



Long term music therapy for people with intellectual disabilities and the National Disability Insurance Scheme (NDIS)

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In plain language:

People with disabilities across Australia now have access to services to help them in their daily lives and to reach their goals through the National Disability Insurance Scheme (NDIS). People who wish to have music therapy need to include it in their plans. Here we talk about the issues which may be experienced by people with severe and profound intellectual disabilities, especially the issue of receiving long term therapy. The NDIS does not support long term therapy and recommends that assistants be trained to provide the service. Why this is a concern and the benefits of working with a registered music therapist are discussed. Examples of how music therapy over the long term may help people with severe and profound intellectual disabilities are given.

responsibility of the individual. Elimination or reduction of the disability is considered to be facilitated by professionals (Gallagher et al, 2013), and places the onus on the professional to facilitate participant improvement within a restricted time frame. Under the NDIS Price Guide support category 3.15, which addresses therapy services, it states “Ongoing funding for therapy is subject to a detailed plan with expected further progress or change” (DHS, 2016, p.42). In an attempt to address this, the NDIS Price Guide states “family or trained assistants will be engaged to deliver ongoing maintenance therapy” (DHS, 2016, p.42). For most participants, this reflects a move away from the reliance on an expert to deliver a program prescribed by a therapist. Physiotherapists, for instance, frequently employ the services of an assistant to deliver a set of exercises for a client. Certainly, a reduction in the involvement of a professional can be regarded as consistent with the social model of disability. However, requiring programs which are ongoing or which provide maintenance therapy, to be delivered by carers may not be the most cost effective or preferred outcome for the participant. Indeed, without the music therapist’s involvement there may be no service at all as the ability of untrained assistants or family members to facilitate music-based interventions without considerable support is improbable. Music therapy requires the therapist to possess a high degree of musical skill and training in the clinical application of music in therapy. It is not a matter of facilitating a set of exercises. Music therapy with this population is an intense interactional exchange through the medium of music, requiring flexibility in presentation to respond to the participant moment by moment.

In comparing music programs delivered to people with intellectual disabilities by community musicians and music therapists, McFerran (2008) found that for people with severe and profound intellectual disabilities, music therapy was considered to be more appropriate for meeting the individual needs of the participants. The focus for the music therapist is the interpersonal interactions and development of relationships (Lee, Davidson & McFerran 2016). In contrast, people with mild to moderate intellectual disabilities may have their needs more appropriately met by the community musician as they focus on the enlivenment of the participants, allowing participants to leave a session in a stimulated state (McFerran 2008).

A typical music therapy group session with people with intellectual disabilities has a bell curve with greeting songs, instrumental activities, songs and relaxation incorporated with a winding down activity and farewell at the end. There is consideration of mood regulation and levels of stimulation and a flexibility of approach to respond to the needs of the participants in the moment. Music therapists seek to meet each participant’s needs and to engage at their level of communication and ability. Musical elements may be modified or a particular music therapy method may be employed such as improvisation or spontaneous song creation in order to respond to a participant in the moment.

The ability of therapy assistants to deliver such a music therapy program would require them to have extensive music skills and therapeutic knowledge to respond appropriately. This is not to say that these therapeutic skills cannot be transferred to carers or to family members and it is beneficial that funding has been included to facilitate training of assistants

and informal and funded carers. Generalisation of skills is extremely important. However, from extensive personal experience, few carers and non-musicians have the confidence or skill set to undertake such work. The transference of these skills, gained over years of training and experience, to an assistant or carer would require extensive training and supervision. Community musicians, who may have the requisite musical skills, focus on using music to activate and stimulate. This may be effective in meeting the needs of people with mild or moderately intellectually disability, as reported by McFerran (2008). However, this approach may not adequately address the needs of people with severe and profound intellectual disabilities who may find such an environment overstimulating. A more nuanced approach to meeting their sensory and communication needs within a musical relationship is provided within a music therapy milieu. Many already have reduced access to social contact and the community and the training and expertise of a music therapist can provide the opportunity for social contact, community engagement and an expressive communication experience through the music therapy process.

