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Rickson, D., Evans, A., Claydon, N. R., Dennis, P., Cree, D., Dovey, K., . . . Watkins, E. (2014). *Active Music*. New Zealand School of Music & IHC NZ. Wellington, N.Z.

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IHC FOUNDATION



ACTIVE MUSIC



RESEARCH REPORT

2013-2014

Report for New Zealand School of Music and IHC Foundation
Prepared by Dr Daphne Rickson with the ACTIVE Music Team
April 2014



ACKNOWLEDGEMENTS (saying thank you) AND AUTHORSHIP (who wrote this book)

From the beginning we decided this book would be from all of us, even though some of us didn't write the words. We agreed to do this because everybody contributed to it. Some of us might write other things based on the words in this book. They might put their own name as the writer, but thank the other people for what they did. This is an important thing for researchers to think about [1].

We all agreed we wanted our real names in the book.

We want to say big thank you to:

- The IHC Foundation for giving us money to do this research
- The New Zealand School of Music for letting us use their room and equipment
- Staff at ACTIVE for supporting us, especially Cam, Julie, Kylie, & Rose
- Dr Sarah Hoskyns for reviewing our research report
- Music therapists Erin Upjohn-Beatson and Patrice Dennis
- All of the ACTIVE young people

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ABSTRACT

We are a group of eleven young people with intellectual disability and three music therapists. We did action research at a university. We wanted to find out how a music group might be helpful for young people with intellectual disabilities. We wanted to tell our own story and use our own words because we have a lot to say. We wanted people to read our story and to use our ideas to help young people with intellectual disabilities to have good lives. We went to twenty sessions of music research, and five more sessions of research analysis. We also did a lot of research work in between sessions.

We found out that music groups can be fun. They can also be hard work. They help us develop skills like listening and waiting. They are places where we can be independent. But music groups are also good places to practice working as a team. They can be safe places for people to express emotions. Music helps us to know people. It brings us together. Playing musical instruments can also help physical development. A good life for us would include having the chance to play music with others or to have music lessons. But it is not always easy for us to go to ordinary lessons or music groups. It might be important for young people with intellectual disability to have support from people who understand them at first. We want to be independent but we need help to develop our dreams in practical ways.

We found that doing research is fun and interesting. We were all researchers but we had different things to do. The adults had to be the organisers, setting up the research. We knew from the start the research would be about what young people think about music. The adults had done their reading and had written the literature review. The young people decided on other questions, and gathered data in lots of different ways. They also did some of the analysis, and decided on the findings of each cycle. The findings of each cycle, with more of the young people's words, are in the appendices. Later, the adults wrote the main findings, the discussion and conclusion.

We all discussed the things we wrote along the way and at the end of the research. The adults have tried to help the young people understand what has been written. The research took a lot of time and it was hard work for everybody. To be a good researcher you need to learn research skills. It is important that young people with intellectual disabilities are not exhausted by research. They need to be able to enjoy the things they are doing. We all liked being involved in research even though it was hard work. We think that research is important and helpful. Young people should be involved in research that is about them.

We learnt that young people with intellectual disabilities can go to university. Going to university was scary at first but we got used to it and we started to enjoy it. We need to do more research to make sure universities are ready to welcome students with intellectual disabilities. We can use our research to show universities that it can be a good idea to support people with intellectual disabilities to go to university. We can also use our research show people what we can do; what we like to do; and what we want to do in the future. Most of us would like to do more music and research in future.

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ACTIVE MUSIC: RESEARCH REPORT (OUR STORY)

INTRODUCTION

We are twelve young people from ACTIVE, and three music therapists from the New Zealand School of Music. ACTIVE is a place for young people with intellectual disabilities to explore, plan and build exciting futures. We are young adults but we want to improve our independence. We have been doing music and research in the New Zealand School of Music at Massey University. Music and research are some of the things young people do at university when they leave school. The music therapists were there to help everyone to do music and talk about it.

We went to twenty music and research groups. We went from September to December 2013, and then we had a Christmas holiday. We started again in February 2014. We were at university for an hour and a half each time. Support staff walked with us to music, or we found our own way there. It was hard walking up the hill to music. At music, we were able to decide together what we wanted to do. We listened to music, played musical instruments, sang, danced, and wrote songs. We also talked about music. We talked about the good, fun, easy, bad, boring, and hard things that happen at music, or other places. After music finished we still went to university to do research on Tuesday afternoons, five more times. We also did a lot of research work between sessions at ACTIVE. Daphne sometimes came to hang out with us at ACTIVE on Thursdays at lunchtime too.

One of the reasons for doing the research is that lots of things have changed for us since we left school and lots of things are hard for us. We are young adults and we want to be more independent. We are learning about places to work, and we do training for work. We also always like to have friends and to have lots of fun. We thought doing music and talking about music would be fun. We would learn a lot about ourselves and others if we did music and thought carefully about it, and then wrote a story about it. Learning things about ourselves might help us to be more independent. We could also tell other people what we had learnt, and that would help them to support us.

We had three main reasons for doing our music research

- 1. We wanted to find out how a music group might be helpful for young people with intellectual disabilities
- 2. We wanted to tell our own story and use our own words because we have a lot to say
- 3. We wanted people to read our story and to use our ideas to help young people with intellectual disabilities to have good lives

A lot of research reports use big words. Big words are confusing, so not many people read research reports. We have tried to make our research report easy to read and easy to understand. This doesn't mean we are not good researchers. We have been doing our research carefully. We have been organised. We know the messages in our book are important for everybody and we wanted people to understand them well. We know

everything in our story is not true for everyone. But we worked together and did a lot of checking on each other's work. We think people who read our story will have a good enough idea about what going to music and doing research was like.



LITERATURE REVIEW (WHAT OTHER RESEARCHERS HAVE WRITTEN)

YOUNG PEOPLE WITH INTELLECTUAL DISABILITY BECOMING ADULTS

It is hard for young people to leave school and go to other places to learn or to work. It might be harder for people who have intellectual disabilities [2-4]. Young adults have to learn and do new things, in new places. People expect more of them. They are expected to understand. Sometimes they leave their home to live in a new place, and this can be hard too. It is easier if they feel good about who they are, and what they can do. It is easier if they have friends and family to support them. When things are easier, young people are more likely to stay well [5]. Young people with intellectual disabilities might not be able to live by themselves, so other people support them [2-4]. If they don't have proper support they can feel lonely; they can feel bad about themselves, and they worry about the future [6]. Many people with disabilities find it hard to keep learning, to get jobs, and to stay well after they leave school [7].

Young people need to learn to "live, learn, work and contribute as active members of their community" [8, 9]. It is important for young people to make choices, set goals, and be involved in planning and organising their futures [4, 10]. It helps them to feel good about themselves when they tell people what they want and need [4, 10]. They need to believe that the things they do are important [9, 11]. So adults also need to listen and support [11]. Young people begin to take risks, and learn from experiences [12]. But they need help to stay safe [4].

Young people need programmes to meet a lot of different needs [6]. It is important for them to be active, to learn to work with others, and to do things by themselves [13]. They need activities that help them learn about themselves. They need activities that provide emotional support. They need to learn about their communities. They need to develop new skills. That means they need to be taught by people in the community [14]. They need to be actively involved. This means they need to be able to get to the programmes. They need to have resources to do the programmes. They need to be interested in the programme. And they need to be able to see why the programme is important. It is also important for programmes to be ongoing in some way.

WHY MIGHT MUSIC BE HELPFUL?

Music is a way to communicate. Researchers have listened to babies communicating with their mothers and fathers [15-18]. They found out that it is just like music and dancing. Their voices have musical things like rhythms, tones, phrases. Their bodies move to the rhythms [19]. Their faces are expressive. When the baby is upset their voice is usually high. They clench their fists, and their face goes tense. The parents understand what the baby needs. The baby understands when the parent is trying to soothe them or excite them. They don't talk with words, they communicate with music. This is how they begin to build their relationship. This is why researchers say that music is in us from the beginning [20, 21]. It is also why music therapists say everyone can do music. Music is inside all of us; we don't have to have musical 'talent'. And we can use music to build relationships[22].

Music is a way of expression that is different to words. We can express and share feelings through music [23-25]. People who find it hard to speak can communicate with music [26]. Even people who can speak might find it easier to express themselves with music when it is hard to find the right words [23, 27, 28]. Researchers found that people with intellectual disability are sometimes frightened to use new words in case they say the wrong thing [29] or they just say 'yes' all the time to please people [30]. When people don't understand them, they can become frustrated, angry, worried, and lonely [23]. They like to express themselves with music instead of words [11, 23]. Going to music and doing music with friends is what a lot of young people do. This is important too.

Music is valued by communities. In some countries, like New Zealand, people mostly listen to music. A lot of people think that doing music is for talented people who have practiced a lot [31]. In other countries music is used as part of everyday life [32-34]. People use music to express themselves and to connect with others. Music and musical performances help people to relate to each other in lots of ways [35]. Music is important at funerals for example. When people are at an outdoor concert they might sing and dance together to the beat of the music.

People like different kinds of music. They might like the music that they hear on the radio, the music their parents like, or the music their friends like [5]. Telling people about the music we like helps them to know us better [36]. We can choose music that other people like because that might help them be friends with us. Or we can choose something different to show that we are individuals [5]. When we improvise music we make it up as we go along. When we improvise with other people they learn more about us right at that moment [37]. If we are composing music together we can make it up over time. When we compose music we can also write things about who we want to be. We can think about it. When we compose with others we can try things out and improve it together. We can find out more about what we can do with other people. We can usually do more together than we can do alone. It can be very satisfying to play, improvise or compose music together.

To do any of these things we need to listen carefully to each other. Some researchers noticed that people's music changed over time because they were improving their listening [29]. They were doing music with adults who had intellectual disabilities. In the beginning the music was loud and messy. Then it got quieter but it sounded like people were being polite. It seemed like they weren't really playing what they wanted to play. Finally the musicians started to listen carefully to each other. When people knew others were listening, they could express themselves better. They started to look after each other while playing music. People learn to listen, work together, take risks, and show respect for each other when they are doing music together [38]. They build relationships and become part of their music community.

It can be important for people with disabilities to do their own work. It is better for them to give their own ideas and make their own choices, instead of being told what to do. This helps them to be independent. It helps them to be confident. When they show others what they can do with music they can feel proud. Some researchers found that doing musical performances at school helped people with disabilities to do more for themselves in other school activities [39].

WHY IS MUSIC IMPORTANT FOR YOUNG PEOPLE?

Music is important in young people's lives [40]. Listening to music is one of the things they do most. They listen to music for many reasons [5, 41]. Sometimes they listen when they are doing ordinary things, like washing dishes. Sometimes they listen because they feel happy or sad. Sometimes they listen because they want to relax, or have more energy. Sometimes they listen because they don't want to think about other things. Sometimes they listen because they want to feel and do the same things as their friends. The kind of music they listen to or play lets other people know who they are. This 'developing identity' is important for young people [5, 40, 42-44].

Young people need to practice being independent. Going to music is something young people can do outside of their families. It is important for young people to be together, and to learn to work with others. It is important for them to learn what it is like to love their families but not to rely on them. It is important for them to learn about other kinds of love, like boyfriends and girlfriends too [45]. When young people have a disability these things can be hard. They might not have many chances to practice being with other young people. They might not have a lot of say in what happens to them.

Working together on things that are hard can change people; make them stronger. Music groups can be good places for young people to work together. They can make friends, help each other, and learn from each other. Young people are often more comfortable learning from one another than from adults [46]. When young people do music together, they tell each other how they are doing. Working in groups and learning what other people think about us is important [47]. Young people can learn more about themselves and how they fit in with others when they are doing music together. It can be a place where they feel they are not alone; they belong [48]. It can be a place where they learn to trust others and feel safe to try out new things [5]. They might try out different kinds of music; like creating their own music to express themselves. They can tell people about their favourite music even if other people don't like it. They can even sing about things that might not be good, or might be hard, to say [48]. Young people can have fun at group music, even when it is hard work. All these things help young people to understand themselves, and others, better.

Music is also a way for young people to change their world. Young people don't have a lot of opportunities to change things, especially if they have a disability. When they are doing music, people notice and listen to them. Other people can learn about young people with disabilities when they do a musical performance. They might see them differently; they might see more of what they can do rather than what they can't do. So performing is one way for young people with disability to change the way their communities understand them [38, 49].

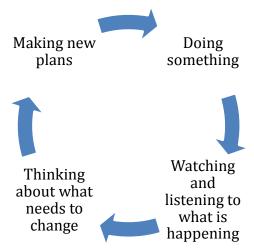
HOW CAN A 'COMMUNITY MUSIC THERAPIST' HELP?

Community Music Therapy is about people developing healthy relationships by doing music together. It is about sharing musical experiences. It is about noticing and appreciating what people can do with music. It is about working together and using music to help people to participate in their communities [50].

Community music therapists find out and think about the things people need, and how music can help [50, 51]. For young people it can be about helping them understand who they are and what they can do. They can learn these things by doing music with other people in the community. But communities sometimes need help to understand what they need to do to support young people [52]. Community music therapists want to help people who are being put down or shut out by their communities. The communities might need to change their ideas. They might need to change their programmes or buy new things so everyone can participate. So community music therapists work with communities as well as with groups or individuals. When people are doing music together they see what other people can do [35]. Community music therapists understand that when people change, their communities change. And when communities change, people change. So they think about the things that seem wrong or unfair. They talk with people about the ways music might help. Then they help them get started on their music programmes.

ACTION RESEARCH

When people want to learn or improve things in their lives, they might do Action Research [53-58]. Action research is about people watching and listening carefully to what they are doing and what is happening around them. They think about what changes they can make to improve their lives. They try new things, and they watch and listen carefully again. They think about how the changes went, and whether they need to make more changes. And so action research goes round and round. This is called cycles of learning. You can see what that looks like in the diagram below.



An important part of action research is being able to improve things for yourself, as you go along. The first idea is only a starting point [56, 59]. Action researchers use their own experience to decide what needs to be done next [60]. They believe that people know what is best for themselves in their particular situation [61]. Everybody who is directly involved has their say [62].

Participatory Action Research (PAR) is particular kind of action research. It is used to help people who might not usually be able to have a say in what happens to them. It helps them to learn how to speak up for themselves and to believe they can make changes in their lives [63]. It is important that they feel as if it is their research, that they

are all researchers, and that they can have a say [64]. They need to know they can make a difference.

Children and young people can be researchers. Adults now understand it is better for children and young people to participate in the research that is about them [65, 66]. People who have intellectual disabilities have been co-researchers in research that was about themselves and other people with intellectual disabilities [1]. They should be researchers because they know what is best for them. It is especially important for them to be involved when adults are developing programmes for them [65]. Children and young people have the right to express their opinion and to have people take notice of them [67]. People who have supported researchers who have Downs Syndrome say it has been very enriching to work with them [68]. It was also helpful for the young people.

Doing research is helpful for children and young people as well as adults [69]. But adults need to teach children and young people how to do research [69]. Adults can support people with intellectual disability by helping them to understand their rights, and to do what they have a right to do [68]. The research is carefully planned so everyone has a role to play. People with intellectual disability will be able to do different things for the research. What they can do will depend on what they have done before, and how confident they are [65]. There are not many research projects which include people with an intellectual disability in data analysis. But people with Down syndrome were able to underline words and make notes on data they found interesting and important [1]. Everyone needs to feel that what they do or say is important. Adults supporting children or young people to do research have to be careful not to take over.

SUMMARY

Being a young person with intellectual disability can be hard. It is hard to keep learning, to get jobs, and to stay well. Other researchers have written things that made us think doing music might be helpful for us. They said you don't have to be able to talk to do music. Everyone can do music even if they have trouble talking, or moving, or playing with other people. Most young people like music. When you do group music you have to communicate with other musicians. When you do music you might learn things, be more independent. This helps you to feel better about yourself. It helps you to get along with people and to be respected in the community.

Researchers also said Action Research can be a good thing for young people to do. They have a right to speak up about the things that are important in their lives. They can tell adults about their experiences. They can decide what they want to do. They can make changes in their lives. And they can help adults to decide what programmes will be helpful for them. We wondered if going to music would be a good thing for young people with intellectual disability so we decided to do action research.

We decided to go to music. We would decide together what music we would do. We would think about and share the things that were easy, hard, good or bad about it. We would think about how doing music together might help us in other ways. If we didn't like anything we would try to change it ourselves. We also wanted to tell our families and supporters what it is like coming to university to do music. Then they will know

how to help us in future. We would go to twenty music sessions at the New Zealand School of Music, at Massey University. Other young people do music and research at university too. Three music therapists would work with us. The music therapists would make sure we had a safe place to do music. They would support us to do music, to work hard but have fun.



THEORY (about why and how we did this research)

How do we know stuff? (Post structuralism)

Post-structuralism is a big word used in research. It means thinking about how people relate to each other, in different places and at different times, and how we understand what is going on. We can't always know what is going on because we don't know what people are thinking. We can ask them what they are thinking but most people most of the time, aren't able to communicate exactly what they mean. Most people have language to help other people *sort of understand* what they are thinking and feeling, but the person who is listening might not get it properly. This is because we all have different experiences; and we can't ever know what it is like to be someone else. But when lots of people communicate the same thing enough times, we start to believe it is 'true'. We make up names for this 'thing' because this helps us to make sense of our world. But made up things are not always helpful.

'Made up Ideas' (Social Constructionism and Critical Theory)

Disability is a 'made up' idea. A long time ago it was an idea to describe what was 'wrong' with people's bodies. Then people started to say that it was more about the world being wrong because most places and people didn't make it easy for those with different bodies to do the things they wanted to do. Another idea that we think is important is that every individual has a different body and different experiences so 'disability' is just normal. But it also is important to think about what it feels like to have a different body in a world that is not always kind and helpful. People with disabilities have been thought about, and talked about, as a big group (such as 'people with Intellectual Disability'). Most people haven't thought enough about how different the people within the group might be, and what their lives might be like.

For example, young people with disabilities can find it hard to get work. Many employers see disabled people as a big group, and can't imagine how each individual might be able to contribute. They worry that people with disabilities won't be able to do the same things as other people, even when they can. This means that people with disabilities often do any kind of work they can get, and accept low wages or even no pay. Yet people with disabilities often can do what is needed. They are loyal to their employer, they come to work when they are supposed to be there, and they help the company to make money [70]. People with intellectual disabilities say that working is very important to them [71]. When people are working they learn things and do things that make them feel better about themselves. They see themselves differently; they feel like a different person. So thinking about people with disabilities as a group or a 'thing' is not helpful.

We need think again and again about our ideas to be sure they are sensible and kind.

'Putting People Down' (Disempowerment)

For a very long time, people with disabilities have been treated unfairly, bossed around, not accepted, and put away in special schools or institutions. They have not been able to participate in society like other people¹. When people are grouped together and treated poorly like this they often believe things people say about them; and do the things other people say they will do, even when they can do better. Researchers have made things worse because they have treated people with disabilities as 'things' rather than people who are experts in knowing what it is like to be themselves. The researchers have considered themselves the experts, and they haven't asked people with disabilities what they have to say.

We need to think about who we are in these 'made up' worlds. Researchers can help people to tell their story about what it feels like to be part of something 'made up', like disability. Finding out what someone's life is like means thinking about the people they hang out with, the places they live in and go to, and how they feel about everything. But we often forget things, or find things too hard to say, even when they are important to us. Researchers have to support people to tell their story as fully and honestly as they can. So they keep asking people "does the story sound right?" and "is this what you meant?" Participants can think about the story and change it as much as they need to so readers might know what they mean. The researcher still knows (and tells the reader) that it is impossible to know exactly what someone's life is like, but it is possible to learn a lot and to understand more about people when you work carefully with them.

What we believe (Assumptions)

When researchers are thinking about their research they have to decide what is important to them, so they go about the research in the right way. We agreed that it was important to think about people as physical, emotional, social, political, and spiritual beings. We understood that people are individuals, who need to have healthy connections to groups and to wider society. Our idea of 'disability' is that it is about

- 1. the things that people can physically do or understand
- 2. the ways that other people limit what individuals can do
- 3. and the ways that people think about who they are and what they can do

We believed it would be important for stories about young people to come from young people themselves. When we have to answer lots of questions, and think about writing our story, we can learn a lot about ourselves. We have to consider what we think about ourselves and what other people think about us. We learn to see ourselves as others see us. This is not always easy, and we might decide that we want to change things. We can try to change other people's ideas, and we can try to change our own ideas. If we decide to change things we need to make a plan of what to do. And so research can help us to be strong and capable. When other people read our stories they might change their mind about what disability is, what people with disabilities can do, or what people with disabilities want to do. Research can change things in the world.

¹ When Tash read this she said, "People have teased us, called us names, and stared at us".

How we looked after each other (Ethical Statements)

Before we started our music and research we went to the university three times to see what it was all about. We talked a lot with Cam and Julie and Nathan (our support staff) about it. When we understood what it was about we wanted to be in the music group. Everyone who wanted to come signed a paper to say they wanted to come.

We liked doing music and being researchers. We learnt things about music, about talking, about writing, and about being with other people, and we felt good about doing things by ourselves, and with other people. But sometimes we felt shy and worried about doing new things too. That was ok. Daphne, Patrice and Erin helped us understand things when we needed help. We helped them too by telling them if we didn't understand, if we didn't like something, or if we wanted to stop coming. One person stopped coming after Christmas.

When you do research, you need to be careful to look after each other. We were careful about the way we talked and about looking after our words. We were honest, kind, and respectful; and we gave people choices. The adults helped us to write a story and to make this book about coming to music. We talked about and decided together what would be in the book. We didn't have to say anything if we didn't want to. We decided together that we would think about having our real names in the book, then each person thought about it and said yes.

