discussion with the therapist about the information needed from the measure and then determine the best possible option. These assessments vary in administration length, ranging from 3-10+ hours.

THERAPEUTIC SUPPORTS

Stage 5 Late non-ambulatory (14 years+)

By this stage, the young person will likely be able to provide input as to which therapies they find most beneficial, as well as those they do not like at all! This feedback can be useful for determining which options to persevere with and which to discontinue.

The focus of therapeutic interventions continues to be maintenance of the individual's capacity for mobility and transfers, as well as their capacity to complete activities of daily living as independently as possible.

Input from an OT will continue as per Stage 4, with a shift in focus from medium-term (ie within 5 years) outcomes, to longer-term (ie beyond 5 years, where relevant) outcomes. This shift in focus will also be important for ensuring that AT, low risk aids and other supports are suitable for the participant not only during their schooling years, but into the future also.

The need for non-invasive ventilation may continue, which will mean the ongoing support from a chest physio may be required. Similarly, the need for health supports may continue and may need to be accounted for within therapy budgets (again, refer to the Health Supports Chapter).

Again, standardised assessments should continue as much as possible at this stage, but with specific focus on the outcomes to be gained from the assessment and selection of individual measures to ensure that outcome.



ASSISTIVE TECHNOLOGY

LEVELS OF ASSISTIVE TECHNOLOGY (AT)

Level 1 (Basic)

Items are typically low cost and low risk products from local retail suppliers or online, that need no or very little assistance to set up and use; examples include non-slip bathmats, walking sticks, long-handled brushes or shoe-horns, “off-the-shelf” shoes which assist with gait or accommodate orthotics, adapted clotheslines and video doorbells.

Level 2 (Standard)

“Off the shelf” products that can be easily accessed through an AT supplier, tested, and trialed before making a final choice; examples include shower chairs (basic models, not those on wheels or with tilt-in-space functions), toilet seat raisers, hand rails, portable ramps and personal safety alarms.

Level 3 (Specialised)

Items are generally adjusted to suit individual support needs and require linking with other AT supports and/or the home/work/place of study, which means an AT Justification and Quotation is required for consideration by NDIS before they can be included in an NDIS plan; examples include power wheelchairs with seating modifications, pressure mattresses, bed sticks/poles, slide boards, slings, mobile or ceiling hoists, bath lifts and non-complex AFOs.

Level 4 (Complex)

Custom-made or “off the shelf” items that are adjusted to suit individual support needs and requires linking with other AT supports and/or the home/work/place of study, again meaning an AT Justification and Quotation is required for consideration by NDIS before they can be included in an NDIS plan; examples include environmental control units for home automation, high-level pressure cushions or pressure care sleep systems, complex AFOs and custom-made (i.e. from scratch) shoes that accommodate feet that cannot fit into standard shoes.

The four levels previously discussed are then further classifiable into three groups:

Low-cost AT

Typically, those items that are Level 1 (Basic) and Level 2 (Standard), and generally cost less than \$1,500 per individual item*.

Mid-cost AT

Items that typically fall into Level 3 (Specialised) and Level 4 (Complex) categories, but that cost between \$1,500 and \$5,000; this category applies to a very specific list of items, which will still need to be assessed against reasonable and necessary criteria, but (once determined to meet these criteria) can be purchased using funds within an NDIS plan without a review being conducted; note, provision needs to be made in an NDIS plan in order for participants to access this mid-cost AT budget, typically through inclusion of a specific item (and its value) or a \$5,000 amount with the wording.

“Please obtain an assessment and retain proof of purchase as the Agency can request this at any time. You are responsible for seeking advice from a regulated AT assessor to ensure you purchase the right AT product.”

Like-for-like replacement

Where a piece of equipment is worn out, unable to be repaired, reached the end of its service life or doesn't fit anymore (i.e. too small), new AT can be purchased to replace this item that is either exactly the same (i.e. same make, same model, same functionality) or a different make and model but with the same functionality (where the same make and model is unable to be purchased due to age or other factors); in these circumstances, a quotation for the replacement of AT can be provided to NDIS for approval, without the need for an AT Justification.