Of further concern is the requirement in the NDIS Price Guide (DHS, 2016) that therapists report further progress and change. Music therapists working with people with severe and profound intellectual disabilities are skilled at recognising, responding, nurturing and reporting on the incremental nature of progress and change. Pavlicevic, O'Neil, Powell, Jones, & Sampathianaki (2014) identified that change can be slow and incremental. The Diagnostic and Statistical Manual for Mental Disorders 5 (DSM-5) also identifies that change and development are slow for people with severe and profound intellectual

disabilities and their needs can best be met through services over an extended period (American Psychiatric Association, 2013).

Given that ongoing therapy and maintenance therapy is specifically not provided for by the NDIS, the achievement of progress and change will be further limited for people with severe and profound intellectual disabilities. The Price Guide (DHS, 2016) states:

For participants where such treatment can only be met through skilled rather than non-skilled care, this treatment is to be funded through medical funds, not NDIS. Ongoing funding for therapy is subject to a detailed plan with expected further progress or change. Providers develop this plan with the participant and it should clearly state the expected therapy outcomes and demonstrate a link to the participant's goals, objectives and aspirations. (p.42)

Of concern is that progress and change will be time limited with reduced potential for achievement of goals and may be delivered by under-skilled personnel. In this way, the ability to choose and access therapy services which meet the needs of people with severe and profound disabilities has been inadequately provided for and is at odds with the Operational guidelines (DHS, 2016) and the DSM-5(2013).

The Operational guidelines state that the objects of the NDIS Act are to: "Enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports" (para 4.41, DHS, 2016). However, it mandates the level of choice and control by the participant through the Price Guide limitations and requires therapists to report

on progress and change. This implies that the disability will progress and change and it is the responsibility of the professional and the participant to deliver that change within a restricted time frame. Therein lays the conundrum of the competing models of social and medical models of disability.

Long term music therapy

A music therapy program I provide has been servicing the disability community for 18 years. Some of the participants have attended for the entire duration. The program promotes community access and participation within a semi-segregated setting and addresses the capacity building tenets of the NDIS, such as choice and control, development of relationships, lifelong learning and health and well-being (DHS, 2016). It is exclusively for people with disabilities, and offers a group program in a community venue where people can participate in a preferred activity. I wanted to create an opportunity for people to mix and meet other people outside their family or work place, with a view to creating new friendships. This is a key measure of social inclusion according to Weisel and Bigby (2016). For people with severe and profound disabilities their needs can be easily and frequently assumed or dismissed. This is a program whereby their needs and preferences are given priority. There is often a desire for repetition of music, modification of tempo, matching of mood through dynamic and style of playing and extemporisation to facilitate or prolong a musical interaction. This responsiveness is required to fully engage, stimulate or provide regulation of stimulus for the group members.

Providing a therapeutic encounter requires careful consideration of the needs of the person who communicates without

spoken or conventional language. It requires sensitive reading of the mood of the group, adjustments to tempo, dynamics and style of playing in order to meet, in the moment, the needs of these members who have severe or profound intellectual disabilities.

Meeting an individual's needs within a music therapy group or in individual therapy for social contact and through attunement with the person's communication style may be the impetus for continuing to access a service for an extended period of time. Discussion regarding duration of therapy has been largely absent in the music therapy literature. Pavlicevic et al (2014) recently discussed the value of long term music therapy and found that rather than leading to developmental change, the value of long term therapy was the ongoing opportunity to experience social connections, and self-confidence. In other research, references to the period of time clients with intellectual disabilities have received music therapy are made but without discussion surrounding the reasons for the length of therapy (Lee, 2014; Rika, 2013; Warner, 2007; Agrotou, 1994). Working with people with severe or profound intellectual disabilities can require a long period of assessment and development of rapport and trust within the therapeutic relationship. Understanding and responding to people with severe and profound intellectual disabilities requires a sophisticated level of skill as well as time in order to develop trust, and enable change.

