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Working It Out Together: Helping Community Support Workers and Family Members to Use Music to Benefit Adults with Learning (Intellectual) Disabilities

Liz Wallace

G Dip Mus Th, BA, LTCL, PG Cert HealSc (Clinical Supervision), NZ RMTh

Music therapist, Therapy Professionals Ltd.; clinical supervision private practice

Correspondence: lizwallacemt@gmail.com

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Abstract

This article describes the development of a music therapist's collaborative work with community support workers and family members to use music to benefit adults with learning (intellectual) disabilities. Examples of collaborative work are given, which show how individually tailored music ideas can improve wellbeing, enhance relationships with community support workers and family, and increase participation in the wider community. This type of collaborative work is recommended as a valuable way music therapists can use their professional skills to help others to use music to benefit adults with learning (intellectual) disabilities.

Introduction

Tēnā koutou.

I am Pākehā / New Zealand European, originally from Ōtepoti Dunedin. I have lived most of my life in Ōtautahi Christchurch. I acknowledge this area as being the tribal territory of Ngāi Tahu.

In this article I discuss the development of my work with community support workers (CSWs) and family members, to help them to use music to benefit people with learning disabilities. This article is based on a presentation at a Music Therapy New Zealand Symposium (Wallace, 2021). I give a brief literature review, give background to how this work came about, discuss the strengths and needs of this group of people with learning disabilities, the context of this work, the diversity of CSWs backgrounds, experiences and roles in this context, underlying theories and models, the process of this collaborative work and provide examples. I argue that music therapists can play a valuable role in helping CSWs and family to use music to benefit people with learning disabilities.

Background

This work focuses on community-dwelling past residents of the Templeton Centre, a former residential facility for people with learning disabilities in Templeton, on the outskirts of Ōtautahi Christchurch. At its peak around 500 to 600 people lived there. At that time parents of children who had learning and multiple disabilities were advised by medical professionals to place their children in institutions. I am using the term learning disabilities, as used by People First New Zealand Ngā Tāngata Tuatahi, a self- advocacy organisation led and directed by people with learning disabilities.[1]

Joan Webster (Registered Music Therapist, now retired), with support from Evelyn Ritchie (Welfare Officer), established music therapy at the Templeton Centre and worked to have music therapy accepted into the allied health team. In 1996 I was employed in the second music therapy position they created. This was during the time of deinstitutionalisation, when people with learning disabilities were moved out of institutions to live in the community. The parents of Templeton residents fought to ensure that their children would not lose access to services when the centre closed, resulting in a specialist

1 https://www.peoplefirst.org.nz

allied health team in the community for former residents. Initially, music therapy was omitted from this team; however, with lobbying it was included.

The Ministry of Health contract for this team was awarded to Therapy Professionals Ltd. (TPL). This business was established by Claire O'Hagan, initially as a physiotherapy private practice, mainly working with older people in the community. TPL grew to include occupational therapists, and with the contract to provide allied health services to ex-Templeton residents, dietitians, speech-language therapists and music therapists were added to the team. In the contract discussed here, much of the work of all disciplines is done through collaboration and consultation with residential or community day programme staff and family members. This work is now funded by Whaikaha Ministry of Disabled People.[2]

Claire had a vision of a transdisciplinary team, which was influenced by the work of Carol Davis, physiotherapist, writer and researcher (Davies, 1988). The transdisciplinary philosophy of encouraging sharing of experience and knowledge, and working together across disciplines for the benefit of the people we work with, continues under the present manager, Shonagh O'Hagan, Claire's daughter (O'Hagan et al., 2004). This has been a supportive culture within which to develop the work discussed in this article.

At the time of deinstitutionalisation in the late 1990s, approximately 460 people were living at the Templeton Centre. We have had over 200 people referred for music therapy. Initially the number of referrals was overwhelming. Joan and I developed a process where only people whose needs were not being met elsewhere were accepted onto the music therapy waiting list. Our focus became people who are nonverbal or have difficulty with verbal communication and social situations.

