What Changes in Relationship with their Children do Primary Caregivers Perceive as Having Occurred Since Being Involved in a Centre-Based Early Intervention Music Therapy Programme?

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Abstract

The purpose of the present study was to examine how participation in music therapy (MT[1]) influenced the carer[2]-child relationship when both carer and child were involved in group and individual MT as part of an early intervention (EI) programme[3]. The study took place at the Wellington Early Intervention Trust (WEIT), a centre catering for children with significant disabilities, and their families.

Four primary caregivers involved in this centre-based, multi-disciplinary EI programme involving both weekly group and individual MT were interviewed. Two carers had more than twenty MT sessions, while two carers were interviewed after only ten sessions. Analysis of the transcripts comparing the carers' responses revealed a number of common features: First, a marked change was observed in the nature and quality of carer-child interactions consequent on participation in a specific EI programme. All four participants[4] spoke positively about their involvement with their children in both the group and individual MT sessions. Second, not only did the carers report positive gains in their children's overall development as a result of their experience of MT in EI, but all four participants reported how they now used music as part of their every day lives as a tool to encourage and maintain positive carer-child interactive experiences. Third, each carer became more aware and confident in how to use their own voice and body language to engage in successful interactions with their child.

This study found that the interactions between child and caregiver changed in nature and quality since being involved in MT in EI. Their relationship with their child had strengthened with positive results for the child's developmental objectives.

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[1] Acronyms are identified when first used

[2] Throughout this thesis the terms primary caregiver, carer, parent, are used interchangeably to refer to primary caregivers who may or may not be parents.

[3] English spelling will be used in text, such as centre, programme, behaviour, colour, favourite. American spelling will be used if it is in the original text being quoted, such as center.

[4] The term "participants" refers to the caregivers in this study.

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This study received ethical approval from the Wellington Ethics Committee (Ref No: 03/05/049). It was also reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 03/107.

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Introduction

In 1990, a New Zealand mother flew one hour, once a month, from Wellington to Christchurch to take her child with Cri du Chat syndrome[5] to a multi-disciplinary Early Intervention (EI) centre. She did this because there was no similar service available in the greater Wellington area. Impressed with several features of the Christchurch programme (e.g., the structure, the degree of family involvement, and the multi-disciplinary nature of the team), she recognised the need for such a centre within her own community. Being proactive, she contacted within her locality other parents who had children with special needs. Together these parents set about establishing the Wellington Early Intervention Trust (WEIT), which was incorporated as a charitable trust in early 1991.

The members of the initial WEIT therapeutic team included a speech language therapist, a physiotherapist and a cognitive therapist. Being known to one of the participating therapists through my work in MT in Special Education, I was invited to join the team in March 1991. None of the few professionally qualified music therapists in New Zealand was working in the field of EI. In effect WEIT initiated a new dimension to the multi-disciplinary approach – the inclusion of a music therapist.

WEIT subsequently became a licensed and chartered Early Childcare Centre in 1998. It is accredited by the Ministry of Education to provide EI services for preschool children with special needs in the greater Wellington region.

In 1994, the 'Year of the Family' seemed an appropriate time to survey the families I was working with in order to gauge their reactions to the inclusion of MT in their children's EI programme. The results of this exploratory survey were presented in a conference paper (Archer, 1995). The survey enquired particularly about the kind of music-making that occurred within the family environment prior to involvement in EI;

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[5] A genetic disorder causing a varied level of physical and intellectual disability.

the changes to the frequency and nature of music-making since EI involvement; the perceived benefits to participating children; and the perceived benefits to their families. Additional questions were directed to perceived benefits arising from the use of resources such as audiotapes as well as to soliciting general comments about the MT programme.

The carers' responses about MT in EI were generally positive. They indicated enrichment in both the frequency and nature of their own music-making at home, and perceived benefits to the overall development of their children. Analysis of the responses to the question about benefits for the family showed that 'enjoyment' was evident in the majority of responses expressed as "family fun," "family togetherness times," "family sharing," and pleasure in seeing their children being responsive and happy.

These were initial indicators that MT may have beneficial effects in EI programmes. One primary caregiver's responses are indicative:

> Music has become a very natural way to respond to our child's initiatives and a very positive way to interact with him. It has been a major contributor to building a bond between him and me. At times, often in fact, I felt I was imposing activities on our child, be they physical, cognitive etc, and I became a therapist not a mother. Through work with our music therapist I have learnt, am learning, to respond to our child, to provide activities in a fun way he will enjoy and consequently the mutual enjoyment has built our relationship.
> (Survey response, from exploratory survey reported by Archer, 1995)

Here is a mother saying that as a consequence to her modifying her behaviour as a result of MT in their EI programme, her relationship with her child strengthened. These words have remained with me over the years as I have observed many carer-child relationship changes take place. And these relationship changes have been important, they are life changing.

So what is happening here? For 12 years, MT at WEIT seems to be making a positive difference to families and their children with special needs. We know little about what aspects of MT are motivating changes, especially within the carer-child relationship. We also don't know to what extent caregivers perceive music as being a source of influence on their relationship with their children.

Anecdotal evidence can go only so far. Research is needed to find out what is really going on: the music activities and strategies used; the role of the music therapist, of the other therapists, of the carer, of the child, of the group MT, of the individual MT. We are a service for the families, not just the children coming to us as clients. My intuition is that even if we as therapists influence children's progress, it is not as important as the carers themselves becoming proactive in both their own and their child's development. Moreover, if positive gains are made in carer-child relationships in the pre-school years, then this must set up a good base for future growth for the child and the family.

Hence the motivation for this research.

In order to put this research into context I will first discuss the literature as it pertains to aspects of my question: carer-child relationships with typically developing children and with children with disabilities; EI and its journey to the present day; MT in EI, the multi-disciplinary approach to EI, and the setting for implementation of EI services (home-based versus centre-based). Following this discussion of the theory I will describe the practice as the researcher experiences it in New Zealand. Reflections on the relevance of the literature to the context of the researcher's clinical practice give rise to the purpose of this thesis. The ensuing study sets out to expose a niche in research and practice of the relevance and importance of MT in EI.

Literature Review

Carer-Child Relationship

The study focuses on the primary carers of a group of children with special needs. In particular, it examines what it is that initiates changes in relationship within the carer-child dyads and what the nature of such changes might be. In order to consider some general aspects of carer-child interactive behaviours when a child has a disability, the character of some frequently reported interactive patterns occurring in dyadic relationships with typically developing children will first be discussed. Subsequently, the interactive behaviours of both child and carer, and the possible consequences for further interactions when the child has a disability, will be addressed.

Typically developing children

Guralnick (1997) identified three essential family interaction patterns that influence a child's development:

1. the quality of parent-child interaction
2. the extent to which the family provides the child with diverse and appropriate experiences with the surrounding social and physical environment
3. the way in which the family ensures the child's health and safety

(p. 5)

The first point is the most pertinent to this study. Primary caregivers and their children learn to adapt, modify and change their behaviours when interacting with each other (Barnard, 1997). Blackman (2002) emphasizes the salience of the period of early childhood for optimal development, "There is no more important period in human development than conception through early childhood in maximizing the potential for living fully" (p. 11).

The family system is known to exert a powerful influence during the early years of life (Minuchin cited in Klein & Gilkerson, 2000, p. 456). The quality of primary carer-child transactions is considered central to the development of all children (Barnard, 1997; Crockenberg & Leerkes, 2000; Greenspan & Wieder, 1997; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Ramey & Ramey 1998; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992; Stern, 1998; Weis & Lovejoy, 2002). Positive carer-child interactions during childhood tend to be linked with better developmental outcomes in subsequent years, including emotional/social development (Robinson, 2002). This is further supported by Zeanah, Larrieu, Heller, & Valliere (2000) with their statement, "Early relationship experiences are predictive of subsequent psychological adaptation in the child" (p. 233).

The primary caregiver is the most important link between the newborn child and its environment (Klaus, Kennell, & Klaus, 1995; Zeanah et al, 2000). The infant is totally reliant on this person for basic needs such as food, clothing, shelter, sensory and social stimulation. But the infant also has its own innate response in perceiving and modulating sensory information. In their attempt to provide a framework for understanding how infants and young children interact with their environment Williamson and Anzalone (1997) categorized responses to sensory experiences into the four A's:

> 1. **Arousal** refers to the ability to maintain alertness and transition between different sleep and awake states. The child's current state of arousal influences sensory registration.
> 2. **Attention** is the ability to focus selectively on a desired stimulus or task.
> 3. **Affect** is the emotional component of behaviour. Modulation of sensory input directly influences emotional responses (e.g., a child may respond to loving light touch with a strong aversive reaction) …
> 4. **Action** is the ability to engage in adaptive goal-directed behaviour
>
> (p. 30)

The character of children's responses to their environment, in this case specifically to their primary caregivers, is also the focus of theorists interested in the subject of 'attachment'. Attachment theorists are interested in studying the link between the child's developing personality, their interpersonal behaviours and the quality of the social environment during these early years. These theorists are interested in the quality of 'attachment' and how this affects relationship skills and self-esteem as it emerges in the child's future development (Bowlby, 1988; Cassidy and Shaver, 1999; Goldberg, 2000; Howe, 1996; Karen, 1998; Meins, 1997; Steinberg, 1998; Svanberg, 1998; Zeanah et al., 2000). Research findings suggest that secure attachment provides the basis for an individual to be more able to cope with stress, to vary behaviour to suit situations, and to recover from setbacks occurring throughout life (e.g., Colin, 1996).

Although attachment theory is clearly important – and is treated briefly on page 11 in relation to carers with children with disabilities – attachment theory per se makes only a partial contribution to the central question guiding this investigation. To make an extensive review of the general attachment literature could direct the present study away from its central focus and accordingly the subject is not examined in substantial detail.

One constraint that the nature of the sample used in this study imposes is in respect of the gender of the primary caregivers – in this case the primary caregivers happened to be females. In reviews of the literature in the early childhood field most studies assume the primary caregiver to be the mother. The majority of studies exploring the nature of carer-child relationships are focused on the mother-child relationship. Although Hauser-Cram et al. (2001) found that the well-being of fathers was somewhat dependent on the mother-child relationship, only a minor body of research discusses the father-child relationship when the father is either the primary caregiver or a major part of the family triad (e.g., Hastings, 2003; Ricci & Hodapp, 2003; Saloviita, Italinna, & Leinonen, 2003; Seligman & Darling, 1989). Each family unit involved in this current study included a male carer, but the primary caregiver was either the mother or grandmother. As no male carers were participants in this study, this aspect of the literature is set aside.

Goldberg (cited in Barnard, 1997, p. 250) suggests three qualities of infant behaviour that influence the carer-child dyad:

1. predictability of behaviour
2. social responsiveness
3. readability of cues.

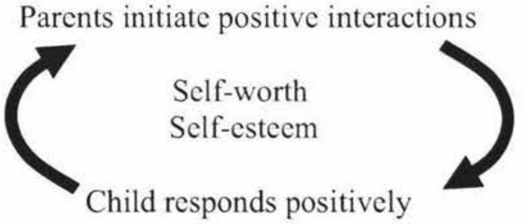
If typically developing children are relatively consistent in the child-carer responses that encourage positive dyadic experiences, future interactions will be affected. The children can begin to anticipate interactive events, and the nature and quality of the interactions are likely to be influenced by their past positive experiences (Affleck, McGrade, McQueeney, & Allen, 1982). Such experiences are stored with associated positive emotions (Weis & Lovejoy, 2002). Positive emotions trigger associated memories, positive thoughts, and impact on expressive behaviour. Conversely, negative emotions trigger associated negative ideas and negative memories may be more easily retrieved.

It is the emotional availability of the carer to the child that forms the basis for regulation (Emde & Robinson, 2000). Even though a certain amount of self-regulation from both physiological and behavioural characteristics occur at birth, the on-going development of a child's self-regulation is influenced by external regulation by the primary caregiver in the early years (Zigler, 2000). Too much excitement or too much distress expressed by the carer can cause the child to be confused or disorganised to such an extent that their responses are erratic. Carers need to manage their own levels of response to sustain relatively consistent emotional availability to their children, and this in turn contributes to the predictability of the situation (Bronson, 2000; Milligan, Atkinson, Trehub, Benoit, & Poulton, 2003; Weis & Lovejoy, 2002).

In order to establish a successful dyadic interaction both carer and child need to be able to hold each other's attention, to acknowledge a sharing of an experience, and be able to "convey emotions, ideas and intentions within the other's frame of reference" (McCollum & Hemmeter, 1997, p. 551). Both members of the dyad also need to be able to receive and interpret the incoming information. Personal differences in temperament, behavioural state, and emotional expression all add flavour to the interaction, and both the carer and the child learn adaptive skills to compensate.

Fahlberg (cited in Schofield, 1996, p. 42) represents in diagrammatic form the sense of self-worth and self-esteem that develops through a cycle of positive interactions:

Figure 1 The cycle of positive interactions



One issue arising from this diagram is whether the cycle holds when the child has a disability and has atypical expressive responses? Another is what impact does the nature and quality of these atypical responses have on the carer's behaviour?

Children with disabilities

Hauser-Cram et al. (2001) and Shore (cited in Ramey & Ramey, 1998, p. 113) address the significance of the nature/nurture debate on developmental achievement.

The current understanding amongst social scientists and molecular biologists is that the process of human development is influenced by a dynamic and mutual interaction between both nature and nurture. That is "genetic expression is moderated by environmental influences and the developmental impacts of experience are moderated by constitutional characteristics" (Hauser-Cram et al., 2001, p. 4). Thus, notwithstanding the different genetic or constitutional characteristics of children with disabilities (relative to typically-developing children), their experiences of their environment are of considerable importance.

Children have their own inherent impetus to develop. Children with disabilities may be more constrained by physical and cognitive limitations, but they still "function as agents in the enhancement of their abilities" (Hauser-Cram et al., 2001, p. 9). If children perceive an environmental response to their actions as positive, then they are more likely to repeat the behaviour, and repetition of a series of positive transactions may result in increasing competence. In a series of studies by Mink, Nihira and other colleagues (cited in Hauser-Cram et al., 2001, p. 13), it was found that the more cohesive and harmonious the carer-child interactions were, the more positive the socio-emotional functioning of the children. Fahlberg's diagram (p. 7) summarizes an important cyclic two-way situation – the more positive the carers, the happier the child, and the happier the child, the better well-being of the carer.

When reviewing the literature on the causal nature of developmental change in a child with a disability, Hauser-Cram et al. (2001) looked at both the learning from self-motivation and the effects of carer involvement. They looked at family and carer adaptation to having a child with a disability, as well as the well-being of the carers, and observed, "Mothers who were more responsive and growth-promoting in their interactive behaviours had children who showed greater growth in mental age, social skills, and communication skills" (Hauser-Cram et al., 2001, p. 84). Their findings indicate that there are positive long-term developmental advantages of early growth-promoting interactions for children with disabilities.

However, it is interesting to note that Hauser-Cram et al. (2001) found that for children with Down syndrome, the impact on positive carer interactions wasn't as evident in the mental age gain as it was in the area of social and communication skills. The implications here are that positive parenting enhances different aspects of a child's development within the limits of each child's trajectory of potential.

Obstacles to a carer-child relationship

An examination of the literature on carer-child interaction patterns suggests that the difference between carers of children with disabilities and carers of typically developing children may indicate the interactive challenges faced by carers of children with disabilities. Affleck et al. (1982) noted that if children are not providing their carer with pleasurable, predictable feedback, then the carers may lose their inclination to initiate an interaction, resulting in unsuccessful dyadic experiences.

Having a child brings about new dynamics in any family; having a child with a disability not only brings about new dynamics, but also gives rise to a testing of completely new coping skills on the part of the carers (Barnett, Hunt, Butler, McCaskill, Kaplan-Estrin, & Pipp-Siegel, 1999; Beresford, 1994; Costigan, Floyd, Harter, & McClintock, 1997; Gilkerson & Stott, 2000; Glidden and Floyd cited in Hauser-Cram et al., 2001, p. 16; Klaus et al., 1995; Roffey, 2001). To begin with there is the impact of the knowledge, and with many cases (such as babies born with Down syndrome) the immediate knowledge at birth, of not having a typically developing child. The expectation of having a healthy baby is immediately shattered. Not only does the mother have the recovery from the birth process, but her perceived ground of parenting and 'happy families' has shifted. 'Happy families' may still occur but the onset of this new situation in most cases causes the family to go through a grief process - grieving having lost a 'normal' baby, and processing the thought of accepting life with a child with a disability (Klaus et al., 1995; Wolfendale, 2000).

Caregivers may go through stages of denial, shock, anger, guilt, overwhelming sadness and depression before they are able to accept the reality of their situation (Roffey, 2001; Romans-Clarkson, Clarkson, Dittmer, Flett, Linsell, Mullen, & Mullin, 1986). Adjusting to the diagnosis may jeopardize the security of early attachment (Barnett et al., 1999; Walters & Blanc, 2000). Even then, the emotional 'roller coaster' tends to be cyclic as further anxiety is caused by different stages or milestones of a child's development, such as, birthdays, entering an early childhood centre, beginning school, or later on into adolescence and adulthood (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003; Klaus et al., 1995). Little research has looked at how the typical developmental milestones and the occurrence of unexpected events over a child's lifespan, affect stress levels in families (Nachshen, Woodford, & Minnes, 2003).

Clearly the quality of carer-child interaction is critical in influencing a child's developmental pathway (Gilkerson & Stott, 2000; Kaiser & Hancock, 2003), as well as their emotional regulation (Zigler, 2000). Not so obvious is the impact that emerging situations of potential stressors have on the carer-child relationship (Guralnick, 1997). McCubbin and Patterson note that many different potential stressors can be in play simultaneously:

> Family stress theory proposes that family adaptation to a crisis event (such as having a child with a disability) is explained by multiple factors. These include the nature of the crisis event, the internally (such as coping strategies) and externally (such as formal and informal support networks) based resources available, and the meaning ascribed by the family members to the event. (McCubbin & Patterson cited in Hauser-Cram et al., 2001, p. 15)

The way carers cope with their emerging situation will depend to a great extent on their sense of well-being. Well-being is a complex concept. It includes the carer's acceptance of and adaptation to the child's temperamental and behavioural characteristics (*child-related stress*), and the carer's own emotional coping skills and adjustment to the parental role (*parent-related stress*, Hauser-Cram et al., 2001, p. 17).