Benefits of long term participation

Long term participation in music therapy has clear therapeutic benefits for the participant with severe or profound intellectual disabilities. Pavlicevic (2014) identified social connections and self -

confidence. Warner (2007) considered challenging behaviours to be communication attempts. She states that “working with very small changes over time may lead to a dramatic reduction in challenging behaviour” (p.57). Lee (2014) considered the need for longitudinal studies to “trace the process and benefits of individual as well as group sessions as building meaningful interactions and relationships with adults with PIMD takes a long time, over several years” (p.260). McFerran and Shoemark (2013) studied the musical engagement of a young man with a profound intellectual disability and identified 4 key principles of music engagement, the fourth being that the “Relationship is built over time”. Here I contend that alongside these benefits development and change may take place as well as ameliorating the deterioration of skills. Also, the opportunity for a person with profound intellectual disabilities to experience choice and control on a regular basis provides the experience of personal agency in a life where these opportunities rarely exist. Here I will detail these benefits and illustrate them through case vignettes.

Communication and self-expression.

Bill is a 41-year-old man who acquired a brain injury at age 3 after falling under a train. Bill has attended my group programs from their inception in 1998. He is severely physically disabled although he can walk with support and communicates through gesture, picture representations and vocalisation. When I first met Bill, I found it a challenge to understand how to effectively communicate with him. He would accept a choice of instrument I had offered (most often the tambourine) then after a short period would carefully place it beside his wheelchair. I continued to offer other small percussion choices and they would be similarly treated. I interpreted this

to mean that he had a limited attention span. However, when I finally offered him the snare drum Bill demonstrated to me that he was communicating a preference and this was not a reflection of his attention span, as he was able to sustain playing throughout the entire session on this instrument. Bill and I have been able to explore his cognitive skills over the years to the delight of many who have seen his playing through the use of the snare drum and the guitar. Through arrangements of various songs, Bill plays different rhythmic riffs and demonstrates his understanding of the form of music by playing the drum or guitar on cue. The assisted playing of guitar through strumming has given me as many insights into Bill’s abilities as well as his mood. Bill prefers to take my arm to strum the guitar although he is capable of playing with his own hand. He is most accurate in conveying his mood and energy levels in this way as he will strum vigorously and hold my arm firmly when feeling well and upbeat. He can also accurately strum the strings depending on the chord, finding just the lower 4 strings for a D chord. When he is less energised and feeling poorly his playing is reflected by slower playing and weaker hand grip.

The ability to fully understand idiosyncratic communication styles and to develop ways of interacting takes time. Communication and self-expression can be supported in an ongoing way and the development of interactional skills and rapport with the therapist can develop.

Choice and control.

Joel is a 25-year-old man who has attended individual music therapy for 11 years. He has a profound intellectual disability, spastic hemiplegic cerebral palsy and uses a wheelchair. Additionally, he has retinal displacement, is legally blind, has

renal failure and is tactile defensive.

When I first began working with Joel I wanted to encourage him to interact with me through tapping instruments. Initially I encouraged him to touch the piano keys hoping that he would indicate for the music to continue through a key touch and perhaps also interact with me musically on the keys. After persisting with this approach over several sessions I realised the full extent of his tactile defensiveness and abandoned this approach. Joel vocalises frequently so I follow his lead and document his responses including the type and timing of vocalisations in the music I play for him. He makes a variety of sounds including ‘Mmm’, ‘Ahh’, ‘blurts’ and high vocals. Joel also recognises the choruses of certain songs and will vocalise on cue. His most favoured music is ABBA but he responds well to a variety of other music and styles. Through noting his preferences and responses and incorporating improvisation extensively into the music I am able to respond to the minute changes in Joel’s breathing and vocal output to meet, match or discontinue a song. At times, he will take a breath, hold it and throw his head back with his mouth open, so I time the music to correspond with the breath expiration and we continue the song. Over the time I have been working with Joel I have been able to gauge Joel’s preferences from his responses. For example, Joel will continue to sing if he wants more and we repeat the song. During the last year or so Joel has developed a small nod which I reinforce with a verbal confirmation “Yes, you want more”. Through personal planning meetings with the other service providers involved with Joel, this skill is being supported and generalised to other environments. Joel’s parents have supported him over the years to attend music therapy because his mother states that it is the one time in his daily life

that Joel gets to have choice and control over the activity and his interactions are fully supported in a musical conversation.