A government funding freeze, and a policy of reducing the contract hours as people die, have led to a reduced service including music therapy. Because of the limited time available, there is a waiting list for music therapy. As well as individual sessions and small group sessions, I work with CSWs in residential homes or community day programmes and with family members, to help them to use music beneficially. Initially this work developed as a

2 https://www.whaikaha.govt.nz

response to the limits to the music therapy hours. As the work developed it became clear it was worthwhile in its own right.

Working in this way was not part of my music therapy training, which I started through the New Zealand Society of Music Therapy accreditation programme before studying music therapy at the University of Melbourne in 1994-1995. As community music therapy (CoMT) and indirect music therapy work continues to expand, I believe this is an area which would be useful to include in music therapy training.

Brief Literature Review

Music therapists around the world have developed and written about work that has moved outside the traditional session model, to frameworks such as CoMT and indirect music therapy. CoMT can be conceptualised as an ecological approach, with multiple modes of practice, where resources are shared collaboratively (Wood, 2016) and including the music therapist following “where people and music lead” (Pavlicevic & Ansdell (2004 p.30). Growth in the development of alternative, multiple modes of practice includes the development of music resources with clients for their own use, as described in Rolvsjord’s (2010, 2016) resource-oriented music therapy. Rolvsjord advocates for empowerment, focusing on clients’ resources and potentials.

Ansdell (2002) wrote that “Community Music Therapy is an approach to working musically with people in context: acknowledging the social and cultural factors of their health, illness, relationships and musics.” He argued that “the aim is to help clients access a variety of musical situations, and to accompany them as they move between “therapy and wider social contexts of musicing”. Indirect music therapy has been described as consultation and collaboration with lay people or other professionals, and sharing knowledge and skills to change social care systems (McDermott et al., 2018; Stige, 2002).

An area showing growth in music therapists working with support workers and family members is the care of people with dementia (Baker et al., 2012; Beer, 2017; Hanser et al., 2011; Hsu, 2017; McDermott et al., 2018; Melhuish et al., 2019; Thurn et al., 2021). The study by Melhuish et al. (2019), showed that a systematic and collaborative approach, music therapy sessions and

exploring suitable ways for music to be used outside session times, yielded positive outcomes for clients and carers.

We can also learn from work in school settings, where music therapists are changing how they work, to include collaborative work (Pethybridge, 2013; Tomlinson, 2020; Rickson, 2008; Rickson & McFerran, 2014; Rickson & Twyford, 2011; Twyford, 2012). Rickson and McFerran (2014) discuss a change to therapists' roles to "building collaborative relationships with learners, teachers, and others; valuing them as equals; and promoting their participation by building on their strengths, resources, and potentials" (p.27).

Music therapists also work in family homes. For example, Thompson (2014) surveyed parents about their use of music in the home with their child with autism spectrum disorder and demonstrated that music therapy could be a successful way to support capacity building in families by embedding therapeutic music experiences into their daily life. Similarly, Castelino's (2021) comments about supporting families with young children are also relevant for other client groups.

Music therapists' work with Community Support workers and family members of adults with learning disabilities is underrepresented in the music therapy literature. Castelino (2019) discussed the need for music therapists to let go of the "expert hat" and to be flexible, adapting their approach to the unique needs of each family and finding family-focused solutions. I have adopted a similar approach in the work described in this article.

Context of this work

The People with Learning Disabilities Supported in this Work

These clients discussed in this article are a diverse group of people, with varying strengths and needs in their day-to-day lives. Ages range from those in their 30s to those in their 80s. This group is predominately Pākehā, with smaller numbers of Māori, Pacific, and Asian people.

A vulnerable group, many of these clients have experienced trauma in their lives, including abuse and neglect. Their needs vary from requiring all activities of daily living and personal cares to be undertaken for them, to being independent enough to travel on their own by bus and do their own shopping. Some are physically very mobile, while others are wheelchair users. Some use verbal communication; others use low or high tech

communication devices, Makaton, or New Zealand Sign Language. Additional sensory challenges, hearing and/or visual impairments affect some people. Some are autistic. Challenges with dementia, neurological conditions, and/or mental health issues are also part of the lives of people within this group.

Location

Currently, the people referred to TPL under this contract live in approximately 95 different residential care homes. Some people live with family some or all of the time. Family involvement varies. While a few people live on their own, and a few others live with one other person, most live in homes with four or five others, and there are a few homes where ten people live together.