These stressors are inevitably intertwined. A child's presentation impacts on the well-being of the carer. For example, Nachshen et al. (2003) formally established that the more severe the child's disability, the more stressful it is for the primary carer. The well-being of the carer impacts on the child's behaviour. The study by Hauser-Cram et al. (2001) found that carers with poor interactive skills felt the greater stress and consequently a highly stressed carer may engage in parenting behaviours that are less growth-promoting. Baker et al. (2003) support this finding, noting that high carer stress contributes to a worsening in child behaviour problems, and extreme child behaviour problems contributes to a worsening in carer stress.

However, Costigan et al. (1997) found that although family patterns, expectations, and routines are disrupted by the birth of a child with a disability, most families gain, over time, a sense of equilibrium in their family relationships and well-being. Their frame of reference was the school-aged child. It is likely that the early pre-school interactions between carer and child are important steps on the way to gaining this sense of equilibrium. These early interactions may be strongly affected where an infant's medical condition affects both the carer's and the infant's functioning

(Goldberg, 2000). Dunst (cited in McCollum & Hemmeter, 1997) identified the core issue for carers of young children with disabilities as readability, the ability to interpret and understand behavioural cues: "Any factor that disturbs or distorts a child's emotional and communicative cues will make it more difficult for the social partner to interpret and respond to those cues" (p. 551).

In addition, sensory integration difficulties may disturb or distort a child's emotional interactive process. Such difficulties may be due to:

- sensory threshold as reflected in registration and orientation
- interpretation (may be perceived as too strong, weak, or muddled)
- organization of a response
- execution of a response

(Williamson & Anzalone, 1997, p. 30)

How these difficulties affect the attachment process is discussed next.

Impact on attachment

If a carer is having difficulty reading and responding to their child's expressive behaviours, then this is likely to affect the attachment process. As suggested in the earlier section (see p. 6), attachment theory is acknowledged as relevant but the field as a whole is too vast to cover in this paper. However, of more direct interest are some of the findings in the small amount of research that has looked at how attachment theory applies to families who have a child with special needs (Barnett et al., 1999; Barnett & Vondra, 1999; Clements & Barnett, 2002; Robb, 2003).

The fact that extended hospitalization of some children may inhibit the development of attachment and affect the carer's confidence in taking care of their child (Affleck et al., 1982), resulting in poor carer-child relationship, is now acknowledged and is being addressed through more family-centred EI intervention services in hospitals. In general, the greater the severity of a child's disability or medical problems, the more evident are adaptive difficulties within the family system (Shonkoff et al., 1992).

Barnett et al. (1999) reviews a number of studies, coming to the conclusion that the proportion of secure attachments among children with congenital problems consistently averages less than 50%, in comparison with approximately 65% in the typically developing population (p. 190). There is also an increased incidence of disorganised attachment with children with disabilities, "Disorganised attachment patterns are believed to result when the caregiver's behaviour is disorganised ... so that the child cannot respond to it in a coherent and adaptive manner" (p. 193). This can be due to unresolved grief reactions, and/or the general difficulties carers may face in coping with the unexpected situation of having a child with a disability. Children whose carers were noted as having accepted their child's disability were nearly three times more likely to be classified as 'secure' than were those whose carers were seen as to be in an unresolved state (Barnett et al., 1999).

Carers may also have difficulty interpreting their children's responses, and may therefore, not be consistent in responding. However, Barnett et al. (1999) caution the usual commonly held interpretation of aspects of attachment behaviours when dealing with children with disabilities, highlighting the need to take into account the child's general neurological condition. This caution is also noted by Guralnick and Neville (1997) who found that even though secure attachment relationships are formed in most instances between children with established disabilities and their primary caregiver, some may be due to a dampened arousal mechanism whereby separation anxiety is not so manifested (e.g., with children with Down syndrome). Goldberg (2000) states that further research is needed to not only gain better understanding of attachment behaviours in children with disabilities but to explore the possibility of new attachment patterns being discovered.

Primary caregiver behavioural responses

Goldberg's ideas of infant behaviours that influence the carer-child interaction process (see p. 6), do not address the characteristics of children with disabilities and the extent to which a lack of self-regulating behaviour interferes with predictability, with social responsiveness, and the ability to give and pick up interactive cues. In contrast, a group of researchers (e.g., Affleck et al., 1982; McCollum & Hemmeter, 1997; Shonkoff et al., 1992) provide evidence suggesting that a lack of self-regulating behaviour has detrimental effects on the interactions between children with disabilities and their carers. A question posed by this current study is how the primary caregiver's interactive efforts are constrained or facilitated by their interactive experiences with their child with disabilities. As Walters and Blane put it, "Parents can display decreased emotional availability to the child, as well as to each other and to the rest of the family, at various times during the lifespan, which will in turn shape the developmental pathway" (Walters & Blane, 2000, p. 277). It is how the quality of interactions affects further interactive efforts, which in turn affects developmental growth, which is of interest to this researcher.

Given that children with disabilities may be less predictable in their behaviours and less likely to take initiative in social interactions, it seems understandable that researchers have found that carers in these circumstances tend to be more directive and more dominant in their roles than carers of typically developing children (Marfo, cited in Hauser-Cram et al., 2001, p. 14). They may also tend to offer more stimulation by putting great effort into trying to create a feeling of mutual interaction.

Carers are in the difficult position of trying to understand their children's behaviour, and trying to assess the best way to respond accordingly. Marfo (cited in McCollum & Hemmeter, 1997) suggests that, "Maternal directiveness may actually represent a responsive adaptation that is necessary to achieve the optimal participation of the children in the interaction" (p. 552).

However, some studies have shown that carers of children may focus too much on achievement of tasks and on what actions they can perform. Costigan et al. (1997) and Kelly and Barnard (2000), found that carers often go to enormous efforts to direct and monitor the children and to manage inappropriate behaviours. This may be to the detriment of the children gaining greater independence through initiating and engaging in playful interactions (Floyd & Phillippe, cited in Guralnick & Neville, 1997, p. 594). Furthermore, behavioural intervention with many children with severe disabilities may result in a dependency. For example, children may only 'perform' in response to specific external prompts. Such situations discourage spontaneity, and do not permit interactive 'play' to occur (Greenspan & Wieder, 1997).

The implication here is that carer directiveness and domination in interactions may have an adverse effect on the development of social competencies in a child with disabilities (as is the case with typically developing children). And although carer-child interactions may be adapted in order for the child to acquire and practice development skills, consideration also needs to be given to the development of social competencies and self-esteem which develop via mutually enjoyable interactions (Blackman, 2002; Sameroff, 1992). Children need opportunities to initiate and need to feel the intrinsic value of being reciprocal partners in the interaction. Such opportunities are likely to boost confidence for further social initiations.

For many varied reasons, children with disabilities often lack peer contact. Consequently, a lack of stimulation to achieve social competency may occur (Guralnick & Neville, 1997). If social experiences have the potential for 'happy times', then many children are missing out on these positive opportunities. The 'feel good' factor not only helps develop social competencies, but also encourages developmental potential (Robinson, 2002). A balance is needed in how best to achieve progress in all developmental areas, and have enjoyment on the way.

Thus, a child's biological and emotional/social presentation may challenge the interactive process. A carer of a child with a disability cannot assume that 'normal' interactive processes will either occur or be successful. The carer may need help in finding optimal interactive techniques to foster a positive developing relationship. Given the importance of the carer-child relationship indicated by the existing research, interventions need to focus on the quality and nature of the developing relationships as much as on the children directly. Research also needs to help the community by understanding more about what intervention will help create positive outcomes for the carer-child interaction and under what circumstances.

Early Intervention

Especially in light of the implication from the research discussed above that early childhood experiences are crucial to the character of subsequent development, EI is a highly-relevant intervention. EI is a systematic approach professionally set up to help children with special needs and their families. As a service it has changed considerably over several decades as EI research continues to inquire about what constitutes best practice.

From approximately 1970 to the mid 1980's, the effectiveness of EI was assessed by comparing outcomes for those children who experienced EI with those who did not. This period is now regarded as the 'first generation' of EI research, and the positive results helped to establish and fund many EI service providers. The years spanning the mid 1980's to the present day are regarded as the 'second generation of EI research.' This latter generation starts with the premise that EI works, but now is looking at what works best for what children within what family circumstances, how intervention programmes are best administered, and with what professional personnel, to achieve optimal outcomes. Guralnick (1997) notes:

> It is the issue of 'specificity' that ultimately informs practice, improves the cost-effectiveness of services, minimizes false expectations, provides a research framework for evaluating innovative approaches, and may even be of value in helping us understand the mechanisms through which interventions operate. (p. 13)

The implementation of EI services will now be discussed, with a focus on the effects that interventions which address the quality of carer-child interaction have on the developmental outcome of a child with special needs.

Early Intervention is a term applied to a general method designed to meet the needs of pre-school children with special needs through the coordination of professional services. According to Wolfendale (2000), children who will benefit from EI services are those who:

> 1. have early-appearing/early identifiable disabilities and special (educational) needs
> 2. are deemed to be vulnerable and at risk by virtue of needs and disabilities, and/or who
> 3. live in a milieux [sic] of social and economic deprivation and disadvantage
>
> (p. 5)

In Wolfendale's view, EI typically has four primary goals:

> 1. to support families to support their children's development
> 2. to promote children's development in key domains (cognitive, social, physical, emotional, linguistic)
> 3. to promote children's coping competence
> 4. to prevent the emergence of future problems
>
> (p. 4)

The needs of pre-school children with disabilities, their rights to health and education, their acceptance into a community, and the support for their families, have all been given increasing attention over the last thirty years. While EI has been generally held to be a beneficial service during this time, researchers and practitioners have continually experienced the growing pleasures and pains of finding out what support is needed and how is it best implemented (e.g., Dinnebeil, Hale, & Rule, 1999; Krauss, 1997; Shahmoon-Shanok, 1997). In spite of the complexity of the field, research has become quite prolific.

Be it infant, toddler or pre-school child, each may present with a disability in the area of communication, cognitive, motor, sensory, social or emotional skills, or a combination of these. The personality and strengths of each may be displayed in differing levels of self-regulation, both as regards motivation for learning, and self-control of emotions and behaviour (Hauser-Cram et al., 2001). Primary caregivers may demonstrate different levels of adaptation, anxiety, grief, rejection/acceptance or pro-activeness. Siblings may display different levels of understanding, of responding, and of adaptation. Communities may make available appropriate resources, support for particular services, and will influence when and where these are to be provided and what funding will be available.

Effects of early intervention on a child's development

Even with all the complexities and the great range of possible influencing variables, there is now within existing research, evidence to indicate the effectiveness of EI programmes for children with special needs across all developmental areas (Shonkoff & Meisels, 2000). The earlier a child's needs are addressed and an appropriate intervention programme implemented, the more progress the child is likely to make (Ramey & Ramey, 1998; Roffey, 2001; Shonkoff et al., 1992).

Much is still being learned about how to measure the success of EI programmes (McConnell, 2000). Up to and including the early 1990's the effectiveness of EI programmes was judged on changes in IQ. If EI resulted in an increase in IQ in a child, the programme was then deemed effective (Shonkoff et al., 1992). At another point on the scale, the measure was one of perception: if carers were seeing positive gains in their child's development they then perceived EI as a successful service (Auckland College of Education, 1992).

Studies examining the benefits of EI have looked more at children's development rather than at carer and carer-child relationship development, and more on the child's cognitive and communication skills than on social and emotional development (Knitzer, 2000; Ramey & Ramey, 1998). The relevance of a focus on carers is indicated by longitudinal studies which have shown that early gains in intellectual ability were not necessarily maintained if the carers were not involved in the intervention strategies (Goodfellow, 1986; Ramey & Ramey, 1998).

The more that human behaviour and development are studied and understood, the more researchers are finding that the emotional response to experiences affects the attainment, maintenance and the potential growth of cognitive, social, physical, and communication skills in children (Greenspan & Wieder, 1998). This conclusion is supported from the neurobiological perspective where it has now been accepted that the developing brain is capable of being modified as a consequence of both negative and positive experiences (Nelson, 2000), and that these experiences accordingly have long term effects on a child's future development. The relative plasticity of a child's brain allows effective EI strategies to be potentially beneficial (Blackman, 2002).

It may be useful to examine which negative and positive experiences are most salient in shaping the emotional response of a child to his or her world. From the moment a child is born, life experience has both a physical component and an emotional one – how one feels about the experience. The emotional coding of the experience guides the child's learning.

Greenspan and Wieder (1998) talk of six 'functional emotional skills' to be developed in children with disabilities in order to lay the foundations for further learning and development:

1. the dual ability to take an interest in the sights, sounds, and sensations of the world and to calm oneself down (the ability to self regulate enables the child to take in and respond to the world around)
2. the ability to engage in relationships with other people
3. the ability to engage in two-way communication
4. the ability to create complex gestures, to string together a series of actions into an elaborate and deliberate problem-solving sequence (initiates contingent play … runs to door to greet Daddy, arms up to get a hug, starts peek a boo)
5. the ability to create ideas
6. the ability to build bridges between ideas to make them reality-based and logical

(p. 4).

The acquisition of these functional emotional skills is based on early emotional interactions and they provide the basis for cognitive skill learning, social competencies, and the development of a sense of self. Emotions give directions for action and meaning to experience. They influence behaviour, the storing and organizing of experiences, the impetus to construct new experiences, the means of solving problems, and the process of thought.

How well a child masters the functional emotional milestones is dependent on three factors:

1. the child's biology, the neurological potential or challenges that enhance or impede his functioning
2. the child's own interactive patterns with his parents etc.
3. the patterns of the family, the culture, and the larger environment

(Greenspan & Wieder, 1998, p. 4)

Thus, EI therapists cannot look at a child's developmental trajectory without also looking at the influence of personal experiences with the family and within the child's environment. Children should be given opportunities to reach their potential within the context of family dynamics (Dinnebeil, 1999). The question arises as to how effective EI services can be on family interactions, and more specifically, on the carer-child dyad.

Effects of early intervention on the carer-child relationship

EI is taking increasing account of the impact of the adaptive characteristics of the child's family (Graves cited in Clarkson, Shelton, Bray, & Ballard, 1996, p. 276; Shonkoff et al., 1992). This change of emphasis has resulted in greater importance being given to multi-discipline approaches to intervention and to encouraging family involvement (Ramey & Ramey, 1998). Instead of the carers being regarded as the recipients of services, they are now seen more as partners in the planning and delivery of services (Wolfendale, 2000). The focus has moved from what the child should do, to what should happen in order for the child to make progress (Baird & Peterson, 1997). Research is shifting its focus from impact-oriented to process-oriented research (Krauss, 1997). Carers are seeking intervention strategies to 'unlock' children's potential for more adaptive functioning (Hauser-Cram et al., 2001).

These findings have implications for the quality of the carer-child dyad at the same time taking into account the child's biological presentation. Evidence suggests that the earlier the intervention and the longer it continues, the greater the benefits to the child and family (Mahoney & Wheeden, 1997). Furthermore, the benefits of intensive programmes outweigh those of less intensity (Ramey & Ramey, 1998).

Krauss (1997) discusses evidence to suggest that with EI involvement there is an increased adaptability over time in ways of parenting a child with a disability. Surprisingly, in his study, stress scores for mothers of children with disabilities were well within the typical range for mothers of children without disabilities. However, the results of a longitudinal study by Shonkoff et al. (1992), conflict with Krauss by finding this adaptability is not likely to be within the typical range for carers of children with severe impairment, or carers of children with motor impairments. Stress levels remained elevated in such cases. These issues are the focus of Graves' (1995) article on therapy methods for cerebral palsy. Graves argues that the child-focused therapies, aiming for functional improvements, detract from the real needs of the child and family. McBride et al. also argue that intervention should be family-centred, and identify three primary principles of family-centred practice:

1. establishing the family as the focus of service
2. supporting and respecting family decision making
3. providing intervention services designed to strengthen family functioning

(McBride et al., cited in Krauss, 1997, p. 618)

There is now a more holistic approach to EI which accepts the importance of nurturing a child's development within the context of the family environment. However, little research has looked at how EI services have affected the families. There is not yet much evidence for the proposition that EI services enhance the ability of families to nurture and care for their children (Mahoney & Bella, 1998). Studies show that EI services have an impact on the stress levels of carers (i.e., the more support carers get the less stress they feel), and this is associated with more positive parental psychological functioning (Hauser-Cram et al., 2001; Krauss, 1997). However, counter to this benefit of social support is research that finds that carers do not necessarily implement the intervention strategies with their children to promote child development. Simply being family-centred "may not ensure that the outcomes associated with this philosophy are realized" (Mahoney & Bella, 1998, p. 91).

The nature and quality of carer-child interactions are known to influence a child's development. Hence, EI therapists are placing greater emphasis on finding out what is happening during these interactions, and what intervention strategies will be more effective. Although family-centred practices are coming to be seen to be pivotal to positive outcomes of EI (Dunst, Trivette, & Jodry, 1997; Gilkerson & Stott, 2000; Mahoney & Wheeden, 1997) there are many different practical implications. Two points will be considered here. One relates to the terminology 'family-focused', and the second is the role of therapist and carer.

The terms 'family-focused' and 'family-centred' intervention appear to have several meanings in practice. As has already been stated there is a trend to involve the family in the EI process. However, how this is put into practice makes the labels somewhat ambiguous (Mahoney and Wheeden, 1997). Many studies note that EI programmes operate within governing guidelines that supposedly provide for 'family-focused' intervention, and follow Individual Family Service Plans (IFSP) (e.g., Bruder and Staff, 1997; McBride and Peterson, 1997). However, when the EI programme is centre-based, the families often seem to be involved only in team meetings and only at the beginnings and endings of EI sessions. When the EI programme is home-based there was still a tendency for the implementation of the IFSP goals to be child-focused. At this point in the history of EI services, the term family-focused does not necessarily imply that families are active participants in the intervention process. In the discussion section of many of these studies, it was acknowledged that a more thorough examination of the family's role in service delivery is warranted.