ASSISTIVE TECHNOLOGY

Stage 1 Pre-symptomatic (Birth - 2 years)

At this stage, typically there is no Complex or Specialised AT required, but there may be some Basic or Standard aids which may be useful, such as shoes which accommodate AFOs or assist with holding the foot in the correct position. Typically, two pairs of shoes per 12-month period is reasonable.

Splinting may be required at this time, which will likely be charged as therapy time (through the Improved Daily Living Skills line within the plan, refer to the Therapy Chapter). The initial pair of AFOs will require an AT Justification and Quotation, and it is recommended that two pairs of AFOs be factored into this initial assessment, to allow for growth and development during these early years.

Following the initial provision of AFOs, quotations can be submitted annually for inclusion within plan budgets as like-for-like replacement (provided the make of the AFOs does not change dramatically, see further info below).

Stage 2 Early ambulatory (3 years - 5 years)

Heading into childcare and kindy (or preschool) years, it may be beneficial to look into a specialised stroller or small MWC, to assist with longer days or distances and when little ones get tired. This support will need an AT Justification and Quotation for inclusion in an NDIS plan.

AFOs will be required bi-annually at this stage, as like-for-like replacement for older pairs. Shoes are likely to be needed at this stage as well (two pairs per annum) and can be purchased through low-cost budgets.

Safety at home is important at this stage, as capacity starts to change and daily tasks, such as personal care, become more difficult. Simple solutions, such as standard shower chairs (i.e. not on wheels or featuring a tilt-in-space features), toilet seat raisers and non-slip bath mats may help to increase safety.

At this stage, it is also important to start thinking about mobility and transfers at school, to ensure you have necessary supports in place prior to school commencement. It may be beneficial, dependent upon individual abilities, to start talking with an OT or PT about a scooter, PWC and portable ramps to assist with accessibility in the school environment.

Stage 3 Late ambulatory (6 years - 9 years)

At this stage, capacity for walking and transferring independently is likely to change, so it is important to stay ahead of these changes and access equipment in advance. If discussions have not been had about PWC and transfer equipment, this is a good time to start looking into this.

It is also important to think about equipment in terms of the type of support that may be required over the proceeding five year period, to ensure that any AT procured is sustainable and capable of providing support for a number of years.

Given the increase in AT required by about this stage, it is important to consider provision for hire or rental of AT within an NDIS plan. Funding for hire or rental of equipment will enable longer trials of AT, to ensure the device suits the individual's needs, as well as short-term solutions for faults with existing AT or attendance at camps or getaways.

PWCs (including sit-to-stand) will require an AT Justification and Quotation, with consideration for any seating modifications that may be required for spinal and postural support. Ideally, any PWC purchased will have capacity for seating modifications over a number of years, prior to replacement of the PWC entirely.

Transfer and personal care equipment, such as slide boards, MSCs, slings and hoists may also be required at this time. All transfer equipment will require an AT Justification and Quotation for initial purchase. Where a ceiling hoist is identified the best option for support, home modifications will need to be assessed and submitted to NDIS for approval (using the NDIS Home Modifications Assessment Template)

www.ndis.gov.au/providers/housing-and-living-supports-and-services/providing-home-modifications

At this stage, it may also be beneficial to look into a modified vehicle, to ensure the PWC can be used at school, home and in the community, with minimal transportation issues (especially as transportation options for schooling vary from state to state).

It is important to note that NDIS does not pay for the vehicle itself, but rather for the modifications to the vehicle, so if you are purchasing a new vehicle they will pay for the ramp or lifter and tiedowns to be installed, whereas if you are purchasing a vehicle that has already been modified, they will fund the portion of the cost of the vehicle that relates to the modification (as determined by a quote). Funding can only be used for vehicles (to complete modifications or with modifications completed) that are less than five years old, have done less than 80,000 kms and are generally suitable for modification.

It may also be beneficial to start discussions about home modifications at this stage, such as structural supports for a ceiling hoist (as mentioned above), and alterations to the entry of the home, widening of doorways throughout the home and creation of

ASSISTIVE TECHNOLOGY

Stage 3 *cont.* Late ambulatory (6 years - 9 years)

a level entry, wet-area-style bathroom, to ensure personal care and transfers can be completed safely despite changes to physical capacity. For further information about home modifications, refer to the Home Modifications Chapter.