There are 26 different residential care providers and more than ten organisations that provide community day programmes. Each residential and day programme provider is different. Some are not for profit trusts; others are businesses. Some are part of national organisations; others are local. There is a bicultural trust and a non-profit charitable Christian Trust. Each home has its own culture, which can change due to internal reorganisation or new staff and residents.

Community Support Workers in this Context

The CSWs are a diverse group, including Māori, Pākehā, and people from all over the world. For many, English may be their second language. They have a range of backgrounds and experience, which may include having family members with learning disabilities, having training in this area, and years of experience, or this might be their first experience working with people with learning disabilities. They have varied music skills and preferences. Their role varies, depending on the needs of people they are supporting. It is low paid work and can be very busy.

Underlying Theories and Models

The Waitangi Tribunal’s (2019) Hauora report recommended principles for the primary health care system, which are also applicable to the wider health and disability system, to help work towards equitable health outcomes for Māori. These include guarantees of tino rangatiratanga (self-determination), and principles of active protection, equity, options and partnership. These

guarantees and principles are essential for addressing the current inequities in health for Māori. People of other cultures can also benefit from these principles. Te Tiriti o Waitangi principles are helpful in this work with people with learning disabilities, CSWs and family, in terms of working in partnership, having them determine the focus of the ideas and participate in developing music ideas, and respecting and protecting their cultural values. We work together to develop music ideas to benefit the person with the learning disability, that include their preferences of music, including music from their cultural backgrounds, music activities they can participate in (independently or with support), and opportunities for choice-making and initiation.

The Enabling Good Lives model (2023) is a new approach to supporting disabled people that is currently being rolled out by the government. The principles from this underpin the work in this contract. They include self-determination, person-centred, ordinary life outcomes, mainstream first, mana enhancing and relationship building. This model was also endorsed by an evaluation study at the Raukatauri Music Therapy Centre (Lowery et al., 2020).

Interdependence is celebrated in Shaw's (2022) description of Post-Ableist Music Therapy. She states that "As the posthuman subject is an interconnected interdependent relational entity, it counters pursuits toward the myth of wholeness ('making the person whole') and does not hold independence as a core measure of success" (p.9). Shaw's ideas relate to this work in terms of using musical ideas to develop relationships between the person with a learning disability, CSWs, and family. We develop ideas which provide the support people need to access music, and support less disabling environments, such as relaxed concerts.

Warner (2017), writing about trainee music therapists working with assistants on placement during vocational music therapy training, argues for "an acknowledgement of [assistants'] knowledge of clients" and the need for "critical reflection on the issues of difference that might be present between the trainee and assistant" (p.69). These issues can include age, class, status, and culture. Warner notes that "contemporary multicultural working practices, such as tolerance and respect of difference, the recognition of dominant or privileged narratives and the capacity to allow different cultures to sit alongside one another, offer new and expanded ways of thinking about the practice of assistance within music therapy." She states that "assistants are

people first and foremost with their own histories, abilities, hopes and needs" – which is very relevant to this work with CSWs and family members. Her comments are helpful as I strive to be aware of and respect the differences between myself, the person with a learning disability, CSWs, and family members – differences that may include age, gender, culture, status, communication, music preferences, and skills. Respecting these differences is essential to develop positive working relationships.

Helping CSWs and Family Members to Use Music

The person with the learning disability and their wellbeing is central to this work. The work is diverse and specific to the person, the CSW and family who are involved. We develop it together. It may happen on its own, alongside music therapy sessions, or after a block of music therapy sessions. CSWs or family can ask for help, and I also offer this option to house managers. I aim to build an encouraging positive relationship with the CSWs and family members, to build their confidence and creativity to use music beneficially.

I have found it helpful to start by meeting with the person, CSWs and family and asking what they are doing already musically. For example they may be putting music on for the person to listen to, or dancing together. Being positive about what they are doing already musically can help build their confidence and encourage them to extend these activities. This is a strengths-based approach which highlights what is going well and builds on this (Berry at al., 2022). This approach is similar to Rickson's (2008) approach in school settings, where "it is likely to be helpful to begin with what the teacher and teachers-aide is already doing, and to develop existing programmes taking into account what resources are available and what could be provided for them, what skills they have" (p.92).