The relative role of therapist and carer also needs to be put in context. Often, carers are encouraged by therapists to carry out specific intervention activities at home, but little guidance is given as to just how these are to be carried out. Guralnick and Neville (1997) suggest that EI programmes need to be encouraged to "emphasise parent-child social and emotional relationships rather than parent-child instructional or didactic types of relationships" (p. 603). Carers are now to be encouraged to modify their behaviour in order to promote a more successful dyadic interaction when engaging in specific intervention strategies (Mahoney, Boyce, Fewell, Spiker, & Wheeden, 1998).

Earlier, in the introduction to this study, the researcher reported the comments of a mother who said that while she was trying to act as a therapist as she attempted to incorporate new strategies encouraged by the specialist intervention team, she felt that something was being lost (Archer, 1995). Others have also noted that the enjoyment of play and being free to explore with their children was becoming secondary to a work focus (e.g., Sameroff, 1992). This phenomenon of carers showing a decrease in positive affect with their children, as they focused on participating in, for example, physiotherapy sessions (Affleck et al., 1982, Mahoney & Wheeden, 1997) adds further impetus for maintaining as a priority in any EI practice the encouraging of a positive carer-child dyad. A statement by Schaffer (1977) sums it up in this way: "Change cannot be imposed from the outside; it can only start from within the relationship between parent and child and thus becomes a matter of mutual adjustment" (p. 77).

Herein lies the importance of relationship-focused intervention. Without the involvement of the family, interventions are unlikely to be successful (Blackman, 2002). Without EI, research indicates that over time carers do not improve their interactive skills (Hauser-Cram et al., 2001). Even though there is an increasing demand for carer involvement in EI programmes and the importance of carer-child relationships is being given more attention, the literature on carer-child interaction as a target for EI remains sparse (Barnard, 1997).

In a longitudinal study of EI services over the period of a year (Shonkoff et al., 1992), the child's responsiveness in carer-child interactions showed a marked increase. This increase was seen to be due to the carers adapting their behaviour to encourage positive interactive experiences. Positive intervention effects on child development were unlikely to occur unless carers modified their style of interacting with their children (Colin, 1996; Mahoney et al., 1998). The nature and level of the carer's modified interactive behaviours contributes positively to their child's developmental outcomes. Mahoney et al. (1998), when looking at different intervention approaches, found that, "The impact of interventions on children's development was directly related to their effectiveness at supporting and encouraging parents to engage in responsive interactions with their children" (p. 14).

Children learn through play, through activating their own abilities in and on their immediate environment (Piaget, cited in Shonkoff et al., 1992, p. 7). However many children with disabilities need additional or specific external stimuli to initiate such activation, to be curious and to grow and learn from their environment. Specific stimuli need to be offered often to motivate consistent responses, and it is the primary caregivers who have the greatest chance to provide these as part of their daily lives. EI aims at empowering "parents to become responsive play partners with their children" (Griffiths, 2000, p. 71).

Interaction intervention

McCollum and Hemmeter (1997) describe relationship-focused intervention as "interaction intervention" (p. 549). If the most important avenue for a child's early development is via the carer-child dyad, and if in order for the child to participate in this dyad a desire and ability to interact is necessary, then for a child with a disability the first intervention is to examine what is going on within the dyadic interactive process. As McCollum and Hemmeter (1997) explain, "Interaction intervention can alter the child's participation in and experience of the interaction ... it may influence developmental outcomes across one or more domains. Interaction intervention therefore may provide a particularly powerful avenue for optimising development" (p. 549).

A limited number of studies have been undertaken to show that intervention can change a carer's responses to a child's cues and that carers can be guided into providing different responses which will encourage a more positive carer-child experience (e.g., Baird & Peterson, 1997; van den Boom, 1994). Kelly and Barnard contend that, "The success of an interaction between a mother and child is heavily reliant on the mother's ability to adjust her behaviour in response to the child's engagement and disengagement" (Kelly & Barnard, cited in Hauser-Cram et al., 2001, p. 14).

If a primary carer is being highly directive either in a quest for seeing progress, or as an overcompensating response for a child's slower response, interaction intervention could encourage the carer to focus more on supporting and expanding the initiations of the child (Greenspan & Wieder, 1998; Guralnick & Neville, 1997). In fact Malphurs et al. (cited in Crockenberg & Leerkes, 2000) found that, "Mothers became less intrusive with their infants when they were trained to imitate them and less withdrawn when they were taught to gain their infants' attention" (p. 68).

Even allowing for certain characteristics such as degree of directiveness and degree of responsiveness or degree of stimulation, there are still other variables to consider for certain situations. The content and context of the dyadic interaction will influence the outcome. Such aspects as the expressive medium used (verbal or non-verbal), the props or toys involved, physical proximity and positions of child and carer, the surrounding environment, and the sensory modes being stimulated – all need to be taken into consideration in this complex milieu of carer-child interaction intervention. As McCollum & Hemmeter (1997) noted, "In none of the studies was process treated as a potentially important independent variable" (p. 571).

Issues relevant to designing effective intervention

It has been established that relationship-based developmental experiences create the context for progress and they need to be at the heart of EI programmes (Greenspan & Wieder, 1997). This is why the carer-child interactive process needs to be examined in more depth for further understanding of best practice. Interactive experiences will be influenced by the circumstances and environment of each family, as well as by individual differences within each family. These are important facets to be considered. Aspects of family circumstances relevant to effective EI practice are the influence of cultural practices and religious beliefs on the carer-child interactive process. Little research has examined different approaches to interaction intervention from these perspectives (Colin, 1996; McCollum & Chen, 2003).

Cultural expectations and religious beliefs may play a role in the attitudes a primary caregiver has when caring for a child with a disability (Gilkerson & Stott, 2000; Seligman & Darling, 1989; Walters & Blanc, 2000). In her study with Taiwanese families who had a child with Down syndrome, McCollum and Chen (2003) found a strong link between beliefs and behaviour, which in turn influenced the value mothers put on EI and their perceived role in the process. These authors favourably cited Ogbu's comment that, "Interventionists must learn to approach each parent from an understanding of that parent's theories about their child and their own parenting" (Ogbu cited in McCollum & Chen 2003, p. 11).

Carer – therapist relationship

Not only do therapists have to be alert to family dynamics within cultural and religious contexts, they also have to be aware of how best they convey strategies for encouraging positive carer-child interactions (Kalyanpur & Harry, 1999). Nunkoosing and Phillips (1999) cite several studies where carers describe disempowering experiences in their dealings with professionals. In a similar vein, Gilkerson and Stott suggest that, "There are concerns about overburdening families with the role of interventionist and interfering with the naturally occurring interactions between parent and child" (Gilkerson & Stott, 2000, p. 457).

Respecting family and individual differences in children with disabilities is vital. The more individualized the programme, the greater the progress (Greenspan & Wieder, 1998). Furthermore, because the dimensions which characterize individual growth rates in children are in constant change, any profiles constructed for diagnostic purposes must be frequently adjusted. The need for ongoing assessment, and the need for treatment to be sequential and constantly adjusted, is clearly evident.

The professionals involved need, at all times, to be ready to be in open communication with the carers. In Roffey's (2001) terms, they need to:

- be aware of parents' feelings, their personal investment in their child and the pressures that may be on them
- focus on the child's strengths as well as his needs
- ensure that parents understand procedures
- not make assumptions about parents' ability to be involved
- respect different perspectives
- respect different needs
- recognise the need for flexibility in timing and structure of meetings

(p. 24)

McCollum and Hemmeter (1997) suggest that when looking at the three-way process of interaction intervention between the carer-child dyad, the family of the carer-child dyad, the carer-therapist dyad, certain questions need to be addressed:

- what intervention contents and processes are most likely to bring about optimal adaptation in the parent-child transactions experienced by the partners as a result of the intervention?
- what contents and processes are most likely to be efficacy enhancing for the child and for the caregiver?
- what contents and processes are most likely to support the caregiver's independence and flexibility in achieving optimal transactions across contexts and time?

(p. 567)

In McCollum and Hemmeter's (op cit.) opinion these questions lead to a need for, "The development and evaluation of new intervention models that recognize and respond to the complexity inherent in individual dyads transactions and their ecological contexts" (p. 572).

Reflecting on the change in EI services towards a more family-focused approach, the therapists themselves are being required to look differently at how they implement individualized programmes (Campbell & Halbert, 2002). This change in emphasis warrants more attention in both professional training programmes (Baird & Peterson, 1997) and by the community at large.

Community responsibility for providing early intervention

In many countries new legislation has promoted the rights to health and education for children with special needs. This has had beneficial effects on the profile of the sector. Wolfendale (2000) comments:

> The profile of special needs in the early years has risen recently, as a consequence of special educational needs legislation, increased provision to meet special needs in the early years and growing expertise and skills on the part of early-years workers and practitioners. (p. 1)

Not only are the rights of children with special needs being addressed, the cost effectiveness of EI programmes is now supported by research (e.g., Barnett, 2000). Effective EI services can stimulate a child's learning and physical and emotional well-being, thereby contributing to maximum independence. The more a child's potential is realized, the less reliance there is on the state for long-term financial health and education support services (Auckland College of Education, 1992).

In summary, evidence suggests that successful EI programmes must focus on the needs of families, with greater emphasis being put on the quality and nature of carer-child interactive behaviours. The implementation of services, whether within a multi-disciplinary context in the home or in a centre, will impact on how effective these family needs are met. Such issues will be considered further on in this paper.

Thus far, carer-child relationships and EI services have been discussed as components relevant to the study. It has been noted that more needs to be known about what types of interventions are most effective, and that some types of therapeutic services that may contribute either individually or as components of multi-disciplinary practice have not been well documented. One of the contributing disciplines offered in the EI programme upon which this study is based is MT. The next section will briefly introduce MT followed by a more detailed discussion of the role of MT in EI.

Music Therapy in Early Intervention

Introduction

For thousands of years music-making has been part of many rituals intended to facilitate healing. However, it was not until the 1940's in the United States and a decade later in the United Kingdom that MT began its journey to professional acceptance (Davis, Gfeller, & Thaut, 1999; Peters, 2000). The impetus for acceptance occurred after WWII, when music was first incorporated into the rehabilitation programmes for soldiers returning with disabilities, and the benefits of using music for such purposes were reported and documented (Davis et al., 1999). MT is now practised in hospitals (neonates to the elderly), in psychiatric settings, in hospice settings, in prisons, in rehabilitation units, in schools and special education settings, in community settings, in geriatric homes, in EI practice, and in private practice (Bruscia, 1998).

MT is about using the unique properties of music to stimulate development in non-musical areas of need (Wigram, Pederson, & Bonde, 2002). MT has the potential to address the needs of persons with physical, emotional/social, cognitive, speech or communicative disorders. Involvement in musical activities such as singing/vocal sound play, playing instruments, moving (gross and fine motor), and listening (receptive skills), provides multi-sensory experiences. It is because most people respond to music in some way that music therapists have at their disposal a medium with which to find and create specific music activities that set out to make positive changes in non-musical behaviours and set out to stimulate processes for skill learning (Davis et al., 2000; Peters, 2000). Music-making has the potential to meet several needs simultaneously by creating an environment conducive to successful participation at several levels of function and ability. Music has the capacity to engage and to maintain an engagement. Music-making "provides opportunities for both synchronous and interactive play" (Bunt, 2002, p. 79).

Role of music therapy in early intervention

If both MT and EI have the potential to facilitate change and generate gains in the developmental, behavioural and rehabilitative spectra for pre-school children with special needs, then these services seem likely to be able to form a positive partnership. Waterman (2000) for example, investigated and found that carers saw positive gains in their children's development as a result of MT in EI. Humpal (1990), Monti (1985), Skewes and Thompson (1998), Standley & Hughes (1996), also show the benefits of this MT/EI partnership for stimulating aspects of a child's development.

Involving children in music experiences can stimulate development and skill learning in many areas such as interactive skills, social skills, imitation skills, listening skills, concentration skills, coordination skills, communication skills, and speech/language skills (Humpal, 1990; Standley & Hughes, 1996). Components of these skills underlie the Individual Development Plan (IDP) goals for children in EI. Thus a child's involvement in music activities can be nurturing the acquisition of important developmental abilities. The music therapist specifically plans and implements particular music activities to promote aspects of a child's development within the context of his or her family.

Music therapists are constantly sensitive to which elements or combination of musical elements elicits which kinds of responses in a child. It is incumbent on the music therapist, carers and children to explore, experience and discover what works best for a given situation.

Music experiences aimed at targeted therapeutic outcomes

The following four examples indicate some of the targeted outcomes of MT in EI practice supported by current literature. First, the use of simple sound play can lead a child into a state of awareness of his or her being, and an awareness of an environment outside the self. Awareness can then become a motivator for making connections between people (Greenspan & Wieder, 1998). The simplest sound can make a connection between a mother and her child (Aldridge, 1996). Through a mother's voice, facial expressions, and touch, her child is being motivated to listen, watch, move, feel, and respond (Trevarthen & Malloch, 2000).

Connections with peers can be facilitated through group music activities (Gunsberg, 1991; Skewes & Thompson, 1998; Wigram et al., 2002). These activities can be taken home and help make connections with siblings and other members of the family. Music-making involves listening, taking turns, responding – all interactive processes from which children and carers can benefit, and processes which are important for further learning (Humpal, 1990). Thus, interactive music experiences become a medium supporting the notion that "mutual attention develops through interaction" (Wieder, 1997, p. 21).

Second, music has the ability to stimulate action, or promote relaxation, and both these states can be maintained with appropriate music for purposeful and constructive participation (Davis et al., 2000; Milligan et al., 2003). Distressed babies in neonate units may be calmed with carefully selected music (Aldridge, 1996; Shoemark cited in Brooks & O'Rourke, 2002, p. 76). A simple voice is music to an infant's ears (Nocker-Ribaupierre cited in Brooks & O'Rourke, 2002, pp 73-74). Auditory, tactile, visual, and vestibular intervention (ATVV) is an intervention technique where the use of simple singing reinforced with touch, movement, and facial expressions, has been demonstrated to result in better feeding by preterm infants. This multi-modal intervention technique has been shown to promote weight gain, an overall improvement in health, and a decrease in length of hospitalisation (White-Traut, Nelson, Silverstri, Vasan, Littau, Meleedy-Rey, Gu, & Patel, 2002).

Third, music is received both auditorally, and physically via the kinaesthetic sense. Responses to music also have a strong emotional component. The emotional response may be retained within, or it may be expressed in some form. Music can alter an emotional state through listening, playing, singing or moving. For centuries, and across cultures, babies have been soothed by the lullaby, testifying to the ability of music to alter emotional states (Oldfield & Bunce, 2001; Shoemark, 1996). Such emotional shifts are not only experienced by the child, these shifts can also relieve possible states of stress in the primary carer.

Another example of using music to alleviate stress is when it can act as a diversionary measure from pain or perceived discomfort. Many children in EI experience periods of hospitalisation and illness, and carers also feel the anxiety of having a sick child. Music can be a medium for a more positive connection during these difficult times (Brooks & O'Rourke, 2002).

The fourth example of the use of music experiences to help achieve targeted outcomes is the beginning of non-verbal and verbal communication, and the use of sign language and other communication systems such as PECS (Picture Exchange Communication System). These can all be promoted and practised through music and movement activities, such as vocal sound play, action songs, finger rhymes, and symbolic representation of instruments for choice making.

Music experiences as a diagnostic tool

Music can be used to promote certain targeted outcomes as just described. It can also be used as a diagnostic tool (Aldridge, 1996; Nordoff & Robbins, 1977). The use of sound play, and the nature of a child's response to the stimulation can be indicative of the state of the child developmentally and emotionally. Observing responses to musical stimuli can contribute to a better understanding of the child (Bunt, 2002; Pavlicevic, 1997). If responses to musical stimuli change, the changes may indicate the evolution of factors relevant to a child's development, e.g., better listening skills, improved coordination. Conversely, if a child's responses to musical stimuli deteriorate, this may be indicative of some degeneration (e.g., of neurological functioning), or suggest some degree of emotional disturbance. Brown (2002) sums this up by saying that if a child's being is distorted or damaged due to pathology or emotional disturbance:

> This will be reflected in every aspect of his being – cognitively, psychologically, physically, emotionally, and musically. By working clinically within the musical relationship, attending to musical limitations and resistances as well as creative strengths, we [music therapists] can work simultaneously towards healing many other aspects of the child's being. (p. 85)

How music makes a difference

Research and clinical practice provide evidence that music used therapeutically can make a difference. However, how this difference is enabled within the musical relationship is complex, and not yet well understood.

Some research begins by examining the use of music in the most primal of human interactions. Consider the notion of a mother's voice being music to a child's ears. The single voice has all the elements of music: pitch/modulation; intensity (loud/soft); rhythm; pace (fast/slow); tone; and a single sound has its own vibration. A mother's voice conveys emotions, and a mother's voice has a visual component through facial expressions and body language, and is often accompanied by a physical component, such as holding and rocking a child to provide comfort (Tomatis, cited in Brooks & O'Rourke, p. 70).

A child's voice may be music to his or her mother's ears, and the music may be just in the child's breath. Therapists and carers are encouraged to look and listen with a special sensitivity (Hoskyns, 2002, Oldfield & Bunce, 2001). A baby's breath can be seen and heard. It is an expression of self. It can also be seen and heard as a musical gesture if one listens and watches the breathing pace, and the quality (Pavlicevic, 1997) – an exercise of perhaps little value in its own right but an exercise of substantial value if the carer thereby learns to listen and interpret. Connections can be made by being *with* the child (Jonsdottir, 2002; Trevarthen & Malloch, 2000). In this sense music can be seen as "an amplifier, which gives voice to the signals sent out by the child, signals often too weak to be perceived in other situations" (Alberti, 1998, p. 639). Alberti expands this further by saying how a child's muscular tone and energy level can be transformed into a sound intensity, how a movement can elicit a rhythmic impulse and can be a cue for dialogue, and how a vocal sound can be reinforced through pitch and timbre variation with physical, kinaesthetic feedback. Small (1998) talks of 'musicking' as a tool in EI and encourages music therapists to nurture the intuitive musicking or the intuitive humming, singing, rocking, playful behaviour that parents generally do with newborns in a natural way.