Low cost aids that should be looked into at this stage include personal falls or safety alarms, long-handled brushes and other aids, shoes that accommodate AFOs or an altered foot position, hand and feet warmers and portable ramps. Replacement AFOs may continue to be required at this stage and should be quoted for annually.

Stage 4 Early non-ambulatory (10 years - 13 years)

By this time personal care, transfers and mobility will require significant support, so it is very important that the appropriate equipment is in place for the safety of the young person, their parents or caregivers and any support workers who may be assisting in the home, school or community.

Funding for hire or rental of equipment continues to be important at this stage to provide options when AT is being repaired or maintained, or when the young person is away from home and require their equipment for longer periods (i.e. overnight or longer).

Typically, a PWC will be in place by this time, with annual modifications being completed to seating to ensure spinal and postural supports are adequate. Depending on when the PWC was initially provided, a replacement device may be required by this time and the OT or PT prescribing the new chair should consider whether the like-for-like replacement option is possible or not, with consideration for the functionality required of the new PWC.

If MSCs, hoists and slings are not in place, these are likely to be necessary by this stage and should be investigated as a priority. Modifications to the home and vehicle should also be investigated to ensure personal care, transfers and transport can be completed safely.

By this stage, the amount of time spent in the PWC is likely to be quite high, so consideration should be given to other supports that will assist with pressure care, skin integrity and comfort. A power bed (with adjustable components for the headrest and lower legs) and pressure care mattress may be valuable, as well as a cloud chair, electric recliner, or other postural seating support, to provide alternatives to hours spent in the PWC.

Respiratory supports may also become necessary at this time, to ensure the young person gets the best sleep they can and is able to wake rested and refreshed each morning. Discussions should be had with a respiratory specialist about what is required and, if necessary, a sleep study conducted. Where a BiPap is recommended for daily use, a chest PT should conduct an assessment and provide an AT Justification and Quotation for this device.

A CAM may also be recommended by the respiratory specialist and, depending upon the specific recommendations (i.e. sporadic versus ongoing use), it may be worthwhile to consider short-term hire or purchase of this device (AT Justification and Quotation will need to be completed by a chest PT).

Low cost aids needed at this stage are consistent with those needed at the Late ambulatory stage. At this stage, a Consumables budget may also be required for BiPap or CAM masks, batteries, or lines (for further information about Consumables, refer to the Core Supports Chapter).

Stage 5 Late non-ambulatory (14 years+)

By this stage, the majority of AT the young person is likely to use should be in place, or at least have been investigated for implementation. It is likely that AT needs into the future will be the replacement or upgrading of existing devices, such as PWCs, power beds, hoists and slings and MSCs, as well as further modifications to the home environment and duplication of AT in work or study settings, as appropriate.

Hire or rental of AT continues to be a necessary inclusion in NDIS plans, again to provide options for trial of new or different AT and as a possible solution when access to equipment is not possible (due to repairs or being away from home).

As the young person approaches the age of 18 years, it is important to consider their living arrangements and, in terms of sustainability, whether AT can transition with the person out of the family or caregiver's home and into an independent living environment.

Low cost aids at this stage may be more specific to the young person's needs for study, work, communication, or community engagement, such as an adapted mouse for use with a computer, Bluetooth headsets and glovebox attachments for PWCs.

ASSISTIVE TECHNOLOGY

A note about “value for money”

When dealing with expensive pieces of AT, such as power wheelchairs, ceiling hoists, modified vehicles, and others, NDIS will want evidence of how the intended support represents value for money. This does not mean the intended support is the least expensive option, but rather that it’s approval will reduce the cost of supports across other aspects of the young person’s life and NDIS plan.

A classic example of value for money is the case for a sit-to-stand PWC instead of a standard PWC, for a 10 year old who attends school full-time and whose father works full-time and mother works part-time, using a standing hoist and sling for transfers with one support worker (mother providing the second person as per safe operating guidelines. In this example, the participant is able to urinate independently and access cupboards in the home and community, which means they do not require as many hours of support from a formal carer (i.e. a support worker). In terms of financial value, the sit-to-stand PWC represents an annual saving of \$45,672.69 in funding for support workers, and a saving of \$288,363.45 over five years, as detailed in Figure 1.