The book is for other young people, our families, and people who look after us. This will help them to know what we like, what we are good at, and what is hard for us. We have also shown our research to family and friends at a concert (see programme on p. 85), and will be showing it again at a conference. Daphne, Patrice and Erin might be writing our story again; the same story, using big words for university people to read too. They might be thinking and writing about how to be better helpers too. Their stories will help university people, teachers, and support staff to understand how to work with people who have intellectual disability. Before we started working with Daphne, Patrice and Erin they already wrote stories and talked to people at conferences about why they thought it was important to do this kind of research, and how they might do it.

There are people who look after researchers too, called the ethics committee. Daphne told the ethics committee we would be doing research. She told them our parents would sign a paper to say it was ok for us to be involved. But we said we don't need our parents or other people to sign a paper for us. We told the ethics committee "we are all 18 years old or older. When people ask us to do things, and explain carefully what it is about, we can decide by ourselves if we want to do it or not. We don't need our parents or other people to sign a paper for us". We cheered when we decided not to ask our parents to sign the letter for us. Daphne videoed some of us talking about this so she could be sure we understood. She sent our words to the ethics committee and they said ok.

METHODOLOGY AND METHODS (how did we do our research)

Cycles of learning (Participatory Action Research: PAR)

We did Participatory Action Research, which is called PAR for short. Doing PAR meant having a question about what we wanted to do, trying to do it, then seeing how well we had done. Then when we saw how well we had done, we decided if we needed to change what we were doing, or move on to new question/s. We did this three times. This means we had three cycles of learning. We were going to have four (see our plan on p. 34), but in cycle two our friend died and we stopped gathering data for two weeks. So we changed to three cycles.

In each cycle

- We did music and took notice of what was happening
- We communicated what we were noticing and thinking in various ways (see our methods below) and
- Our communications were our data.

We encouraged all our researchers (lead researcher, contracted researchers, and coresearchers) to be involved in all aspects of the research process, including writing to the ethics committee, doing data analysis and telling people about the results. People were supported to do what they wanted to do. We wanted young people to have a say in how their lives should be, and also to learn things about themselves.

In this kind of research, people work together and gather data from watching and listening carefully to what they and other people say and do, talking to them (sometimes chatting and sometimes in an interview), looking at drawings and anything else they might make, listening to their music, and thinking about the things they have done together. You can use any kind of data that seems useful. A list of where our data came from is below.

A PAR story is about the people who participated and the communities they live in. Our story can't be 'true' for everyone in our group. And some things in our story are only 'true' for some of us. But we have worked very hard to include every individual in our music and research sessions. We have worked hard to find out what it was like for them. We have made our research story out of everyone's words, and we think our story represents our group.

How we communicated (Methods)

- We all had research journals (a book to write or draw in).
- We had coloured pencils, pencils, pens, highlighters.
- We watched video of our sessions, and stopped the video when we wanted to talk about something and write it down or draw it. Our support staff helped us with this task.
- We talked in the group and wrote things on our whiteboard. The whiteboard was a photocopier and we could print our data from the board.
- We chatted to other researchers and to support staff and made notes of our ideas
- We had individual interviews with Daphne (see p. 5)

- We had a video diary. People could talk to the video after music about what they
 were thinking (only two people did this and we couldn't really hear them very
 well).
- We had a Facebook page
- We wrote and sang songs
- We read things (other people's research) and highlighted what we thought was important

You can see examples of some of our data on pp. 73, 74, 75, 83 and 84. And you can see two of our songs on pp. 91-92.

Interviews

Eight of our young people agreed to be interviewed. The interviews were at our ACTIVE. They were 15 to 25 minutes long. Most of the interviews were done when we had finished about 15 sessions of music research (but Edward's was at the end of the music research sessions). This meant that Daphne could ask us what we had done, and how we felt about it. She could also talk to us and ask us questions to see if we understood and agreed with the findings of music research so far. We were really just talking together. Daphne asked simple questions. She was careful about waiting for our answers. Sometimes she turned the recorder off. Then we might remember something so she turned it on again. She typed what we said just as we said it. Then she used our words to make a story. Then gave us the story and we read it, or someone read it to us. We talked about the story with Daphne, Patrice, or Erin to decide if it sounded true. We changed it if we didn't like it. We read the story again after Daphne made the changes and agreed that it sounded true. We have included people's individual stories, from interviews; at the back of our book (see pp. 63, 64, 65, 66, 67, 68, 69, 70, 72).

Reading

The adults were reading about 'music with young people', 'communicating with young people who have intellectual disability', and 'what young people with intellectual disability need'. They highlighted the things that seemed important. The highlighted bits were codes. They brought the codes together to make themes. They made a story of their themes and read it and gave it to us (see examples of research stories on pp. 57, 58, 60, 61).

How we sorted it all out (Data Analysis)

We did thematic analysis. We had to think about our questions and look carefully to see if the answers were in the data (this is called 'deductive analyses'). Then we would look for other things that were important (this is called 'inductive analyses). We talked about what we found, and wrote sentences about it. These the sentences were themes. Then we had to agree about what we would do and what our questions would be for the next block of sessions. Then we would do more music. We would watch, listen and think; and we would be gathering more data. We have written more about how we did it in the paragraphs below.

For each cycle, we had to bring all our data together. One of the young people photocopied the journals each week. The adults typed the data that came in words and photocopied it ready for analysis. We talked about the pictures people had drawn; read each other's journal entries and highlighted the things that seemed important; drew pictures of happy/sad faces, or pointed to happy/sad faces to show what we thought of things.

Cycle One

In cycle one our research question was "what do we think about coming to music?" We thought that people might say "good", or "bad" or "it's hard" or "it's easy". Then we would have a very short story! So we needed to have more questions. Our questions were:

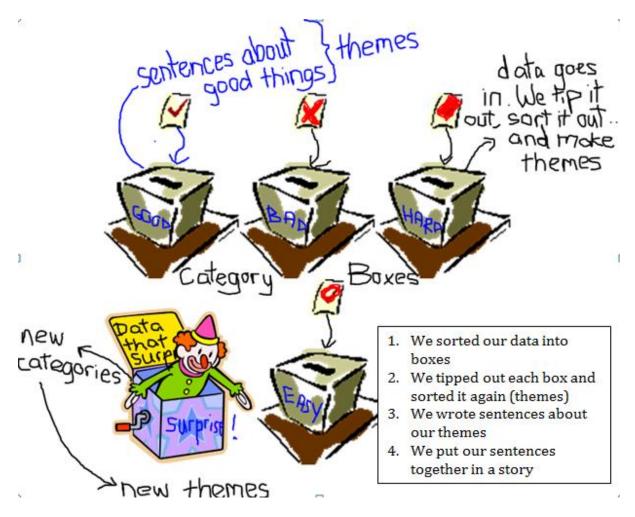
- 1. "What is good about coming to music?"
- 2. "What is bad about coming to music?"
- 3. "What is easy about coming to music?"
- 4. "What is hard about coming to music?"

Looking for answers

Five young people and three music therapists came to do data analysis. We searched our data to see what it could tell us about good, bad, easy and hard things. We needed to know because we wanted to make 'coming to music' better.

- 1. We worked in three groups. An adult was in each group.
- 2. Each group had a copy of the words and pictures from the whiteboard and journals
- 3. We had boxes labelled "good", "bad", "hard", "easy"
- 4. We needed someone from each group to have scissors
- 5. We went through the words and pictures from the whiteboard and journals together and decided which box we wanted to put the words in.
- 6. If we didn't think the words fit in one of the boxes, we made a new box and put a new label on it
- 7. Each time we decided where the words or pictures should go; someone cut out the words or pictures and put them in a box. We sometimes put the same words in different boxes (we had three copies of the data so we could do this)
- 8. We talked about our choices. Sometimes we didn't all agree and we had to sort again.
- 9. When all of the words or pictures were in boxes, we wrote a story about each box

See the picture on the next page.



Looking at our answers

After we had written our story we read it again to find the most interesting bits. This is called Inductive Analysis. When we read our story we were wondering:

- Should we keep coming to music? Why, or why not?
- What is going well? Why?
- What can we improve? How?
- What new things should we try? When?

We talked about what we needed to change to make coming to music better, and tried to write some new questions for our next cycle. We had HEAPS of questions and it felt very messy. So we decided to make a questionnaire so everyone had a chance to tell us what they thought about our story. You can see our questionnaire on p. 53 and you can see our answers for cycle one on p. 35.

Agreeing about what we would do next

After we had done our questionnaire, we looked at the answers and we could tell which of the things people thought were most important. We decided we would keep coming to music. We thought we could improve our music sessions. We wanted to keep trying new things like song writing; continue to be individuals but work as a team; try working in smaller groups; feel comfortable listening when we didn't want to play or dance;

communicate in ways that were comfortable for us; and tell each other about the things we like and don't like. And we would ask for help if we needed it.

We decided our questions and actions would be to:

- 1. find out if it was a good idea to do song writing
- 2. work in smaller groups so we don't have to wait so long for our turn
- 3. continue to be individuals but try to work as a team
- 4. tell each other about the things we like and don't like
- 5. tell someone if we are worried, sad, or happy
- 6. ask for help if we need it
- 7. ask people what they mean if we don't understand
- 8. communicate in ways that are comfortable for us
- 9. keep trying new things
- 10. try not to play too fast
- 11. say "no", "don't come" when reporters and photographers want to write stories or take pictures of our work
- 12. listen when we don't want to play or dance

Cycle Two

We kept doing music and took notice of what was happening. We gathered more data. Eight people came to do data analysis for cycle two (five young people and three music therapists). We went into groups of two and three. An adult was in each group. We did some Deductive Analysis. That means we looked through our data searching for information that would help to answer to our questions.

Looking for answers

We had a different coloured highlighter for each code. We searched our data to see if we had done what we said we would do, and to find out how that had worked out.

- 1. One pair highlighted everything they could find about song-writing and working in groups.
- 2. Another pair highlighted everything they could find about working as individuals and working as a team, and when people had asked for help. They also looked to see if we communicated anything about playing too fast or playing together.
- 3. Another pair highlighted the times when we told each other about the things we like and don't like, and then they highlighted new activities or people trying new things.
- 4. Another pair highlighted the different ways we communicated, especially when we didn't want to play, sing, or dance.
- 5. Altogether we decided whether we said "no", "don't come" when reporters and photographers wanted to write stories or take pictures of our work. This was easy. No reporters or photographers came.

Developing Categories

The highlighted bits were codes. We read the data that we coded (in our small groups) and put all the same colours together. This made a category. For example our first

category was 'song writing'. We made a story about song writing. When we were writing our story we moved things around so they went together. These were our themes. We didn't have time to do all of this together, so Daphne, Patrice and Erin took our highlighted ideas to finish the others

Looking at our answers and deciding what to do next

We put all our stories together. We looked at them again without thinking so much about our questions (Inductive Analysis). We were looking for more interesting bits, to get new ideas. After we read them we decided what to do for Cycle Three. Some things were the same as Cycle Two. We wanted to:

- 1. keep trying to listen to each other carefully
- 1. keep trying to speak up even when it is hard to speak up
- 2. talk about whether to do song writing or not (some people liked it and some people didn't)
 - a. Why do we want to do it?
 - b. Why don't we want to do it?
- 3. do the things people ask to do, if we can. For example people have asked to
 - a. play the piano,
 - b. do a song from the Lion King
 - c. try to get more computers
- 4. work together in sessions without support staff when we can
- 5. ask for help if we need it

You can see our answers for Cycle Two on p. 40.

Cycle Three

We kept doing music, took notice of what was happening, and gathered more data. Daphne also interviewed eight young people. Ten people came to do data analysis for cycle three (seven young people and three music therapists). The adults had already typed up the journal data.

Daphne had already typed up our interviews, coded them, made categories, found themes, and wrote our personal stories. We had time to read our stories. We made changes and added things.

Looking for answers

Then we did our 'Deductive Coding'.

- 1. We went into four groups
- 2. We looked through our data, including our personal stories, and highlighted information about listening, speaking up, doing song writing, doing what people wanted to do, working without support staff, and asking for help.
- 1. We had a different coloured highlighter for each code.
- 2. We used the whiteboard to put our codes together in categories, and made some notes about themes (Daphne finished doing the themes later)

- 3. Daphne made photocopies of the whiteboard so she could write up our story.
- 4. We found parts of our personal stories (from interviews) that were related to our questions. We would put some of our exact words in the research story.

You can see our answers for Cycle Three on p. 46.



FINDINGS

ANSWERS TO OUR MAIN RESEARCH QUESTIONS

We had three main reasons for doing our music research

- 1. We wanted to find out how a music group might be helpful for young people with intellectual disabilities
- 2. We wanted to tell our own story and use our own words because we have a lot to sav
- 3. We wanted people to read our story and to use our ideas to help young people with intellectual disabilities to have good lives

So our questions were:

- 1. How can a music group be helpful for young people with intellectual disabilities?
- 2. Can young people with intellectual disabilities tell their own stories in their own words?
- 3. Will people read our story and use our ideas to help young people with intellectual disabilities to have good lives?

Ouestions

1. How can a music group be helpful for young people with intellectual disabilities?

Answer

Music groups can be fun

We enjoyed doing a wide variety of musical activities. We like music, we believe it is good for us to go to music, and we feel as if we have achieved a lot of things. Music group was mostly a fun and happy place.

"At music we do warm up games. I like that clapping one. I like playing the drums at Massey University and I like the beat on the drums. It's so good to give a beat." (Axel, Interview)

"I love playing music. When I started music I wanted to play the guitar, but now I've changed from the guitar to the piano... I wanted to try the piano. It's sort of easy, and hard... It's sort of easy because sometimes I know the chords off by heart. ... Sometimes I do have the notes in front of me, but then I try to add more chords to it." (Janiece, Interview)

Music groups are good places to develop social skills (fun but hard work)

We enjoyed being with friends. Having a place where we can hang out with friends is very important to us. We felt sad when one of our friends decided not to come back to music.

"I like to listen to music with my friends at ACTIVE. It's pretty important to me....I felt sorry of Kwame leaving us and the music university. It's so sad for people. He was so good last year at music. It's so, so sad that he left music at Massey." (Axel, Interview)

We learnt about the different ways people can communicate. We were often laughing but on several occasions we also cried together as we shared our grief over friends who had died, or who were absent. Music groups provided us with the chance to express ourselves with words, or though music. We talked about important things and chatted about the 'everyday' things that are important to us like what people were wearing, or what we had done at the weekend (see 'music helps us to know people').

The music group was both fun and hard work. We had different ideas about what we liked at music, and it was often hard choosing what music to do. We learnt a lot about how to work together. We found out quickly that very noisy places were not helpful for some people because it hurt their ears, or because they couldn't hear each other. We learnt to adjust the volume and tempo of our music to fit in with what others in the group were playing. The size of the music group meant that people could not always do what they would choose to do. We had to be patient and tolerant while waiting for our turn. We got better at listening to each other, helping each other in practical ways, and working out what we would do as a group.

"We can help each other at music. But I would like to work in small groups too. It's very good for me...because I don't like big groups. Because another person talks to you, another person talks to you, another person talks to you... (in) small groups, one person talks, and the other people listen" (Axel, Interview).

Sharing what we were doing at music with families and friends was important. We wanted families and friends to see what we had been doing and we asked if we could do a concert. We wanted the people who are important to us to be there.

"(I enjoyed) singing, writing new songs...and the jams, and all kinds of cool music stuff. It's a unique opportunity. I can't wait for our concert tomorrow. It's going to be fun."(Tash, interview)

Even though we liked showing people what we had been doing we liked to be private. After the first cycle of learning we didn't want reporters and photographers coming to our sessions. And we weren't sure about other people either. One day Daphne had a visitor working with her for a week. We were sure about her watching or joining in our work. We talked with her before we started the session and decided it would be ok for her to join in. We also thought it was interesting when a university teacher came to play us his saxophone. We asked him questions but we didn't play with him.

Music groups can be good places to develop independence

At first we liked familiar things. New things can be scary for us. Being in a new place and trying new things was difficult for most of us. The university was a confusing and daunting place to be in and some of us found it hard to talk with staff and other

students, especially at first. When we started our music research we liked having our support people with us. Later we were keen to be at music without them because we wanted to be independent.



Over the twenty weeks we became more relaxed. We explored the university a bit more when we had been going there for a while, and some of us talked to other students and staff when we had jobs to do like photocopying the data in the staff room. We like being with friends, but meeting new people can be good too. We began to enjoy being in the university environment. It might take a bit longer for us to be completely comfortable, but we like lots of things about it now.

We walk every Tuesday to the university. It's such a big space that Massey. It's such a cool room ... because it's like a teacher's room. It's quieter and it's got glass windows for some fresh air, and that drinking tap. I also like the library. This year I'm going to the library. And I've been to the cafeteria. I eat my lunch outside. I might go in to buy a coffee one day because I'm very independent. (Axel, Interview)

Figure 1: Axel at Music

"(I've been to) the Massey building, the Massey music one, and sometimes we go to the library or the café. We went to the café a couple of times with the whole group. I think I could go by myself or with friends. I went to the library with friends mostly just to see what it was all about. We looked all around where the library is and stuff. (If I was coming longer) I would go to the library to read a book or study". (Tash, interview)

"We are enjoying coming to Massey for music and research. It's fun and it's really what we want to do". (Tash, Interview)

It is hard when we want to be independent but still need help. The music group was a place where we were encouraged to ask for help, and we could practice asking for help when we needed it. We asked Daphne, Patrice and Erin to help us to play our favourite instruments by showing us ways we could join in. Trying new things was hard, but when someone suggested a new music activity, most people wanted to "give it a go". We thought it was good to learn how to do something different. We made mistakes but it was good to learn by practising. We wanted to learn new things, and we worked hard to get them right.

Over time we became more independent. We decided by ourselves that we wanted to put on a concert for family and friends. We sent invitations, booked the room, borrowed some instruments and organised supper by ourselves. Tash took a very important organisation role as well as being 'master of ceremonies' on the night.

Music groups are good places to practice teamwork

In music groups we learnt to notice what other people were doing. We learnt to accept that people contribute in different ways and that everyone's contribution is important and helpful. Sometimes someone did a solo, and others listened and watched. Listening and watching is important. Some people found it hard to join in but they kept trying to. We learnt which part to play, practised our parts, played together, and took turns.

"One day Erin and Janiece were playing the guitar and Kate joined in with her guitar and then Tess, Axel and Tessa joined in with their instruments. Janiece sang, and Erin helped her with the guitar. It was cool. It was really cool that we all sound cool together" (Journal entry)

Some of us were able to do things that we had never done in the group before, like doing a solo song, or playing an instrument on our own without help. One person liked doing the filming. We all had individual parts to play, but we felt as if we were a team when we were playing music together. We made mistakes but it was good to learn by practising. We liked it when other people were good at music. Someone wrote in their journal "Being respectful and nice is good".

We practised some things to get them better. Even if we didn't like the music we still practised because the other people liked it. We made mistakes but it was good to learn by practising (Janiece, journal entry).

But we thought it might be easier to do music and research if the group was smaller. Sometimes it was too noisy for people. Sometimes we had to wait too long for our turn to play or to talk. We think some people would be able to say a lot more if they had more time and space to communicate. Edward said he didn't want to come to group music again because it was too big.

I enjoyed guitar and singing music from Aladdin. I brought a music book to sessions so I could play guitar. I was choosing from my book and sang in front of the group and played guitar. ...I came to Massey by myself with my guitar, and sometimes I stayed at the back of the room. It was hard for me to sit with the group. I was tired. I was sometimes happy at music; but sometimes angry. I wanted to go home. I came to music to meet Julie. I like playing with Julie. I wanted to come to music; I liked it but it was hard to hang around. Playing with one person is easier. If it was my music, if it was smaller, it would be better. If one person could play at a time and everyone was listening it would be easier. I like it when people listen to my music. I wouldn't come to music group again. I want to do music a different way. (Edward, Interview)

Music groups can be safe places to express your emotions

A fierce spring storm is being recreated ... The music rolls in waves, building steadily to a gusty roar, before dying away. The musicians watch each other for cues, responding to the sounds of drums and chimes and adding their own textures. When they finish the room is silent. Then it is smiles all round [72].

The words above were written by a reporter who heard our music early on. It shows how we were able to improvise on musical instruments to express ourselves. We made the music up as we went along. We worked together, listening and watching each other, we told a story, and it made us feel good.

Our music and research group was a place where we felt safe. We trusted each other. This was important. We could express things that were difficult for us. Sometimes we did this in the music, sometimes we did it with words, and sometimes we did it in other ways. Even though music was mostly a happy place, sometimes we were sad, confused, and even angry.

"Inside I was feeling angry inside my heart. Some people think – they don't like the Lion King? They said, that's boring, let's do a different one. But, no, this is the best one I've chosen, that I chose, for others, not for you. (If I feel angry I need) to talk to you guys; I need to have calm down time, calm down time and then I'll come back inside. And practice asking to have a turn, and being patient" (Kwame, Interview).

We agreed that doing music, or listening to music, can be helpful when we are feeling upset. People wrote in their journals, "the music helped, the beat makes people happy" and "it is good that there were less sad people after music". But Tess noticed that she also needed the support of the people at music as well. Having good relationships with other members of the group is important.

"I love music because it calms me down when I'm upset. But I can't go to music lessons by myself - I would need you to come with me because I get a bit nervous. If I get upset I go outside for fresh air, or I go near the door of music and I come and sit down. I just sit down and listen. Being at music and listening to it on the tape as well or you know listen to CD ...just listening to nice music and hugging people and all that stuff... calms me down." (Tess, Interview)

Music reminded Kwame of his family, who live far away, and this made him sad. Listening to music made him feel so sad he felt he couldn't come back to our group after Christmas. He wanted to try, but in the end he stopped coming.