Music-making has the potential to be a positive, successful experience at any level of involvement. For music in EI, the ability to generate positive, successful experiences is a crucial feature (Shoemark, 1996). One member of an EI team (not a music therapist) observed children participating, concentrating, and attending for up to twenty minutes in a group MT session, but barely working for three minutes in other conventional therapy situations (Archer, 1995). This illustrates the point that the addition of music puts 'work' into a framework that can be more stimulating and more sustaining.

Similarly, music can aid the repetition of necessary physical exercises, or the repetition needed for developing cognitive processes, by providing an enjoyable medium helping to motivate muscle memory and to promote skill learning, almost without the child realising. Music also has a unique property of being able to be repeated without becoming tedious (Aigen, 1996). Repetition and practice are needed to improve abilities and for them to be consolidated into muscle and cognitive memory.

Music is an expressive medium that doesn't require words to evoke feelings. Many children in EI are non-verbal but can express themselves very clearly without words, whether that expression is of frustration, discomfort, pleasure, or some other state. Responding to these nonverbal expressions through a nonverbal medium can make a connection with the child. If the child feels good about making a connection, or feels supported, even if it is nonverbal, then it is highly likely that the child who has just had the 'feel good' supported experience will engage in further nonverbal exchanges. Music then becomes a highly motivating medium for further interactions. Using music as a nonverbal means to establish early communication processes is the basis of many music therapists' clinical practice (e.g., Monti, 1985; Skewes & Thompson, 1998). This practice supports the general theory that the:

> turn-taking nature of early communication, the first exchanges between mothers and infants have the to and fro pattern of a prototype conversation…it is necessary to establish early processes of inter-personal non-verbal exchange, before attempting to promote later stages of expressive language. (Griffiths, 2000, p. 72)

This interpersonal non-verbal exchange is, in the present researcher's opinion, at the heart of MT in EI, and allows communication processes and relationships to develop before verbal dialogue.

Helping the carers: interaction intervention via music therapy

An interesting development in infant-carer psychotherapies is encapsulated in a new therapy method designed by Chambers (2000) to remediate disordered attachments. Chambers' approach is to assist the mother to gain a clearer view of the habitual patterns of interaction she has with her child, "to bring new interactions and possibilities to the relationship" (Chambers, 2003, p. 1). One crucial aspect in the remediation experience is encouraging the mother simply to look at her baby before starting to care for it. The time taken to do this allows mother and child to begin viewing their relationship in a different light.

Interestingly, much of the research into the use of MT in EI has paid only limited attention to the role of carer-child interactions. For example, Gunsberg (1991), Humpal (1990, 1991), and Standley and Hughes (1996), focused on the effect of music and MT in early childhood educational settings which by nature of the structure did not involve the carers in their programmes. Skewes and Thompson (1998) had parents attending some sessions within a centre-based structure but in their published MT research the parents were not discussed. Monti (1985) chose to have a mother in a MT session, observed some dysfunctional dyadic relationship behaviour, intervened through music making and commented, "the musical interaction that Michael and his mother created together provided the bridge between Michael and his ability to experience the external world" (p. 26). Monti's discussion focused on the effects of music in making connections at a pre-verbal, early developmental play stage but did not take the ensuing positive parent-child interactions any further.

There is however a small body of literature that does focus on the parent-child relationship within the EI setting, where MT is the active mode of intervention. Witt and Steele (1984), Shoemark (1996), Jonsdottir (2002), Small (1998) and Oldfield & Bunce (2001), all note the importance of the parent-child relationship in EI and the positive contribution MT can have as an intervention. Witt and Steele's 1984 single case study was one of the earliest studies to note the "development of the relationship between the parent and child" (p. 19) through MT intervention. Shoemark was the music therapist involved in an EI playgroup programme that specifically set out to nurture the early development of healthy family relationships. In her 1996 study Shoemark found that MT in this programme supported families in "developing skills which would enhance their relationships" (p. 3). As in Archer (1995), Shoemark's results were collated from a questionnaire to parents, and the author's impression was that the parent-child relationship had improved. Jonsdottir and Small discussed various parameters involved, related the findings of relationship theorists Stern (1998) and Trevarthen (2000) and applied those findings to the case of the music therapist in EI. They argued the importance of music making affecting relationships lifelong. Oldfield and Bunce (2001), as music therapists working in child and family psychiatry, also set out to improve the parent-child relationship by way of music-making experiences, stating, "Relationships that have become mainly negative can again be seen in a more positive light as families rediscover the ability to have fun together through music-making" (p. 33).

Thus, to date, the role and perspective of the carer involved in EI MT with their child has had only limited attention from researchers in comparison with its probable importance in achieving therapeutic objectives.[6] Chambers, in the field of infant-carer

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[6] Since finalizing the text, this researcher has become aware of another useful paper highly relevant to this line of enquiry: Michelle B. Kennedy, "Through Their Eyes: An Exploration of the Parents' Experience of Music Therapy", unpublished thesis, Lesley University Graduate School of Arts & Social Sciences, May 2001.

psychotherapy, and Oldfield and Bunce in the field of family psychiatry define their roles as including encouraging carers to view their relationship with their children in a different light, to not only look, but also to listen, to be alert to the signals that Alberti mentioned (see p. 30 above). However this is not an easy task for a carer who may still be carrying the anguish that goes with learning their child has a disability.

As has been indicated earlier, many carers of children with a disability enter an EI programme with a multitude of feelings including grief, loss, and concerns for the future (Wolfendale, 2000). These feelings are cyclic and swing in intensity. One of the purposes of involving families in EI programmes is to support the primary caregivers and encourage them to maximise their own abilities and competencies (Mahoney & Wheeden, 1997). The resulting improved well-being of the carer will influence the child's development and well-being. However many of these carers will need tools for developing a better relationship with their children, and they will need strategies to encourage positive interactions (Roffey, 2001).

In fact these carers have a set of tools: they have their voices and they have their body language (Jonsdottir, 2002; Small, 1998).The music therapist guides carers into how they can use and change their voices to keep an engagement going with their children, to change the pitch, to change the intensity, tone and pace, to add body language, touch and facial expressions, and to remember the importance of silence to not only capture attention, but to allow the chance for an interactive response.

This is where music becomes a useful tool for interaction intervention. One is reminded of Schaffer's statement that "change cannot be imposed from the outside; it can only start from within the relationship between parent and child and thus becomes a matter of mutual adjustment" (Schaffer 1977, p. 77). However, the music therapist when working with the carer and child in EI can be a catalyst in creating change. The music therapist will not only observe information being conveyed by the carer, but observe how he or she is conveying an expression of interactive intent. The elements of sound are so flexible and adaptable that by changing just one of them, such as the dynamics or the tempo, a carer can keep a child motivated to participate.

While it is one thing for carers to become more aware of a useful tool that they possess, it is another to be confident in using it within their own situations (Nunkoosing & Phillips, 1999). This is where the opportunity for the music therapist to work regularly with the carers over many months is important. The carers need to feel comfortable about singing, chanting, humming, moving, playing, and listening, if MT is to impact on their relationship with their children (Shoemark, 1996).

This is exactly what Norwegian music therapist Frisk (1997) focused on in her case study of working with a mother and infant. The infant had Down syndrome and Frisk began working with both mother and child when the infant was five weeks of age. With twice weekly MT sessions over a six month period, Frisk set out to change the mother's interactive techniques with her child. Her goal was to encourage the mother to feel more comfortable playing with her child. The achievement resulted in a positive developing relationship between mother and child.

Music therapists in EI are not reinventing the wheel. Historically and scientifically there is now greater awareness of the impact of sound on the human body, mind and spirit. The role of a music therapist in EI is to assist carers in developing a greater awareness of why, how and what music to make with their child. They will become more aware of how to read their children's signals, to note changes, and to feel more confident and better equipped with their responses in order to encourage successful engagements. This interactive process has to be sensed, practised and nurtured. Music can be a constantly flexible medium for mutual participation by both carer and child.

Involvement in an EI MT programme can develop carer-child interactions by encouraging carers to become responsive play partners with their children, and by heightening their awareness of how effective sound play and movement is in stimulating interactive responses. These experiences in turn lead to the promotion of developmental skills and appropriate social and emotional behaviours. MT provides carers and children with strategies for positive and meaningful engagements.

The Multi-disciplinary Approach to Early Intervention and Associated Issues

Thus far, there has been no discussion of either the institutional setting or the type of structure best suited to effective implementation of EI services. The issue of the range of disciplines offered in EI services has been raised by several researchers. EI services that use a multi-disciplinary approach to enhance a child's development seem to be more successful than ones which offer a limited range of services (Ramey & Ramey, 1998). Blackman (2002) supports this by adding that, "EI programs that succeed in achieving long-term benefits are typically broad-based and have strong parental participation" (p. 21). However, research does not clarify which 'broad-based' services are necessary for EI best practice. Research does not yet clarify how individual disciplines can best contribute modes of practice in order to achieve successful EI.

When Campbell and Halbert (2002) asked service providers for their 'wish-lists' for improved EI services, the following six categories emerged:

1. improved work environments
2. more services
3. changed training opportunities
4. increased opportunities for teaming
5. a return to centre-based services
6. increased parent participation in services

The article written by Ramey & Ramey (1998) support these requested improvements by establishing that EI programmes which involved only the child, were not as effective as EI programmes involving both child and primary carer. However, the issue of just how these children and primary caregivers are best involved is still unresolved. If family involvement is regarded as crucial to long term gains, and the idea of interaction intervention an important catalyst to realizing a child's potential, there is still the question concerning which disciplines can effectively promote this interactive process. Historically, speech language therapy (SLT), early intervention teaching (EIT) and physiotherapy programmes, for example, have not focused on carer-child relationship. They encourage carers to carry out pertinent aspects of the programme at home, but are not so focused on the emotional/social aspect of the interactive experience. As intimated in earlier sections, it is this emotional/social aspect of the experience that is going to determine whether the intervention is successful, and that in turn influences the responses and motivation of both carer and child to any further implementation of the programme. Blackman (2002) reiterates the problem of putting theory into practice:

> Despite the philosophical shift to recognition of social and emotional aspects of intervention, the bulk of EI services will tend to address cognitive and motor problems, because they are most easily recognized, they are what early childhood specialists have been trained to deal with, and often their treatment is what health and education funding agencies are most likely to pay for. No one would suggest that these problems should not be addressed, rather that they should be addressed with the goal of optimising emotional and social

competence – in the context of the family. (p. 21)

Is this where MT can offer its services in a multi-disciplinary approach? To answer that question, consider what is happening in practice.

Music therapy within the multi-disciplinary approach

Some music therapists working with young children with special needs are working in private practice. Music therapists involved in EI programmes generally coordinate with other therapists and pediatric professionals within a multi-disciplinary structure (Wigram et al., 2002). How this coordination is carried out seems to vary in practice. The literature reports relatively few examples of music therapists working in a family-involved, centre-based, multi-disciplinary team. Apart from Shoemark's (1996) article describing the positive results of MT in an EI playgroup programme where the focus was on developing healthy family relationships, and Oldfield's and Bunce's (2001) work in family psychiatry, it seems that the majority of music therapists working with children (e.g., Bruscia, 1991) be it in pediatrics (e.g., Lathom-Radocy, 2002), or EI, work individually with individual children, or in a preschool educational setting (Gunsberg, 1991, Humpal, 1990, Standley and Hughes, 1996). Not all music therapists in such situations have regular contact with the other professionals involved with the same client. Furthermore, the carers of these children do not usually participate in the actual intervention process. An example, cited in Wigram et al., (2002) acknowledges that the music therapist "often has contact with the child's parents … informing them about developments experienced in working with the child" (p. 180). This is not fully consistent with the view that best practice in EI should:

1. involve the primary caregivers within the intervention process, and
2. be multi-disciplinary in approach.

In addition, the length of time a carer and child participates in an EI programme will influence the effectiveness of EI best practice. It has been noted that the more regular and frequent the programme, as opposed to irregular home visits, the better the measurable outcomes (Wasik, Ramey, Bryant. & Sparling, cited in Ramey & Ramey, 1998, p. 9). But over what period of time?

As part of the researcher's personal inquiry this point was discussed with an Australian music therapist involved in a centre-based, family-focused, multi-disciplinary EI programme. In this Australian situation, carers with their children were involved in a block of ten weekly sessions that focused on a particular developmental aspect e.g., communication skills. The music therapist's comment was, "By session ten I was just starting to form a relationship and feel progress was beginning to happen, and then that block of ten sessions finished" (G.Thompson, personal communication, April, 2003). This comment relates to the therapist-child dyad. It would be interesting to know how the carers felt about such blocks of sessions, and whether they felt there was enough time to gain new strategies and assimilate these into their everyday lives. Oldfield and Bunce (2001) found that even after six sessions MT had positively impacted on carer-child relationships. However if other research previously cited is taken into consideration there is an implication that although an awareness of change may have taken place, the maintenance of change may not hold over the long term. As stated on page 18 above, the longer intensive EI programmes continued, the greater the long term benefits for the child and family.

What is not clear in much of the EI literature is whether or not a home-based or centre-based service is more effective. Although the providers in Campbell and Halbert's (2002) study felt that a return to centre-based services was optimal, there is evidence to suggest it is not just the setting of service implementation, but it is the nature of the implementation itself that has the greatest impact on effective practice.

Home-based versus Centre-based Early Intervention Practice

Early intervention in the home

There are differences in how EI programmes are implemented, especially as regards to carer participation. Research indicates that home-based EI services still tend to be child-focused (Mahoney et al., 1998). Families are given new ideas and activities relevant to their children's needs, with little regard as to how families could modify their interactive behaviour to enhance carer-child experiences. This may be partly due to the training of the professionals involved (Blackman, 2002). For instance, training has not always reflected recent research findings. Understanding the importance of the carer-child dyad, the implications of different interactive styles, and understanding family systems is new information for many therapists. The gap between research and practice was the focus of Campbell and Halbert's study (2002). They suggest that therapist's values and beliefs about natural environments may be a barrier to the support of recommended practice, or even if they do support family-centred care, this is not necessarily reflected in their interactions with families and children.

If there is concern about family-centred intervention services within the home environment, can one be confident that family-centred, centre-based environments are any better? The critical factor for EI best practice is still the nature of carer involvement. Family-focused intervention is, it appears, still not consistent in practice. Centre-based EI may well be family-focused, but with quite varying degrees of family involvement in the programme.

Early intervention in a centre

Some EI centres work along the lines of a specialist pre-school where children come in for several hours, several days per week. Within that time frame, specialist teachers and therapists will engage in the children's individual programme. Carers in these circumstances are welcome but are not an integral part of the overall session time. This approach is exemplified by the setting described by Stanier (2000):

> Parents come with their child for as long as they like when the child starts; some children settle very quickly, while others are more anxious. We like the parents to stay with their child until they relax and feel confident about the provision. It can be daunting for parents to leave their very disabled child who has taken such a large part of their lives ... we keep in touch with parents through 'home-school' books, phone calls, home visits ... social occasions ...formal interviews, as well as parents visiting when they choose. (p. 18)

This example is not in keeping with the view that interaction intervention between the child and carer may be the most effective intervention strategy. As with the home visits, the carer's relationship with her child, in this example of an EI setting, is not being seen as being of primary importance to the maximization the child's potential. An optimal family-focused programme would feature a different arrangement of professional services, with a stronger emphasis on participation by the primary caregiver.

Music Therapy in Context of This Study

The New Zealand scene

There are three family-focused, centre-based, EI programmes in New Zealand, two in the North Island, and one in the South Island. Most other EI programmes come under the auspices of the Ministry of Education, Special Education Group (GSE). GSE has offices in many cities throughout the country. Teams of specialists provide a range of family-focused, coordinated EI services for children 0-5 years.[7] Depending on the children's needs and the wishes of the carers, therapists visit the family at home and work with the children in an early childhood facility where an Education Support Worker (ESW) is guided in facilitation techniques useful for the children's development. The 'team' for each child comes together for IDP meetings every four to six months to establish the new base line and new goals for the child and family. The focus in working alongside families is to not only improve the child's overall development, but the quality of living for the whole family (Auckland College of Education, 1992).

It is not known whether this is an efficient and effective service. The therapeutic disciplines offered depend on the availability of staff in each centre. The regularity of visits will vary from area to area, case by case. It is not known whether family systems are being taken into account to get maximum benefit of intervention implementation.

The Wellington Early Intervention Trust

The Wellington Early Intervention Trust (WEIT) is one of the three family-focused, centre-based EI providers in New Zealand. WEIT is a provider of EI services where families are involved in a weekly intensive multi-disciplinary programme, and is where this researcher is employed as a music therapist. Children attend a two-hour session once a week, accompanied by a parent or caregiver. Up to five children attend each session. Sessions begin with a twenty minute group MT session. Each family unit then rotates around SLT, physiotherapy, individual MT, and EIT. There is a brief food/drink break in the middle, and another short group MT session completes the two-

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[7] In contrast, in the U.S.A., EI services are targeted at children 0-3 years. This may have implications for comparative evaluation of research results from these different countries.

hour programme. For children who also attend an early childhood centre, an ESW is assigned. Two EIT's from WEIT make regular visits to the early childhood centre as a link and support for the implementation of the intervention programme.

The structure of this centre-based EI programme is designed to achieve the benefits of a multi-disciplinary team approach, with frequent, regular sessions, and with carers being present with their child for each therapy session. Each family unit sees four therapists from different disciplines during the same two-hour time slot, once a week. The music therapist facilitates the group sessions as well as having an individual session with each family dyad. This intensity of service is consistent with the findings of recent research into effective EI programmes. However, it has still not been formally established that the therapies offered, and the manner in which they are offered, are of sufficient benefit to satisfy needs of the families involved. MT has an important role in this particular WEIT programme.