Participation in music therapy may be the one situation where choice and control is enabled. Over a longer period of time opportunities to experience choice and control is enabled and consolidated. These are important elements of a good quality of life and enable the person to be self-determining and empowered. (Kostikj-Ivanovikj and Chichevska – Jovanova, 2016).

Social contact and ameliorating deterioration.

Scott has attended my group program since 1999. A man in his 50’s, he has Down syndrome and is verbal, although electively mute. Set in his ways, Scott has always sat close by me at the keyboard. In 1999 Scott demonstrated his ability to read as he quoted for me without prompt, the establishment date and name of the hall we were in, read spontaneously from a wall plaque! This incident reminded me not to take for granted the skills which Scott possesses although he may not choose to display them. His comprehension is good and he typically varies his responses depending on his mood and energy level.

Scott’s participation is somewhat ritualised but always incorporates choice. He likes to choose whether he strums the guitar or not and will often go to the song card to select the same cards each week, with his favourite being ‘Better be home soon’. When the microphone is handed around he considers whether he will sing into it, motivated more if his turn is ‘forgotten’. Recently another member, who enjoys assisting with the microphone, forgot to offer Scott a turn to sing a verse of ‘Big Yellow Taxi’ and he took the opportunity to get the microphone for him-

self to sing a verse. While Scott has the ability to verbally communicate, his elective mutism has masked the deterioration of his verbal skills, which therefore has not been easy to track. Hence, he now sings with poor articulation and frequently mumbles the words. A preliminary diagnosis of dementia has also been given. Despite this, music continues to be effective in encouraging him to use his communication skills. I was recently able to interpret Scott's desire to have 'Better be home' sung twice in a session. He held up the song card at the start and I confirmed that he wanted me to sing it at the start. "Yes" he confirmed with a slight nod. So, I played the song with strong rhythms at a moderate pace and with a moderately loud volume, appropriate for the start of the session. Later, he held the card up to his chest again, indicating the desire for a reprise and I played it with soft arpeggiated chords for the final song of the night. Music therapy has been able to maintain communication skills for Scott and to provide him with an ongoing avenue of social contact.

Maintaining social contact and communication avenues which are idiosyncratic are possible through music and therapeutic attunement. Additionally, maintenance of skills and ameliorating deterioration are valid goals in therapy.

Development of skills.

Zac is a man of 37 who also has attended my group program since inception in 1998. He has a profound intellectual disability and autism. He laughs at times when happy and conveys his mood through his facial affect and body language. He displays limited awareness of others, giving no eye-contact and moving into another's space without recognition. In the groups, Zac has always participated with an assistant's support. He shows preference for different

songs by vocalising occasionally and giggling. His favoured mode of participation is to tap the tambourine with a strong beat. Over the years he has not modified his beating to match the tempo of the music or stopped when the music stopped unless the assistant intervened.

This year, after 18 years of involvement Zac has begun to show an awareness of the music by spontaneously stopping with a pause in the music and looking towards me. This awareness of me and my playing is a new development and I respond by resuming my playing and then pausing again, encouraging a back and forth interaction. He seems to acknowledge this by looking at me with a direct side long look, which demonstrates another new development, of seeking my attention.

Learning and development as result of a participant's severe or profound intellectual impairment requires long term teaching and support according to DSM- 5 (APA, 2013 p. 36). Therefore, enabling change and meeting of goals takes time.

In summary, communication and self-expression, choice and control, social contact through participation and interaction, maintenance and development of skills, ameliorating deterioration and enabling development are valuable and important goals for people with severe and profound intellectual disabilities. Achievement of these goals requires a considerable amount of time and skill.