Music reminds me of my family. After they visit me I often go visit them overseas. I can't come back to music because I'm missing my family. I feel sad at music. But I trust you guys. I might come back after Christmas." (Kwame, Interview)

Some of us found it hard being at music when our friends were away too. But music can be comforting because it is familiar. So we were mostly relaxed at music.

We talked a lot about how difficult, embarrassing and frightening it can be to play music or speak in front of other people or a video camera. Two people knew they should be speaking out more about what they wanted to do, but they didn't feel brave enough yet. We think they would be able to speak up if they were coming to music for longer. Some people worked hard at speaking up though.

"I need to tell people next Tuesday that this is what I want to do." (Kate, Interview)

Even though new things could sometimes be embarrassing or hard for us, music was a place where it felt safe for most people to have a go. We laughed when we tried hard, and helped each other to succeed.

Music helps us to know people, and connects us

We talked about music that was important to us. We noticed that music is very personal, and that it reflects people's personalities. When we listened and talked about the music that we love, we learnt more about each other. We found that it was very helpful to do music for a friend who died. It helped us to remember her; it helped us to cry; and then it helped us to feel better.

"...when our favourite friend passed away on the 4th of October, it was so sad; everyone was really sad. And so I gave everyone a hug, especially (the people) that went to school with her. We were doing songs that she loved". (Tash, Journal Entry) We spent a lot of time remembering our friend who died, and we thought about other people who had died. We heard that Nelson Mandela died. We talked about him and we played music that had been written for him. We thought he was a great man. Daphne told us about people from around the world doing a tribute for Nelson Mandela. Some of us wanted to do some music for the tribute and we felt good about that. Our tribute is online. You can see it at in Appendix 8, p.62 and hear it at https://voices.no/index.php/voices/article/view/758/639.

Writing our own songs was one way of expressing ourselves. It was hard work. It took a long time, especially in a big group. Some people couldn't say what they wanted in the song. Some of us were bored sometimes, especially if we had to wait. But when the songs were finished we liked them. We liked singing them. We were proud that they were our songs with words about us in them.

Music provides opportunities to develop physical skills

Axel was very interested in drumming. He noticed, all by himself, that it helped him with eye coordination and hand movements, as well as social skills and communication.

"ACTIVE is very important for music. Music is such a good, great personality for the ACTIVE people. It's such a good personality for eye coordination, hand movements, and talking with your own voice. And I like Tessa's dance moves. Music is such a good thing for ACTIVE." (Axel, Interview)

Music and research are normalising

Going to university, doing music, and doing research are things that young people do. We liked doing these things because it's just what you do. Tash (Interview) said, "Yes (I like it). Because we are in the university school, in like, in with all the other people and stuff ... it's fun." We were just doing usual stuff so we didn't want reporters to come and watch us. We also didn't like it when journalists took photos of us - that made it hard to do music. We just wanted to work hard like the other students.

I like that big book we have started to write. It showed the whole research we did last year. And... it's a big book. It's very important to hear about that. We are Massey. We do research. The music and the research have been awesome. I'd like to do some more this year! I need to work my butt off! It's hard work but its good fun." (Axel, Interview)

2. Can young people with intellectual disabilities tell their own stories in their own words?

Answer

Doing research is fun and interesting, but hard work

"Music is fun and it's interesting and we learn more stuff, when we do research." (Tash, Interview).

Tash said what a lot of people thought: that doing music research is hard but it is also fun and interesting. It was hard thinking of ideas, it was hard finding a way to express our ideas, and sometimes it was boring sorting things out. Sometimes that was because there were too many good things to choose from; and sometimes it was because it was hard to think of ideas and/or to express them. When it is hard to think of ideas, it is hard to do research. But people contributed in different ways. For example, Kwame found it hard to write in his journal. He did a very good job of copying all the journals though.

"I was going to make notes in my diary. I could bring my diary in, and bring it so I can make notes. And it's been my job putting notes into the printer. Putting them in to printer and printing them out. It was a hard job and it's good that it's finished" (Kwame, Interview).

Data can be gathered in lots of ways

We worked hard to communicate, and each person found their own way to do it. "When I do my data I write. Some people write, but other people draw pictures, and sometimes we write something underneath what it is all about. (Sometimes we do it together on the whiteboard or by interview like this?)...and we help each other with it and stuff... (And we watched the video) and wrote the things we like and stuff, and we copied it in our books and gave it to Daphne to copy and then when the research was coming we sorted them out to see if it was good, bad or worse or maybe or both. And then we would do that and then the boxes were tidied up and we could tell Daphne what to write on the laptop and stuff. We are confident (and) comfortable to do it, to tell people what we like or something." (Tash, Interview)

"At research you write on your journal, things that are easy, hard, good, bad, and difficult ... and changing. It's part of our research. We watched video of our music. You can listen with your ears and write some things on your papers, on your books. It's good! It shows us we can research. Writing every Monday at ACTIVE is important. Monday I might do some more research in my folder. I like those folders actually. (They're) so good. You can put stuff on that folder." (Axel, Interview)

We need to learn research skills. That takes a lot of time.

We were proud of our developing research skills and wanted to be good researchers. We learnt about 'data', and we learnt how to sort it out into 'themes'. It would have been good to have more time to learn about research but we wanted to do music. That was a hard balance. We wanted to improve our music skills and we wanted to improve

our research skills. Janiece told us very early on that she was very interested in what other people were thinking and writing about music. She was interested where each piece of data might go when we were doing the analysis. She was very quick at sorting it out and was able to help others. We called her the "data demon"!

Research is important and worthwhile

We wanted to continue doing research so we could find out more about what other people liked; this would help us improve our own music group. Tess said, "Research makes me tired! But I think it's important... to know about music" (Tess, Interview). We also knew that it was important to tell other people about what we had been doing, because they are interested in us and what we have been doing.

"We can make a story out of our research. That is good. Our family will think it's good. Just people like that... (and) people at ACTIVE need to know what we've been doing as well." (Janiece, Interview)

"After we have finished the research and have all the information we need to do we will make a book, a research book, for our family and friends... so our friends and family will know what we have been up to and what Massey Music is all about and what research is all about ... they will know what we talked about. They can read it or write similar things to what we did." (Tash, Interview)

Our research might also help to change things. Tash suggests when other people read our research they might take our ideas and use them for their own music or research. We also knew that our research might help change things for us.

"ACTIVE and IDEA Services or something, need to know what we do at Massey Music every Tuesday and that's fun and it's our last music session with our leaders. We need to let other people know what we want to do in our future, a long time in the future and things. And it just like helps us and stuff with everything we need to do for our future. ...like could we have smaller groups than what we have been using and stuff. And everyone could have a smaller group coming to Massey and then have a smaller group each day and stuff and it won't be that noisy". (Tash, Interview)

"It is a good idea to do research actually. Because it means we can get help. We do have research to back up (the things we need)... a lot of research to do actually! I'm getting my butt into research this year." (Axel, Interview)

3. Will people read our story and use our ideas to help young people with intellectual disabilities to have good lives?

Answer

We have some ideas about what should happen in the future. The people in our group want to share music with other young people. Young people with intellectual disabilities should have opportunities to play music with others, to do group music and to form bands.

"I want to keep doing music because I like it and it was fun I want to keep playing the drum kit. It was cool and fun. I want to play the drum with a group of people and I want to sing a song of the Beach Boys. The group can join in..." (Dave, Interview).

When the music is over and done with I'm going to miss it a lot! I like Daphne and Erin and all the ACTIVE people who go to music. I hope we do a big band here. When we have finished and the ACTIVE party starts, we should do a band... with the whole of ACTIVE people. I would be the drummer! (Axel, Interview)

Some of us also want to have lessons. We want to improve our playing on particular instruments so we can play in groups.

"I don't know what I want to do next with music. I might still do piano and guitar. I basically sort of get guitar lessons from Julie. Maybe I could keep playing the piano at ACTIVE. It would be good to play with people rather than just getting piano lessons. Julie knows how to play piano as well. I could still play it with Julie. Sometimes I play guitar with Julie, and I play it by myself. I never played the piano here at ACTIVE though, and I don't know why. But I wouldn't want to play it where other people can hear me, except at ACTIVE." (Janiece, Interview)

We want to be independent. But it is not always easy to go to regular lessons or to regular music groups. We think it is helpful at least at the beginning to work with support staff or teachers who understand us. We need to feel comfortable so we can speak up and ask for help if we need it. It is important to make sure young people know what the possibilities are for doing music too. We might need to be encouraged to participate at first.

"I would do more music if I could. I'd like to try the piano because I have a keyboard at home. I didn't play at Massey, because I didn't speak up. I would like to play keyboard with a group because I like doing the keyboard with other people" (Kate, Interview).

Young people with intellectual disabilities have dreams they are passionate about. We need others to work with us, to talk about our dreams, and to help us to develop our interests in a practical way.

"Music has been pretty awesome. It's ok. I like music. I would like to make a Lion King movie at music. I feel great thinking about that. We will have music, soundtrack, the props, and the movie making ... everything" (Kwame, Interview)

Young people should be involved in research that concerns them. Some of us would like to do more research even though it is hard work.

(Daphne: What would you like to do next?) "I don't know, probably like, probably do some more music or research or stuff like that. The research is fun, so we know what other people think, so we can know what other people think, what they feel about music and stuff" (Tash, Interview).

DISCUSSION

We did this research to find out how we could make the world a better place for young people with intellectual disability. We thought that it might be good to do music. We thought that it might be good to go to university. We thought that it might be good to do research. We all had a right to do music. The young people had a right to be involved in research that is about young people with disabilities. We did Participatory Action Research because it is about claiming our rights and improving our lives. In our discussion we will write about the music, going to university, the research, and what we think should happen next.

Music

We were all musicians. We were all able to do music. We agree that is important for young people to do music to express ideas; to make and be with friends; to find out more about themselves; and to grow and change [5, 11, 40].

Like others, we found that music group is a place where young people can express their emotions [11, 23]. We felt safe. We trusted each other. We could express things that were hard for us by playing our own music; writing our own music; or sharing music that was important to us. When we improvised music we were sharing feelings and stories [73]. Other researchers have found that young people with intellectual disability can express themselves through music [23]. Parents and other listeners can appreciate their expression. The young people noticed that music changed their emotions too when they said "it (was) good that there were less sad people after music" and "(it) calms me down when I'm upset". We noticed that music reminds us of people and places [11]. Playing music helped us to remember and celebrate the life of a young person who died. Other young people with disabilities have also noticed that music can bring up and change emotions [11].

From our readings we learnt that it is important for young people to learn to do things by themselves, and to work with others[13]. When we were doing music solos, or playing music together, we did these things. We had to wait and be patient. We had to listen to each other. We agree with the researchers who said people who do music together learn to listen, work together, take risks, and show respect for each other [38]. Sometimes we felt differently about the things we did at music and we had to work out what to do. We were individuals but we worked as a team. Other young researchers [11, p. 5] have also said "we have learnt to work together as a team". Like others, the young people with disabilities in our group felt like music was a place they belonged; they were responsible and looked after each other [11, 74-76]. When people do music together they feel 'joined' together; they learn new things about themselves and each other [5, 40]. We noticed that when we listened and talked about the music that we love, we learnt more about each other. When we played together we felt like a band.

Other researchers found that young people also started going places together outside music [11]. The young researchers in our project were already a group who did lots of things together. But we did grow into the 'ACTIVE Music' group. We laughed together sometimes and cried together sometimes, and looked after each other like brothers and sisters.

Other researchers have said that people with disabilities can 'create a world of their own' at music [11]. This is interesting because it seems like we wanted our own world. We were happy in our own group. We liked seeing other staff and students around the university and we liked it when Colin, the saxophone teacher, came to play for us. But even though we talked about it at the beginning, we didn't invite other students to come to our music sessions. And nobody talked about wanting to go to other music classes. But they might, in time. We have written about this in our 'university' section. Perhaps it might have been helpful for the adults to encourage us to be brave about being with other students, right from the beginning.

Our readings told us it can be important for people with disabilities to 'own' their work. For a very long time, people with disabilities have been bossed around, put away, not accepted and have not been able to participate in society. When people are grouped and treated like this they often believe they are as others describe them; and act as others suggest they should act [14]. Some of the young people had to practice saying what they wanted to do and asking for help when they needed it. They were encouraged to give ideas, make choices and try new things. The music group was a place where they could work at becoming more independent. They weren't bossed around; they tried to work things out for themselves.

For example, the young people told the adults that they didn't like the reporter and photographer coming to music. We decided that we didn't really want visitors coming when we were working so hard. But we had a visitor who was working in the music therapy room for a week and instead of asking her to go away, the adults asked the young people if she could stay. The young people thought that it would be best if they interviewed her before they decided. They each asked her a question so they could get to know her, then took a vote to see if she could stay. The young people were the ones with the 'power' at that time. It was also the young people's own idea to have a concert for their families, friends and supporters. Sharing what they were doing at music with families and friends was important to them. They organised the concert themselves. They wrote or talked to people about when they could have the room, and equipment. The adults offered some money from the research budget and they brought groceries and did catering. This was a good example of being independent. The young people seemed to be confident preparing for, and participating in, the concert. They showed what they could do with music and they felt proud.

Going to music was an important part of the young people's week. They enjoyed doing music together. They would like to do more music in future, in groups or in lessons, even though they know it is hard work. When young people have important things to do each day they want to do even more; their lives are more satisfying; and they are happy and well [11, 13]. This is important information for people who run programmes [3]. Most of the young people needed support to get to music. The instruments needed to be supplied. They needed help to play them. People who do the programmes for young people with intellectual disability might consider offering a range of music programmes for them.

Research

Who did what?

We were all researchers but we had different things to do. This is ok, because all the roles are valuable [1, 65, 77, 78]. It is not useful to have all researchers doing all parts of the research [1].

The adults had to set up the research and be organisers. When we started the research the adults already knew it would be about music with young people with disabilities coming to music. They had done their reading and had written the literature review. They talked to IHC and university people about how the project might work, and they got funding for it. And they talked to the ethics committee to make sure the project was safe. So they were able to tell the young people how the research would start. The adults wrote the literature review, the main findings, the discussion and conclusion. The young people decided what their questions would be, gathered data, contributed to analysis, and the findings of each cycle. We discussed the things we wrote along the way and at the end of the research. The adults have tried to help the young people understand what has been written. The young people have agreed that the words in the research report are ok.

Getting started: Research training

We got to know each other before we decided to carry on with the music and research. This is important because you need good relationships to do research together [1, 65, 69]. We got together to do music, talk about research, and ask questions. The adults gave the young people the things they would need if they decided to go on with the research; like folders, journals, pencils, highlighters (and later an audio recorder, and white board).

When we started the research properly, the young people had lots of research tasks to do. So the adults had to train the young people to be researchers. The training was part of our usual Tuesday music sessions. We learnt about how researchers keep each other safe. The young people told the ethics committee that they didn't want their parents to sign for them. Then the young people decided what they would do for music, and what questions they would ask. They decided on some of the ways they could gather data. We had to have lots of ways to gather data because we could all do different things [1]. The young people gathered data and helped to analyse it. To be analysts they needed to be able to understand the questions. They needed to be able to work with the data in an organised way. They needed to work hard. And they needed to understand how important their jobs were [1]. We used research language as much as possible and some of the young people would talk about 'data' and 'themes'. Having training on Tuesdays meant the music and the research were always a bit joined up. This was a good thing in some ways, but not in others.

It was good because we could play music if we needed a break, or if we were bored. We even played music games to help us be to be better researchers. Like when we were having trouble speaking up, we played a two-team game where we chanted things to each other and shouted out "yes!" and "no!" When we were writing songs about the

things that were important to us, the information in our songs was data. We were listening and communicating; and these are good research skills. It was good because the adults were always playing music with the young people. We were always working together and helping each other with music things. The adults became friends with the young people, kind of like big sisters and a mother. The young people helped each other like brothers and sisters too. This seemed to happen more and more as we worked together. This was good for our research because the young people trusted the adults, and we would try to communicate our ideas to each other. Having training during our Tuesday music and research sessions was hard though because some of the young people were more interested in music than research. When things got hard someone might say "let's get back to the music".

It is not easy to include people with intellectual disability in data analysis. It takes a lot of time. It is important for adults to check that the stories they write sound true. Even though the stories were from the young people's words the meaning might have changed when Daphne wrote them [30]. It was good to meet with each person, to read their story, and to make sure they sounded true for that person. We changed the words if it didn't sound true.

Being responsible adults

The adults wanted the young people to be happy, relaxed and to have fun. But they knew that there were other important things that young people could learn and practice, to be better researchers. While we were working and playing together, the adults watched and listened to the young people carefully. They were watching how the young people were feeling. They watched to see how much the young people seemed to understand. They watched to see how interested they were in the music and the research. They were looking after the young people but also thinking about the research. They talked with the young people or each other about the things they saw and heard; that added to the data.

Doing good research with young people with intellectual disability can be hard for adults. Adults and young people both need to learn new ways of doing things. Daphne, Erin and Patrice talked a lot and reminded each other when they needed to change their ideas or actions. They didn't want to have bad ideas that would change the research. For example, adults have to remind themselves that they don't always know what is best for young people. They need good relationships so that young people feel they can talk to them. They wanted the young people to be the ones to decide what was important, but also knew young people needed guidance. So they were thinking and talking a lot about what was the best thing to do. They talked a lot together about it after sessions, when the young people weren't around. When researchers talk together they can improve the research by asking each other hard questions, or make it worse by putting in too many of their own ideas [1, 11, 79, 80].

Even though it can be good for adults to talk together about the research, the adults worried about talking without the young people. They wanted to include them in everything. They didn't want the research to be full of their ideas. But they also needed to be leaders, responsible for looking after the young people. The skills of a good researcher are the same skills that you need to look after young people [80]. For

example, everyone agreed that young people have a right to participate in research. But when they agree to participate they also need to act responsibly. The adults reminded the young people that they needed to do what they could, the best that they could. They could stop coming to music research altogether if they didn't like it. But they couldn't stop coming just because they had something else to do, unless it was very important.

Treating people as individuals

We showed that young people with intellectual disability can be researchers with support. We recognised that young people are unique, and that made our research richer. We worked very hard to include everyone. Everyone could join in activities in some way. We found ways for each young person to give us data. Each young person did as much as they could do, with support. Some people could ask questions. Some could make suggestions. Some people could have a discussion. Some could listen and agree or not agree. They could do this by smiling, pointing, and highlighting. Some people could write, some people could draw pictures. They knew that what they had to say was important. Sometimes parents and others say it is too hard to involve young people with intellectual disability in research [23]. We know it is hard. But it is fun and we learnt a lot.

Trusting the data

Sometimes we noticed that people said things in their journals that they didn't say on their faces at the time. For example, one person wrote that they didn't like playing a warm up game when they were tired and grumpy. Others had thought everyone looked like they were enjoying themselves during that game. As well, sometimes people wrote things in their diaries that we didn't understand, even after we talked about it. This means we couldn't trust all our data, so we didn't include it. But these things didn't happen very often. And we had a lot of data.

Interviewing young people

Interviewing young people with disabilities can be tricky. Adults sometimes don't give them time to talk, or decide for them what they think they were going to say [81, 82]. Daphne went most weeks to hang out at ACTIVE. They made her coffee. She went to their Christmas party at the park. They talked to her about other projects they were involved in, or things about their private lives. They trusted her, so when she did the interviews at ACTIVE it was just like chatting. They knew they were being interviewed. They liked having the audio recorder on because it was like being interviewed by a reporter. But it was a friendly place and it was easy to talk. Daphne gave them lots of time to talk. So the young people gave good information in their interviews.

Did we do a good piece of research?

It is important for research to be believable. It is important that other people might be able to use the findings. It is important that they are accurate and dependable. We have written about each of these things below.

Are the findings believable (credible)? We checked a lot with the young people about whether they agreed with the findings. We have used the words they wrote in their journals or told us in their interviews. These are things that make our research believable. But some people were not able to give us words, so it might be hard to believe that our findings are from everyone. We did check with them though, and they could point or smile or show us another way that it was ok. For example, when we started the research we learnt that one of the young people liked to copy what we said. If we asked him "yes... or no" he might say "yes... or no". We were patient with him. We helped him communicate in different ways using words, pointing, drawing, highlighting. This helped him understand that what he said was important to us. In the end if we said "yes... or no" he might say "yes". To check, we might ask him "no?" Then he would say "Yes!" again in an angry voice to tell us he really meant it.

<u>Can the findings be used by other people (transferability)?</u> We are just one group. Other groups might have different experiences. But one of the main reasons for doing the research was for us. We wanted the research to help us change. We think it did. The story of the young man above is one example. Another example is that we noticed some people really didn't like loud noises. We decided to try not to play too loud, and to listen to other people rather than talking over them. Then, because we were doing research, we were checking ourselves carefully to see if we were doing it. The research made us notice things, and we changed our actions.

Being a researcher helped us learn more about what we can do. We learnt we could be strong and speak out for ourselves. Some of us might know more about what we need to learn next. But we also think that other young people, and maybe music therapists too, will be able to read our story and say "ah ha" this is the same for me. And we think that the people who look after us might read our research and realise we have a lot to say. That might mean that people listen to us even more in future. We think that they might understand that what we have to say is valuable. That might mean we have more chances to do music and research in future. We might be able to make a difference in our communities, like convincing universities to include us. Universities can make a difference for young people by changing their ideas and plans. But they need to believe that it is good for young people with intellectual disability to go to university.