FIGURE 1.

SCENARIO 1: SIT-TO-STAND PWC		SCENARIO 2: STANDARD PWC	
SUPPORT	COSTS	SUPPORT	COSTS
Cost of sit-to-stand PWC, with seating modifications - estimation only	\$50,000.00	Cost of standard PWC, with seating modifications - estimation only	\$35,000.00
Transfers for toileting, personal care and hygiene - estimated as 2 hours / day on weekdays and 4 hours / day on weekends and Public Holidays X 52 weeks / year	\$40,448.46	Transfers for toileting, personal care and hygiene - estimated as 4 hours / day on weekdays and 8 hours / day on weekends and Public Holidays X 52 weeks / year	\$80,896.92
Support to make food or drink, access cupboards above 1.5m height and other ADLs - estimated as 0.5 hours / day on weekdays and 1 hour / day on weekends and Public Holidays X 52 weeks / year	\$20,224.23	Support to make food or drink, access cupboards above 1.5m height and other ADLs - estimated as 0.5 hours / day on weekdays and 1 hour / day on weekends and Public Holidays X 52 weeks / year	\$40,448.46
TOTAL COST PER FIRST YEAR:	\$110,672.69	TOTAL COST PER FIRST YEAR:	\$156,345.38
TOTAL COST PER FIVE YEARS:	\$353,363.45	TOTAL COST PER FIVE YEARS:	\$641,726.90

Another example of value-for-money is the case for a ceiling hoist instead of a standing hoist, for a 14-year-old who attends school full-time and whose parents both work full-time. In this example, the participant would require only one support worker for all transfers and personal care, instead of the two required for safe operation of a standing hoist. In terms of financial value, the ceiling hoist represents an annual saving of \$45,896.92 in funding for support as detailed in figure 2.

FIGURE 2.

SCENARIO 1: CEILING HOIST		SCENARIO 2: STANDING HOIST	
<i>SUPPORT</i>	<i>COSTS</i>	<i>SUPPORT</i>	<i>COSTS</i>
Cost of ceiling hoist, with structural modifications to install - estimation only	\$40,000.00	Cost of standing hoist - estimation only	\$5,000.00
Transfers for toileting, personal care and hygiene - estimated as 2 hours / day on weekdays and 4 hours / day on weekends and Public Holidays X 52 weeks / year	\$80,896.92	Transfers for toileting, personal care and hygiene - estimated as 4 hours / day on weekdays and 8 hours / day on weekends and Public Holidays X 52 weeks / year	\$161,793.84
TOTAL COST PER FIRST YEAR:	\$120,896.92	TOTAL COST PER FIRST YEAR:	\$166,793.84
TOTAL COST PER FIVE YEARS:	\$444,484.60	TOTAL COST PER FIVE YEARS:	\$813,969.20

HOME MODIFICATIONS

WHAT ROOMS WILL BE MODIFIED?

NDIS typically focuses on those rooms that are necessary for completion of personal care and activities of daily living, consistent with age-appropriate expectations; for example, for a 10 year old participant, modifications would be reasonable for the participant's bedroom, living area, kitchen and bathroom, but not for the laundry or siblings or parents bedrooms, whereas for an adult participant, almost all areas of the home would need to be accessible (i.e. laundry and other bedrooms, depending on who resides in the home).

WHAT WOULD BE FUNDED?

NDIS will typically fund the following re home modifications:

- Modifications to the participant's primary place of residence
- Standard modifications and fittings
- Additional costs incurred if the NDIA recommends or requires the use of qualified builders, trades people, project managers, building certifiers, building assessors or OTs
- Costs of normal repairs and maintenance to specialised fittings and assistive technology that have been installed as part of a home modification
- Costs related to council or other building approvals which are payable as a result of the required home modifications

WHAT WOULDN'T BE FUNDED?