Limitations of long term therapy

The limitations of long term participation in therapy may include a reduced ability to create new connections. Watson (2007) suggested that long term therapy may "prevent the development of new relationships in the future" (p.32) whereby dependence on one environment to provide social interaction may reduce

access to new experiences. Hudgins (2013) noted that in community mental health, closure can help empower a client through reducing dependency on the therapist, signaling a new phase of independence and positive change. However, people who access a music therapy program over a long time may do so because this is their “community”. From a social role valorisation perspective (Wolfensberger, 2000) whereby social conditions set by mainstream society are to be emulated for people with intellectual disabilities, people who are non - disabled may also have a limited number of friends and friendship groups and do not always seek to gain new friends or leave a group. Long term participation is generally valued in society. Therefore, long term participation in a music therapy program may not necessarily lead to the exclusion of other social connections being developed.

Of concern is that many people with profound disabilities do have few or no friends outside paid carers or family (McVilly, Stancliffe, Parmenter and Burton- Smith, 2006). In a systematic review Verdonschot, de Witte, Reichrath, Buntinx, and Curfs (2009) found that people with intellectual disabilities were less likely to be involved in community activities, more often engaged in passive leisure activities and had 3.1 people in their social network including paid workers. Social participation has been shown to increase wellbeing (Wilson, Cordier, Parsons, Vaz, and Buchanan, 2016) and may be protective of mental health problems. Participation in music therapy over the long term, delivered by a registered music therapist may be an important avenue for ongoing social connection, creating opportunities for developing relationships, community participation and improved mental health

for people with severe and profound intellectual disabilities.

Conclusion

The NDIS represents a unique opportunity for people with disabilities to access funding for services they require to live an “ordinary life” (Operational guideline 4.1, DHS, 2016). For people with severe and profound disabilities the need for maintenance or longer-term therapy may be a reasonable and necessary support. The requirements of further progress or change is a conundrum as development, and therefore change and progress, occurs very slowly and incrementally and usually over an extended period of time. Of more relevance for these participants is the opportunity to have ongoing experiences of social connectedness and personal agency (Pavlicevic et al, 2014). As described here, there are benefits to be derived from long term involvement in music therapy in the areas of communication, self- expression, choice and control, social contact and developmental change through accessing music therapy over the long term.

For the people who currently access music therapy and who have attended programs for an extended period, it is important that they are able to continue to access such services. The current NDIS Price Guide (DHS, 2016) is unclear in its treatment of people seeking to include their long- term access to services in their plans. Success in gaining funding from NDIS is dependent upon the knowledge of music therapy by the NDIS planners. Anecdotally, some people who have a NDIS plan implemented report that the current services an individual receives are being maintained. While this is encouraging, it is still an ad hoc approach. It is incumbent upon the NDIS to clearly articulate this and continue to fund support services if this is the NDIS participant’s

preference. Additionally, the opportunity to access the services that the participant requests in order to live an “ordinary life” (NDIS Operational guideline 4.1) should be reflected not restricted. The provision of a tailored plan, which acknowledges that reasonable and necessary supports may include long term therapy by a registered professional, needs to be reflected clearly in the guidelines and not be dependent upon the knowledge or discretion of an NDIS planner.

It appears that the NDIS has financial restrictions to consider (Bonyhady, 2016) and the current rate for individual therapy may well cause strain within the system. Consultation and negotiation could address these issues. The use of community musicians and music therapy assistants to deliver ongoing maintenance therapy may serve to reduce dependence on specialised services and deliver a cost saving to the NDIS. However, in the long term, these personnel will require extensive supervision to meet the complex needs of this group of people and therefore will incur an added financial cost. Participation in music therapy for people with severe and profound disabilities over the long term with a registered music therapist has clear benefits and should be included in participants’ NDIS plans if this is their preference. As evidenced by the participants who continue to attend the author’s JAM music therapy group and individual therapy over 18 years, there is a demonstrated need for long term therapy due to the unique benefits of music with a registered music therapist.

Note. All names have been changed to protect their identity.

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