Are the findings dependable (coherent)? We wanted to do Participatory Action Research. That meant that we had to work together. We had to make sure that young people had control over the research as much as possible. We have tried to write it in a way that shows our promise to do that. We have shown how our data matches up with our findings by including a lot of data in the appendices. The young people did not ask deep questions, and the findings and discussion show that. The adults tried not to clarify the findings too much (over interpret). We let the young people's words tell their story. The young people were able to tell us about what they did, what they liked or didn't like, and sometimes how they felt about it. It was much harder for them to say why. It was also easier for the young people to look for particular things in the data (deductive analysis). It was harder for them to understand what things might be important just by looking carefully at the data (inductive analysis).

<u>Is the data accurate?</u> We gathered different kinds of data. We saw patterns in our data and came to agreement about what that meant. The young people were able to tell us

things that we expected and things that surprised us. We agreed on a lot of things, but not everything. The adults thought a lot about how they were affecting the research (reflexivity). We asked another teacher at the university to check our research to see if we did it properly. We have a lot of pages in the back of our book (appendices) so people can see how we did the research.

Things that could be different (limitations)

We have made a story and we agree that it is from all of us. But we know that some people in the group could tell us more than other people. We know that most of the words in our book come from the people who could say or write the most. Some of us can't read these words, but some can. Some of us can't understand all of these words, but some can. But even if we don't understand all of these words, most of us understand the ideas. We brainstormed the ideas in lots of different ways, with words, music, pictures. We worked hard to find out what everyone wanted to say. We worked hard to find out if everyone understood our different ideas. We worked hard to find ideas that everyone agreed with. Then the adults worked hard to make sure the words in the book were our ideas. So we have worked hard to tell an honest story about things that were good, bad, hard and easy. We know that it isn't perfect but we it was good to do it and it might be helpful for other people.

We know the findings could have been more useful if the young people could have told us more. It would be especially helpful if they could explain things. Explaining things is hard for people with intellectual disability [83]. So the adults had to come up with ideas. Then they would ask the young people if the ideas seemed right. If the young people had been able to give their own ideas about "why", the research would be more dependable. And we know there were little bits of data that we couldn't trust so we didn't use them. This makes it harder to trust that our story has all the ideas that people wanted to include.

There are different ways to do research. Doing research is hard work. Doing research with people who have intellectual disability takes a long time. It might have been better to have more time to learn about being researchers before we started the music sessions. Other people have done two days of training before they started [69]. Sometimes we ran out of time and the adults had to finish the data analysis that the young people had started. The adults would go over what they had done with the young people at the next session. But it would have been better if the young people could have done more. The adults talked carefully with them about whether they wanted help to finish, or whether they would trust the adults to finish the work. They wanted to be sure the young people knew they had done all they could themselves, and were pleased with their work. Then they would be ready to do more another time.

The young people worked hard and they were tired sometimes. Sometimes they were bored too. They needed encouragement to do their research tasks. Most of them were willing. Some were even excited about it. But they had busy lives, and the adult researchers had to watch and listen to them carefully and 'ease off' if the research seemed too much for them. For example, they had work experience and other training to go to. Most of them were also involved in a big drama production near the end of the research project. While they were doing music research sessions their friend died and,

while we were writing up the research, another friend died. This showed us that young people with disabilities seem to have to deal with grief more than other young people. But perhaps we struck a bad patch. Maybe, if we had longer to do the research life events might not have interfered with it as much.

When you do action research you usually read things as you go along, to help you answer your questions. The adults read things and told us what other researchers were writing about. If we had more time it would have been good for the young people to read, or to be read to, more often. Knowing what other researchers had done or found out might have made our research better.

The adults were paid to do the research because it was part of their job. The young people didn't get paid but they were able to go to university to do music and research without paying student fees. They received CD vouchers for their hard work on the research tasks. If they were paid they might think they were doing it just for money. We believe they did the research because they were interested in it and thought it was valuable.

University

We learnt that students with intellectual disabilities can go to university [84-88]. Going to university is an exciting time for all young people and it is just as important for people with intellectual disabilities. Because we live in a city, universities were already part of the young people's background. Some of them were interested in going to university before this project began. Although most of them were shy to begin with, most of them liked being at the university. But it is not easy for young people with intellectual disability to go to university. Researchers say when people with intellectual disability leave school, people don't usually talk to them about it [89].

Researchers and other people need to work with universities to make sure young people with intellectual disabilities have chances to go to university. The adults in our project organised for us to go. They were able to do this because Daphne was working at the university. Doing research was part of Daphne's job. She was happy to have people coming to work with her. She wanted to help young people with intellectual disabilities to have the experience of going to university.

Sometimes young people with intellectual disabilities go to usual classes with nondisabled peers as well as classes with other students with disabilities; sometimes they only go to classes with other students with disabilities, like we did; sometimes they go to usual classes with nondisabled students, with support [89]. Some universities have centres that help people with intellectual disability go to university with nondisabled peers [90]. We wondered if other students would come and do music with us. We wanted to settle in to music before we decided. Then we were already doing music, and we wanted to keep things going like they were. But it might be a good thing to be with other students another time. When people with disabilities go to university they can still be excluded [85].

We met different people; like other students, lecturers, and librarians at university. We learnt more about a 'different world'. We liked going to university and we agree that

young people have a right to go to university. Some of us would like to go to university again. There are lots of things that people with intellectual disability can do at university. Sometimes they sit in on classes but don't do exams for credit [89]. In Ireland students with intellectual disability can go to university to do a two-year certificate in community living [85]. In Sweden and in England they can go to university to help teachers to learn how to work with people who have intellectual disability [86, 87]. They learn things, develop skills, become more independent, speak up for themselves, are confident, and get jobs [89]. They feel more like the other students, not 'different' [89]. People with intellectual disabilities who go to university feel better about themselves [85, 91]. They develop social skills and they have more friends [85, 91].

OUR FINAL IDEAS ABOUT WHAT NEXT (Conclusion and Recommendations)

We agree that doing music is helpful for young people with intellectual disabilities. It was hard work, but it was fun. We could express emotions by playing or talking about music. It is important to be able to share ideas and feelings with other people. We also learnt social skills and developed confidence. We became more independent, but we know we still need support. Going to music groups is a good thing to do. Learning music is also a good thing to do. Some other researchers working with young adults with physical disability said music helps individuals 'grow towards the future' – they can become more hopeful [11]. They can be themselves; they can learn new things and develop skills [11] . These researchers said other people haven't thought enough about how expressing emotions is an important part of people's daily lives [11]. We think it would be good for young people with intellectual disability to be able to choose to be involved in music programmes, by themselves or with others.

People with intellectual disability can do research but its hard work too. People need to be trained to be researchers. We think that it is important to ask young people with intellectual disability about their lives. They have a lot of important things to say. But they don't have a lot of chances to tell their own stories [1, 23]. The best way to understand what life is like for someone is to let them tell you about it. More research from people with intellectual disabilities is needed [83]. Participatory Action Research is a good way to do it. People with intellectual disability can decide questions, gather data, and do some analysis. We tried to be honest with our research. We didn't dig deep down into things that people didn't want to say. We just tried to give a clear picture of what going to music and doing research was like. We believe we have a true enough picture. We did this by working together and doing a lot of checking on each other's work. This takes a lot of time.

Adults who are supporting young people to do research need to understand them. Daphne and Patrice and Erin are music therapists who have trained and worked with young people with intellectual disability. This was very helpful. The adults knew that the young people had a lot going on in their lives. The young people could do a lot of things for themselves, but the adults knew they had to look after them too. It is important that research does not exhaust young people with intellectual disabilities. They need to be able to enjoy the things they are doing.

Young people with intellectual disabilities can go to university. We agree when people with intellectual disabilities leave school people should talk with them about going to university [89]. All universities should have rules and action plans for disabled students [88]. They should value and be pleased about differences amongst students [88]. We can use our research to show university that it can be a good idea to support people with intellectual disabilities to go to university. But we need to do more research to make sure universities work for students with intellectual disabilities [85].

There is more research to be done in other areas too. First, the people in our group had very different levels of ability. It might be useful to do the same kind of research with people who were able to understand and communicate in similar ways. Second, the adults were interested in what they might be able to learn by listening to the music more closely. Some music therapy researchers say the music can tell us a lot about how

people are managing [29, 92]. It might be a good idea to do some more research looking at the videos of young people with intellectual disability making music [93].

REFERENCES

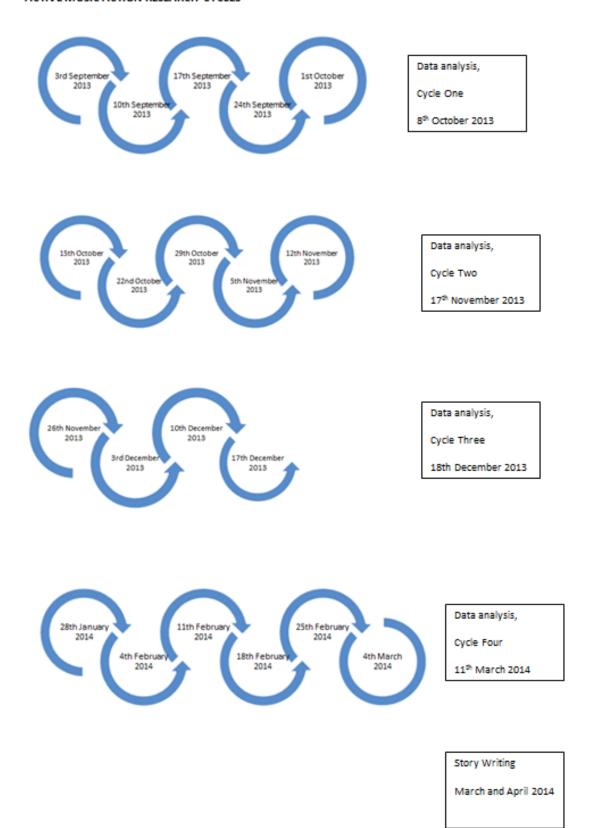
- Stevenson, M., Participatory Data Analysis Alongside Co-researchers who have Down Syndrome. Journal of Applied Research in Intellectual Disabilities, 2014(1): p. 23.
- 2. Blacher, J., Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. Research & Practice for Persons with Severe Disabilities, 2004. **29**(1): p. 53-57.
- 3. King, G.A., et al., *The Effectiveness of Transition Strategies for Youth With Disabilities*. Children's Health Care, 2006. **35**(2): p. 155-178.
- Morningstar, M.E., P.J. Kleinhammer-Tramill, and D.L. Lattin, Using Successful Models of Student-Centered Transition Planning and Services for Adolescents with Disabilities. Focus on Exceptional Children, 1999. 31(9): p. 1-19.
- 5. McFerran, K., Adolescents, Music and Music Therapy: Methods and Techniques for Clinicians, Educators and Students. 2010: Jessica Kingsley Publishers.
- King, G. and K. Meyer, Service integration and co-ordination: A framework of approaches for the delivery of coordinated care to children with disabilities and their farmilies. Child: Care, Health & Development, 2006. 32(4): p. 477-492.
- 7. Ministry of Social Development, *Achieving inclusion and independence for disabled New Zealanders*, M.o.S. Development, Editor. 2011, New Zealand Government: Wellington, NZ.
- 8. Ministry of Education. *Key Compencies: capabilities for living and lifelong learning*. 2007 [cited 2012 21/12/2012]; Available from: http://nzcurriculum.tki.org.nz/Curriculum-documents/The-New-Zealand-Curriculum/Key-competencies.
- 9. Carrington, S. and N. Lennox, *Advancing the Curriculum for Young People Who Have an Intellectual Disability. Advocacy in Health: A Pilot Study.* Australasian Journal of Special Education, 2008. **32**(2): p. 177-186.
- 10. Winn, S. and I. Hay, *Transition from school for youths with a disability: issues and challenges.* Disability & Society, 2009. **24**(1): p. 103-115.
- 11. Eidevall, K. and C. Leufstadius, *Perceived Meaningfulness of Music and Participation in a Music Group among Young Adults with Physical Disabilities.* Journal of Occupational Science, 2013: p. 1-13.
- 12. Trainor, A.A., *Self-Determination Perceptions and Behaviors of Diverse Students with LD During the Transition Planning Process.* Journal of Learning Disabilities, 2005. **38**(3): p. 233-249.
- 13. IHC, Next Generation Strategy. 2013.
- 14. King, G., C.J. Curran, and A. McPherson, *A four-part ecological model of community-focused therapeutic recreation and life skills services for children and youth with disabilities.* Child Care Health and Development, 2013. **39**(3): p. 325-336.
- 15. Barrett, M.S., *Musical narratives: A study of a young child's identity work in and through music-making*. Psychology of Music, 2011. **39**(4): p. 403-423.
- 16. Malloch, S., et al., *Music therapy with hospitalized infants. The art and science of communicative musicality* Infant Mental Health Journal, 2012. **33**(4): p. 386-399.
- 17. Trevarthen, C., Musicality and the intrinsic motive pulse: Evidence from human psychobiology and infant communication. Musicae Scientiae, 2000. **Special Issue, 1999-2000**: p. 1029-8649.
- 18. Volgsten, U., The roots of music: Emotional expression, dialogue and affect attunement in the psychogenesis of music. Musicae Scientiae, 2012.
- Pavlicevic, M., Music therapy in context: music, meaning and relationship. 1997, London: Jessica Kingsley Publishers.
- 20. Trevarthen, C., *Origins of Musical Identity*, in *Musical Identities*, R.A.R. MacDonald, D.J. Hargreaves, and D. Miell, Editors. 2002, Oxford University Press: Oxford.
- 21. Trevarthen, C., First things first: infants make good use of the sympathetic rhythm of imitation, without reason or language. Journal of Child Psychotherapy, 2005. **31**(1): p. 91-113.
- 22. Wigram, T., I.N. Pederson, and O.L. Bond, *A Comprehensive Guide to Music Therapy*. . 2002, London: Jessica Kingsley Publishers Ltd.
- 23. Pavlicevic, M., et al., *Making music, making friends: Long-term music therapy with young adults with severe learning disabilities.* Journal of Intellectual Disabilities, 2013. **Online 6th November**.
- 24. Nordoff, P., C. Robbins, and D. Marcus, *Creative Music Therapy : A Guide to Fostering Clinical Musicianship with CD (Audio)*. . 2007, New York: MMB.
- 25. Ansdell, G., Music for Life. Aspects of Creative Music Therapy with Adult Clients. . 1995, London, England: Jessica Kingsley Publishers. 237.
- 26. Keen, A.W., *Using music as a therapy tool to motivate troubled adolescents*. Social Work in Health Care, 2004. **39**(3-4): p. 361-373.
- 27. McFerran, K. and T. Wigram, *A review of current practise in group music therapy*. Bristish Journal of Music Therapy, 2007. **16**(1): p. 46-55.
- 28. John, D., *Towards music psychotherapy*. Bristish Journal of Music Therapy, 1992. **6**: p. 10-12.
- 29. Richards, E., & Hind, H., Finding a Space To Play: A Music Therapy Group for Adults with Learning Disabilities, in Music therapy and group work: Sound company, A. Davies, & richards, E., Editor. 2002, J. Kingsley London.

- 30. Richardson, M., Involving People in the Analysis. Journal of Intellectual Disabilities, 2002. 6(1): p. 47.
- 31. Lubet, A., Music, Disability, and Society. 2011, Philadelphia: Temple University Press.
- 32. Small, C., Musicking: The Meanings of Performing and Listening. 1998, Hanover: University Press of New England.
- 33. Pavlicevic, M. Worksongs, playsongs: Communication, collaboration, culture and community. in 11th World Congress of Music Therapy. From Lullaby to Lament. 2005. Brisbane.
- 34. Kenny, C. and B. Stige, *The Greatest Distance between People is not Space but Culture.* Voices: A World Forum for Music Therapy, 2008: p. Retrieved April 21, 109, from http://www.voices.no/mainissues/mi40008000265.php.
- 35. Ansdell, G. Being who you aren't; doing what you can't: Community Music Therapy and the Paradoxes of Performance. Voices: A World Forum for Music Therapy, 2005. **5**.
- 36. Ruud, E., Music and identity. Nordisk tidsskrift for musikkterapi/Nordic journal of music therapy, 1997. 6(1): p. 3.
- 37. Ansdell, G., Where performing helps: Processes and affordances of performance in community music therapy, in Where music helps: Community music therapy in action and reflection, B. Stige, Ansdell, G., Elefant, C., Pavlicevic, M., Editor. 2010, Ashgat Publishing Limited: Surrey.
- 38. Oliveros, P., Miller, L., Heyen, j., Siddal, G., & Hazard, S., *A musical improvisation interface for people with severe physical disabilities*. Music and Medicine, 2011. **3**: p. 172.
- 39. Nicholls , T., 'Could I Play a Different Role?': Group Music Therapy with Severely Learning Disabled Adolescents, in Music therapy and group work: sound company, A. Davies, Richards, E. , Editor. 2002, J. Kingsley: London.
- 40. Laiho, S., *The psychological functions of music in adolescence*. Nordic Journal of Music Therapy, 2004. **13**(1): p. 47-63.
- 41. Herbert, R., *Private lives*. Music Teacher, 2012. **91**(7): p. 33.
- 42. Cobbett, S., *Including the excluded: Music therapy with adolescents with social, emotional, and behavioural difficulties.* British Journal of Music Therapy, 2009. **23**(2): p. 15.
- 43. North, A.C. and D.J. Hargreaves, Music and Adolescent Identity. Music Education Research, 1999. 1(1): p. 75.
- 44. Tarrant, M., A.C. North, and D.J. Hargreaves, *Youth identity and music*, in *Collected Work: Musical identities*. *Pages: 134-150. (AN: 2002-04979).* 2002.
- 45. Erikson, E.H., *Identity and the life cycle*. Identity and the life cycle. 1980, New York, NY US: W W Norton & Co.
- 46. Dies, K., *The unfolding of adolescent groups: A five-phase model of development.*, in *Group Therapy with Children and Adolescents*, P. Kymissis, & Halperin, D., Editor. 1996, American Psychiatric Press: Washington.
- 47. Malekoff, A., Group Work with Adolescents: Principles and Practice. Second Edition. Social Work Practice with Children and Families. 2006: Guilford Publications.
- 48. McFerran-Skewes, K., *Using songs with groups of teenagers : How does it work?* Social Work with Groups, 2005. **27**(2-3): p. 143-157.
- 49. McFerran, K. and C. Elefant, *A fresh look at music therapy in special education*, in *Oxford handbook of music education*, A.C. McPherson and G. Welch, Editors. 2012, Oxford University Press: Oxford. p. 51-64.
- 50. Stige, B. and L.E. Aaro, Invitation to community music therapy. 2012, New York, NY: Routledge.
- 51. Pavlicevic, M. and G. Ansdell, Community Music Therapy. . 2004, London: Jessica Kingley Publishers.
- 52. Bruscia, K.E., Defining Music Therapy. 2nd ed. 1998, Gilsum, NH: Barcelona Publishers.
- 53. Piggot-Irvine, E. *The Nuts and Bolts of Action Research*. in *NZARE*. 2003. Auckland.
- 54. Piggot-Irvine, E., *Key features of appraisal effectiveness*. The International Journal of Educational Management, 2003. **17**(4): p. 170-178.
- 55. McTaggart, R., *Participatory Action Research: International Contexts and Consequences*. Australasian Psychiatry. 1997, Albany: State University of New York Press.
- 56. Elliott, J., Action Research for Educational Change. Australasian Psychiatry. 1991, Milton Keynes: Open University
- 57. Abraham, S., Exploratory Action Research for Manager Development. Australasian Psychiatry. 1994, Upper Mt Gravatt, Australia: Action Learning, Action Research & Process Management Society (ALARPM) Inc. and Gibaran Management Consultants Pty Ltd.
- 58. Susman, G. and R. Evered, *An assessment of the scientific merit of action research.* Administrative Science Quarterly, 1978. **23**: p. 582-603.
- 59. McNiff, J., *Action Research: Principles and Practice*. Australasian Psychiatry. 1988, Hampshire: McMillan Education Ltd.
- 60. Ambrose, D., K. Lang, and M. Grothman, *Streamlined reflective action research for creative instructional improvement* Educational Action Research, 2007. **15**(1): p. 61-74.
- 61. Brooks, A. and K.E. Watkins, A new era for action technologies: A look at the issues, in The Emerging Power of Action Inquiry Technologies. New Directions for Adult and Continuing Education, A. Brooks and K.E. Watkins, Editors. 1994, Jossey-Bass: San Francisco. p. 5-16.
- 62. Armstrong, F. and M. Moore, *Action research: developing inclusive practice and transforming cultures*, in *Action Research for Inclusive Education: Changing Places, Changing Practices, Changing Minds*, F. Armstrong and M. Moore, Editors. 2004, RoutledgeFalmer: London. p. 1-16.
- 63. Bray, J.N., et al., *Collaborative Inquiry in Practice: Action, reflection, and making meaning*. 2000, California: Thousand Oaks.
- 64. Stige, B., *Culture-Centered Music Therapy*. Australasian Psychiatry. 2002, Gilsum, NH: Barcelona Publishers.