The following wouldn't be funded by NDIS for home modifications:

- Modifications to buildings that are not the participant's primary place of residence (such as holiday homes); note, if a participant resides across two dwellings (e.g. a child with separated or divorced parents, an argument may be made for modification to both properties)
- More expensive fittings or fixtures (i.e. above the standard) – but you can opt to use your NDIS funding and 'top-up' with your own to achieve the desired result
- Modifications for a property purchased after a participant was granted access to the NDIS, unless the NDIA was involved in the decision to purchase the property, or the purchase of a more accessible property was not possible;
- Installation of swimming pools (including hydrotherapy) and spas
- Repairs to damage to the home that is pre-existing or discovered during modifications
- Any additional insurance premiums for insuring the property once home modifications are completed
- Ongoing repairs and maintenance to non-specialised structures, fixtures, or fittings of the home (even when these form part of the modification work), such as repainting the modified bathroom or maintaining plumbing

- Remediation of work that does not comply with the specifications of work or did not comply with the Building Code or relevant Australian Standards (this is the responsibility of the builder)
- For modifications to be removed when a person no longer requires them (except when there has been prior agreement in the case of a rental property)
- Capital building additions, such as entirely new rooms, stories, lifts, or escalators / inclinator, except when considering other factors (refer to note re “value for money” below)

CAN MODIFICATIONS BE COMPLETED TO A RENTAL HOME?

Provided there is agreement from the owner of the property (usually documented) and the participant has the option and intends to stay in the property for about five years, modifications can be approved for a rental home; to demonstrate options to stay and intention, typically a letter from the owner of the property is helpful.

WHAT IF MY HOME CAN'T BE MODIFIED?

Not all homes are able to be modified, due to structural or other issues, in these circumstances, there is still support available from NDIS; where an engineer's report determines that a home is unsuitable for modifications, NDIS will fund the following, in terms of relocating a participant to a more suitable dwelling (ie a dwelling that has more suitable access requirements and only needs basic or low cost modifications in the future):

- Assistance with moving and removalist costs
- Costs associated with selling the participant's current property, such as advertising, agents fees and legal costs
- Costs associated with the purchase of the alternate property, such as stamp duty and legal costs
- Minor modifications to install special equipment if necessary

DO I NEED AN ASSESSMENT?

All home modifications require an assessment by a therapist, typically an OT, and completion of the NDIS Home Modifications Assessment Template - www.ndis.gov.au/providers/housing-and-living-supports-and-services/providing-home-modifications

HOME MODIFICATIONS

HOW MANY QUOTES WILL I NEED?

For modifications under \$15,000 only one quote is required, over this price threshold you will require two quotes and for modifications exceeding \$30,000, you will need to engage an NDIS Registered Building Works Project Manager (BWPM) to oversee the design and completion of the modification.

Stage 1 Pre-symptomatic (Birth - 2 years) >

Stage 2 Early ambulatory (3 years - 5 years)

Across these stages, typically there are no Home Modifications required, as the little one is usually within safe weight ranges for manual transfers (i.e. under 25 kgs) and can still navigate small steps, such as a step up to their front door or over the edge of a shower.

Stage 3 Late ambulatory (6 years - 9 years) >

Stage 4 Early non-ambulatory (10 years - 13 years)

Throughout these stages, capacity for walking and transferring independently will change significantly, so it is timely to start looking at the home and adjusting the environment for accessibility and safety.

Ceiling hoists may be considered at this time; the structural supports required to install this will require assessment and recommendation via an HM Justification and SoW. A quotation will also be required from a builder, itemising the works to be completed as part of the modification.

In addition to ceiling hoists, consideration may be given to ramps at the main entry point to the home and widening of doorways into the young person's bedroom, bathroom, kitchen, living areas and thoroughfares (e.g. hallways).

Alterations to bathrooms may be necessary to remove step-entry baths or showers and create level-entry, wet-area style shower alcoves (to provide sufficient space for a mobile shower commode and support worker). Basins may need to be adjusted to suit the height of the young person in their mobile shower commode or power wheelchair. Consideration should also be given to heat lamps to minimise risk of illness as a result of undertaking personal care in a cold environment.

Stage 5 Late non-ambulatory (14 years+)

At this stage, it is important to consider the young person's living arrangements and, in terms of sustainability, where they will be living when they reach 18 years. In line with NDIS rules for sustainability of supports, consideration should be given to the length of time the young person is likely to remain in the family or caregiver's home.

Typically, the NDIS would like assurance that the young person will continue to reside in the home for a minimum of five years after modifications have been completed. If the young person moves out of the home before this five-year timeframe has elapsed, it is possible NDIS will require a higher standard of justification or may refuse modifications to another home environment.