The role of music therapy at the Wellington Early Intervention Trust

MT has the ability to complement and support all the other disciplines in EI. At WEIT MT reinforces SLT, physiotherapy, and the EIT programme. The goals from these therapies are embedded in a musical framework in both the group MT sessions and the individual MT sessions. The therapy team for each two-hour session at WEIT is fully involved in the group MT sessions, thus keeping the pertinent goals for each child and strategies for implementing them consistent across the team. However, even though the carers are fully involved in every aspect of the WEIT programme, the majority of IDP goals remain child-focused. As indicated earlier, the established therapeutic disciplines such as physiotherapy, EIT, and SLT still tend to focus on child-oriented outcomes. These therapists at WEIT fully involve the carers in their children's programme. However, the emotional/social dimension of the carer-child relationship is not always given as much priority within each discipline as are that discipline's child-oriented outcomes.

It is in this domain that MT may and can offer something more than child-focused outcomes. The impetus for this assessment comes not from just the researcher's personal clinical experience, but from anecdotal evidence from carers involved in MT in EI.

Carers' perceptions

As reported in the introductory chapter, the researcher surveyed carers involved in the WEIT programme (Archer, 1995).The response to this exploratory survey indicated something over and above the child-focused developmental gains was happening. Carers were expressing they were having fun with their child, and music-making in the home created positive family 'togetherness' times through statements such as:

- The other children and my husband now sing the songs to my son.
- We can enjoy music without inhibitions and we do it together.
- I [mother] get a great feeling seeing my child enjoy music.
- My husband is more accepting of our child's disability since he has joined in our family music circle.
- Suggesting a music session in our children's [twins] room, which includes taking pots and pans and spoons as well as the instrument, is always successful in providing me with coffee time.

(Survey response, from exploratory survey reported by Archer, 1995)

The reporting of positive interactive experiences accompanied the descriptive responses to the question of, "Do you feel your child has benefited from these music-making activities? If so, in what ways?" 100% of respondents noted some form of benefit with the following keywords being used most often in their descriptive responses:

- Concentration … attention … focus
- Personal enjoyment
- Memory
- Language
- Listening
- Co-ordination … action … movement
- Co-operation … comfort

It is of interest to note that the abilities and skills gained, according to the carers, referred to the children's overall development rather than their musical development. It appeared that the carers had assimilated what the music therapist had modelled, and, through their own explorations at home, had experienced the benefits reported.

What comes first – the activities, the relationship, the skill learning? As discussed in the preceding chapters, research indicates that 'feel good' experiences are a strong motivator for learning. Pushing the learning without a 'feel good' feeling is likely to be counterproductive. Can music-making between a carer and child be advantageous in creating positive interactive moments, which will then encourage motivation for further interactions and skill learning to take place? Although not based specifically on a music experience, Albert (1998) emphasises how important the sense of joy is in developing a sense of self, "It is very important to stimulate to the highest degree the joy of participating in the child, for through perception he moves towards becoming" (p. 641). Music-making has the potential to foster such necessary experiences.

Research in EI is looking for the procedures which constitute best practice for which children, and in what family circumstances. There are only a few texts that examine the use of MT as a constructive mode of intervention. It is hoped that this study may add to the knowledge base of EI best practice.

Reflections on Theory and Practice - Towards a Research Topic

Evidence from the literature supports a family-focused, multi-disciplinary approach to EI. Whether the service is implemented in the home or a centre does not seem to be as important an issue as how the intervention is carried out. Family involvement in the process is paramount for sustained outcomes. However, it is not just the fact of the family being involved, but how they are involved that affects the intervention process. The quality of the carer-child relationship affects the realization of a child's potential, hence the acknowledged value of interaction intervention. However, the literature does not discuss which therapies constitute best practice and under which circumstances in relation to interaction intervention.

MT has the potential to influence many aspects of an EI programme. Music-making seems to be a stimulating and enjoyable experience for both carer and child, and carers report developmental gains in their children through being involved in MT. But apart from the few articles cited in this section, and several passing comments such as Bunt's remark "the music clearly helped to deepen the relationship between mother and child" (Bunt, 2002, p. 83), MT literature supporting the possible influence of a positive change in a child's social/emotional development on improved carer-child relationships is sparse. Also sparse is research on the impact of MT on the carer of a child with special needs. Research on whether a carer who is fully involved in an EI MT programme changes the frequency and nature of her own music-making with her child is limited, as is research indicating that a change in the frequency and nature of music-making occurring in the home environment influences the carer-child relationship.

The researcher's clinical experience strongly indicates that MT in EI has the capacity to stimulate social/emotional developmental needs in a child through a combination of both individual and group MT experiences. Primary caregivers fully involved in the EI MT programme provide anecdotal evidence which indicates that MT may well influence a positive change in the carer-child relationship. However, other factors that may impact on the degree and nature of the change are:

- age of child at time of entry into EI programme
- nature and degree of disability
- carer and child involvement in individual and/or group MT
- length of time attending EI

If carers are gaining new skills and strategies through MT experiences, the length of time being involved in MT in EI may influence the degree of change in interactive behaviours. Is there an optimal number of MT sessions necessary to make an effective impact? From her clinical experience Croxson (1999) felt that a series of six MT sessions with a child and family was not sufficient for carers comfortably to engage in effective interactions using music. She also states that families "find it very difficult to sustain an interactive programme without the continued support of a professionally trained person or persons" (p. 48).

It appears that carers need time to adjust to what a new therapy offers, and to what their role is in applying it. They need time to gain confidence and need to feel supported as new skills and modifications to interactive behaviours are nurtured. Furthermore a therapist may note a change in a carer-child relationship but this may not necessarily imply the carer's will perceive the change, or attribute any change to the MT. What is the carer's perception? Do they see the quality and nature of their musical interactions with their child as making a positive difference to their developing relationship?

Such questions are the catalysts for this research project to allow some primary caregivers to tell their story, hence the present research question: What changes in relationship with their children do primary caregivers perceive as having occurred since being involved in a centre-based early intervention music therapy programme?

Method

An adapted qualitative case study approach was utilized, with descriptive data gathered from in-depth exit interviews with four primary caregivers of children with special needs who were involved in a centre-based, music therapy-inclusive EI programme. A qualitative approach was appropriate, given that the context of the study was in the natural and familiar setting of the Early Intervention Centre, and that the focus of the research was on the qualitative experience of relationships between carer and child (Aigen, 1998; Langenberg, Aigen & Frommer, 1996; Smeijsters, 1997; Wheeler, 1995).

In this researcher's case, the phenomenon of interest was the perceptions of primary caregivers of children with multiple special needs. A qualitative study allowed for the caregiver's experience to be the source of data (Creswell, 2003; Murray, 2003; Rice & Ezzy, 1999; Riessman, 2002). The context was significant to them, and to the study, and helped to define the parameters.

The study explored:

- the perceptions of carers about EI at WEIT
- the perceptions of carers about MT
- the consequences of the MT, as experienced, on child behaviour, carer-child relationships, and child development.

This study involved interviews as the data collection method. Interviews allowed for the expression of meaning and perceptions, and provided the opportunity for the carers to 'tell their stories'. Standard interview protocols (Minichiello, Aroni, Timewell, & Alexander, 1995) were used, with the interviews transcribed verbatim.

Due to the researcher having the primary clinical role in this study (on-going contact before, during and after the study with the participants) a research assistant was the interviewer, to avoid any conflict of interest.

Context for the Research

The present study was undertaken at the WEIT centre which operated for three days a week catering for 34 pre-school children who had multiple special needs. It was staffed by a manager, a speech language therapist, a music therapist (the researcher), a physiotherapist, and an EI teacher.

The mission of the centre was to provide a therapy based EI programme for families who had a child with developmental delay or disabilities. The children attended a two-hour programme once a week, accompanied by a parent or caregiver. Up to five children with their carers attended at a time. Each carer-child dyad had individual time with each therapeutic discipline, as well as participating in an opening and closing group MT session.

The study was bound by its context, the context being WEIT, its particular mission and its staff. That mission was implemented by way of a multi-disciplinary family-focused service. Also relevant to the context was the particular set of primary caregivers and children attending WEIT at the time of the study.

Music Therapy Procedures at WEIT

There were three different formats offered in the MT programme at WEIT: opening circle time, the individual session, and closing circle time.

Opening circle time format (group music therapy)

The group MT sessions comprised music activities that were specifically planned according to the age and needs of the group, and focused on:

- experience of playing together
- social skills
- listening skills
- physical skills
- experience of different expressive energies
- gross and fine motor movements
- communication skills
- speech and language
- cognitive skills
- body awareness

Typically a group MT session opened with a welcome song, followed by playing instruments, action songs involving fine motor and gross motor movements, and songs and rhymes. The session typically ended with a group activity such as using a large piece of lycra, or a large material 'rainbow' ring, followed by a song "music time is finished, it's time to move along ...". Each group session lasted 20 minutes.

Individual music therapy session format

The individual session focused on activities to support the child's IDP. After discussion with the carers and other therapists, (speech/language therapist, EI therapist, physiotherapist) certain goals became the focus. Specific music activities were then established to motivate the acquisition of specified skills, and these were discussed with the carer and modelled within the session. Activities were kept simple with a focus on the nature of vocal and physical interaction. Resources used in the session included soft toys and tuned and untuned percussion instruments.

The music therapist engaged the child in interactive music experiences, often non-verbal, to allow for a relationship to develop. When the child was comfortable, trusting, and engaging with the music therapist, then the child was ready to learn within his or her own ability. This process of establishing a rapport happened in every session, but the nature and length of time it took to get to a constructive interactive state would depend on the nature and degree of disability, the child's state of physical and mental health, and the level of comfort developed through familiarity.

The carers were fully involved in each session. They were aware that the music therapist's initial focus was to engage the child in interactive play via musical means. Often improvisational techniques were used. As the child engaged, or showed interest in a particular instrument or activity, improvisational techniques were able to move to more structured musical activities as appropriate. These might be composed on the spot supporting the child's initiative. The therapist could then repeat such an activity over the next few weeks to encourage familiarity, memory recall etc. Carers were encouraged to not only participate in the interactive play, but to become more aware of how the therapist:

- was working with the child's response
- was pacing the engagement
- was using her voice and body to maintain an engagement
- was making use of silence

The goal was to be playing with the child, not *doing to* the child.

Closing circle time format (group music therapy)

The five families and therapists gathered together for the last ten minutes of the two-hour session. The music therapist led a group music activity (e.g., for the older mobile children, a circle dance), then there were a few carer-child action songs, before quietening down with more gentle songs where the child was usually on their carer's knee, the last song usually being hummed. A quiet goodbye song was then sung to each child.

Recruitment for the Study

Four carers were interviewed for this study, two of whom had been involved in the WEIT programme with their child/grandchild for over twenty sessions, and two who had been involved in ten sessions with their child. For selection purposes, the criteria for this study stipulated that the carers needed to be the primary caregiver of the enrolled child, and needed to be the carer regularly attending the WEIT sessions. Eighteen carers who had been at WEIT for over twenty sessions and who fitted the inclusion criteria were given an information sheet (Appendix 2). All eighteen carers responded positively, and a process of selection was implemented by randomly drawing out two names.

To select the two participant carers of ten sessions, two families who met the criteria within the interview time frame, were informed as their tenth session approached. Both carers agreed to be part of the study.

Participants

The caregivers and their children who were part of the study were (see Table 1):

#1 Sonya, grandmother of James
#2 Leanne, mother of Garth
#3 Jacqui, mother of Gene
#4 Eva, mother of Pippa

The four children were involved in both group MT, and in individual MT sessions.

Table 1 Participants' situation at time of study

Participant	Relationship to child	Child's Diagnosis	Child's age at time of interview	Length of time in centre-based EI programme
Sonya	Grandmother to James	Down syndrome	4yrs 7mths	4 yrs 4mths
Leanne	Mother to Garth	Sotos Syndrome	3yrs 0mths	1 yr 10mths
Jacqui	Mother to Gene	Fragile X Syndrome	4yrs 8mths	10 weeks
Eva	Mother to Pippa	Autistic spectrum	4yrs 5mths	10 weeks

Procedure for Data Collection

The interview

The interview took place at WEIT outside normal session hours and at a time suitable for both interviewer and participant. The interviewer was an EI specialist who has worked at WEIT and for the area Special Education Service. The interviews were audio-recorded using a Digital Audio Tape recorder and the length of interviews were as follows:

Case #1:	35m 46s
Case #2:	1hr 0m 20s
Case #3:	1hr 27m 35s
Case #4:	43m 52s

Open-ended questions were listed as guidelines for the interviewer (Appendix 4) to stimulate the participant to tell their story, but also to elicit specific pieces of information (Belgrave, Zablotsky, & Guadagno, 2002). The interview was transcribed verbatim from the tape by the researcher and independently verified.

Procedures for Analysis

In the first part of the analysis of the interviews, the responses of each carer were collated and summarized. These responses are presented in a case study format, where the background information on the child sets the scene for discussing the qualitative component of the relationship with carer and child.

In the second part of the analysis of interview data, the four carers' responses were compared and contrasted to draw out similarities and differences in their experience.

Results[8]

In this chapter each carer's experience of MT at WEIT and the effect on the relationship with the child will be presented using a case study approach. The experience of all four carers is then compared and contrasted.

Case #1 Sonya (primary caregiver to James)

(S = Sonya, timings relate to the point on the interview recording)

Background

James was born to a teenage mother who "had a lot of problems" (S. 0:40). Sonya is James' maternal grandmother who, with her husband, had "looked after him from day one" (S. 0:40).

Sonya was "absolutely devastated" (S. 20:04) when she heard James had Down syndrome and felt as though she didn't know anything and didn't know what to do, having not had any experience with anyone with Down syndrome. She became pro-active from the beginning by gathering information from the Down Syndrome Association and both she and her husband decided to change their lifestyle to focus on James: "I gave up work so I could spend time with him 'cos I was determined that he was going to be able to do things when he went to school" (S. 18:26).

Responses

Initial experience of the early intervention centre

Sonya began at WEIT with James when he was three months old. Sonya remembered that she was a bit nervous, "cos you didn't know what to expect and what the people were like" (S. 8:00) and that at first she didn't know what to make of it, "He was so young he couldn't do anything anyhow ... Christine used to say just sing to him and talk to him, so we used to do that um, I don't know if that's what started him off with his music thing, but he's always done that, always done the music thing, and we've always talked to him and sung to him" (S. 12:36).

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[8] Some transcription details in the analysis of responses, such as "y'know", and "um", have been omitted in the interest of readability.

Attitude towards the early intervention centre

Sonya related how important the weekly support of the staff at WEIT had been to her, and how, "I've got a lot of enjoyment plus a lot of education skills out of it" (S. 14:22).She talked confidently about how she worked on specific things at home that had been encouraged by the therapists, and how she had taught other family members communication signs through action songs. She kept in contact with James' peer group (from WEIT) and their families, and she was comfortable talking to and supporting carers new to WEIT. Sonya took on some part-time work as an ESW for a pre-school child with special needs as a result of what she had learnt from being at WEIT, and is now, along with her husband, teaching adults with Down syndrome how to Rock n' Roll.

Caregiver-child relationship before WEIT

Sonya recalls how James was such a perfect baby as he never cried or demanded to be fed. Her concerns in the early days were what to do with him and how to teach him things.

Music-making and the caregiver-child relationship

Sonya noticed that James enjoyed music and was learning things through music activities, "You can teach him things to music" (S. 8:50), "always through a song" (S. 9:42). However, for a while Sonya was a bit worried because James was not talking but miming everything, "I spoke to Christine about it and she said it will come, don't worry, and I'm thinking when's it going to come 'cos he just wouldn't talk and then all of a sudden it did come and now at circle time [group MT] he's there and he's singing away and doing the actions" (S. 15:38).

Sonya became more confident working and playing with James, and using music in different ways when at home, "Most times the next week when he comes to a session he's been able to do what he was doing the week before and couldn't quite get there, and yeah especially with the music, just like, just singing all day long, walking round the house doing 'stupid songs' (laughing)" (S. 31:05). Sonya and James had an interactive tool for both fun experiences and for skill learning, "Music has done it for him, if he could have learnt everything to music, even his maths, everything done to music, he'd learn it" (S. 25:14). James learnt to say his own name and to recognize his name through music activities.

Caregiver enjoyment at seeing her child feeling good through music-making

Sonya enjoyed seeing James getting pleasure from music, "He loves his circle time [group MT] … he's there and he's singing away and doing the actions" (S. 15:38). James remembers the songs and music activities from WEIT, "Music's his favourite thing, he's always got a music toy, or he's humming or something, he's always got music in his head (laughing)" (S. 11:54).

Caregiver's sense of pride in child's achievements

Sonya is very proud of her grandson's achievements, "He's doing really well" (S. 1:40) and, "He's ready for school (S. 32:58) … he will fit in in the social way, he will definitely fit in" (S. 33:24).

James gained more control over his physical energies and coordination through music activities, "Now he will go the fast and slow, and he'll wait which has taught him that you can do things fast and do them slow but you've got to wait; that was a big achievement for James too, 'cos everything was like vroom, straight in" (S. 10:06).

Using music as an aid to regulate child's behaviour

Through music activities Sonya knew James had the concept of fast and slow and being able to wait. She was able to use this knowledge to manage James difficulty when running. When James stumbled as a result of a slight hip problem, "We can say to him now, now stop James and wait and don't run so fast" (S. 10:46).

Caregiver's confidence leading to creative use of music

Sonya not only took home from WEIT specific songs and activities, but she also became more confident in using her own music. Knowing that James' coordination needed further development, and also knowing that music was a strong motivator for James to cooperate and practise new skills, Sonya combined the two, "We've been teaching him ball skills and it wasn't very good but it is now, we do it to music. We do throwing the ball and rolling the ball to music and yeah it works every time" (S. 32:10).

Caregiver-child relationship at time of interview

"Coming every week with him … the different therapists have shown me what to do and I've been working on that at home, yeah, we have a lot of time at home, and it's like the speech therapy and coming into Christine's ring music and they sort of go through and show you what to do and that's how I've been carrying on with James [at home]" (S. 6:24).