- 65. Conder, J., P. Milner, and B. Mirfin-Veitch, *Reflections on a participatory project: The rewards and challenges for the lead researchers*. Journal of Intellectual & Developmental Disability, 2011. **36**(1): p. 39-48.
- 66. O'Brien, N. and T. Moules, *So Round the Spiral Again: A Reflective Participatory Research Project with Children and Young People.* Educational Action Research, 2007. **15**(3): p. 385-402.
- 67. UNCRC, UN Convention of the Rights of the Child, Article 12. 1989, http://www.everychildmatters.gov.uk).
- 68. Stevenson, M., Flexible and Responsive Research: Developing Rights-Based Emancipatory Disability Research Methodology in Collaboration with Young Adults with Down Syndrome. Australian Social Work, 2010. **63**(1): p. 35-50.
- 69. dela Cruz, T., et al., *Small Steps, Great Strides: Doing Participatory Action Research with Children*. Program on Psychosocial Trauma and Human Rights. 2001, UNICEF Manila, SE Asia.
- 70. Graffam, J., et al., Employer benefits and costs of employing a person with a disability. JOURNAL OF VOCATIONAL REHABILITATION, 2002. 17: p. 251-264.
- 71. Jacobsen, Y., Making the jump into employment. Adults Learning, 2003. 14(6): p. 25.
- 72. Stewart, L., Commentary on cultural diversity across the pacific: The dominance of western theories, models, research and practice in psychology. Journal of Pacific Rim Psychology. **6**(1): p. 27.
- 73. Harding, P., In tune with changing times, in Community Moves. 2013, IHC: Wellington. p. 4.
- 74. Stige, B., On a notion of participation in music therapy. Nordic Journal of Music Therapy, 2006. **15**(2): p. 121-139.
- 75. Faulkner, S., DRUMBEAT: In Search of Belonging. Youth Studies Australia, 2011. 30(2): p. 9-14.
- 76. Travaglia, R., *Adolescents, Music and Music Therapy: Methods and Techniques for Clinicians, Educators and Students.* New Zealand Journal of Music Therapy, 2010(8): p. 92-94.
- 77. Cocks, E. and J. Cockram, *The participatory research paradigm and intellectual disability*. Mental Handicap Research, 1995. **8**(1): p. 25-37.
- 78. White, E.L. and M.F. Morgan, *Yes! I am a researcher. The research story of a young adult with Down syndrome.*British Journal of Learning Disabilities, 2012. **40**(2): p. 101-108.
- 79. Lincoln, Y.S. and E. Guba, Naturalist Inquiry. . 1985, Beverly Hills, CA: Sage.
- 80. Onwuegbuzie, A.J., N.L. Leech, and K.M.T. Collins, *Interviewing the Interpretive Researcher: A Method for Addressing the Crises of Representation, Legitimation, and Praxis*. International Journal of Qualitative Methods, 2008. **7**(4): p. 1-17.
- 81. Brewster, S.J., *Putting words into their mouths? Interviewing people with learning disabilities and little/no speech.*British Journal of Learning Disabilities, 2004. **32**(4): p. 166-169.
- 82. Lewis, A. and J. Porter, *Interviewing children and young people with learning disabilities*. British Journal of Learning Disabilities, 2004. **32**(4): p. 191-197.
- 83. Kramer, J.M., et al., Following Through to the End: The Use of Inclusive Strategies to Analyse and Interpret Data in Participatory Action Research with Individuals with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 2011(3): p. 263.
- 84. McDonald, L., et al., An inclusive university program for students with moderate to severe developmental disabilities: Student, parent, and faculty perspectives. Developmental Disabilities Bulletin, 1997. **25**(1): p. 43-67.
- 85. O'Brien, P., et al., *Opening up a whole new world for students with intellectual disabilities within a third level setting.* British Journal of Learning Disabilities, 2009. **37**(4): p. 285-292.
- 86. Brandon, T. and J. Charlton, *The Lessons Learned from Developing an Inclusive Learning and Teaching Community of Practice.* International Journal of Inclusive Education, 2011. **15**(1): p. 165-178.
- 87. Nilsson, M.-H.Z. and C. Ericsson, *The Silenced Discourse: Students with Intellectual Disabilities at the Academy of Music in Sweden*. Australian Journal of Teacher Education, 2012. **37**(9).
- 88. Tinklin, T.J., Getting Round Obstacles: disabled students' experiences in higher education in Scotland. Studies in Higher Education, 1999. **24**(2): p. 183.
- 89. Hart, D., et al., *Postsecondary Education Options for Students with Intellectual Disabilities. Research to Practice. Issue 45*. 2006, Institute for Community Inclusion.
- 90. Syracuse University. *the Taishoff Center for Inclusive Higher Education*. 2014; Available from: http://taishoffcenter.syr.edu/about-the-taishoff-center/inclusive-higher-education/.
- 91. Grantley, G., Towards inclusion in university of people with intellectual disabilities, in ISEC: Including the Excluded. 2000: Manchester, UK.
- 92. Aigen, K., Music-centered music therapy. 2005, Gilsum, N.H.: Barcelona.
- 93. Wosch, T. and T. Wigram, eds. *Microanalysis in music therapy : methods, techniques and applications for clinicians, researchers, educators and students* 2007, Jessica Kingsley: London; Philadelphia.

Appendix 1: ACTIVE MUSIC ACTION RESEARCH CYCLES

ACTIVE MUSIC ACTION RESEARCH CYCLES



Appendix 2: DRAFT FINDINGS - cycles of learning and action

We began by writing about the things that were 'good', 'bad', 'hard', and 'easy' about music

CYCLE ONE

1. Things that were good

Drumming, beat, and rhythm, are good

Lots of us thought it was good beating drums and listening to different beats. People also said playing on the drum kit was fun and they wanted more.

"We copy Erin's beats then we do our (own) and other people copied ours as well. It was fun and everyone was happy".

"I play the drum. I like the drum kit and I want have a go on the drum kit".

"I like playing drums it's my favourite"

Song-writing is good

We wrote words (lyrics) to the music of We Will Rock You. Lots of people said it was fun when we wrote our own song and they asked if they could do it again. So next time we came to music we added more lyrics. When it was hard thinking about lyrics it was good to think about rhyming words. One person was keen to write a song for her boyfriend but we haven't had time to do that yet. People said:

"That's the song we made on our own",

"It was fun making our own song to write",

"It was cool doing our old song that we wrote to sing again",

"The funnest thing I did was making the song" and "Bring it on!"

"I love music because you can learn new things like writing your own songs with friends"

It's good being together in a group, listening, helping each other, noticing each other, learning new things about each other and ourselves. We are a team.

Lots of people thought it was good to hang out with friends and buddies, and to meet new friends. Someone enjoyed meeting other staff at Massey University. A few people said that it was cool and nice having Patrice and Erin to make music with. Some of us thought it is also good to have Julie and other people we know well at music with us. It was good seeing all the new things we could do. Teamwork lets us get ideas from different people.

"I am happy to have Patrice with us because I enjoy making music with her" and "it was cool listening to Erin and Kate play(ing) their instruments".

"It was really cool, Erin and Patrice was playing the instruments with the song that Patrice picked because she wants us to know her better with the songs and Erin was playing her flute with the song we sing was 'Lean on Me' it was cool and also it was cool meeting Patrice for the first time she was cool and a nice person"

It is good to work out what is ok, and what is not ok

It was good to be respectful of each other. Like its ok for people to join in when they are ready, and it's ok to play and do things in different ways. Listening and rocking instead of playing is ok too. It was good to listen when people gave us feedback, and it was good when we helped each other. It was good when Jacob did Karakia for us. It was nice to give balloons to each person when we played the balloon game. People said

"It was cool helping (someone else) in the band" and

"Music was good, I'd say because we played as a group".

Someone was especially happy because they enjoyed making music, and other people were happy listening. It is good that most people are more smiley now than when we first started coming to music. Some people have told us that they were looking forward to coming back to music and learning more next week.

It's good to talk about what is going on in our lives; to share about ourselves.

Sometimes at music we talk about what is going on in our lives. One of the young men had a cool necklace. He told us that he saw someone wearing it, and he said he liked it and the man who was wearing it gave it to him. Someone told us that they were moving house.

"Mum and I move into mum's new flat on Saturday and the flat looks really new and clean because its new apartments that people haven't lived in them before so it's mum first people lives in them. I'll stay with Mum for a little bit until I find my own flat to live in...I like helping my mum packing our stuff to move to my mum's new flat in Newtown"

It was good that someone told us it was their birthday on Wednesday too, because we could celebrate with them!

Things we liked doing at music

It is fun walking to music. And it is good that there are lots of things we like doing at music like dancing to Katy Perry and One Direction and playing musical statues. Lots of people liked dancing. Lots of people like singing too, so we sang Michael Jackson (Beat It), Katie Perry, Lean on Me, and Singing the Blues. It's good that we like playing musical instruments like guitar, flute, and boomwhackers (even blowing into the boomwhackers!).

"I love coming to music because it's fun to play new instruments and new songs to learn"

"I feel excited to play the keyboard".

We had different ideas about what we liked at music and that was ok. Even though some people thought balloons were boring, one person wrote:

"It was fun playing the balloons game because we say really fun sounds and we all laugh and it was cool"

Reflecting

It's good that some people are able to tell us why they like or don't like things. And it's good that some people can give us helpful ideas about how to do things better. For example, people said:

"I like coming to music because I have been here before"

"I feel comfortable in the corner"

"Copying actions step by step would be good next time"

"It is helpful to watch the video of us" and

"We can sort the data by having a big piece of paper and brainstorm"

It's good that we have research folders, library cards, and a Facebook page.

2. Things that were hard

We like having library cards but it can be hard going to the library. The university is a big confusing place. Some of us have been talking to students at the university. Some of us have been talking to the other staff members too. That was hard. We had to be brave. We know we have to try new things but trying new things is hard.

"You have to be involved with music to see if you would like it"

Some people thought having a music research folder was easy, but some thought it was hard. We thought it was a good idea for everyone to have a folder so nobody missed out. But it might have been hard for some people to have a folder if they didn't want to draw or write. It is hard to know what to put in the research folder. It can be hard to think of ideas. Research is hard. We like to get back to doing music.

It can be hard to communicate our ideas. We have a video diary but it is hard to talk to the video diary. We get nervous when the video camera is on. Sometimes we hide from the camera. We are different when the camera is on. It is funny hearing ourselves on the video. Some parts of the videos were black – that was funny too.

It can be hard choosing what to do, what song to play. Some people like to choose between two things, but that can be hard too. It's hard if we want both of them. It's hard if we don't want either of them. Sometimes we just have nothing to say.

Music can be a noisy place. Music is sometimes loud. That is hard for some people because it can hurt our ears. It is hard for some people because we can't hear each other. The first time we played 'Beat It' some of us couldn't hear the guitar. We did the blues using the loop machine. We could hear the first person playing, and we could hear the next person playing, but then it got noisy and we couldn't hear the different parts. Some people like to drum. It can be hard hearing the other instruments over the loud drum kit. And it can be hard concentrating when other people are talking. So we wondered if we needed to do music in smaller groups.

Doing music can be hard. Writing a new song can be scary because it is hard to think of words to put in it. We did a brainstorm and got lots of ideas but it was hard sorting them. It can be hard to know where to put your fingers when you are playing the keyboard. And it can be hard to keep a beat. The timing can be hard. Dancing can be hard too. It is hard for some of us to move our bodies in time to the music, even though some of us have awesome dance moves. When we were doing "We will Rock You" it was hard to do the actions and sing at the same time. We don't like people to help too much

though. Like when someone played the drums he didn't want to be shown or told what to do. It was ok to 'conduct' him though.

It can be hard coming to music when you feel sad about something else. It can be hard sitting with other people, if the friend we like to sit beside isn't there. It can be hard coming to music at all if our friends aren't there.

It's hard when our plans can't go ahead. Sometimes we have good ideas but they don't work out because someone is not there to help. Like if you want to do a duet and the other person is away. And like when some of us wanted to help write the letter to the ethics committee but we were away on the day of the meeting.

It can be embarrassing playing music in front of other people. Performance is hard. Sometimes our voices shake because we are nervous. It's like doing a speech. It's hard to talk about music in front of everyone. We know what we did at music, but it's hard to say what it felt like. 'Reflection' is hard.

3. Things that were bad

Some people make mistakes which might seem bad, but other people don't mind.

Some people didn't like things but couldn't say why they didn't like it. We did 'We will Rock You' at ACTIVE Music; someone thought this was bad but we are not sure why. Some people thought other activities were boring. They said the balloon and sound game, musical statues, song writing, and dancing around the room was boring. One person thought the balloon game was scary. It is noisy when balloons pop – maybe that is why it is scary. Some people found it hard to be clear about which games they didn't like, or what they found boring. It is bad that we can't always have the songs we want when we want them.

People can feel bad when the music is too loud. Some people couldn't hear the guitar, especially when the drum kit was playing. The first time we played a Michael Jackson song together the drums were loud, there was a lot of background noise, and it was too fast.

Some people think it sucks when the video goes black and we can't see the pictures. Some of the things we wanted to see weren't on the video.

4. Things that were easy

We did 'Boom Shakalaka' and somebody thought this was easy. Someone thought copying Erin's beat was easy, and another person thought listening to music was easy too. The adults found a way to make playing Michael Jackson and 'Lean on Me' easy to play on the keyboard, but it was too easy for someone because she was getting so good at the keyboard! The boomwhackers are an easy instrument for some people to play.

It is easier to do research when we are using a computer. One person drew a computer in their journal to tell us this. It was also easy for some people to watch themselves on video when they were doing research.

It is easier to do things we already know. It is easier to be part of the group when our good friends are present. It is easier to join in when we are all laughing. One day we were all laughing and someone said "hallelujah" and we all laughed more.

Someone thought it was easy to talk to university staff.

Other things

5. We are learning lots of things about each other.

The music room has lots of resources. Music stuff is everywhere. We like lots of instruments. This can be exciting but scary too. Some people like to play ukulele, guitar, tambourine, keyboard, chimes, drums or piano. One person brings her own ukulele. Some people like more than one thing. One person especially likes rapping and rhyming. He makes up his own raps. Another person can play A, D (with help), & G chords on the guitar. Some people like to do duets, or play in groups. One person used to play the drums at high school. We know the kind of music we like too; like someone loves Michael Jackson ("Beat It"), other people like Sister Sledge "We are family", and Beach Boys "Fun Fun Fun".

6. We are learning to work together.

We are individuals. We are learning to listen to each other. We all listen to each other's ideas. We are a team.

"The first time we done it and it was too fast but the second time was really good because we all do the same part of beats on our instrument and we all listen everybody's ideas as well. So we all happy..."

7. We learnt about the ways we can communicate.

We can use cell phones, talk (one at a time), listen, Skype, Facebook, play music, point, show on our face, use computers, email, take photos, draw, write letters, sign, or gesture. Someone puts their hands of their ears. Someone drew a smiley face in their book. These are good communications.

8. We are beginning to relax at music

When music is finished, there seems to be happy chatting in the music room. Most people are more smiley now than when we first started coming to music.

Someone was excited about playing the keyboard, meeting some new friends, writing their own songs and doing music.

Summary of Cycle One Findings

The things that were good were drumming, beat, and rhythm; song writing, listening to music, dancing, and playing instruments, especially new ones. It was also good being together in a group; noticing, listening and helping each other, and learning new things about each other and ourselves. It was good working as a team; thinking about what is going on; and finding out what is ok to do in the group. It was good talking about what

was going on in our lives, and to share things about ourselves. It was good to do things for ourselves.

It can also be hard trying new things. At first some people thought some of the activities were boring or scary. It was also hard getting around the university and talking to people; and it was hard doing research, because it was hard to think of ideas. Brainstorming helped us to think of ideas. But it was hard when the video went black.

But we liked to get back to doing music even though playing new instruments and getting the music right - or dancing and getting the movement right - was hard at first. It was hard choosing what to do at music; and it was hard when we had ideas that couldn't go ahead. Sometimes music was a noisy place and we couldn't hear or concentrate. It can be embarrassing and scary playing music or speaking in front of other people too. Some people found it hard being at music if they felt sad, or if their friends weren't there.

Some of the music activities were easy; and even though we thought it was good to do things for ourselves, we knew some were easier when we had help. It was easier to do things we already knew about. It was helpful to be part of a group, and to have friends with us, because we could laugh and that made it easier to join in. We learnt a lot about each other, and about different ways we can communicate. We learnt to listen, to be individuals, but to work as a team. We were starting to smile more at music.

What we decided to do next

We wanted to keep trying new things like song writing; continue to be individuals but work as a team; try working in smaller groups; feel comfortable listening when we didn't want to play or dance; communicate in ways that were comfortable for us; and tell each other about the things we like and don't like; and we would ask for help if we needed it.

Here is what we found (Cycle 2)

CYCLE TWO

1. We wanted to continue to be individuals but work as a team

We noticed even more of what other people were doing. Even when there were a lot of us at music we took turns to play guitar, drums, and piano; and to sing, rap, and dance to our favourite music. We learnt which part to play when the group was doing a song; like playing the piano when the group did Fireworks or Stand by Me. Sometimes someone wouldn't feel like doing much, but we noticed that they still joined in.

Sometimes someone did a solo, and others listened and watched but didn't join in to the actual performance. Tessa had a dance that she would do for Zi Zi, our friend who died. We liked watching her do that dance, even when it felt hard to think about Zi Zi. She performs awesome dance moves. She danced to the song by Beyonce called 'Single Ladies'. It was good that Tessa's dancing is for the memory of Zi Zi. We made a video recording of Tessa dancing, and gave it to her to keep. We talked about music that was

important to us and learnt more about each other because we picked songs that we love in our hearts. Music reflects people's personality. Jacob told us what a song meant to him, and it was a sad story. Tash said even though she felt really happy about coming to music, there were lots of sad times too.

"Like when our favourite friend Zi Zi passed away on the 4th of October. It was so sad; everyone was really sad. And so I gave everyone a hug, especially (the people) that went to school with her. We were doing songs that she loved. Jacob was sad when one of his lovely family members passed away; he was really sad, so some of us gave him a hug to make him feel better inside. He felt sad another day when we did the Nelson Mandela tribute and I gave him another hug to make him feel better inside. (Tash, journal entry)

We felt as if we were a team when we were playing music together, but we all had individual parts to play. It was fun doing the same beats as someone else on our own drum, sharing a drum, or sharing the piano. Sometimes we played instruments, with no song, and we each had our own part to play. We practised some things to get them better. Even if we didn't like the music we still practised because the other people liked it. We made mistakes but it was good to learn by practising. If people didn't know the song they could learn the lyrics or learn how it goes. Janiece liked playing the piano because it was good to learn how to do something different from guitar. She thought the piano sounded good in Firework. It was hard trying to get all the keys on the piano and sometimes she would get the wrong key. But it got better with practice. She really liked playing the piano. It was hard when people were taking pictures though.

We made each other laugh because we had individual responses to the music. Sometimes when an individual started something like dancing, we would all join in. It was really funny when we were following each other's moves and we finished like monkeys! We were laughing too when we played the 'Beat Busted' game².

From our data we could see we were able to continue to be individuals but still work as a team.

2. We wanted to work in smaller groups

We thought it might be easier to do music if some people left the group because it would be smaller. We did some things in small groups, like song writing. Sometimes smaller groups just happened because people were listening and watching us dance. But most of the time there were about twelve or fourteen people in the room and that was a lot for some people to cope with, because "some people don't like noisy" (Tash, interview).

"(I don't like it noisy). I drew a picture of myself with headphones listening to Michael Jackson. It is easier to listen to music with headphones on. But I listen when I am playing the shaker egg too" (Shafiq).

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² (Someone had to leave the group while we decided who would be leader. The leader would choose a beat and the group would follow. Then the leader would change the beat without saying anything and the group would follow. When the 'someone' was called back to the group they would watch and listen to guess who was leading the beat).

3. We wanted to feel comfortable listening when we didn't want to play or dance

Listening when music is happening is important too. We noticed that some people listen because they find it hard to move their bodies to play. Some people listen because it just doesn't *feel* right to play. Some people listen because they don't like the activity. Some people listen just because they want to. "*Listening to music from other countries is fun*" and "*listening to African music was easy*". We thought we could bring more music from our countries and our childhood memories to listen to. Sometimes listening is just the right thing to do.

"It was really cool listening to other people's songs from their childhood grow(ing) up".

"It's bad when we talk when other people are talking. We should listen to other people."

4. We agreed to communicate in ways that were comfortable for us

We all had different ways of communicating that were comfortable for us. When we were all together doing music, we noticed a lot of things about each other. Watching the video back helped us to notice things too, and remember what happened in the group. Sometimes when we watched the video we noticed things that happened that we didn't notice during the group. Some people found the video a helpful way to reflect on what has happened. For example, someone said,

"We could keep watching ourselves on the video to do research because it is fun to watch our video to see how we did well... we write (about) what we like and then we give our book to Daphne so she can copy our book to be read for research"

Writing in our books about what we saw was one way of thinking back and communicating our ideas. It suited some people, but we wondered if it would suit everybody in the group. Finding out ways to communicate with people is important and we thought we should continue to give helpful ideas about how to communicate even better. Listening to each other is really important and something we can keep trying to do better, it is about respecting people when they choose to speak up.

We found out that speaking up can be hard for some people sometimes, but that it is important to tell people if something makes us feel uncomfortable, or we don't want visitors in the group. Like when reporters want to do stories on us, and photographers want to take pictures. This is something we discussed as a group, and we decided how to communicate what we want and don't want when reporters or visitors want to come and see our group.

Making music together and playing musical games meant we needed to listen carefully to each other, and we noticed when things got too fast or too loud. We took turns to lead different games and songs, and everyone got a turn at leading, not just always the same person which is good.

5. We wanted to do song writing

We wrote a group song about ACTIVE, we did this as one big group, sometimes singing together.

Then we tried writing songs in smaller groups. Although some people really want to do more song writing, other people really don't. Some people continued to enjoy song writing and some people didn't. Some people found it fun and easy and other people found it hard. Sometimes, because it was a process, it was hard to describe.

"I think I enjoyed making songs up. It was hard making the first song we made up last year; it was the hardest song, and I didn't really like it when it was finished" (Dave).

We started to discuss whether we would continue to do song writing or not, but we need to talk some more about it.

6. We wanted to keep trying new things

We tried many new things in the music sessions including: new songs, singing new words, rapping, waiata, games, dancing, musical statues, listening to music from our childhood memories or from our cultures and countries, playing the instruments in new ways and with different people. We also made new friends.