Similarly, if it is possible the young person will apply for Specialist Disability Accommodation (SDA) when they reach 18 years, consideration should be given as to other measures (AT or other) that could be implemented instead of home modifications, to ensure their opportunity for SDA is not negated by the previous funding for home modifications.

A note about **“value for money”**:

When dealing with home modifications, NDIS will want evidence of how the intended modification represents value for money. This does not mean the modification is the least expensive option (most likely it will be the most expensive option, in the short term), but rather that it's approval will reduce the cost of supports across other aspects of the young person's life and NDIS plan.

A prime example of value-for-money is the case for modifications for installation of a ceiling hoist instead of a standing hoist, for an 11-year-old who attends school full-time and whose parents both work full-time. In this example, the participant would require only one support worker for all transfers and personal care, instead of the two required for safe operation of a standing hoist. In terms of financial value, the ceiling hoist represents an annual saving of \$45,896.92 in funding for support workers, and a saving of \$369,484.60 over five years, as detailed in Figure 2.

HOME MODIFICATIONS

FIGURE 2.

SCENARIO 1: CEILING HOIST		SCENARIO 2: STANDING HOIST	
SUPPORT	COSTS	SUPPORT	COSTS
Cost of ceiling hoist, with structural modifications to install - estimation only	\$40,000.00	Cost of standing hoist - estimation only	\$5,000.00
Transfers for toileting, personal care and hygiene - estimated as 2 hours / day on weekdays and 4 hours / day on weekends and Public Holidays X 52 weeks / year	\$80,896.92	Transfers for toileting, personal care and hygiene - estimated as 4 hours / day on weekdays and 8 hours / day on weekends and Public Holidays X 52 weeks / year	\$161,793.84
TOTAL COST PER FIRST YEAR:	\$120,896.92	TOTAL COST PER FIRST YEAR:	\$166,793.84
TOTAL COST PER FIVE YEARS:	\$444,484.60	TOTAL COST PER FIVE YEARS:	\$813,969.20

NDIS typically will not fund capital building additions (such as additions of rooms, stories or lifts or inclinators) to allow access to multiple levels of a home or steep blocks of land.

However, NDIS will consider capital building additions in light of the following:

- Whether other parts of the house can be reasonably organised as an alternative - such as whether the participant could be moved to another bedroom, or a bathroom could be installed at a different location
- Whether alternate accommodation which is more accessible or more easily modified is available and the cost - such as whether the cost of moving house would represent better value for money than completing the capital addition
- Whether there are compelling factors related to the participant, their family, community, or employment which makes moving premises unrealistic - such as age of the participant and family size
- The long term costs and benefits of alternative funded supports against the costs and benefits of the modifications to the home - specifically, are alternative options feasible (are they even able to be completed?) and how long is the participant likely to remain in the home that is proposed for modifications?



COORDINATION OF SUPPORTS

WHAT IS COORDINATION OF SUPPORTS?

NDIS recognises that some individuals and families require additional support to navigate service pathways and utilise their NDIS plans effectively; support coordination is specifically funded within NDIS plans for individuals and families to access this additional support.

Support coordination has three distinct levels, which have been designed to respond to certain levels of complexity for individuals and families. These levels are:

- **Support Connection:** this level is typically provided by Local Area Coordinators (LACs), who work on behalf of NDIS (as part of community organisations) to undertake planning and review meetings and implement (i.e. talk through) NDIS plans when they are first approved; this support is extremely limited and typically only involves connecting individuals and / or their families with services and supports (it typically does not involve designing and establishing support systems, resolving crises or coaching);
- **Coordination of Supports (CoS):** the majority of support coordination is funded at this level, to support those individuals and families who require more support than is available through LACs and mainstream channels;
- **Specialist Support Coordination (SSC):** this specialist level is usually funded for individuals or families who have extremely complex situations, such as involvement with Department of Corrections, Housing SA, Public Trustee and / or Office of the Public Advocate, and require an extremely high level of support due to the involvement of the offices above or family circumstances; this level may also be funded for individuals and families wishing to complete an Exploring Housing Options investigation, which is a specific process that assesses the individual's capacity and support needs, then recommends the most suitable housing option for that individual.