Sonya and James had a strong relationship. Sonya has spent a lot of time with James. Many of their daily interactive experiences involved music in some form. A 'feel good' factor was evident in the tone and content of Sonya's comments in the interview when she talked about both James' music-making experiences and their shared music-making experiences. These experiences encouraged the building of a "fun" and loving relationship.

Sonya also acknowledged her own efforts in preparing him for school, "I've achieved my goal … he's ready for school" (S. 32:58).

Summation (Case #1)

Sonya was absolutely devastated to hear that her grandson had Down syndrome, but she became proactive, gathered information and gave up her job in order to care for him.

At the outset, Sonya was nervous about the EI centre - she didn't know what to expect. But the weekly support of the staff helped her and she gained skills which she incorporated at home. She had taught other family members how to communicate with James.

Initially, Sonya didn't know what to make of James in so far as "he couldn't do anything" (S. 12:36). But Christine suggested she sing to him and since then she has always talked to him and sung to him. Sonya still needed the support when James was not talking, to keep the relationship positive and relaxed, and then, all of a sudden, James' speech did come.

Sonya found that music worked really well, and that she could teach James things to music through songs. He could say his own name, and could go fast and slow and he could wait. He always had music in his head. Sonya was proud of James' achievements. She has spent a lot of time with him and feels he is now ready for school.

As time went on, Sonya became more confident and creative with her own music-making, and she and James have a strong relationship now, and they sing all day long. Sonya and her husband now teach adults with Down syndrome how to Rock n' Roll.

Case # 2 Leanne (primary caregiver to Garth)

(L = Leanne, timings relate to the point on the interview recording)

Background

Garth is the first child of Leanne and Rob. He was born at thirty five and a half weeks and "had a really really hard start" (L. 5:04). He spent the first two months in specialist care units, most of which were 660 kilometres away from home. Leanne was with him all the time and Rob visited when he could, usually around the various surgery times. Garth's neurological examination indicated Garth "would have difficulties with learning and movement" (L. 5:04) and Leanne noticed, "There was something different about him" (L. 5:04) regarding his physical features. He was diagnosed with Sotos syndrome (Appendix 1) at thirteen months of age. His muscle tone changed from being like a "floppy rag doll" (L. 0:34) to being "really stiff" and "he did this sort of unusual posturals at times" (L. 5:04). "They actually think he's got cerebral palsy in the background, then this Sotos syndrome over the top" (L. 14:51).

"I felt I was in a tumble drier with a bag of rocks, absolutely traumatized – I'd see my son be resuscitated three times, I'd see him blue black and purple, lifeless and thought I was losing him, and it's like, that was really incredibly hard, I mean there was all this medical intervention, we were in ICU [Intensive Care Unit], we were in hospital, my kind of picture being home with my healthy baby within three days had just gone totally out the window and not only did I have like a baby with all these medical problems, I also thought there was something else; there was cerebral palsy and then I was thinking [takes a deep breath] y'know ongoing tests and it was hard. It was really hard, um, having all the medication and follow up, and just a lot of intrusion. And to be able to have, spend that time with a baby, and just not even being able to breastfeed. I was expressing milk and then I got so stressed … I just dried up and then I couldn't do it … that got really hard, that was hard" (L. 11.17).

Leanne changed from working full time to doing some casual work, but then found, "I couldn't do both, I just decided to stay home" (L. 59.31).

Leanne initially got support from a visiting neurodevelopmental therapist, before being advised to look at some EI options. She chose WEIT as it seemed "well organized, well integrated, and it offered a really comprehensive range of services that I thought would really help Garth, and help the family" (L. 18:48). Garth was a year old when they began the EI programme at WEIT.

Responses

Some comments included in the responses are extracted from written notes that Leanne made after the interview. They are included as they present additional information to that gathered in the interview.

Initial experience of the early intervention centre

Although believing that WEIT was the best place for Garth, Leanne found the reality of weekly visits, initially, a challenge, "I wanted to run away" (L. 22:46). It was like "holding on to my breath, and as soon as the session's over it was out the door" (L. 35:01). Leanne had no previous experience with children with special needs and found "the whole acceptance and coming to terms with him" (L. 39:00) and, "the whole kind of concept of having to come to a place and do stuff" (L. 40:36) very hard. However she could see how it helped Garth and how, "Garth was fine, he loved it" (L. 22:46). She also found it was "very grounding in a way too, to have the expert knowledge and care and to put a plan in place to say this is where we are now and this is where we can go in six months" (L. 22:46).

Attitude towards the early intervention centre

Leanne's attitude towards WEIT changed dramatically over time. She thought WEIT provided "a wonderful service" (L. 53:41) and she felt "incredibly lucky to be able to come and participate in a programme like this" (L. 55:55). She found the centre "invaluable" and the comprehensive multi-disciplinary approach "hugely important" (L. 53:41). It consolidated "more and better" (L. 22:05) all the early work and support she had received at home. The weekly visits were appropriate, "I don't think you need to come every day because what I learn here I take home with me and we have the individual development plan, so once a week's fine … I just take everything home" (L. 53:41).

Caregiver-child relationship before WEIT

Garth was not a well baby and had many medical interventions in the first few weeks of his life. He was unresponsive, a "grey pale floppy rag doll lying in my lap" (L. 0:34). He couldn't breast feed, and bottle feeding took up to an hour. Leanne was concerned about his starey blank spells and thought, "Oh Garth where are you, and he'd just kind of disappear" (L. 5:04). Garth was not smiling for several months, and not showing any recognition of his mother or father. Leanne was a worried mother.

Then came the practical implications and expectations of caring for a very sick child, "God, it's like all this work to do, how do I be a mum, there's all this stuff to do?" (L. 58:04). An added obstacle to forming a bond with her baby was that Garth did not always like being touched, "He's tactile defensive at times, and I've found that hard, trying to help him and he's like don't touch me sort of thing" (L. 31:24).

Music-making and the caregiver-child relationship

Leanne saw the benefits of MT for Garth, "It helps bring everything else together for him, cognitively, emotionally and physically ... it's been a tremendous help" (L. 36:17). But she also saw benefits for herself. By participating in both the group and individual MT sessions with Garth, MT gave Leanne, "amazing tools and experience to be given as a mum to be able to take home and have it in the family" (L. 42:17).

When Leanne was feeling anxious about Garth's prognosis and her own ability as a mother of a child with special needs, she found MT "helped me better manage my stress levels, work through grief and feel confident about my parenting role" (written). "The music has just been essential really to get through that hard time, 'cos it just ... works with all the other therapies ... and on its own it works well" (L. 37:18).

Garth was in need of daily exercises and physical stretches. Leanne found the use of music enabled her "to do the really hard repetitive work with Garth" (written) and it "just made it fun and it helped me to relax and enjoy and that whole attachment and bonding came together ... it [music-making] could just pull it all together" (L. 58:04).

Leanne came to enjoy the group MT, "I love it, now it's not scary (laughing) and I can see the huge impact it has ... especially in the relationship like me, and Garth and the family, and the other kids and the social skills that come with it" (L. 35:01). Leanne found that through music-making she and Rob looked at Garth through different eyes. Music-making had promoted positive interactive experiences and, "It's like, wow, Garth, you've got something here that you can do. You haven't got all these awful behavioural problems, you've got actually tools that I can use, and Rob can use, and Garth understands" (L. 45:52).

Garth is non-verbal and "has dyspraxia" (L. 23:51), and Leanne found music acted as a motivator for cooperative behaviour. Music helped Leanne, "to be able to engage Garth on a level where he's going to engage in like a helping working relationship, it's when he can't vocalize, it's a really good grounding platform to work on to get the other skills" (L. 36:17). Leanne felt more skilled in how to use music more effectively when helping Garth develop motor skills and communication skills.

Leanne incorporated music into daily activities and said it had undoubtedly fostered their relationship, "It is a two way process. Garth is very responsive to music so by incorporating music into our daily activities a strong parent-child relationship has developed" (written). From being a worried mother, Leanne found MT helped her to 'catch her breath' and form a loving relationship with her son, "The wonderful thing about music therapy … it normalises the whole experience." (written)

Caregiver enjoyment at seeing her child feeling good through music-making

When Leanne observed Garth's involvement in the group MT sessions, "although he couldn't kind of move his hands and he couldn't talk, you could just see his face watching and engaging" (L. 40:36). She knew, "from the expression on his face, he loves it" (L. 29:48). Leanne noticed that when he was back in his home environment, he explored the actions and motor sequences in his own time, which was advantageous developmentally because Leanne often had difficulty trying to help him with his motor skills due to his tactile defensiveness, "Music has definitely helped in that 'cos it motivates him to do the work himself … his motor planning is coming together" (L. 31:24). Music was a tool that Garth "has really been able to use and use it well. He just seems to relate, whether it's because his language is late coming, but he can, he works with it … it moves him, and it motivates him" (L. 28:30).

Music-making as contributing to a caregiver's 'feel good' experiences

Leanne found music an "amazing resource" as it helped her "as a Mum to feel good" (L. 26:12) about what she was doing with Garth.

Caregiver's sense of pride in child's achievements

Leanne saw music as having helped Garth develop a greater awareness "of what was happening around him" (L. 40:36), and of his body in space. She got very excited when Garth actioned or vocalized things "out of the blue" (L. 46:58). She attributed this to "that's the music" (L. 46:48) and this made her feel like, "Wow, what a rocket, our Garth … I can just imagine that that's going to get better for him … he'll get more control" (L. 46:58). Leanne was very proud of Garth's progress and felt that MT helped them to "celebrate his successes" (written), "He's doing so well … he's such a happy boy" (L 37:54).

Using music as an aid to regulate child's behaviour

In the early days Garth presented as being "uncoordinated, sporadic, haphazard" and "quite static" (L. 46:58). Music had helped him to regulate his breathing and to settle.

Garth had difficulty sitting and staying on task and Leanne used music to keep him focused and engaged. Music had helped Garth to "regulate his energy levels" (L. 46:48). When the music had relaxed him, then Garth was able to participate more appropriately and constructively, "He gets a bit more organised" (L. 43:28).

Because Garth had more developed receptive language than expressive language skills, he became frustrated when he struggled with his motor planning. Leanne used music to help manage this behaviour. She either used it as a distraction device, or she used "songs and actions to help validate his feelings". Music helped Garth "to explore constructive ways of expressing himself and dealing with his feelings of frustration". Music helped "to distract Garth when everything has become too overwhelming and stimulating for him" (written).

Caregiver's confidence leading to creative use of music

Leanne became more confident and creative with her own music-making at home when interacting with Garth, "I just see the change in him when he gets upset, and I sing a song or do some action things and his whole demeanor changes" (L. 43:28).

When out walking or riding his bike Leanne would sing songs to help him "get into a rhythm" (L. 25:04). She now incorporated music "into normal day to day things so it just normalizes it more, it's not so scary" (L. 25:47). "Music therapy gives me day to day skills that I can use creatively as a mum when helping Garth with his daily activities e.g., I sing a song when helping Garth to put his shoes on or when brushing his teeth. These can be challenging tasks for Garth as sometimes he dislikes sitting still and sometimes he does not like his face being touched. Music helps Garth to complete these tasks and this makes both of us feel good" (written).

Leanne also became more aware of how her own vocal and physical expressions impacted on Garth's behaviour. Through interactive experiences in MT at WEIT Leanne became aware of how her enthusiastic verbal and non-verbal behaviour towards Garth was actually impeding his self-regulation and not allowing him enough space to practise his motor skills. Her intent to be motivating was too stimulating for him. "I get a bit excited sometimes, I have to slow myself down (L. 39:00), and speak in a calm and well modulated voice. Music therapy helps me to be more aware of my behaviour and language and how to work more therapeutically with Garth" (written).

Caregiver-child relationship at time of interview

Leanne saw Garth, not as a little boy with problems, but as a little boy with potential. She is a devoted mother who was willing to learn more about her son and herself in order to strengthen their relationship and advance his development. She still had moments of anguish such as when watching Garth trying to engage socially with his peers, "He'll go up close, and he will try and engage them, it pulls on my heart strings sometimes, 'cos he can't talk" (L 33:04). However, Leanne had found music to be a wonderful tool to create positive interactive opportunities, to have fun together, and to promote constructive learning experiences. Leanne wanted to be able "to sit down and look him in the eye when he's fifteen and say, hey, we've done a good job" (L. 37:54).

Summation (Case #2)

Garth had a very difficult start to life, and Leanne felt absolutely traumatised by the ordeal. She was in a hospital with him away from home and she found all the medical interventions intrusive and really hard to accept. He was unresponsive towards her, and did not always like to be touched. She wondered how she was going to be a mother when she had all this work to do to look after him. It was hard. Leanne gave up work to stay at home with Garth. Garth was diagnosed has having Sotos syndrome with cerebral palsy.

Leanne welcomed the support and knowledge provided by staff at WEIT but initially she found the reality of weekly visits a challenge. Even though Garth loved it, she wanted to run away. Over time she came to feel it was the best decision she had made. She felt very lucky to be part of the multi-disciplinary programme and was diligent about working on Garth's programme at home.

Leanne saw how responsive to music Garth was. She could see how it helped Garth in many areas of his development and how it worked with all the other therapies. It also provided her with an amazing tool to take home and have in the family. She found music-making helped her to feel more confident about her parenting role. It became a positive medium with which to engage Garth in a working relationship. She found music made everyday happenings easier to manage, and she used music to help Garth regulate his own behaviour. Leanne enjoyed seeing Garth use his own music, and in his own time, to practise developmental skills.

Through MT, Leanne had learnt how to modify her own expressive behaviour in order to improve the quality of interaction between herself and Garth. Music-making had helped normalise and strengthen their relationship. Music-making made both of them feel good.

Case # 3 Jacqui (primary caregiver to Gene)

(J = Jacqui, timings relate to the point on the interview recording)

Background

Gene was born on his due date with no complications. He was an "excellent baby" (J. 1:20) and there were no concerns. Gene had a sister nine years older who was physically advanced for her age in the early years, so Jacqui did not start to question things until Gene was about twelve months old. At this point she became concerned about his "Charlie Chaplin type walk" (J. 3:42). After hip x-rays, two separate specialists said things were fine, but Jacqui's concern increased, "I was still really disillusioned by all this because I still felt I was hitting my head against a brick wall basically and that no one was really listening to me (J. 10:41) … I don't care what they say this isn't right … just watching him and I could just tell" (J. 14:21)

By the time Gene began pre-school kindy (kindergarten) when he was three years old, Jacqui was also encountering some behaviour problems, "We tried everything" (J. 59:10). Jacqui felt the stress every day of not knowing how Gene would respond to her, for example, would he come up and bite her clothes? She wondered what she was doing wrong, started doubting herself, and wondered what she could do "that could be different" (J. 1:16:59).

Just prior to his fourth birthday Gene's pre-school teacher recommended Jacqui attend a child therapy clinic run by a physiotherapist and an occupational therapist. Jacqui found them wonderful and felt a sense of relief that finally, "Somebody can see what I can see and is listening," and that she "wasn't just going crazy" (J. 16:21). They had twelve sessions.

The Child Therapy Clinic noticed some communication difficulties along with some physical delays and recommended Gene attend WEIT, "As hard as that was to really come to terms with that he did have trouble, did need help; on the other hand it was very comforting to know that we were here [WEIT] with them [crying] and they were the perfect people to give it to us" (J. 29:07).

Gene began at WEIT when he was 4 years 5 months. After ten sessions at WEIT and four days before the interview for this study, Gene was diagnosed, as a result of genetic testing, with Fragile X syndrome. Once again Jacqui felt the roller coaster of mixed emotions but, "Finally there was a name to this" (J. 40:07). The whole scenario was a new experience for Jacqui, "We never really had anyone that had needed help" (J. 21:10).

Responses

Initial experience of the early intervention centre

Jacqui "knew instantly that [WEIT] was the right place" and she felt "it was going to be great for [Gene]" (J. 29:07). She felt welcomed even though it was a "reality check" (J. 29:07) as she began to realize there was more going on with Gene other than a bit of a walking and speech problem, "There's so much to take in the first time. There's not only the reality of meeting new people and learning their way; it's the reality of realizing that's something that your child is needing, so I think it's a very mixed emotions but as I say I couldn't find better people to deal that with, and help us accept and get on with that and teach us than they are here … I'll start crying again … they are, I mean yeah, it is, that side of it, that side of it was, when you have so much going on, and to deal with … as I said it is such a natural way … it's just not forced" (J. 1:08:45). Jacqui's tears during the interview came when she spoke highly of the staff at WEIT. It was as though she had shared her burden and found huge comfort in feeling supported at last.

Attitude towards the early intervention centre after ten sessions

Jacqui was very pleased that she was attending WEIT when Gene was diagnosed as having Fragile X syndrome. "I didn't even really know where to start" (J. 34:42). "Thank God he's here [at WEIT] and we've got help for him and the best possible help we could ever ask for … a comforting side of realizing that there was a problem" (J. 40:43). Jacqui thought the staff at WEIT were "exceptional" and she found it "amazing … to come to one house and go into different rooms and find that sort of quality of people" (J. 1:21:14).

Jacqui remarks on Gene's progress after only ten weeks, "How could I ever do without them, I mean, how far they've brought him, how he's changed over the weeks that he's been coming here is just amazing, I mean, family notices it, my sisters, his speech, his communication, everything I mean it's just obvious to everybody how much this has helped him, I'm in no doubt about that" (J. 32:34).

Jacqui felt the structure of the opening group MT, individual sessions, then finishing off with group MT worked well. Even though Gene was not at the moment, "such a group child", she felt he was "definitely come along" (J. 1:11:02), and was "learning to deal with a small, group situation ...it's not overwhelming for him ... he just takes it all in" (J. 47:06). Jacqui felt Gene benefited from "the best of both worlds" with both group and individual sessions. She "wouldn't change a thing" (J. 1:11:02) about the EI programme.

Being part of the WEIT programme had impacted greatly on Jacqui's well-being. "I can sit back and feel comfortable with what I'm doing for my son, and I think that's really important, for me it is" (J. 1:14:52).