Trying something new could be embarrassing, like telling everyone a favourite song. Trying new things could also be hard, like finding the right keys on the piano. Even though new things could sometimes be embarrassing or hard for us, we laughed when we tried, and helped each other to succeed. Some of us were able to do things that we had never done in the group before, like doing a solo song, or playing an instrument on our own without help. We thought it was good to learn how to do something different.

Being without Active staff at the music session was another new thing we tried. We thought that "Being without staff was easy but it was also challenging". Overall, "It is good that staff stopped coming to sessions".

There are some specific new things we really want to do now, like a song on the piano with Daphne or Erin, music from the Lion King, or getting more computers "so people can find more stuff".

7. We decided to tell each other about the things we like and don't like

We thought about the many things we liked and didn't like at music. We liked playing games like the yes/no game. We liked walking to the music session, because we knew it was good for us and it made us feel better to walk. We loved the challenge of doing our group song to 'we will rock you'. Some of us didn't like the Michael Jackson song "I'm Bad" because we found it boring. Shafiq really liked Michael Jackson though, and he also liked Spice Girls, Britney Spears, Madonna, The Wiggles, Leann Rimes and Kelly Clarkson.

"I take my ukulele to music every Tuesday when I remember. I want to learn how to play guitar, drums, violin, all sorts of music, and bring my CDs like Beyonce, and all those things I want to do. I need to tell people next Tuesday that this is what I want to do. I can talk to you about it when I arrive to see if we have time. I talk to Erin and Patrice; and Janiece and Dave too." (Tess, Interview)

We didn't like it when the music was too loud, and one of us felt that the drumming was too loud and boring. One person liked how Daphne played a song that was important to them on the piano, and how we had fun singing other songs that were important to us. As well as playing music, we thought it was really cool listening to music in the session, especially music from other countries, songs from our childhood, or songs that other people 'loved in their heart'. Many of us wrote that we enjoy music and twice we heard that someone loved performing.

We had fun doing things by ourselves, like playing the piano or singing. We also had fun doing things together with one other person, like with a boyfriend, playing guitar with Patrice, or sharing drums to play the same beat. Doing things in small groups could be funny, like copying each other's dance moves. We found it fun to be friends with new people at music. Sometimes everybody had fun doing things as a whole group, like singing songs we all knew really well. That put us in a positive mood. We thought it was good to practise the songs so that everyone could learn how they went. We liked it when, as a group, we didn't play too loud, and we liked it when we arranged a song and worked together to play it.

We liked capturing everybody on the video, and one person liked doing the filming. We found it fun and cool to watch the video on the TV and see the things we did well at music, but we hated it when the playback of the video went black. We didn't like the video focussing closely on one person. For example, one person would hide because they didn't like having the camera near them and one person got embarrassed when they saw themselves in the video. We also didn't like it when journalists took photos of us - that made it hard to do music.

Sometimes we felt differently about the things we did at music. Most of us liked playing instruments like guitar, piano, keyboard and drums but one person thought the musical instruments were boring. Some people would love to do more song writing, but some people don't like song writing that much. One person thought dancing and singing to recorded music was exciting and we should do more of it, another seemed to agree saying it was bad there had been no dancing that week, but another person thought it was bad when their peer performed awesome dance moves. We're not sure why. We thought it was ok when not everyone liked an activity: "I liked singing firework because some people liked it and some people didn't like it." However, we were very aware of when an activity was causing someone else discomfort, for example some people really didn't like loud noises. We think "being respectful and nice is good", and we wanted to stop playing the balloon game, because balloons make loud noises when they pop. We also wanted to try not to play too loud, and to listen to other people rather than talking over them.

We worked hard to communicate in our data. We wanted to continue doing research so we could find out more about what other people liked; we thought this was important. Sometimes we even wrote about things we liked from other parts of our lives, like going to a ball, and seeing a brother.

We were sometimes able to say things in our data that we didn't say on our faces at the time. For example, one person wrote that they didn't like playing a warm up game when they were tired and grumpy. Others had thought everyone looked like they were enjoying themselves during that game.

In our data we showed that we noticed what other people did at music, and we liked it when other people were good at music. We said good things to each other when they achieved something, like playing the guitar, the drums, or having fun with a supporter. Sometimes it bothered us what other people in the group chose to do, for example one person hated it when another bit their nails, and another thought it was not good that a group member wasn't joining in.

"I came to music every time, to join in. It's pretty hard for me to join in. I achieved on drums though. ...Drums were not that much enjoyable for me though (unless it was the drum kit). My favourite thing was playing the drum kit and I didn't get enough of that. I used to play it, but we had to do new songs. I was a bit nervous when people asked me to have a go on the drums though. I would like to play with a tutor, but maybe with a big group as well. But I want to focus on drums, not other things" (Dave).

We have had some really tough things happen in the time we have been coming to music, and sometimes we have felt very sad. When our friend died, we thought it was good to play music for her; she liked Beyoncé but we also played an African Lullabye because she was from South Africa. Sometimes our mood could change at music too.

"Zizi's music was good." "Being sad was bad. The music helped, the beat makes people happy." "It is good that there were less sad people after music". "Joining music picks up my brain."

We thought it was good that the Active staff stopped coming to sessions. This might show we can support each other without extra staff in the music sessions.

8. We agreed that we would ask for help if we need it

We didn't write in the data about asking for help when we needed it. Maybe we didn't need help, maybe we didn't ask, or maybe we just didn't write about it in our data.

Someone wrote "Tess doesn't like the man taking photos of her with others. Axel talked to the man about the photographer." Maybe Axel was assertively helping Tess? But we are not sure. Someone else wrote in the data "Put the video on a stand because you can see everyone". This is not asking for help, but it is asking to do things in a different way.

What we decided to do next

We wanted to keep trying to listen to each other carefully; speak up even when it is hard to speak up; talk about whether to do song writing or not; do the things people ask us to do, if we can (we will play the piano, and do a song from the Lion King because people have asked to, and we would try to get more computers). We would work together in

sessions without support staff when we could; and we would still ask for help if we need it.

CYCLE THREE

1. We can keep trying to listen to each other carefully

Janiece listens to other people when she plays the piano; and Tash listens while playing the drums. Janiece listens to what the whole music sounds like even when she is playing the two instruments (guitar or piano) that she loves. Listening to other people's music is important when you are trying to play together. We listen to each other when we improvise. We can support Sarah by improvising music with her. We can all finish together just by listening; we don't need to talk about it.

Kate and Axel listened to other people talking about music too. We had to 'listen' in other ways too, like when Shafiq drew a picture of himself listening to Michael Jackson with headphones on. This was his way of telling us that he sometimes preferred to listen through headphones. And we had to 'listen' to him when he highlighted other people's words because this was his way of tell us he agreed with them.

2. We can keep trying to speak up even when it is hard to speak up

Axel practised speaking up, and he is good at it now.

"I don't mind people hearing my story. I do have a lot to say to people... a lot of people... the whole crowd!" (Axel, Interview)

Axel was able to suggest we do a PowerPoint presentation at the concert, and gave us ideas about what to put on it. Tess also said she learnt to speak up when she needed to, to tell people what she wanted. Janiece was able to say what she liked about music at Massey, and thought that it was fun to be able to speak out. Kate was trying really hard to speak out too, especially during her interview. She said:

"Talking about things is important. It's important to talk about music. I would do more music if I could. I'd like to try the piano because I have a keyboard at home. I didn't play at Massey, because I didn't speak up. I would like to play keyboard with a group because I like doing the keyboard with other people" (Kate, Interview).

Someone else said "I love music. It's so much fun when I choose what song to sing". Shafiq said he was able to tell us that he liked Michael Jackson, Spice Girls, and Britney Spears. This is important because he finds it hard not to copy what other people have said. Shafiq and Edward were both able to "speak up" by giving us drawings and words, or highlighting, on paper. Daphne noticed how well six people spoke up when she interviewed them. Tash said:

"We are confident and comfortable to do it, to tell people what we like or something. When I do my data I write. Some people write, but other people draw pictures, and sometimes we write something underneath what it is all about. Sometimes we do it together on the whiteboard or by interview like this...and we help each other with it and stuff" (Tash, Interview).

"It's enjoyable introducing myself and making new friends; telling people what I do for sport, and ... in my spare time. I do making movies in my spare time. When I get bored, I shut the door of my house and go for a walk, check out music, and talk to people" (Kwame, Interview).

3. We will talk about whether to do song writing or not. Why do we want to do it? Why don't we want to do it?

We still have different ideas about song writing. Some people found writing the first song hard, and they didn't really like it. Doing the song writing is different to hearing, singing, or playing the song. Some people didn't like writing the song, but they like the song. Most people like playing the second song we wrote. We like the songs now that they are finished.

4. We do the things people ask to do, if we can. We will play the piano, and do a song from the Lion King because people have asked to. We will try to get more computers.

We were able to do some of the things people especially wanted to do. Tess played the drum; Shafiq heard Michael Jackson music; Kate played the instruments she wanted to play like the tambourine and the egg shaker; Axel played the drums and got good at it; and Janiece got to play the piano, a lot. Some of us did music in other places, like when Shafiq played the guitar.

We couldn't do everything we wanted to do though. Tess didn't play the piano; Shafiq didn't hear Spice Girls music; Kate didn't learn to play the piano or the maraccas; Tash didn't learn how to play the guitar or the piano; and Axel didn't get to play drums with a band.

There are three main reasons why we didn't get to do all the things we wanted to do. One of the reasons is that we didn't have time. Another reason is we didn't speak up. Trying to speak up was one of our goals. The third reason we didn't get to do all the things we wanted to do was about money. We didn't have enough money to buy new computers, but we did buy an audio recorder for talking about research, and an earphone multi-box for the computer. We also got a whiteboard for our club rooms from the university so we could do research on it.

5. We will work together in sessions without support staff when we can

Sarah's helper came when Sarah was at music. We thought that was important because Sarah needed help to stay safe. But we worked without support staff for most of our sessions. We were all happy about that. It is good to be independent.

6. We will ask for help if we need it

We noticed that a lot of people were able to ask for help. Kate felt she asked for help when she needed it. People asked her for help too. She helped the group to find music on her iPhone. Janiece was able to ask Daphne when she needed help to play the piano. Axel asked Janiece to help him with his PowerPoint presentation for the concert. Tash

asked people to help her with the preparation for the concert; and Axel helped Tash to do the music band invitations.

Some people had a hard time asking for help because they were shy or because it is hard for them to talk. Shafiq needed more help to speak out. He wanted to ask for more guitar and singing. Shafiq can speak out with his writing. This takes time, but it is important. When he had time to write things down Shafiq said "that's better, yes". We will include Shafiq's writing in our research story. In her interview Kate said:

"Talking about things is important. It's important to talk about music. I would do more music if I could. I'd like to try the piano because I have a keyboard at home. I didn't play at Massey, because I didn't speak up. I would like to play keyboard with a group because I like doing the keyboard with other people".

Other things that we found

FURTHER THEMES

1. We like music, believe it is good for us to go to music, and feel as if we have achieved things

"At music we do warm up games. I like that clapping one. I like playing the drums at Massey University and I like the beat on the drums. It's so good to give a beat. ACTIVE is very important for music. Music is such a good, great personality for the ACTIVE people. It's such a good personality for eye coordination, hand movements, and talking with your own voice. And I like Tessa's dance moves. Music is such a good thing for ACTIVE." (Axel, Interview)

"I love playing music. When I started music I wanted to play the guitar, but now I've changed from the guitar to the piano... I wanted to try the piano. It's sort of easy, and hard... It's sort of easy because sometimes I know the chords off by heart. ... Sometimes I do have the notes in front of me, but then I try to add more chords to it." (Janiece, Interview)

2. Music can help us manage our emotions

"Inside I was feeling angry inside my heart. Some people think – they don't like the Lion King? They said, that's boring, let's do a different one. But, no, this is the best one I've chosen, that I chose, for others, not for you. (If I feel angry I need) to talk to you guys; I need to have calm down time, calm down time and then I'll come back inside. And practice asking to have a turn, and being patient" (Kwame, Interview).

"I love music because it calms me down when I'm upset. But I can't go to music lessons by myself - I would need you to come with me because I get a bit nervous. If I get upset I go outside for fresh air, or I go near the door of music and I come and sit down. I just sit down and listen. Being at music and listening to it on the tape as well or you know listen to CD ...just listening to nice music and hugging people and all that stuff... calms me down" (Tess, Interview).

3. Being in a university environment was important

We began to enjoy being in the university environment. It might take a bit longer until we are completely comfortable here, but we like lots of things about it now. And we know it is important to be with all the other students when we can.

We walk every Tuesday to the university. It's such a big space that Massey. It's such a cool room ... because it's like a teacher's room. It's quieter and it's got glass windows for some fresh air, and that drinking tap. I also like the library. This year I'm going to the library. And I've been to the cafeteria. I eat my lunch outside. I might go in to buy a coffee one day because I'm very independent. (Axel, Interview)

(Interviewer asks: University is important?). "Yes. Because we are in the university school, in like, in with all the other people and stuff. (University)...it's fun. (I've been to) the Massey building, the Massey music one, and sometimes we go to the library or

the café. We went to the café a couple of times with the whole group. I think I could go by myself or with friends. I went to the library with friends mostly just to see what it was all about. We looked all around where the library is and stuff. (If I was coming longer) I would go to the library to read a book or study". (Tash, interview)

4. Being with friends is at music, and sharing what we are doing at music with families, is important.

I like to listen to music with my friends at ACTIVE. It's pretty important to me. I felt sorry of Kwame leaving us and the music university. It's so sad for people. He was so good last year at music. It's so, so sad that he left music at Massey. (Axel, Interview)

We wanted families and friends to see what we had been doing and we asked if we could do a concert. We wanted the people who are important to us to be there. We sent invitations, booked the room, borrowed some instruments and organised supper by ourselves. One of the young people took a very important organisation role as well as being 'master of ceremonies' on the night.

"(I enjoyed) singing, writing new songs... writing our new songs, and the jams, and all kinds of cool music stuff. It's a unique opportunity. I can't wait for our concert tomorrow. It's going to be fun. ... I listen to music at home, sometimes I sing. (Massey music is important for doing music). Yes!" (Tash, interview).

One young person felt sad when music reminded him of his family, and wanted to leave the music group. He explained:

Music reminds me of my family. After they visit me I often go visit them overseas. I can't come back to music because I'm missing my family. I feel sad at music. But I trust you guys. I might come back after Christmas. Six weeks in a row. I can cope with six weeks. I can cope with that. If I feel sad I'll have to talk to you guys. Even though he wanted to 'give it a go' he decided not to come back to music after Christmas (session 14).

5. Doing music research is fun and interesting. It's hard work but it's worth doing.

"Music is fun and it's interesting and we learn more stuff, when we do research. Some days... Daphne just copies our things and then we do that thing with the other guys, to see what they think music is all about and stuff. And then we know what they like and stuff, whether it's noisy and stuff. Some people don't like noisy. And yeah... after we have finished the research and have all the information we need to do we will make a book, a research book, for our family and friends... so our friends and family will know what we have been up to and what Massey Music is all about and what research is all about. And help each other with confidence.

(When people read the research) they will know what we talked about. They can read it or write similar things to what we did. ...ACTIVE and IDEA Services or something, need to know what we do at Massey Music every Tuesday and that's fun and it's our last music session with our leaders. We need to let other people know what we want to do in our future, a long time in the future and things. And it just

like helps us and stuff with everything we need to do for our future. ...like could we have smaller groups than what we have been using and stuff. And everyone could have a smaller group coming to Massey and then have a smaller group each day and stuff and it won't be that noisy.

(Interviewer asks: Was it important that it was at Massey, or important that it was music?) Both! Because we like – we are enjoying coming to Massey for music and research. It's fun and it's really what we want to do". (Tash, Interview)

"This year I'm going to get good at music and research.

I like that big book we have started to write. It showed the whole research we did last year. And... it's a big book. It's very important to hear about that. We are Massey. We do research. The music and the research have been awesome. I'd like to do some more this year! I need to work my butt off! It's hard work but its good fun. It is a good idea to do research actually. Because it means we can get help. We do have research to back up (the things we need)... a lot of research to do actually! I'm getting my butt into research this year". (Axel, Interview)

"Research makes me tired! But I think it's important... to know about music". (Tess, Interview)

6. We understood the research process

Janiece told us very early on she was very interested in what people were writing about music, and which box it might go in when we were doing the analysis. She said she was interested in other people and what other people think.

"I was the data demon (when we did the analysis). Me and Patrice were data demons and we had to try to help everyone out. Research is good. Sometimes it's boring. Sorting it out into piles is boring. ...We can make a story out of our research. That is good. Our family will think it's good. Just people like that... (and) people at ACTIVE need to know what we've been doing as well" (Janiece, Interview).

After we had done the research, quite a few people talked about the research process.

"(When we are not at Massey) we just read what's on the video and write it in our books and yeah... We don't do any music. ...When we went to Massey we got a video recorder up to see the whole group, then Daphne came with a CD or another thing and during the breaks wrote the Massey research, and wrote the things we like and stuff, and we copied it in out books and gave it to Daphne to copy and then when the research was coming we sorted them out to see if it was good, bad or worse or maybe or both. And then we would do that and then the boxes were tidied up and we could tell Daphne what to write on the laptop and stuff. We are confident (and) comfortable to do it, to tell people what we like or something. When I do my data I write. Some people write, but other people draw pictures, and sometimes we write something underneath what it is all about. (Sometimes we do it together on the whiteboard or by interview like this?)...and we help each other with it and stuff" (Tash, Interview).

"At research you write on your journal, things that are easy, hard, good, bad, and difficult ... and changing. It's part of our research. We watched video of our music. You can listen with your ears and write some things on your papers, on your books. It's good! It shows us we can research. Writing every Monday at ACTIVE is important. Monday I might do some more research in my folder. I like those folders actually. (They're) so good. You can put stuff on that folder" (Axel, Interview)

"I was going to make notes in my diary. I could bring my diary in, and bring it so I can make notes. And it's been my job putting notes into the printer. Putting them in to printer and printing them out. It was a hard job and it's good that it's finished" (Kwame, Interview).

7. The future

"I want to keep doing music because I like it and it was fun I want to keep playing the drum kit. It was cool and fun. I want to play the drum with a group of people and I want to sing a song of the Beach Boys. The group can join in..." (Dave, Interview).

"I would do more music if I could. I'd like to try the piano because I have a keyboard at home. I didn't play at Massey, because I didn't speak up. I would like to play keyboard with a group because I like doing the keyboard with other people" (Kate, Interview).

"I don't know what I want to do next with music. I might still do piano and guitar. I basically sort of get guitar lessons from Julie. Maybe I could keep playing the piano at ACTIVE. It would be good to play with people rather than just getting piano lessons. Julie knows how to play piano as well. I could still play it with Julie. Sometimes I play guitar with Julie, and I play it by myself. I never played the piano here at ACTIVE though, and I don't know why. But I wouldn't want to play it where other people can hear me, except at ACTIVE. ...I've also been trying to get rid of the nerves. ...It is worth doing again because it's fun, just fun!" (Janiece, Interview)

"Music has been pretty awesome. It's ok. I like music. I would like to make a Lion King movie at music. I feel great thinking about that. We will have music, soundtrack, the props, and the movie making ... the everything" (Kwame, Interview)

. (Interviewer: What would you like to do next?) "I don't know, probably like, probably do some more music or research or stuff like that. The research is fun, so we know what other people think, so we can know what other people think, what they feel about music and stuff" (Tash, Interview).

When the music is over and done with I'm going to miss it a lot! I like Daphne and Erin and all the ACTIVE people who go to music. I hope we do a big band here. When we have finished and the ACTIVE party starts, we should do a band... with the whole of ACTIVE people. I would be the drummer! (Axel, Interview)

Appendix 3: OUR QUESTIONNAIRE (4 pages)

We agree we should stop doing the balloon game.

WHAT DO WE WANT TO DO AT MUSIC?

YES

NO

We agree we like drumming and beating rhythms. We agree we could try the boomwhackers. We do not agree about song writing. Should we do song writing? YES NO I DON'T KNOW We do not agree about dancing Should we do dancing? YES NO I DON'T KNOW We do not agree about musical statues Should we play musical statues? YES NO I DON'T KNOW We should continue to repeat things we know and enjoy NO I DON'T KNOW YES We should invite university music students and other music staff to visit the music room to play with us? I DON'T KNOW YES NO We should set up the keyboard? NO I DON'T KNOW YES We might learn more about people by asking them to bring music from their country or family? YES NO I DON'T KNOW We should keep trying new things YES NO I DON'T KNOW We should practice performing in front of each other so it gets easier

I DON'T KNOW

HOW WILL WE COMMUNICATE AT MUSIC?

We do not always understand what people mean when they talk or give us data. How can we become more confident about understanding each other?

We should	tell each other ab	out the things we like and don't like
YES	NO	I DON'T KNOW
	ask for help if we	
YES	NO	I DON'T KNOW
TAY 1 11	. 11	
		e are worried or sad or happy
YES	NO	I DON'T KNOW
We should	nractice telling no	eople <i>why</i> we feel worried or sad or happy
YES	NO NO	I DON'T KNOW
IL3	140	I DON I KNOW
We should	give ideas then le	t people to choose what they want
YES	NO	I DON'T KNOW
<u> </u>	<u>'</u>	
We should	try not to talk wh	en people are trying to listen to other things
YES	NO	I DON'T KNOW
We should	try to communica	te in ways that are comfortable for us
YES	NO	I DON'T KNOW
	be able to talk to	each other; not in front of the group
YES	NO	I DON'T KNOW
TAT 1 11	1 1 1	1
	î î	they mean if we don't understand
YES	NO	I DON'T KNOW
Wa should	nlaw come mucica	ll games to help us be assertive (say what we feel)
YES	NO	I DON'T KNOW
ILJ	NO	I DON I KNOW
We should	keep asking peop	le what they like
YES	NO	I DON'T KNOW
We should	work in smaller g	roups so we don't have to wait so long for our turn
YES	NO	I DON'T KNOW

HOW CAN WE BE RESPECTFUL OF EACH OTHER?