WHAT DOES A SUPPORT COORDINATOR DO?

The Support Coordinator is the person who delivers the CoS or SSC, as funded within the NDIS plan; their ultimate aim is to make themselves redundant, by developing the skills, knowledge and capacity of the individuals and / or their families to navigate service pathways and utilise their NDIS plan effectively.

In order to develop these skills, knowledge and capacity, the Support Coordinator will connect the individual and / or their family to service providers, community networks, specialist expertise and general information sources.

The Support Coordinator will also work with the individual and / or their family to design the supports that will be accessed using the funding within the NDIS plan. In order to do this, they will spend some time getting to know the individual and / or their family to identify existing skills, understanding and priorities. From there, they will provide information about ways in which the NDIS plan funding can be utilised (as well as mainstream or community based options

that will complement services accessible through NDIS) and work with the individual and / or the family to design support solutions in line with the identified priorities.

Dependent upon the skills and understanding of the individuals and / or family, the Support Coordinator may assist with identifying individual support providers, including researching and shortlisting options that align with identified priorities. The Support Coordinator may also assist to establish the service relationship, by negotiating with or on behalf of the individual and / or family about the services to be engaged (including frequency, duration and intensity) and assisting the individuals and / or family to understand the Service Agreement (the agreement developed by a service provider that outlines key information, such as which services will be delivered, what price will be charged for these, when and where services are to occur and how to end the service relationship).

As much as possible, the Support Coordinator's role aims to be proactive, and involves planning for and building systems of support that bring stability and confidence to the individual and / or their family's lives. Despite this, crises do occur, and the Support Coordinator will work with the individual and / or family to resolve these when they arise, and to develop contingent strategies (where possible) to reduce the likelihood of reoccurrence.

Finally, as a role that ultimately aims to replace itself, a key component of the Support Coordinator's role is coaching the individual and / or their family to take ownership of their NDIS plan and system of supports, as well to assist with annual (or more frequent) reflection and revision, through NDIS plan review processes.

WHAT DOESN'T **A SUPPORT COORDINATOR DO?**

Firstly, Support Coordinators do not pay bills or invoices for services received, this is the role of a plan manager (or the individual and / family or NDIS, dependent upon how the NDIS funds are managed within the plan). Support Coordinators may help with reviewing budgets and forecasting expenditure, to ensure the individual and / or family can continue to access supports and services for the duration of the plan (or to determine whether further supports and services should be engaged to utilise plan funding), but they are not responsible for the actual payment of the bills.

Support Coordinators should also not be involved in direct supports, such as personal care, daily living and domestic tasks, social participation, or even the administration (i.e. recruitment, rostering, scheduling, and invoicing) for direct supports. The situation may arise where an individual and / or family engage one person who is able to act as their Support Coordinator and provide direct supports; in this situation the tasks should be very clearly delineated, to ensure the charges for support coordination and direct supports (i.e. through core supports) are consistent with the hours of service provided for each role.

COORDINATION OF SUPPORTS

Finally, a Support Coordinator does not sign service agreements on behalf of an individual and / or their family. The Support Coordinator will assist with negotiating the terms to be included in the service agreement, as well as explaining and interpreting the document when it is received by the individual and / or family, but they have no legal capacity to sign on behalf of the individual and / or family.

HOW DO I **CONVINCE NDIS THAT I NEED SUPPORT COORDINATION?**

Despite the value of (good) support coordination in ensuring an NDIS plan is utilised to its fullest potential, the support is not granted to all individuals.

In order to include this funding with a plan, there needs to be evidence of its need. This means that the individual and / or family will need to tell their story:

- Describe the supports needed within the individual's daily life, including the number of service providers engaged
- Identify which supports within the individual's day-to-day are provided by family and informal supports, who would typically be expected to take on the roles of designing support systems, establishing service relationships, and resolving crises
- Provide detail about any barriers or difficulties accessing services and service providers, especially when living in an area that has limited range or availability of service providers
- For parents of children, present a snapshot of daily life in your household, beyond the supports needs of your child with DMD, this can help to explain why the roles expected of you are unrealistic (and why additional support is required)
- For parents of children, talk about how you are coping with your daily situation and how your ability to cope impacts upon your capacity to undertake the roles expected of you
- If there are any other factors or circumstances that prevent you from undertaking the roles expected, be sure to mention these; examples include secondary diagnoses (such as Autism Spectrum Disorder or Intellectual Disability), more than one child in the household with a disability and accessing NDIS, marriage breakdown and disagreements between parties, conflicts between service providers, etc