Caregiver-child relationship before WEIT

The immediate and extended family of Gene was very close. Gene was "definitely Mummy's boy" (J. 24:26), and Dad was "a great father and he's hands on with him when he's not working" (J. 25:25). Jacqui had spent a lot of time with Gene but over the four years she had found their relationship an emotional roller coaster due to Gene's unpredictable behaviour, "I never knew what sort of reaction I was going to get" (J. 1:16:59) and this was compounded by her own feelings of not being listened to by professionals when she felt there was something wrong. She cried as she spoke of her "tend[ency] to overcompensate for him" as she could "see him struggling" (J. 24:26), and Gene "did rely on me because he knew I was probably his other set of hands" (J. 25:25).

Jacqui was choking back the tears as she talked of some of her responses to Gene's behaviour before she had knowledge of his diagnosis. Not understanding his anxiousness and associated inappropriate behaviour she would coax him along, "Don't be silly mate, c'mon ... this is how it is, and let's just do this, get on with it" (J. 40:43). As a result, Jacqui was "always the one he takes it out on ... I'm the one that cops it" (J. 58:30).

Music-making and the caregiver-child relationship

Jacqui found the group MT a time to observe Gene, reflect, and action some new relationship strategies. For the first few sessions Gene would sit right beside Jacqui, but as Gene become more comfortable and familiar with the structure of the session, she gradually distanced herself from him. Jacqui was participating fully; Gene did a lot of observing. "He was quite happy just to sit there and he would watch Christine and take it all in ... he would sing the songs on the way home in the car ... more was going in than what met the eye … he would come out with all these songs at home" (J. 47:06).

Jacqui became more aware of what brought on anxious behaviour, "As soon as you put attention on him, forget it … now I realize it's just a whole anxiety thing that I think he feels like the whole worlds coming in on him and we've learnt you just don't do that, I mean, praise him in a different way" (J. 47:06). Jacqui began to observe how Christine, during the group MT, managed to keep Gene engaged and in 'comfort zone' using non-verbal language, "she gets eye contact with him" (J. 47:06).

Jacqui found the interactive experiences in the individual MT session "as beneficial for me as well as him." She learnt about "the way of teaching him, showing him, and just getting across to him" (J. 1:05:14) and she felt, "It was just so natural" (J. 1:04:41).

Caregiver enjoyment at seeing her child feeling good through music-making

Jacqui got pleasure out of hearing and seeing Gene come out with songs and actions when he was not at WEIT, "He loves music, he really actually relates to it" (J. 47:06). To Jacqui, this was very evident in the individual MT sessions, "I like the fact that when he comes into Christine's room [individual MT], he's full on … he's a whole different child being brought out in a whole different [way] … he just loves coming in here" (J. 47:06).

She noticed how music-making put things "at a different angle" (J. 47:06) and that Gene was learning new skills without realizing it. Gene had difficulty with listening and waiting, yet, "she [music therapist] does it all with music and he doesn't even realize that he's doing it, and I truly believe it's helped a great great deal with that … it's just this whole teaching him of every day skills that are brought out by doing that [specific music activities], and he just absolutely loves it" (J. 47:06)

Music-making as contributing to a caregiver's 'feel good' experiences

Jacqui found there were songs and actions she "didn't know" but she found they were done "in such a neat way that they are catchy and … we find ourselves going home singing these songs … you just get them in your head and you sing them so everything's fun" (J. 1:07:37). Jacqui was becoming more confident using music in their home environment. She has also found resources useful, "Christine had made us tapes up and written out the words … we'd put the tape on, and we'd all sing and that was really really helpful too" (J. 1:07:37).

Caregiver's sense of pride in child's achievements

Jacqui was thrilled that over "the last few weeks, he's actually started to do some things and participate [in the group MT]; he's done really well … it's really beneficial and it's really been very helpful for him" (J. 47:06). And in the individual MT sessions she was very proud of his improved ability to wait and take turns, "he's done it SO well … it's just amazing" (J. 47:06).

Using music as an aid to regulate child's behaviour

Jacqui had become more confident in using music to prevent an onset of anxious behaviour, or to defer the escalation of an already stressful situation. Gene became anxious when situations changed such as leaving someone's house. Gene would, "lose the plot, basically, when it was time to go so now I have CDs in the car and he knows we say goodbye now and when we get to the car you can have the CD on … so he quite happily 'bye bye' and off we get into the car and 'I have my CD on now', and … y'know music came in by helping him because he loves it, and he would go out and say goodbye and lose the fact of, y'know, the other anxiety of leaving and to going to wherever" (J. 53:39).

When at home, Jacqui used tapes and CDs when she sensed Gene was "panicked about something," and "it pretty much snaps him out of it" (J. 57:23). When he went to bite at her clothes, she could distract him with, "Come on let's go and put a CD on … Instantly it'll turn him around" (J. 59:10). By offering music, not only was this redirecting Gene's level of anxiety to a more regulated state, but Jacqui also had a tool for managing a stressful situation. Whereas, before attending WEIT, her verbal and physical responses in telling Gene not to bite may have exacerbated the situation, she now was more aware of how to phrase what she said and how to shape physical reactions to achieve a more constructive outcome.

Caregiver-child relationship at time of interview

Jacqui now had a "better understanding of what his needs are, why he's like the way he is, and how to deal with it" (J. 1:03:11). She felt the therapists had guided her in "just doing things in a different way that I would never have known how to do before … I think we've learnt as much from this as what Gene's learnt … it's really made a huge huge difference in our lives" (J. 1:03:11).

She talked confidently about how she shared Gene's stories openly with her friends and family and acknowledged that the more people understood Gene, the more it would help him, "They see the change anyway, so they find it amazing … they are seeing how much he's coming along … because I believe that if what they are told and understand, that's helping Gene in itself" (J. 1:12:22).

Jacqui was more positive about her relationship with Gene. She realized that she had to think "two or three steps ahead of myself all the time" (J. 1:20:15), but knew that this helped decrease Gene's anxiety, and this in turn made life easier all round. "As much as some days you think whoa, it was a tough day … I see light at the end of the tunnel, and I think … now we're onto it" (J. 1:26:04). "He's a wonderful child and he's a great little boy" (J. 1:25:21).

Summation (Case #3)

Gene was an excellent baby and there were no concerns until he was about a year old. Jacqui then observed some physical difficulties and began encountering some behaviour problems. She tried everything. She felt like she was hitting her head against a brick wall as specialists and others did not seem to be listening to her. She wondered what she was doing wrong.

Jackie felt a sense of relief when she attended a child therapy clinic. Someone at last believed her story. Even though it was hard accepting that Gene needed help, she felt WEIT was the perfect place for Gene. Within ten sessions at WEIT Jacqui began to see and understand Gene with greater insight. His inappropriate and unpredictable behaviours were as a consequence of high anxiety levels. She became more aware of how different interactive techniques produced different responses.

Gene was diagnosed as having Fragile X syndrome after attending WEIT for ten sessions. Jacqui felt she was on an emotional roller coaster and did not know where to start but was comforted by the support and knowledge she got from the staff at WEIT.

Jacqui thought highly of the EI programme and wouldn't change a thing. She felt she was learning as much as Gene. She thought Gene had the best of both worlds with group and individual MT. Through the enjoyment of musical interactions Jacqui could see Gene was learning other skills such as listening and waiting. Jacqui was proud of his progress in such a short time.

Jackie now used music as a management strategy and to help Gene regulate his anxious behaviour. She could redirect inappropriate behaviour by offering music as a suggested activity. Jacqui enjoyed seeing Gene express himself through music and they both enjoyed singing songs and doing the actions together when at home.

Jackie could now sit back and feel comfortable with what she was doing for her son. With greater understanding she now had an improved relationship with Gene, and he was progressing developmentally as a result.

Case # 4 Eva (primary caregiver to Pippa)

(E = Eva, timings relate to the point on the interview recording)

Background

Pippa is the second child of Eva. Her brother is four years older. Eva suffered post-natal depression with both children, "Her father and I separated when she was two-and-a-half, so, I think she's had kind of a rough start to her life, it's been sort of full on" (E. 2:43). "Things still aren't great, I really still don't believe that she's in a great environment for her disability … I am planning on moving down south at the end of this year, which will take her away from her father, but I think it's going to give her that stability and that routine that she really needs" (E. 3:59). Pippa "was never an easy baby, she screamed a lot, she was reflux, she never slept" (E. 0:18). But Eva also had other concerns, "I always felt there was something not quite right, she sat late, she crawled late, she walked late … it wasn't until she was about two that I really noticed that she wasn't talking and I would raise this with people and they would say, no just wait (E. 1:51) … I didn't feel like I was being listened to … people would say she will catch up but I just knew she was getting further and further away from the mark … the screaming, the meltdowns … as she got older it was becoming apparent that there was something up with her" (E. 6:11). At four years of age, Pippa was "diagnosed with autism, at the mild end of the spectrum" (E. 1:51). Eva was "relieved" yet "very sad" on receiving the diagnosis but felt she had some understanding of "how their world works" as she had grown up with a cousin "who's quite severely Aspergers" (E. 6:11). "I'd say she [Pippa] behaves like a mildly autistic child, the most noticeable thing about her is her speech and her meltdowns" (E. 2:43). Even though Eva got support with what she was entitled to through the Autistic Association she felt she "just didn't really know what to do" (E. 7:24), but "then just decided that, ok, well what can we do?" (E. 6:51). Eva received information about WEIT and went on the waiting list. "It was so great striking someone like Sara [manager of WEIT] ... I rang Sara and said look, I'm on my own, I'm really starting to struggle here ... feel like I'm getting out of control, so they got me in here as soon as they could, which was fantastic" (E. 7:24).

Responses

Initial experience of the early intervention centre

Eva "knew it was good" (E. 8:26) to come to WEIT and knew Pippa would be in a place where her behaviour would be understood, but Eva still felt "completely and totally overwhelmed." She "just wanted to run" but told herself she had to stay. It was a shock "to see other parents and other children in a similar situation" (L. 8:26).

Attitude towards the early intervention centre after ten sessions

For Eva and Pippa, attending WEIT was not easy. Eva felt exhausted at the end of the sessions, but also noted the benefits, "I just feel really supported here, (E. 39:15) just having somewhere to come where everything is totally accepted, absolutely totally accepted (E. 38:18) ... we're very lucky to have it [WEIT]" (E. 43:35).

Pippa tended to react adversely to change and Eva wondered if the rotation between the four therapists was "just a little bit too overwhelming for Pippa, that she feels the expectation and seems to react to it, but she loves coming here ... she loves it" (E. 11:28). Eva was "quite happy" with the overall programme and she especially enjoyed the end of session group music time, "We all love that" (E. 23:02).

Eva felt Pippa had "definitely benefited" (E. 37:34) from coming to WEIT and noted "the biggest response" (E. 12:00) that she saw in Pippa was in the MT room [for individual MT], and when the SLT was using the computer with her. "With moving, and leaving the Centre I know there'll be a void in the music therapy; that is the one thing that I can see that is really hard to fill" (E. 29:35).

Caregiver-child relationship before WEIT

"I bonded immediately with Pippa and I didn't really bond with my first child … I suffered post-natal depression with both my children – not as severely second time because mental maternity health were on my case, I was monitored … It was very stressful and I think with what was going on around her as well with the marriage not being so great as well it was probably not a great environment for her to be in" (E. 3:24)

Eva found Pippa "hard work" (E. 5:13) with her meltdowns and with her being "constantly" 'on' her, "She's on me the *whole* time … she's not touching me, she's leaning on me, she's lying over me" (E. 27:33). Yet Eva found Pippa "incredibly cuddly" (E. 28:04).

In managing Pippa's meltdowns, Eva was able to sometimes hold her tightly and calm her down by quietly saying "it's ok it's ok." However, "at other times I can't even get near her so I just actually let her thrash it out" (E. 12:54). Eva could not always predict Pippa's behaviour – "you just never know" (E. 26:20). But Pippa was capable of having "her independent times when she will just go off for hours and do her own thing" (E. 28:18).

Music-making and the caregiver-child relationship

Eva and Pippa enjoyed dancing together at home, "She loves her music, everyday we do dancing, everyday at home, she'll just grab me 'Dancing Mum' (E. 13:45). We put on music and dance (E. 13:58). We have fun just with music … what she responds to (E. 31:49). She loves that train song that they do here [WEIT], and we do that at home, she'll set up the chairs and she's in the lead" (E. 17:42).

But, "You can always tell the music she doesn't like (E. 32:52), some music just makes her completely shut down" (E. 31:49). This usually happened when they were listening to the radio when travelling in the car, "She likes songs with sort of a good steady beat, she really gets into that, her whole body is going, sometimes some songs that are just too full on, too much, she just 'blrrr'" [indicating shut down, head turned away, thumb in mouth] (E. 32:21).

In the group MT sessions Pippa clung to Eva, "but I know that she loves it, she's always got like one eye out there sort of like … oo oo what's going on?, and I enjoy it … I think music is great for Pippa. (E. 9:49). When we do dancing around I still have to carry her around, and she still won't sit beside me, she still has to sit on me, and we do like with the sticks, she's right there in front of me and we're doing our things with the sticks and she will join in now, she'll do the odd one and then sort of like pull back, but she's participating but on her own level, so she's definitely with the group and like some weeks she'll just get down and hold onto the piece of lycra fine, and do the rainbow ring fine, other weeks no" (E. 16:47).

Caregiver enjoyment at seeing her child feeling good through music-making

"Pippa loves her music, she really responds well to music (E. 9:49). She gets so much out of it" (E. 31:20). Eva enjoyed seeing Pippa happily expressing herself through music-making, especially when she was sharing the experience in an interactive and creative way.

Pippa began her most recent individual MT session with a "huge meltdown ... but by the end of the session we were both standing there with the drums, banging away, like she just loves the drums, she can really express herself on the drums ... Christine has picked up on that right from the beginning ... it's always good to watch 'cos Pippa will lead like how she's feeling and Christine will start playing ... if Pippa is [demonstrating disturbed/aggressive sounds], Christine will start [same sound], and then Pippa will just quieten it down, Christine will just quieten it down and then Pippa will just 'ohh' [indicating an interactive gesture responding to supportive engagement], yeah, y'know she gets creative, she'll get the drums and go on the side of the drums and just do, just different things, yeah, so, she really does express herself when she comes in here.(E. 33:19). She's like 'what will she [music therapist] do if I do this?'" [indicating Pippa's possible thoughts while engaged in interactive musical play with music therapist] (E. 34:26).

"When Christine gets the blackboard out with the chalk, I can sit right back from her [Pippa] and Christine, and Pippa is making like marks and Christine will be doing like vroom noises, or d d d [indicating sound play responding to Pippa's energy on chalkboard], and Pippa just gets into that, she loves that ... and she doesn't care if I'm here or not" (E. 35:00). Pippa was independent from Mum and happily engaged in an interactive activity where she was exploring different energy levels.

Caregiver's sense of pride in child's achievements.

Eva was very proud of Pippa with her toilet training. "She's just been toilet training for over a week and it's just fantastic, and little things like that really has helped her development as well, it really has, and she's so proud of herself, and I can see that just pushing her along a little bit more as well, because she's not going to be in nappies now, and people notice that she's in nappies" (E. 40:48).

Using music as an aid to help regulate child's behaviour.

Pippa had a low tolerance to change and this was evident when rotating between therapists for the individual sessions. "Pippa is normally quite tough when she comes in but Christine always manages, by the end of the session it, every session's always ended well, so I'm really happy with the way things are going" (E. 23:02).

Pippa's meltdowns were often accompanied by strong aggressive physical behaviour. As Pippa regained more composure during the non-verbal musical interactions, Eva had noticed the change in the quality of the interactions, "In here I see Pippa display and recognize things like fast and slow, and soft and loud and stuff like that and Christine does like (lowers voice) quietly and she'll try and say to Pippa now quietly and she recognizes that, and softly" (E. 12:00). These quiet interactive moments made everyone feel good.

Eva was picking up ideas of how the music therapist interacted with Pippa, especially when supporting Pippa to move from a distressed state to a more regulated state, "What I notice with Christine is that Christine can pick up and put her finger on where Pippa is at very quickly and like she'll just say to me something like [lowered voice] 'we'll go non-verbal, just go non-verbal', and even just by her [music therapist], I've actually learnt a lot from that and I've been passing that on to my parents … and I would only receive that information from participating and seeing how it works" (E. 10:32).

Caregiver's confidence leading to creative use of music.

Trying to toilet train Pippa a year ago before she was diagnosed "was an absolute disaster and she regressed something shocking" (E. 41:25). After attending WEIT, Eva decided to come "at it from a different angle. We sing "I'm going to the …

toilet." I make it fun ... I pick her up and I swing her around and we dance away to the toilet, 'cos otherwise it's 'no no no'" (E. 42:43).

Caregiver-child relationship at time of interview

At the time of the interview the personal life of Eva was emotionally stressful. Dad had brought Pippa to a couple of the latter EI sessions. Mum and Dad were not talking to each other. The staff at WEIT noted an escalation in disturbed behaviour from Pippa.

However, Eva felt she had "taken a lot of stuff home" (E. 12:00). She had picked up some management strategies such as the idea of saying "one more and then it's finished" and commented that Pippa's "tolerance level is much better" (E. 14:34). During group MT the children had their own mats beside their carers. Eva was reinforcing that with Pippa, encouraging her to "sit beside me" (E. 35:41).

Eva was feeling more confident about her relationship with Pippa, "As you go along you sort of pick up things that you've heard or talked about here ... it sort of comes to you ... I find her a lot easier to manage" (E. 15:01). Eva could "push her along a little bit more" (E. 40:48), and add some boundaries. She was more aware of how her own verbal and physical expressions could impact on Pippa, and she had observed how non-verbal behaviours could be used to an interactive advantage. Eva had also seen Pippa engage in constructive quiet interactive play and she had become aware of what musical strategies were involved in getting to that point, and how the interaction was maintained.

Eva and Pippa were leaving the area but Eva was set to continue with having musical happenings in the home. Christine had made her a tape "and I can take it with me, and that will be great, and I can set aside a part of a day when we can do that together and do some stuff ... I was thinking we might get her a drum and stuff like that" (E. 36:23).

Eva saw these times as something to look forward to, having a happy time together.

Summation (Case #4)

Eva's personal life had been stressful due to post natal depression and the break up of her marriage.