Discussing what the person, CSWs and family are hoping for, and their expectations about the benefits of using music, is helpful. Being realistic about the person's strengths and needs, can help develop appropriate ideas, for example considering how long the person's attention span is, and the time needed to wait for a response.

We talk about what the person with learning disabilities musical preferences and skills are, what the CSWs and family member's musical preferences and skills are, and what they feel comfortable doing. Twyford (2012) notes it is

“important to encourage school staff to do what they feel most comfortable doing and can realistically achieve within the time and resources available to them’ (p.65). The aim is to find common musical ground, which might be singing, dancing, playing instruments, or listening to music. We discuss what is possible within the context of the house or day programme, and what is realistic for the CSW or family within the time they have available and their skills.

We discuss what resources the person, the house or day programme has and what they need. The people provided for in this contract live on government-funded support and often have very little spare money. Buying instruments for birthday or Christmas presents may be possible. If the person has had music therapy previously, I can often recommend specific instruments they have positively responded to, that are good quality, durable, and appropriate for the individual. We work together to come up with ideas. It is important to acknowledge the CSWs and family member’s skills, experience and knowledge of the person with the learning disability. The decisions about which ideas will be tried are led by the CSWs and family, as they are the ones who will implement the ideas.

McDermott et al. (2018) highlight that music interventions may not always be beneficial. Murakami’s (2021) Music Therapy and Harm Model details potential harm that can happen within a music therapy session, an issue that has implications for this collaborative work. I address this by discussing with CSWs and family members the importance of monitoring people’s responses when engaged in listening to or making music. I suggest ways of protecting them from harm, including too loud music and musical overstimulation, and support them to provide positive, healthy music experiences. I usually document the ideas as a resource for CSWs, family, and future staff. We agree on a time when I will contact them to review how the ideas are going.

Reviewing

Reviewing how the music ideas are going is a very important part of the process and part of building positive relationships. Often this happens a month or two after ideas have been developed, to give CSWs and family members a chance to implement some of the ideas. Some CSWs and family like to have regular contact, and reviewing at intervals may continue for some time if it is seen to be beneficial. Twyford (2012) notes “follow-up work in

some form should be considered to ensure that momentum, modifications and reinforcement for ongoing work can be achieved” (p66).

Having a positive relationship is important so that CSWs and family feel comfortable enough to discuss what is actually happening, as not all of the ideas will have happened for a variety of reasons, or ideas have been tried and not worked. We discuss what went well and why and what did not work and why, which may lead to adapting ideas or developing new ideas. Hsu (2017) when talking about working with caregivers in dementia care states: “Time should be allowed for music therapist caregiver communication. Then caregivers can try out what they have learned from music therapists and incorporate the new ideas and methods into their practice. Most importantly, ongoing support should be available to help resolve difficulties and evaluate effectiveness” (p.125). Ray (in McDermott et al, 2018) describes music therapists providing ongoing support for Certified Nursing Assistants and residents by adapting activities and providing updates of music as needed. In this work with CSW and family, ongoing support is essential.

Inclusive Community Music Resources

I keep a list of inclusive community music opportunities in Ōtautahi Christchurch, to pass on to CSWs and family. These include relaxed concerts by the Christchurch Symphony Orchestra and the New Zealand Symphony Orchestra, where people can move around, vocalise, or leave; and outdoor concerts, for example, Christchurch City Council outdoor summer concerts. Being an audience member at concerts is an important role and can promote wellbeing for the person, CSW, and family member.

Ōtautahi has a number of inclusive community music opportunities and resources, including Te Roopu Tuhono inclusive kapa haka group, the Friendship Choir, Humdinger singers, Jolt dance company’s inclusive dance classes and performances, the Learning Needs Library (which has percussion instruments for loan), Enrich Community Chaplaincy Trust (who coordinate with churches to provide inclusive services with singing), and the Southern Centre’s multi-sensory experience.

Examples of Practice

The following are some examples of this work. Names have been changed to protect privacy, and written consent has been gained for sharing these examples.