We should try not to let the music get too loud					
YES	NO	I DON'T KNOW			
We shoul	We should try not to play too fast				
YES	NO	I DON'T KNOW			
We should let other people model the beat for us to copy					
YES	NO	I DON'T KNOW			
We can listen to music when we don't want to play or dance					
YES	NO	I DON'T KNOW			
We can le	et people try harder	things on the keyboard			
YES	NO	I DON'T KNOW			
We could	all try to be relaxed	d and have fun			
YES	NO	I DON'T KNOW			
We shoul	We should let people do as much as they can by themselves				
YES	NO	I DON'T KNOW			
We shoul	d continue to be inc	lividuals but try to work as a tear	n		
YES	NO	I DON'T KNOW			
We should say "no", "don't come" when reporters and photographers want to write stories or					
take pictures about our work					
YES	NO	I DON'T KNOW			

HOW CAN WE IMPROVE OUR RESEARCH

We still want to know more about the music young people like, and about how we can make their lives better

Should we continue to do research?					
YES	NO	I DON'T KNOW			
	1 • 1 • • • • • • • • • • • • • • • • •	e university to hang out			
YES	NO	I DON'T KNOW			
We can let people do research their own way (we don't all have to do the same things)					
YES	NO	I DON'T KNOW			
We could	d talk to each other	about what is going on in our lives			
YES	NO	I DON'T KNOW			
We could	d talk about what w	e like and what we don't like			
YES	NO	I DON'T KNOW			
_					
We could	d tell people when the				
YES	NO	I DON'T KNOW			
We could give people helpful ideas about how to do things better					
YES	NO NO	I DON'T KNOW			
. =0	1				
We shou	ld keep watching ou	rselves on video and talking about it			
YES	NO	I DON'T KNOW			
					
We shou	ld keep the video or	n so we get used to it			
YES	NO	I DON'T KNOW			
We should turn the video off for some of the time					
YES	NO	I DON'T KNOW			
We should put the video on a stand					
YES	NO	I DON'T KNOW			
We should get more computers for watching the video and for going on Facebook					
YES	NO	I DON'T KNOW			

Appendix 4: READING NUMBER ONE

A research story about a group of people with intellectual disability doing art and drama in Australia

By Ken Sprague Written in 1991

Ken was an art teacher. One day a group of people with intellectual disability were passing his room and looked in his window. They were excited to see the art room so he invited them in. They ended up coming every week to do art with other students. They made friends. Ken and the other students thought it was good that the young people with intellectual disability joined the class. They thought the young people with intellectual disability could paint and draw more freely and simply than they could. But the young people with intellectual disability called the other students 'proper' students.

Ken thought everyone in his class should be treated fairly and equally. But he noticed that the young people with intellectual disability found it hard to join in like the others. He thought this was because people were always telling them what to do and how to do it. When you are always told what to do, you don't think your own ideas are valuable. You don't think you can just have a go to try something new. And if you don't join in, helpers take over.

Ken wondered whether doing drama together would help his students to be more comfortable with each other. But they wouldn't join in unless he told them what to do. He knew they were shy and worried about whether they would do the right thing. He knew it would take a long time for them to feel comfortable so he worked with them for a long time. They played games. One day one a boy with intellectual disability told him he "fell off the bus". So they made a play about falling off the bus. The boy didn't want to join in but the others did the play anyway. They made him lie down on the ground by a pretend bus. They pretended they fell off the bus too. That made the boy more comfortable to try his own ideas.

Ken also noticed that his students couldn't speak up for what they wanted. They didn't want to get in trouble. He wanted them to practice asking hard questions. One of his students wasn't getting paid the same pocket money as his brother. Someone pretended to be the boy's dad, and he practised asking for more money. Then he went home and asked his real dad for more money. And he got more money.

Ken's story tells us that we need to try new things even when it is hard. It is ok to disagree with people too. When we disagree with people we should tell them. When we want something we should tell someone. It gets easier to give our own ideas if we practice.

Appendix 5: READING NUMBER TWO

A story about music research in England

By Mercdes Pavlicevic, Nicky O'Neil, Harriet Powell, Oonagh Jones and Ergina Sampathianaki

Written in 2013

Music therapists were working with a group of young people who have intellectual disability. The young people came to music for a long time. Some young people came back for years. The music therapists wanted to know how music was helping the young people. They had a question about whether it was good for young people to come to music for a long time.

Many of the young people found it hard to communicate with words. But each week they played music together. Their music was mostly improvised. That means made up on the spot. The music therapists played with them. The music therapists listened to the music and watched the young people carefully. They could tell that the young people were communicating. The young people listened to each other. They shared feelings. They told stories through music. They were expressing themselves. But the music therapists wondered whether communicating at music helped the young people in their everyday lives.

The music therapists wanted to ask the young people, their parents and adult helpers about how music helped them. Some of the parents said the young people shouldn't be involved because they might disrupt the talk. So the music therapists asked the young people's parents and helpers to talk about the young people's lives. Then they asked them to look at video of the young people at music and tell them what they thought was happening.

The adults talked about how intellectual disability made life hard. The said young people need help to understand the world. They need help to make choices. They need help to tell people what they want. They said young people with intellectual disability have trouble communicating. So it is hard for them to make friends. They also said other people sometimes make things worse because they don't understand what it is like or don't know what to do. When life is hard and other people don't understand, young people can feel bad about themselves. It is frustrating when you can't make people understand what you are trying to say. Young people sometimes behave badly because they are frustrated or worried. Young people sometimes behave badly so they don't have to keep trying hard things. They are often lonely and sad. Young people need friends and helpers. They need to feel useful and helpful themselves. People need to give them chances to do useful things. Young people like to do things by themselves. But they might also need help so they can be successful.

The adults said music is helpful because it is communicating without words. When you communicate with words you can get it wrong. Made up music doesn't have wrong notes. You can play anything. People can't say "that is wrong". So doing music can be easier than talking. Young people feel confident to play. Nobody is 'better' at it than someone else. You feel good because you can do something well. You can play happy music or frustrated music to express yourself. When people play happy music or frustrated music with you it feels good. It feels like they understand. It feels safe. Music therapy feels supportive and reassuring. You can make friends. It feels good to play music with friends.

When the adults watched the video they could see that the young people were having fun. They could hear the young people 'teasing' each other in the music. The young people were practising and improving their communication.

The young people came to music for a long time because it helped them to cope with everyday life.

Appendix 6: READING NUMBER THREE

A story about people with intellectual disability communicating with doctors

By Suzanne Carrington and Nick Lennox Written in 2008

People with intellectual disability want to be safe and healthy. They want to have a home. They want to have a job. They want to do things with friends. They want to have a boyfriend or girlfriend or husband or wife. They want to make choices. They want to make their own decisions. They want to do things the way they want to do them.

They need to be able to solve problems. They need to understand themselves. They need to be able to set goals. They need to be able to look after themselves.

Children learn many things at school to help them do things by themselves when they grow up. They might learn how to do the shopping. They might learn to cook. They might learn to use the internet. They could learn how to keep safe and healthy too. But people with intellectual disability often need help to do these things.

This story is about helping young people who have intellectual disability to do more things by themselves. It is about people with intellectual disability learning to communicate with doctors and other helpers.

In this story young people were given a health diary by the researchers. Their teachers helped them to use it. Their teachers helped them to write about "the best way I communicate", "places I have lived", "what I am good at doing" and "what I find difficult". They also learnt about what to take to the doctor, how to tell the doctor what they might need, and what might happen at the doctor's office. These things were written in the diary. The young people would take their diary with them to the doctor. They could go by themselves and show the doctor the diary.

The teachers and the students liked using the diary. The teachers found out that young people with intellectual disability need to learn to ask for help. They need to learn about how to look after their bodies and their minds. But the teachers also learnt that people with intellectual disability can do lots by themselves. They were surprised.

Appendix 7 : READING NUMBER FOUR

A story about the best way to do research with community groups

By H. Gremillion Written in 2013

This story is written by a researcher. She wanted to find out the best way to do research with groups of people. She said people often disagree. It is ok to disagree. But what happens if we disagree about our research question? What if we disagree about the answer?

We can work together to come up with something we are all happy with.

- 1. But sometimes we think other people are smarter than us, so we just say "ok... whatever" to them.
- 2. Sometimes we are scared of them, so we just say "ok... that's ok".

We could just say "here are some different ideas".

- 1. But some people might think they have the best answer and they might not listen to other people.
- 2. Sometimes when we are talking about different ideas we change our minds.
- 3. The person who writes the story might put their answer in because they think it is best.

We could film everyone giving their ideas and then make a video documentary

- 1. We could look at ourselves on video
- 2. We could talk about what we are seeing and hearing on the video
- 3. Someone could film us talking about the video
- 4. We could use the video of us talking about ourselves too!

This researcher says that making video documentary is a good idea. People can give their ideas even when they disagree. But it is hard work.

Appendix 8: OUR TRIBUTE TO NELSON MANDELA

https://voices.no/index.php/voices/article/view/758/639

Members of the 'ACTIVE Music' group, who are doing music and research at Te Koki, New Zealand School of Music. The ACTIVE Music project is a collaboration between music therapists and young people who have intellectual disabilities. The young people who put this together are engaged in a twenty-week music and participatory action research programme. They naturally use the space to reflect on things that are important to them, and the death of Nelson Mandela was something that they brought to sessions. The words that we have put together emerged over time as we discussed Nelson Mandela's life and death.

Our tribute is called Nga Iwi E. It was written by Hirini Melbourne. Hirini was Maori. Hirini wanted children to learn to speak Maori. He played traditional Maori instruments. Hirini died too. His wife said it was ok to use his words.

Nga iwi e! Nga iwi e! Kia kotahi ra te Mo-a-na nui kiwa.

All you people! All you people! Be united as one, like the Pacific Ocean.

Nelson Mandela was a great man. He died. He was very old.

In South Africa people were separate. Black and white people were treated different. Nelson Mandela told the government to treat people fairly. They put him in jail. Disability advocates want people to be treated fairly too.

People in New Zealand stopped the rugby game against South Africa because black people couldn't play. Nelson Mandela heard about that when he was in prison. He was pleased. He said "it was like the sun came out".

When he got out of jail Nelson Mandela was President of South Africa. He came to New Zealand. Maori people welcomed him. To be a guest of Maori was a great honour.

Thank you to Jacob Dowbroski (Tuhoe / Ngati Porou), Tessa Haanen, Natasha Claydon, Patrice Dennis, and Erin Upjohn-Beatson for recording our tribute to Nelson Mandela.

Appendix 9: TESS'S STORY

I take my ukulele to music every Tuesday when I remember. I want to learn how to play guitar, drums, violin, all sorts of music, and bring my CDs like Beyonce, and all those things I want to do. I need to tell people next Tuesday that this is what I want to do. I can talk to you about it when I arrive to see if we have time. I talk to Erin and Patrice, and Janiece and Dave too.

I love music because it calms me down when I'm upset. But I can't go to music lessons by myself - I would need you to come with me because I get a bit nervous. If I get upset I go outside for fresh air, or I go near the door of music and I come and sit down. I just sit down and listen. Being at music and listening to it on the tape as well or you know listen to CD ...just listening to nice music and hugging people and all that stuff... calms me down.

Research makes me tired! But I think it's important... to know about music.

Appendix 10: JANIECE'S STORY

I love playing music. When I started music I wanted to play the guitar, but now I've changed from the guitar to the piano... I wanted to try the piano. It's sort of easy, and hard... It's sort of easy because sometimes I know the chords off by heart. ... Sometimes I do have the notes in front of me, but then I try to add more chords to it.

I don't know what I want to do next with music. I might still do piano and guitar. I basically sort of get guitar lessons from Julie. Maybe I could keep playing the piano at ACTIVE. It would be good to play with people rather than just getting piano lessons. Julie knows how to play piano as well. I could still play it with Julie. Sometimes I play guitar with Julie, and I play it by myself. I never played the piano here at ACTIVE though, and I don't know why. But I wouldn't want to play it where other people can hear me, except at ACTIVE.

My mum knows I will be doing mostly doing the piano in the concert. My brother said "what about the guitar?" and I'm like "nope!" I think my brother will most probably laugh but my mother said "no, you're not allowed to laugh at her". But he's got training that night because it's on a Wednesday. It starts at 5-something and he won't be able to get up here with my mum. He will most probably have to come with my step-dad.

I was the data demon (when we did the analysis). Me and Patrice were data demons and we had to try to help everyone out. Research is good. Sometimes it's boring. Sorting it out into piles is boring. I like watching videos, but then it's annoying when I can hear my voice. I'm very loud. Most of the time when the video is on me, and I'm on the piano, you can't even see my face; I'm looking down at the piano chords, because I know the video camera is there. It's ok though. My mum is probably going to video me at the music concert. She was like "can I video you?" and I said "yes, only you!" You could do one too though. My mum wants to show she can show my dad what I have been doing.

We can make a story out of our research. That is good. Our family will think it's good. Just people like that, because dad doesn't know about the music concert OR the play. He lives all the way in the Hutt, but sometimes works in town. People at ACTIVE need to know what we've been doing as well. (This music research) is worth doing again because it's fun, just fun! I've also been trying to get rid of the nerves.

Appendix 11: EDWARD'S STORY

Music is hard. I like music. I enjoyed guitar and singing music from Aladdin. I brought a music book to sessions so I could play guitar. I was choosing from my book and sang in front of the group and played guitar. I did some singing and played guitar in the concert too. (Cam wasn't there. Daphne was there. She said she saw me smiling and playing, and putting thumbs up as if I was proud of myself). I came to Massey by myself with my guitar, and sometimes I stayed at the back of the room. It was hard for me to sit with the group. I was tired. I was sometimes happy at music; but sometimes angry. I wanted to go home. I came to music to meet Julie. I like playing with Julie. I wanted to come to music; I liked it but it was hard to hang around. Playing with one person is easier. If it was my music, if it was smaller, it would be better. If one person could play at a time and everyone was listening it would be easier. I like it when people listen to my music. I wouldn't come to music group again. I want to do music a different way.

Edward's Mum read the story and said:

Hi Daphne,

Thanks for the feedback. I think you captured Edward's feelings well.

My feedback would be that even though he didn't enjoy the group work being involved in this project heightened his awareness of his ability to do music. Since the project started he is singing much more at home with much more volume and focus. This is honed further by his enjoyment of the music/singing sessions on Monday mornings with Julie at Active.

I think Edward learned a lot through being part of your research project and the opportunity has made his world a whole lot better - so thank you.

Appendix 12: KWAME'S STORY

Music has been pretty awesome. It's ok. It's enjoyable introducing myself and making new friends; telling people what I do for sport, and ... in my spare time. I do making movies in my spare time. When I get bored, I shut the door of my house and go for a walk, check out music, and talk to people. I like music. I would like to make a Lion King movie at music. I feel great thinking about that. We will have music, soundtrack, the props, and the movie making ... everything.

Music reminds me of my family. After they visit me I often go visit them overseas. I can't come back to music because I'm missing my family. I feel sad at music. But I trust you guys. I might come back after Christmas. Six weeks in a row. I can cope with six weeks. I can cope with that. If I feel sad I'll have to talk to you guys. Inside I was feeling angry inside my heart. Some people think – they don't like the Lion King? They said, that's boring, let's do a different one. But, no, this is the best one I've chosen, that I chose, for others, not for you. (If I feel angry I need) to talk to you guys; I need to have calm down time, calm down time and then I'll come back inside. And practice asking to have a turn, and being patient.

I was going to make notes in my diary. I could bring my diary in, and bring it so I can make notes. And it's been my job putting notes into the printer. Putting them in to printer and printing them out. It was a hard job and it's good that it's finished.

Appendix 13: DAVE'S STORY

I came to music every time, "to join in". It's pretty hard for me to join in. I achieved on drums though. And when one of my friends was down, I cheered them up a bit. Drums were not that much enjoyable for me though (unless it was the drum kit). I think I enjoyed making songs up. It was hard making the first song we made up last year; it was the hardest song, and I didn't really like it when it was finished. My favourite thing was playing the drum kit and I didn't get enough of that. I used to play it, but we had to do new songs. I was a bit nervous when people asked me to have a go on the drums though. I would like to play with a tutor, but maybe with a big group as well. But I want to focus on drums, not other things.

Appendix 14: AXEL'S STORY

I don't mind people hearing my story. I do have a lot to say to people... a lot of people. The whole crowd!

We walk every Tuesday to the university. It's such a big space that Massey. It's such a cool room ... because it's like a teacher's room. It's quieter and it's got glass windows for some fresh air, and that drinking tap. I also like the library. This year I'm going to the library. And I've been to the cafeteria. I eat my lunch outside. I might go in to buy a coffee one day because I'm very independent.

At music we do warm up games. I like that clapping one. I like playing the drums at Massey University and I like the beat on the drums. It's so good to give a beat. ACTIVE is very important for music. I like to listen to music with my *friends* at ACTIVE. It's pretty important to me. Music is *such* a good, great personality for the ACTIVE people. It's such a good personality for eye coordination, hand movements, and talking with your own voice. And I like Tessa's dance moves. Music is *such* a *good thing for ACTIVE*. We can help each other at music. But I would like to work in small groups too. It's very good for me…because I don't like big groups. Because another person talks to you, another person talks to you, another person talks to you... Small groups, one person talks, and the other people listen.

I felt sorry of Kwame leaving us and the music university. It's so sad for people. He was so good last year at music. It's so, so sad that he left music at Massey.

This year I'm going to get good at music and research. At research you write on your journal, things that are easy, hard, good, bad, and difficult ... and changing. It's part of our research. We watched video of our music. You can listen with your ears and write some things on your papers, on your books. It's good! It shows us we can research. Writing every Monday at ACTIVE is important. Monday I might do some more research in my folder. I like those folders actually. (They're) so good. You can put stuff on that folder.

I like that big book we have started to write. It showed the whole research we did last year. And... it's a big book. It's very important to hear about that. We are Massey. We do research. The music and the research have been awesome. I'd like to do some more this year! I need to work my butt off! It's hard work but its good fun. It is a good idea to do research actually. Because it means we can get help. We do have research to back up (the things we need)... a *lot* of research to do actually! I'm getting my butt into research this year.

When the music is over and done with I'm going to miss it a *lot*! I like Daphne and Erin and all the ACTIVE people who go to music. I hope we do a big band here. When we have finished and the ACTIVE party starts, we should do a band... with the whole of ACTIVE people. I would be the drummer!

Appendix 15: KATE'S STORY

I like coming to music. It's fun. It's all fun, like doing the concert. I'm singing songs; Lean on Me, Fireworks, and Roar. I've played drum, tambourine and shaker at music. I feel happy about coming to music. But there were sad times. Like when our friend ZiZi passed away on the 4th of October. We were all upset. We sang Beyonce, and it helped because she liked that song. (Another time) I was able to share that my sister was coming home. Talking about things is important. It's important to talk about music. I would do more music if I could. I'd like to try the piano because I have a keyboard at home. I didn't play at Massey, because I didn't speak up. I would like to play keyboard with a group because I like doing the keyboard with other people.

Appendix 16: SHAFIQ'S STORY

Shafiq highlighted the things that he thought were important in other people's interviews (17th March 2014). Daphne has joined them together to make his story.

I like coming to music. We walk every Tuesday to the university. I've been to university... it's fun. University is important. But the university is a confusing place. There is a library. It's such a big space that Massey. Our room is like a teachers' room, quieter, with glass windows for fresh air, and a drinking tap. Massey music is important for doing music. I want to go to music every Tuesday to play guitar and drums, and listen to CDs. I can't go to music lessons by myself. I like coming to music because I've been here before. I eat my lunch outside. There is coffee.

Music is good for ACTIVE people. I noticed hand movements and Tessa's dance moves. She danced to Beyoncé 'Single Ladies'. It's very good. It's good being together in a group, listening, helping each other, noticing each other, learning new things about each other and ourselves. It's good being with friends. We are learning lots of things about each other. We are a team. Joining music picks up my brain.

I don't like big groups. I wanted to work in smaller groups. Some people don't like noisy. We should talk one at a time. It's bad when we talk when other people are talking. We should listen to other people. Sometimes we hear the first person playing, and then we hear the next person playing. Sometimes I feel comfortable in the corner. We wanted to feel comfortable listening when we didn't want to play or dance. I drew a picture of myself with headphones listening to Michael Jackson. It is easier to listen to music with headphones on. But I listen when I am playing the shaker egg too.

I enjoyed when we are not at Massey?

You have to be involved with music to see if you would like it. We wanted to try new things. We decided to tell each other about the things we like and don't like. I'm playing music and singing songs; Lean on Me, Firework and ACTIVE (We Will Rock You). That's the song we made on our own. It was fun making our own song to write. It was cool doing the old song that we wrote too. We haven't had enough time. I like Spice Girls but we didn't do Spice Girls. I've played drum and I want to join in the drum kit. I like playing drums. Drumming, beat, and rhythm are good. Doing beats is fun and everyone is happy. I would like to make a Lion King movie. Some people think they don't like the Lion King. I like musical statues, boomwhackers (even blowing into the boomwhackers), chimes, and balloons. I like keyboard and piano. And I like songs from our childhood. I like The Wiggles. I like world music too. I like singing too – Spice Girls, Michael Jackson (Beat It; Bad), Katy Perry, Leanne Rimes, Britney Spears, Lean on Me, We are Family, and singing the blues. Michael Jackson and Lean on Me were easy. It can be hard playing the keyboard, dancing, and doing We Will Rock You. I didn't like We Will Rock You at ACTIVE Music. Can we do 'Hallelujah'?