For many individuals and children with DMD, support coordination becomes most valuable at the late ambulatory or early non-ambulatory stages. At these stages, reliance upon equipment increases as functional capacity changes. For children within this age range, differences between themselves and their peers become more apparent, meaning additional supports may be required to ensure their psychological, emotional, and social wellbeing. The capacity for many parents to navigate these pathways is limited, especially if they are experiencing their own reactions to the changes occurring within their child. With support coordination in place, systems of support can be developed and implemented to fortify the individual and family as they face a period of significant change and adjustment.



SHORT TERM GOALS





LONG TERM GOALS





GLOSSARY

DE = Developmental Educator

ADL = Assistance with Daily Living

SCCP = Social, Community and Civic Participation

AT = Assistive Technology

OT = Occupational Therapist

PT = Physiotherapist

SP = Speech Pathologist / Therapist

EP = Exercise Physiologist

TA = Therapy Assistant

PEG = Percutaneous Gastrostomy tube

AFOs = Ankle-Foot Orthoses

PWC = Power Wheelchair

MWC = Manual Wheelchair

MSC = Mobile Shower Commode/Chair

BiPap = Bilateral Positive Airways Pressure Machine

CAM = Cough Assist Machine

AT Justification = assessment and recommendation, completed by a relevant therapist (OT, PT or podiatrist) using the NDIS approved template - www.ndis.gov.au/providers/housing-and-living-supports-and-services/providing-home-modifications

HM Justification = assessment and recommendation, completed by a relevant therapist (OT, PT or podiatrist) using the NDIS approved template - www.ndis.gov.au/providers/housing-and-living-supports-and-services/providing-home-modifications

SoW = scope of works, typically completed by an OT and builder in collaboration, which outlines the work to be completed as part of the home modification and identifies the components that are expected to be funded through an NDIS plan

CoS = Coordination of Supports

SSC = Specialist Support Coordination

AUTHOR

Marguerite Botha

NDIS Support Coordinator



Marguerite Botha completed her Bachelor of Arts, with a Major in Sociology in 2005, before undertaking a Diploma in Psychology, with the aim to working in the forensic psychology field.

Following graduation, she then moved into regulatory enforcement and compliance for a number of years, but was challenged by the social injustice and inequity embedded in the communities she was working with on a daily basis.

Driven by the desire to change this, she returned to her studies to complete a Bachelor of Behavioural Science (Psychology) and Certificate IV in Project Management. It was during this time her focus shifted to addressing the barriers and challenges faced by people living with disability.

She commenced in the disability sector working with adult day options services to expand programs, enhance clinical practice and prepare for the move from block-funded services to consumer-driven, fee-for-service models.

Soon after the commencement of NDIS trials in SA, she moved to the early intervention space to play a key role in building therapeutic programs for children on the Autism Spectrum. She worked as a behavioural therapist for a number of years before moving into a management role, overseeing delivery of behavioural programs and providing pre-planning support and Support Coordination for NDIS Participants. It was here that Marguerite found her calling, working with individuals and families to maximise their supports, both funded and natural, and achieve their goals.

From 2017 to 2019 she worked at Muscular Dystrophy SA, where she first connected with the neuromuscular community and played a key role in developing their NDIS service portfolio.

During her time with Muscular Dystrophy SA, she worked with clients of all ages and capacities providing advocacy, intensive preparatory support (prior to acceptance into the Scheme), attending planning meetings, navigating review processes and delivering Support Coordination and Specialist Support Coordination.

Following the closure of Muscular Dystrophy SA in late 2019, she transitioned with her team to I Can Jump Puddles, where she continues to provide support coordination and specialist support for housing and health complex care for the neuromuscular community.

Most recently she has resumed her behaviour support work through I Can Jump Puddles, as part of the NDIS Quality and Safeguards Commission's pilot project for the implementation of the new Positive Behaviour Support Capability Framework.

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