Michael, Sarah and Grant

Michael is a 69-year-old Pākehā man, who is autistic, has Parkinson's disease and dementia, is non-verbal, and is a wheelchair user. This work with family and CSWs followed individual music therapy sessions. Sarah (CSW) and I talked about what music activities Michael liked. She said he liked listening to music and had liked going out to the Buskers Festival. We discussed the possibility of him being taken to outdoor concerts and relaxed classical concerts. We also discussed instrument and instrument app possibilities for use at home. At our next meeting I met with Michael, Sarah, and Michael's brother Grant. Grant was excited about attending concerts with Michael, as their family has a strong connection to music, particularly Western classical music.

I brought instruments and instruments apps to trial. Michael showed interest in looking at them and moved his finger to make them sound. Following this, Grant bought him an iPad and later some chimes. The CSWs and Grant were very pleased to see Michael moving his hands to make the chimes and apps sound, and moving his head to make the AUMI Adaptive Use Musical Instrument app sound. One of the CSW suggested they could take the iPad with them when Michael has to go to hospital to help distract him while they are waiting. We also discussed practical aspects of transport to concerts and events. At a recent review Grant said he can organise transport to take Michael to concerts. The possibility of attending concerts with his brother could be a way of developing their relationship and also a way for Michael to participate in the community.

John and Belinda

John is a 72-year-old Pākehā man, who is non-verbal and autistic. He had individual music therapy sessions, which included vocalising to songs, vocal improvisations, moving to music and playing instruments. He knows a wide range of songs and can vocalise parts of melodies. Through the music therapy sessions and discussions with CSWs we discovered songs John

knew and liked to listen and vocalise to. I provided song lyrics for the staff, which included songs for calming, enjoyment, participation and interaction.

Once the sessions finished the team leader Belinda asked if she could have the chords for the songs. She plays the ukulele and wanted to play and sing songs with John. I provided lyrics of the songs with chords, which she made into a song book.

Belinda is around two generations younger than John and is from a different cultural background. When I rang to review how things were going, Belinda said she had only tried a few times and felt overwhelmed by the number of songs that she did not know and by trying to learn songs from YouTube. We discussed focusing on his favourites that she already knew.

Differences in age and cultural background influence the songs we know and share. It takes time to learn new songs and CSWs do not have that time available within their work hours. By focusing on John's favourite songs that Belinda already knew, we aimed to find musical common ground. Belinda also said that some of the chords were too difficult. I was able to simplify them for her. When I followed up again, she said that had helped but she was still having to look up ukulele chords on her phone at the same time as trying to sing them, which was difficult, so I provided a chord chart on one page for her, to make it easier. She commented that it was good to have seen and heard John in music therapy to see what he enjoyed, what songs he hummed to, and what instruments he played

Staff sing with John at home, in the van and at picnics. They sing Amazing Grace with him to relieve anxiety. They do action songs with him and copy his movements in movement to music. Belinda said she had used the action song *Head, Shoulders, Knees and Toes* with John at his doctor's appointment to help diagnosis when he had had a stroke. They give him percussion instruments to play and they play with him.

Belinda said, "It was nice to incorporate staff at the house in music ideas." She reported that they were not able to consistently provide a music time for John every week. This example shows the need to be realistic about the time CSW's have to do music with people. It also shows the importance of supporting their musical skills, helping simplify things to make music making easy, and validating what they are doing already.

Mary and Ruth

Mary is in her 40s; she is Pākehā and has physical and learning disabilities. She is non-verbal and is a wheelchair user. I worked with Mary in a group of two in 2020. The aims in music therapy were to extend her pleasurable experience, maintain her independent hand movement, and to increase her communication. Sessions included playing instruments and instrument apps, and using switches to choose and for greetings.

From July, Ruth (one-to-one carer) assisted in the music therapy group, and after sessions we discussed what she could do with music with Mary on her own. One of these ideas was to continue using an iPad with instruments apps on it to encourage Mary to stretch out her right hand and arm. We put music instrument apps on it that Mary had liked in music therapy. Ruth was able to use it at home with her, gradually moving it further away as Mary moved her hand out.

When music therapy finished, I met with Ruth, and we came up with more music ideas, including buying a lollipop drum for Mary, using a switch with lines of songs recorded on it, and sharing information about relaxed concerts she could attend.