When Erin and Patrice were playing the instruments with the song that Patrice picked because she wants us to know her better with the songs, Erin was playing the flute. The song was Lean on Me. It was cool meeting Patrice for the first time. She was cool and a nice person. One day Erin and Janiece were playing the guitar and Kate joined in with her guitar and then Tess, Axel

and Tessa joined in with their instruments. Janiece sang, and Erin helped her with the guitar. It was cool. It was really cool that we all sound cool together.

It's good to work out what is ok, and what is not ok. We shouldn't laugh at each other when we are learning the guitar. Being respectful and nice is good. People said "it was cool helping (someone else). It's good to talk about what is going on in our lives; to share about ourselves. It was good that someone told us it was their birthday on Wednesday. Trying to speak up was one of our goals. I wanted to ask for more guitar and singing. Yes.

Tess doesn't like the man taking photos of her with others. Axel talked to the man about the photographer. Maybe Axel was assertively helping Tess? Videoing music and taking photos is ok. Video is for research. It's helpful to watch the video of us. Put the video on the stand because you can see everyone. We could keep watching ourselves on the video to do research because it is fun to watch our video to see how we did well. We write what we like and then we give our book to Daphne so she can copy our book to be read for research. Some people write; sometimes we do it together on the whiteboard. We can sort the data by having a bit piece of paper and brainstorm. It's good that we have research folders, library cards and a Facebook page. Writing at ACTIVE every Monday is important. When people read the research, research helps us get the things we need. It would be good to have more computers so people can find more stuff. We didn't have enough money for new computers.

People can play with help. We agreed that we would ask for help if we need it. The first time we played it was too fast but the second time was really good because we all did the same part of beats on our instrument and we all listed to everybody's ideas as well. So we were all happy. Copying actions step by step would be good next time.

Sad things happen at music. Being sad was bad. Zi Zi died on the 4^{th} of October. But listening to African music was easy. Zi Zi's music was good. It's so sad that Kwame left music at Massey. Then Jacob told us what the song means to him. It was a sad song that Jacob told us. The music helped, the beat makes people happy. It is good that there were less sad people after music.

I like Daphne and Erin and all the ACTIVE people who go to music.

If I feel angry I need (to talk). If I get upset I go outside for fresh air. It calms me down.

It is good that staff stopped coming to sessions. Working with people with disabilities, it's easy. We thought it was important for Sarah's helper to be there to keep her safe.

Appendix 17: TASH'S STORY

Music is fun and it's interesting and we learn more stuff, when we do research. Some days we just - Daphne just copies our things and then we do that thing with the other guys, to see what they think music is all about and stuff. And then we know what they like and stuff, whether it's noisy and stuff. Some people don't like noisy and yeah; after we have finished the research and have all the information we need to do we will make a book, a research book, for our family and friends... so our friends and family will know what we have been up to and what Massey Music is all about and what research is all about. And help each other with confidence. (When people read the research) they will know what we talked about. They can read it or write similar things to what we did. ...ACTIVE and IDEA Services or something, need to know what we do at Massey Music every Tuesday and that's fun and it's our last music session with our leaders. We need to let other people know what we want to do in our future, a long time in the future and things. And just like help us and stuff with everything we need to do for our future. ...like could we have smaller groups than what we have been using and stuff. And everyone could have a smaller group coming to Massey and then have a smaller group each day and stuff and it won't be that noisy. (Was it important that it was at Massey, or important that it was *music?*) Both! Because we like – we are enjoying coming to Massey for music and research. It's fun and it's really what we want to do. (University is important?). Yes. Because we are in the university school, in like, in with all the other people and stuff. (University)...it's fun. (I've been to) the Massey building, the Massey music one, and sometimes we go to the library or the café. We went to the café a couple of times with the whole group. I think I could go by myself or with friends. I went to the library with friends mostly just to see what it was all about. We looked all around where the library is and stuff. (If I was coming longer) I would go to the library to read a book or study.

Research Process

When we went to Massey we got a video recorder up to see the whole group, then Daphne came with a CD or another thing and during the breaks wrote the Massey research, and wrote the things we like and stuff, and we copied it in out books and gave it to Daphne to copy and then when the research was coming we sorted them out to see if it was good, bad or worse or maybe or both. And then we would do that and then the boxes were tidied up and we could tell Daphne what to write on the laptop and stuff. We are confident comfortable to do it, to tell people what we like or something. When I do my data I write. Some people write, but other people draw pictures, and sometimes we write something underneath what it is all about. (Sometimes we do it together on the whiteboard or by interview like this?)...and we help each other with it and stuff.

(I enjoyed) singing, writing new songs... writing our new songs, and the jams, and all kinds of cool music stuff. It's a unique opportunity. (When we are not at Massey) we just read what's on the video and write it in our books and yeah... We don't do any music. Sometimes Edward comes and some other days some other music stuff. I listen to music at home, sometimes I sing. (Massey music is important for doing music). Yes!

(What would you like to do next?) I don't know, probably like, probably do some more music or research or stuff like that. The research is fun, so we know what other people think, so we can know what other people think, what they feel about music and stuff.



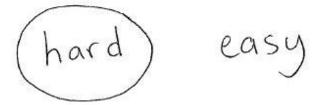
Appendix 19: Facial Expression Answers

wanted to work in smaller groups



Singing Michael Jackson Songs

(hard) easy



Some people don't like noisy



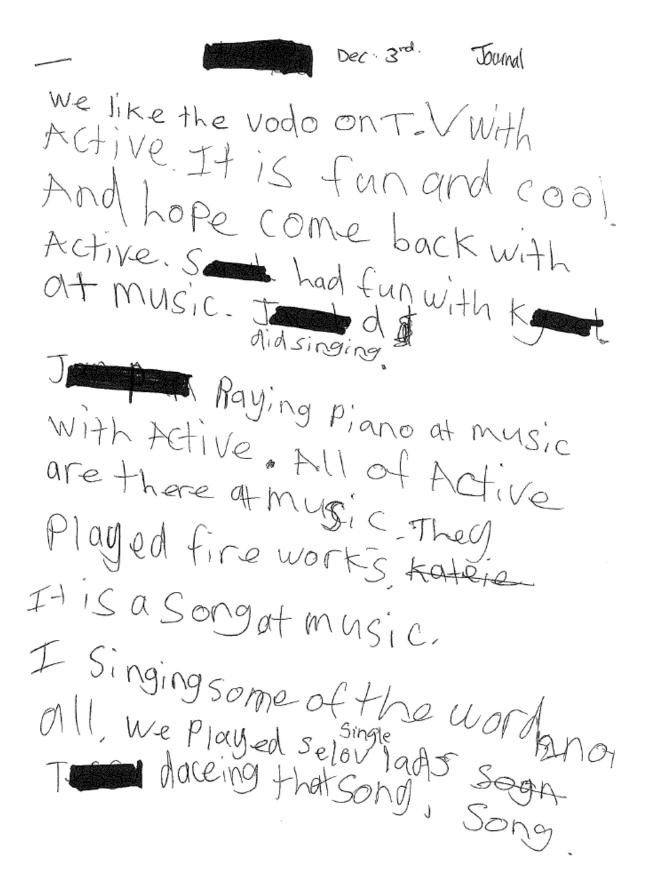
You Don't like when it's noisy?



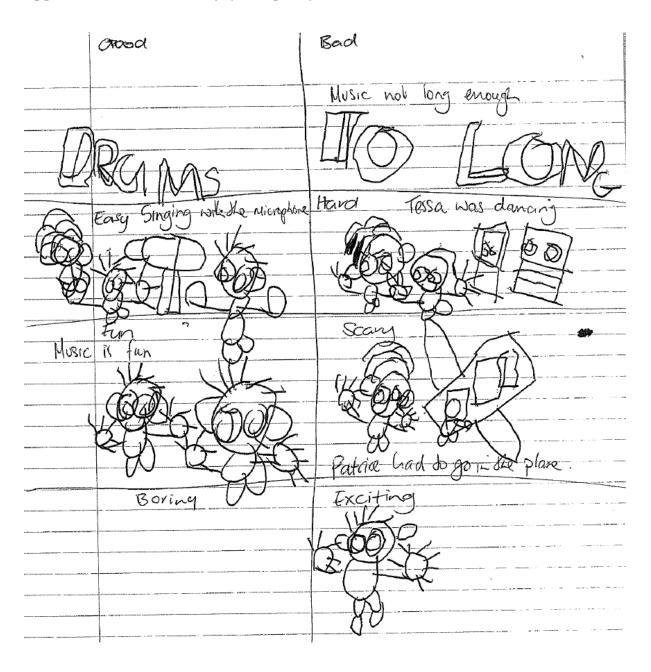
Appendix 20: Journal entry (example 3)

02/10/13
The video was really good Everyor
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we were trains out to
exercise - T Kent laughing
alot Everyone rapked Joak ed
exercise. The stranghing alot Everyone rooked Jooked Jooked Jooked Jooked
201/20 1 (de 1) p 51
and the work he wash
the the work of the state of th
The I walken I be
TO WITH TO
patrido Kept putting the Car
near me z would hide Pavid
Kept aughing alot. The Ye
no game was really fun
It was fun because everyone
knen the senq. They were yn a
positremond) were qui a
-11 MA

Appendix 21: Journal entry (example 4)



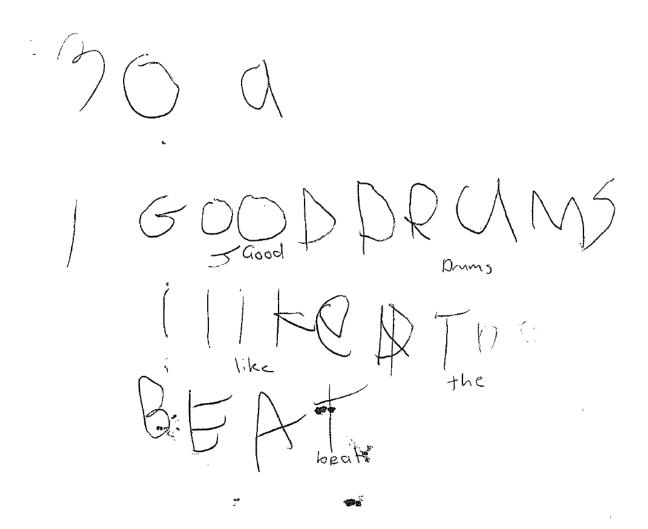
Appendix 22: Journal entry (example 5)



Appendix 23: Journal entry (example 6)

MUSEY MUSE Friends & patrice

Appendix 24: Journal entry (example 7)



Appendix 25: Drawing



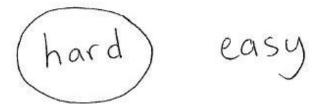
Appendix 26: Facial Expression Answers

wanted to work in smaller groups



Singing Michael Jackson Songs

(hard) easy



Some people don't like noisy



You Don't like when it's noisy?



Appendix 27: Highlighting the Important Bits

We walk every Tuesday to the university. It's such a big space that Massey. It's such a cool room ... because it's like a teacher's room. It's quieter and it's got glass windows for some fresh air, and that drinking tap. I also like the library. This year I'm going to the library. And I've been to the cafeteria. I eat my lunch outside. I might go in to buy a coffee one day because I'm very independent.

At music we do warm up games. I like that clapping one. I like playing the drums at Massey University and I like the beat on the drums. It's so good to give a beat. ACTIVE is very important for music. I like to listen to music with my friends at ACTIVE. It's pretty important to me. Music is *such* a good, great personality for the ACTIVE people. It's such a good personality for eye coordination, hand movements, and talking with your own voice. And I like Tessa's dance moves. Music is *such* a good thing for ACTIVE. We can help each other at music. But I would like to work in small groups too. It's very good for me...because I don't like big groups. Because another person talks to you, another person talks to you, another person talks to you... Small groups, one person talks, and the other people listen.

I felt sorry of Kwame leaving us and the music university. It's so sad for people. He was so good last year at music. It's so, so sad that he left music at Massey.

Appendix 28: Communicating with facial expressions or through choice making

when you don't like the writing, cross it out in black, like this: can we do Hallelyjah to music through headphones (easier harder What he wants to hear

Appendix 29: Answering questions on paper

Old you ask the holp when you needed it at mus Help Music What did you need help with? Help More Music? More Help Me Music How. could we help you more? With Help with or song Guitar and Singing. Another time, would you like to do more guitar and singing? No Yes Guitar? NolYes singing:

that's better, yes "

Appendix 30: Typed up journal data, October 2013

Music was good.

The lion King is good.

It is good that there were less sad people after music.

Zizi's music was good.

It's good that we weren't too loud.

Being sad was bad. The music helped, the beat makes people happy.

It is bad that there was no dancing...

Being without staff was easy but it was also challenging.

Reading the fireworks lyrics was hard.

Using Facebook is hard.

Nothing was boring.

Being with friends and Patrice and Daphne is fun

Listening to music from other countries is fun.

It is good that staff stopped coming to sessions.

Listening to African music was easy.

Hard: ZIZI

Fun: (a picture of several people)

The drums were good

Music isn't long enough

Singing with the microphone is easy

Hard: Tessa was dancing

Music is fun

It was scary when Patrice had to go on the plane

Exciting: (a picture of one person)

On Tuesday I was embarrassed when I told everyone what song was important to me and my favourite.

But I liked how Daffodil did the song on the piano.

The song that is important to me is called "from this moment on" by Shania Twain.

Then I played lean on me on the piano.

The video was really good.

Everyone was having heaps of fun when we were doing our warm up exercise. I kept laughing a lot. Everyone looked like they were enjoying themselves.

When we were singing "don't worry, be happy" everyone was having so much fun.

I liked playing the guitar with Patrice.

When Daffodil kept putting the camera near me I would hide.

David kept laughing a lot.

The yes no game was really fun.

It was fun because everyone knew the song. They were in a positive mood.

It was easy to pack up the stuff from the ball

It was hard without my mum
It is fun at the ball, it was so good
I'm excited when I come home with my mum to see my brother at mum's place.

The beat 'busters' game was good. It's bad that Tessa performs awesome dance moves

Me joining the music picks up my brain The "beats" were exciting Mondays went I did the data! At the beginning of the week my brain gets bonkers.

The World Music, Spice Girls, Michael Jackson off best Leann Rimes, Britney Spears bad Music you are here. Remember and do you are music video sing song and To be before The wiggles a Very good.

Music video. It was fun/I was happy
I like playing keyboard
We did musical statues with song Katy Perry
We made our own song about active
I enjoy music (picture of smiling face with a crown)
It makes me happy Playing Balloon game Playing different songs. I like Katy Perry, Miley Cyrus, Queen, Britney Spears
Playing songs like Katy Perry single ladies by Beyonce
Patrice played the song 'Lean On Me' (included picture of stars and musical notes)

We should keep doing song writing Being respectful and nice is good Having fun is good

It's good that Tessa's dancing is for the memory of Zizi Making new friends is good Katy Perry Firework is good I love performing Tessa's performing is sexy.

It's bad when we talk when other people are talking we should listen to other people. The Michael Jackson song was bad.

Playing the keyboard was hard We played lean on me, it was hard We love doing we will rock you, it is hard We can communicate with others, it is hard Finding the right keys is hard

Playing One Direction for the memory of Zizi was easy

We should keep on videoing I love singing and performing in front of everyone, it's easy I love working with people with disabilities, it's easy

We listened to a South African song it was fun I love doing music, it is fun
Being respectful to others is fun
We could continue to do research its fun

The drumming was scary
The loud music was scary
Too much noise is scary
The drums were scary
It was too loud

We should do some more dancing and singing to music, it's exciting The musical instruments were boring Michael Jackson is boring

Michael Jackson "I'm Bad" was boring The loud music was boring The drumming was too loud and boring

Appendix 31: Direct quotes from young people

"When we were practising Firework, I thought it was good to practise it. Because if people didn't know the song they could learn the lyrics or learn how it goes. I liked singing Firework because some people liked it and some people didn't like it" (21/10/2013)

"I liked playing the piano with Erin because it was good to learn how to do something different from guitar. I thought the piano sounded good in Firework. Sometimes I would get the wrong key. It was hard trying to get all the keys on the piano. It was hard doing music while people took pictures of us. Piano is my second fave instrument" (21/10/2013)

"When we were dancing it was funny how me (and two peers) were doing the same moves as each other. It was funny how we were all copying (someone else's) dance moves" (21/10/2013)

"I like filming everybody. When we were making a thunder sound the drumming was good and it sounded like that everyone was copying D and T. But when I put the video camera onto T she was looking at me weirdly. It was hard trying to listen to the thunder sound because it was really noisy. It was good how no one leaded it. Everyone was leading it not just one person. Which was good" (21/10/2013)

"I really want to do a song on the piano with Daffidol or Erin" (21/10/2013)

"The video was really good. Everyone was having heaps of fun when we were doing our warm up exercise. I kept laughing a lot. Everyone look like they were enjoying themselves. When we were singing 'don't worry be happy' everyone was having so much fun.I liked playing the guitar with Patrice. When Daffidol kept putting the camera near me I would hide. D. kept laughing a lot. The 'yes no game' was really funny". (27/10/2013)

"It was fun because everyone knew the song. They were in a positive mood"

"This is good, so fun, ©, le cool bro"

"Go zcal"

"Looks hard to sing over drums"

"I like listening to others; I don't think there was enough of this while they played..."

"E. shouldn't hide. It's better when he joins in"

"I don't like Katy Perry's song. I wasn't at music last Tuesday... I was getting stiches"

"S is sleepy"

Appendix 32: Our concert programme

ACTIVE MASSEY MUSIC CONCERT

For all instrumental pieces:

Piano - Janiece, Daphne, or Erin

Drums - Jacob, Dave, Axel, Tess, Kylee and Sarah

Shaker - Shafiq

Guitar – Edward, Patrice or Erin

Vocals - Tash, Tessa, Kate

For all arrangements:

Piano then

Drums then

Guitars then

Voices then

3 x through.

Quieter --> stop

Our set list is on the next page.

SLIDE ONE

ACTIVE IS AN AWESOME TEAM! WE WILL ROCK YOU! YOU'RE GONNA HEAR US ROAR AT THIS CONCERT!

1. FIREWORK by Katy Perry

Instrumental arrangement as above

2. ACTIVE IS A TEAM by the Massey music group and Queen.

Body percussion – Everyone! Drums – x 2 for support and soloing Song start leader – Jacob Song end leader – Tash

3. Roar by Katy Perry

Instrumental arrangement as above.

- 4. JANIECE TALKING ABOUT LEARNING PIANO
- 5. WHAT WE HAVE BEEN DOING (PLAY TRIBUTE TO NELSON MANDELA)
- 6. TRIBUTE TO NELSON MANDELA (THE WORDS)
- 7. GOING TO UNIVERSITY
- 8. RESEARCH
- 9. ANALYSING OUR DATA

10.Lean on me

Instrumental arrangement as above. Slow and steady.

11. Percussion Improvisation

Tuned and untuned percussion: everyone!

Leader: Sarah, if well

12. MARVELOUS MUSIC by the Massey music group and Tina Turner

Instruments as above.

Arrangement: straight through song, repeat end chorus.

Song end leader – Janiece (piano roll)

13. WHAT DID WE FIND

14. AXEL TALKING ABOUT RESEARCH

15.CREDITS

16. THANKS

Appendix 33: One of our compositions

SONG: 'MARVELLOUS MUSIC' (ACTIVE & TINA TURNER)

TUNE: 'ROLLIN' ON THE RIVER'

ACTIVE is awesome, Mandela's cool We've done a Nelson Mandela tribute Don't disgrace him, he was a president Active is helping remember him, cos

CHORUS

We're gonna keep on singing We're gonna keep on playing Rolling OOH, Rolling down to Active!

ACTIVE is awesome, Mandela's cool We've done a Nelson Mandela tribute Don't disgrace him, he was a president Active is helping remember him, cos

CHORUS

Janiece plays 'Firework' on the piano And she likes to play the guitar That's what she likes, She goes to Massey music She is a diva superstar!

CHORUS

We're gonna miss Massey music, Erin, Patrice and Daphne too They are fun to play with, They are good leaders We are all good friends as well

CHORUS

We had fun at music So much fun at music Marvelous OOH, Marvelous music!

Appendix 34: Another one of our compositions

SONG 'ACTIVE IS A TEAM' (ACTIVE & QUEEN)

TUNE: 'WE WILL ROCK YOU'

VERSE ONE

ACTIVE IS A TEAM, DON'T DISGRACE THEM

WE DO MUSIC RESEARCH, BRING IT ON!

WE GOT SONGS TO DO

GOT BEATS TO MAKE

WE'RE NOT GONNA BE YOUR PANCAKE!

WE DO WE DO RESEARCH!

WE DO WE DO MUSIC!

VERSE TWO

THINKING IS ELASTIC, SINGING IS BOMBASTIC

PINGING BALLOONS ** DRASTIC!

HERE COMES THE BOOM, BOOM BOOM SHAKALAKA

DON'T MESS WITH ACTIVE

BOOMSHAKALAKA!

WE ARE WE ARE THINKING!

WE ARE WE ARE SINGING!

MASSEY UNIVERSITY

MASSEY RESEARCH ONLINE

http://mro.massey.ac.nz/

Massey Documents by Type

Research Reports

Active music

Rickson, Daphne

2014

http://hdl.handle.net/10179/5458

20/01/2020 - Downloaded from MASSEY RESEARCH ONLINE