Part of my role is to talk about the trial and error aspects of this work and provide reassurance that not all of the ideas may work. When we reviewed, Ruth said she “felt silly” trying to use ends of lines of songs on the switch as Mary had not participated in this at all! Another issue was that the music shop had not been able to get the lollipop drum due to Covid supply issues. In another review, we problem solved to get an appropriate piece of foam to build up the drum stick handle to help Mary hold the drumstick. We discussed setting up the iPad so Mary could use it independently with her left hand, as well as someone holding it and moving it out as her right hand relaxed and Ruth facilitated this.

This example shows the importance of regular checking in, to see how things are going, and building trust so CSWs are comfortable to feed back what does not work as well as what works. Reviewing gives opportunities to modify or let go of particular ideas and support other creative ideas the CSW has come up with.

Peter and Christine

Peter is in his 40s. He is Pākehā and has a learning disability, tuberous sclerosis, a right hemiplegia, visual impairment and epilepsy. His mother reported he is functioning cognitively at around a 12 to 18 month level. I saw him individually at his day programme, initially with staff support until he felt comfortable to be on his own with me. When music therapy finished the manager of the day programme asked if I could meet with her and other staff to come up with music ideas they could use with him.

I met with Christine, a CSW who had sat in some of the music therapy sessions. She makes up songs for Peter and uses instruments and movement to music. We shared ideas about what setting works for him, e.g. having music in their sensory room away from distractions in their main room, where he likes to watch other people come and go, and likes to continually spin on a revolving chair. We discussed what movement to music and instrument activities he had liked in music therapy and instruments Christine had seen him use. We discussed Peter's short attention span. I suggested interspersing instrument activities with movement to music activities. I gave ideas of how to simplify and extend songs by making up new words and suggested changing words to simplify actions in movement to music.

When I visited again, they had a keyboard mat up on the wall which Peter was enjoying using. I was able to give some improvisation ideas about using this, for example call and response. His mother had bought the percussion instruments we had discussed, and they were using them.

Christine fed back to me that it was helpful meeting with me, as she had not done anything like this before. This example shows the importance of ideas which are appropriate for the strengths and needs of the person, and realistic in terms of attention span and a setting away from distraction.

Findings

This work has shown that working with CSW and family to develop music ideas can enhance relationships between CSW, family members and adults with learning disabilities. Another finding is that it is essential for the music therapist to develop a positive relationship with the CSW and family so that they are comfortable sharing what has worked and what has not worked. The importance of reviewing how things are going and having ongoing times to communicate how things were going was another finding of this work. The

need to respect differences of age, class, culture, communication and music preferences and skills, in order to build positive relationships, was highlighted. The role of music therapists in understanding and informing others of the potential harm of music listening and participating was another important finding. The music therapist needs to be realistic about the time available for CSWs to support music activities with adults with learning disabilities, and the practicalities that can be barriers, e.g. transport to concerts. The music therapist can support CSWs' creativity in using music and help simplify things to make music-making easy.

Conclusion and Recommendations

In this article I have described the development of collaborative work with CSWs and family members, to help them use music to benefit adults with learning disabilities. I have looked at the diverse strengths and needs of the people with learning disabilities, the contexts of the work, the roles of the CSWs, and the range of backgrounds, skills and experience of CSW and family members. I have discussed the underlying theories, models, and processes, and provided examples.

In this work I try to help CSWs and family to develop and use music which is appropriate for the person with learning disabilities and realistic within the context, including time available and skills of the CSWs and family, and provide information on mitigating the potential harm of using music. I aim to build their confidence, encourage creativity and make using music easy! This work creates individually tailored music ideas for people, which improve wellbeing, improve relationships with CSWs and family, and increase participation in the wider community.

Working it out together is another way, as well as music therapy sessions, that music therapists can use their professional skills with music to improve the wellbeing of adults with learning disabilities. This work will continue to evolve. I believe it would be helpful for music therapy training to include working in ways like this and I encourage other music therapists to develop these ways of working.

I believe music therapists can play a valuable role in helping family members and CSWs to use music to benefit adults with learning disabilities.

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