Although Eva felt she always had a close bond with Pippa, Pippa was never an easy baby. Eva always thought there was something not quite right. She didn't feel she was being listened to. At four years of age Pippa was diagnosed with autism, at the mild end of the spectrum. The most noticeable thing about her was her speech and her meltdowns. Eva was struggling and got into WEIT.

Having attended with Pippa for ten sessions Eva felt very lucky to have been part of WEIT. She felt very supported, but found participating in all the sessions to be exhausting. Pippa reacted adversely to the rotation system of seeing the four therapists. Eva found Pippa hard work. Pippa tended to cling to Eva. Eva enjoyed and participated in the group MT session even if Pippa was 'on' her.

Pippa responded well to music. Eva and Pippa enjoyed dancing together to recorded music at home.

Eva had noticed how the music therapist used non-verbal techniques effectively to decrease meltdown behaviour and redirect this stressful emotional state into a more positive and regulated state. Eva enjoyed seeing Pippa able to express herself through music, exploring a range of energies through interactive musical experiences.

Eva was becoming more creative with her own music-making when encouraging skill learning and cooperation e.g., making up a song and dancing Pippa to the toilet. Eva wished to access resources and musical instruments so she and Pippa could continue positive music-making experiences when they moved from the area.

Eva now found Pippa a lot easier to manage.

Comparison of Carers' Responses.

The responses from the four carers were grouped to discover similarities and differences in their experiences. The grouped responses are organized under the following headings:

1. the experience of a centre-based EI programme
2. the caregiver-child relationship
3. the experience of MT
4. the length of EI involvement

1. Experience of a centre-based early intervention programme

The following responses are brought together under this heading:

- initial experience of the EI centre
- attitude towards the EI centre

All four participants 'knew' they needed help with their children. All four participants enrolled at WEIT believing it was the best option for them, and there was a sense of relief that a group of professionals were there to support them. However it was also a reality check to have to come to a centre, to be with other families similarly in need, and to be actively involved as a carer. Each participant began at WEIT in an emotionally fragile state.

The carers' discomfort tended to abate as they saw their children enjoying aspects of the programme. As the carers gained knowledge and insight into their personal situations, their outlook changed. They all felt very lucky to be part of WEIT and they wouldn't change any aspect of it. They spoke highly of the multi-disciplinary approach and found the regular weekly service very helpful. In between sessions they explored new ideas and strategies at home. They found huge comfort in the overall support from the WEIT staff.

2. Caregiver-child relationship

The following responses are brought together under this heading:

- caregiver-child relationship before WEIT
- caregiver-child relationship at time of interview
- caregiver's sense of pride in child's achievements

The personal situation for each of the four participants is quite different, the nature and degree of disability of the children markedly different, and the age at which each child started WEIT quite varied. Nevertheless, there were some commonalities of experience. Before beginning WEIT each participant had the insecure feeling of not knowing how to parent their own child effectively; they felt they didn't know what to do. They did not feel comfortable in their relationship with their children.

At the time of the interviews all four carers noted positive changes. They gave examples of their children's achievements with a sense of pride. They talked lovingly about their children and of the happy times they now experienced together. Each carer remarked on strategies, picked up from WEIT, that they found helpful to their situations at home. A sense of increased well-being and confidence permeates all four transcripts as each carer comes to a better understanding of their child and of their own interactive behaviours. They all had moved to having a more positive outlook about the present and future. They all felt happier in their relationship with their children.

3. Experience of music therapy

The following responses are brought together under this heading:

- music-making and the caregiver-child relationship
- caregiver enjoyment at seeing her child feeling good through music-making
- music-making as contributing to a caregiver's 'feel good' experiences
- using music as an aid to regulate child's behaviour
- caregiver's confidence leading to creative use of music.

All participants noticed how positively their children responded to a variety of musical experiences both in the group MT and individual MT sessions. They observed developmental benefits as a result of participating in music-making activities. They saw their children having fun. By participating in the sessions with their children the carers gained confidence in their own music-making abilities and they began to share enjoyable interactive musical experiences at home.

These musical experiences outside WEIT were having positive benefits on their children's progress, both developmentally and behaviourally. The carers were feeling more confident using music when encouraging the practice of specific developmental skills. All had observed the music therapist successfully using different interactive techniques with their children, such as non-verbal interactive play, and the sharing of a variety of different expressive energies. Each carer talked of successful experiences with their children when incorporating some of these new strategies at home and in their community. They reported using music to help them ease a stressful situation and to modify their children's behaviour into more acceptable forms.

All carers indicated a sense of being relaxed and confident about using a tool such as music to encourage positive interactive experiences with their children.

4. Length of early intervention involvement

Comparison of carers' responses of ten sessions versus more than twenty sessions

Findings were examined to see if anything emerged regarding length of time at the EI centre. Both Sonya and Leanne had had well over twenty sessions (a stipulated criterion in this study), lasting over four years, and nearly two years, respectively. Music-making in some form not only played a large part in their every day lives, but both Sonya and Leanne were becoming more creative with their own music-making – they were making up their own songs and chants to suit specific situations and to encourage successful engagements. They felt good about being able to do this; they found it fun.

Jacqui and Eva, on the other hand, were interviewed after only ten EI sessions (another stipulated criterion in this study) involving MT. They talked about the benefits of MT and they were beginning to incorporate music successfully into their lives. But a difference was noted. Jacqui and Eva were taking the structured aspects of their MT experiences, the specific songs, the specific audiotapes, and using these when interacting with their children, or when diversionary tactics were necessary. At this point they didn't seem to be as confident with their own music-making to freely create something on the spot, with one exception. Eva made up her own 'toilet' song and proudly reported that to the interviewer that she successfully gained Pippa's cooperation.

The implications of these results for the questions of interest for this study will now be discussed in more detail in the following chapter.

Discussion

The transcripts provide clear evidence that the carers in this study perceive strong benefits from their participation in the programme offered by WEIT. These benefits were seen for their children, themselves, and for their immediate and extended families. They all expressed the view that they were very lucky being able to access an EI service such as WEIT within their community.

Reflections on Centre-Based Early Intervention Programmes

The programme offered at WEIT is consistent with research trends that indicate that effective EI programmes need to be not only family-focused but need to provide for regular family input, to be multi-disciplinary in approach and to be commenced as early as possible and be maintained for as long as possible. WEIT is centre-based, multidisciplinary in approach, and encourages family involvement. The positive outcomes that have been reported in each account of the four participant's experiences are likely to be attributable to the above features of the programme, as described in the recent research literature (Blackman, 2002; Dunst et al., 1997; Gilkerson, 2000; Guralnick, 1997; Hauser-Cram et al., 2001; Krauss, 1997; Mahoney & Wheeden, 1997; Ramey & Ramey, 1998; Roffey, 2001; Shonkoff et al., 1992; Wolfendale, 2000).

However, even though all participants reported experiencing an increase in the effectiveness of therapeutic intervention since being at WEIT (compared with the limited intervention services they experienced with individual professionals prior to attending WEIT), and they all spoke very strongly about the support they got from the centre-based service, it is difficult to ascertain whether the gains and support are due specifically to WEIT being centre-based or multidisciplinary in approach, or to other factors. One also has to take into account the influence the type of therapies offered and the competencies and personalities of the therapeutic team has on any perceived benefits to a carer and child.

These complexities aside, WEIT seems to be offering a successful EI service. WEIT seems to be carrying out the recommendations of the service providers in Campbell and Halbert's (2002) study who not only recommended an increase in carer participation in a wide range of services but also a return to centre-based programmes. Furthermore, the service provided by WEIT is consistent with the findings of Blackman (2002) and Ramey and Ramey (1998) who report that intervention successfully produces long-term benefits when carers participate in a broad-based programme.

But what constitutes a broad-based programme? Publications discussing the effectiveness of multi-disciplinary approaches to EI do not go into detail as to what disciplines may be necessary for best practice. Nor is there any evaluation of the most effective therapeutic interventions for best practice outcomes. The results of this current study, admittedly limited by sample size, indicate that all four participants were happy with the four disciplines offered, MT, EIT, physiotherapy and SLT. They indicated that they would not wish for any change to the WEIT service being provided. (Eva did question whether the rotation system had a negative impact on Pippa's behaviour, but was also aware that the process of transitioning was part of the IDP goals). No further comments were made that referred directly to EIT, physiotherapy or SLT. However, the transcripts reveal how MT was perceived to interact with the other disciplines, and on their children's overall development. To quote relevant examples:

> It [MT] brings everything else together for him, cognitively, emotionally, physically (L. 42:17). The music has just been essential really to get through that hard time, 'cos it works with all the other therapies … it makes it a lot easier" (L. 37:18). I just think the music has helped integrate and put everything together … it just complements them all … music just cuts across the board with all of them [other therapies] (L. 56:53).

This integration across several therapeutic disciplines is clearly highly relevant to previous research that favours multi-disciplinary approaches over programmes based on single disciplines. Given the centre-based context for WEIT's combination of disciplines, by implication the results also support the arguments in favour of such settings.

Music Therapy's Role in Achieving Favourable Therapeutic Outcomes

The role of MT as a key agent for the generation of gains from participation in the WEIT programme clearly came to the fore within the interviews. Even though the participants in this study brought different life experiences to the interviews, there was a common thread of music-making becoming a greater part of their daily interactive experiences with their children the longer they were involved with a music therapist in EI. Obviously with MT being part of the programme, these family dyads had been exposed to both weekly group and individual MT experiences. However, the transcripts reveal that the carers experienced more than just involvement in MT sessions – the way in which MT influenced the dynamics of the carer-child relationship over time also came out as a dominant feature of the interview responses.

The carer-child relationship is of particular interest to this research, and to be sure it was a focus of the interviewer's questioning. Nonetheless, the detailed content of the interviewees' responses shows quite clearly the value of MT as an intervention agent with respect to the quality of carer-child relationships and what flows from that. This concurs with the findings of Shoemark (1996), Witt and Steele (1984), and Oldfield and Bunce (2001).

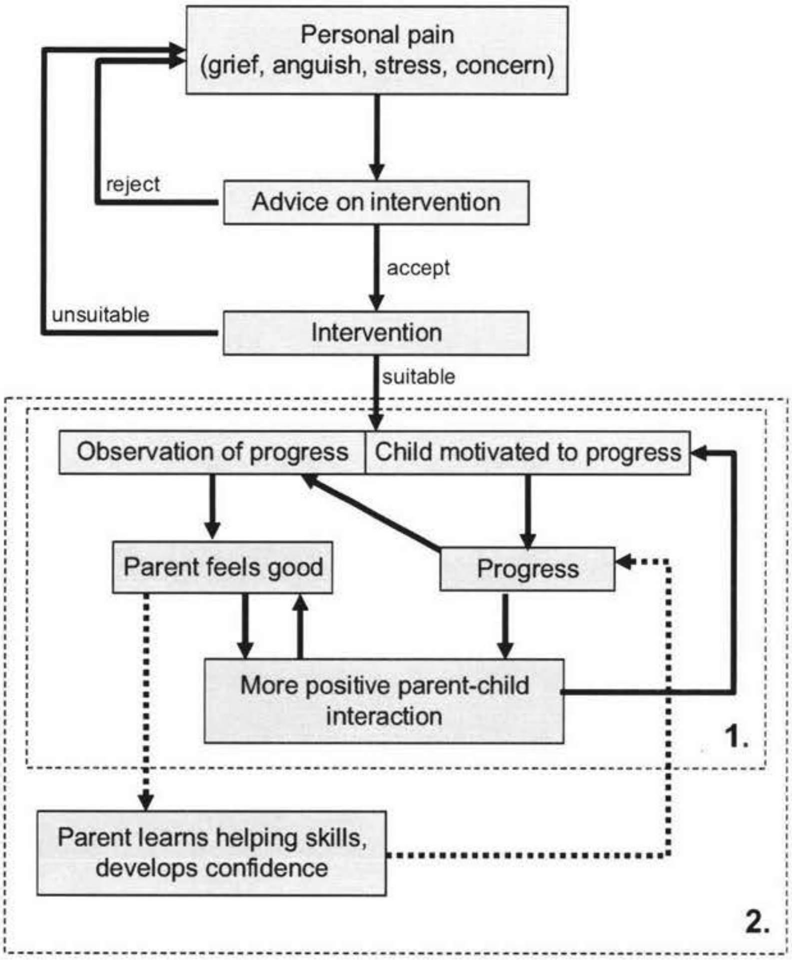
To explore this feature in more detail, it is valuable first to draw out a broad pattern that emerged from the reported experiences of each of the interviewees.

The Intervention Process: Generating Positive Feedback Dynamics

Within each of the interviews, and as collated in the comparison of grouped responses, a common pathway can be detected in the reported experiences of the carer-child dyad from the time of starting at WEIT to the time of the research. In each of the cases examined, positive developmental feedback linking therapeutic outcomes to a change in carer-child relationship, and a change in carer intervention techniques were able to be identified. These changes were contributing to significant gains relative to the IDP objectives. The positive feedback dynamics can be thought of as a cycle of reinforcing feedback loops as has been represented in diagrammatic form in Figure 2 (next page), which is an expanded version of that presented by Fahlberg (see Figure 1 on p. 7).

Figure 2 recognises the point that achieving positive developmental feedback may involve overcoming significant hurdles that are not present within carer-child relationships with normally-functioning children. As was the case for each participant in this study (which reflects similarly to the findings of e.g., Klaus et al., 1995) when carers received the information that their children had special needs, personal pain in some form was felt. If advice on intervention services was either rejected or deemed unsuitable by the carer, this sense of anguish continued. If the carer found a suitable intervention service where they felt supported, then this tended to promote an improvement in the sense of well-being and tended consequently to promote developmental gains in their children. The carers consequently felt good about their children's progress and, as Shoemark found (1996), they themselves learned new strategies for encouraging skill learning and for more effective behaviour management. Within the centre (the context for families in this study) the families reported experiencing positive carer-child interactions. As the carers gained more confidence in their own abilities, they explored new strategies at home. The success of these experiences encouraged further positive carer-child interactions, which were correspondingly motivational for the child's overall development.

Figure 2 Positive and negative feedback processes in intervention



1. Positive dynamic within EI Centre structure. The sustainability of gains after leaving EI structure remains an issue.
2. Positive dynamic extends beyond EI Centre, with an increased chance of gains being sustained.

In the case of the four participants in this study, the personal pain that was felt included the feeling of inadequacy – of not knowing how to 'mother' their children. They were open to advice, but when they felt uncomfortable with what was suggested, or felt they were not being listened to, carer stress increased. As observed by Greenspan and Wieder (1998), the well-being of the carer typically impacts on their children's emotional development, which in turn impacts on the child's overall development. Cases #3 and #4 illustrate this cyclic dilemma. They were frustrated as mothers, knew something was wrong, and knew their parenting skills were not meeting the needs of their children. They were seeking help. All four participants enrolled in the EI programme at WEIT hoping to get advice and support, with their main focus being on getting help for their children. They all reported developmental gains associated with the EI programme. In addition, they reported important changes in their relationship with their children, changes that came about through positive feedback experiences.

The Role of Changing Relationships in the Intervention Process

The fact that all participants identified changes in their relationships with their children as a part of reporting developmental gains support the arguments made in the literature by Emde and Robinson (2000), Hauser-Cram et al. (2001), Robinson (2002), and Zigler (2002), that in order to be effective, EI programmes need to focus on carer-child relationships as well as on the children directly. It is the critical role that the carer-child relationship plays in shaping carer-child interactions that is of particular interest to this study.

As illustrated in Figure 2, the relationship between carers and children is at the centre of a process that is potentially highly important to the nature of outcomes for children with significant disabilities. Research cited earlier (e.g., Griffiths, 2000; Mahoney at al., 1998) draws particular attention to the importance of this relationship and the associated quality of child-carer interactions. Focusing on the carer-child interactive process is coined by McCollum and Hemmeter (1997) as "interaction intervention" (p. 549). There is evidence from this current study that by attending to how a carer and child interact with each other, via interaction intervention, a change in relationship can be stimulated.

Cases #3 and #4, for example, reported how interaction intervention played a major role in improving their carer-child relationship. This intervention focus was especially important for these two carers as relationship difficulties due to the delay in their children's diagnosis had lead to several years of stressful carer-child interactive experiences. Baker et al. (2003), Barnett et al. (1999), Dunst et al. (1997), Gilkerson and Stott (2000), Kaiser and Hancock (2003), Williamson and Anzalone (1997), and Zigler

(2000) all talk about how the quality of carer-child interactions influence a child's development and emotional regulation. Even though Jacqui and Eva (Cases #3 and #4) had only a few months to digest all that was offered with an EI programme, both carers expressed their developing confidence in managing their children's behaviour, "I came at it from a different angle" (E. 42:43); "Just understanding things ... and looking, and doing things in a different way that I would never have known how to do before" (J. 1:03:11).

Even though Pippa in Case #4 still had 'meltdowns,' the reasons for them were now more understood. The mother, Eva, after only ten sessions, acknowledged that she was still struggling some days more than others, but there was an overall sense of improved well-being as she began to see her child in a different light and responding in different ways to certain stimuli, "As you go along you sort of pick up things that you've heard or talked about here, it sort of comes to you ... I find her a lot easier to manage" (L. 15:01). In this case, Eva, although going through personal strife and fully aware that this state of affairs was not helping Pippa's progress, was adopting new strategies that she believed would be helpful for Pippa's development, and expected to be able to implement them more frequently when they were both in a more settled position.

All participants reported feeling more positive about their parenting role since attending WEIT. For Leanne (Case #2), involvement in the WEIT programme "helped me better manage my stress levels, work through grief and feel confident about my parenting role" (written). Feeling more positive is conducive to improved carer-child relationships (Mink, Nihira et al., [cited in Hauser-Cram et al., 2001, p. 13]; Schofield, 1996). These conclusions, illustrated in the self-reinforcing loops of Boxes 1 and 2 (Figure 2), are consonant with the view that interaction intervention, where primary caregivers learn to modify their own behaviour and implement strategies to encourage more positive interactive experiences with their children, is effective in long term EI outcomes (Crockenberg & Leerkes, 2000; McCollum & Hemmeter, 1997).

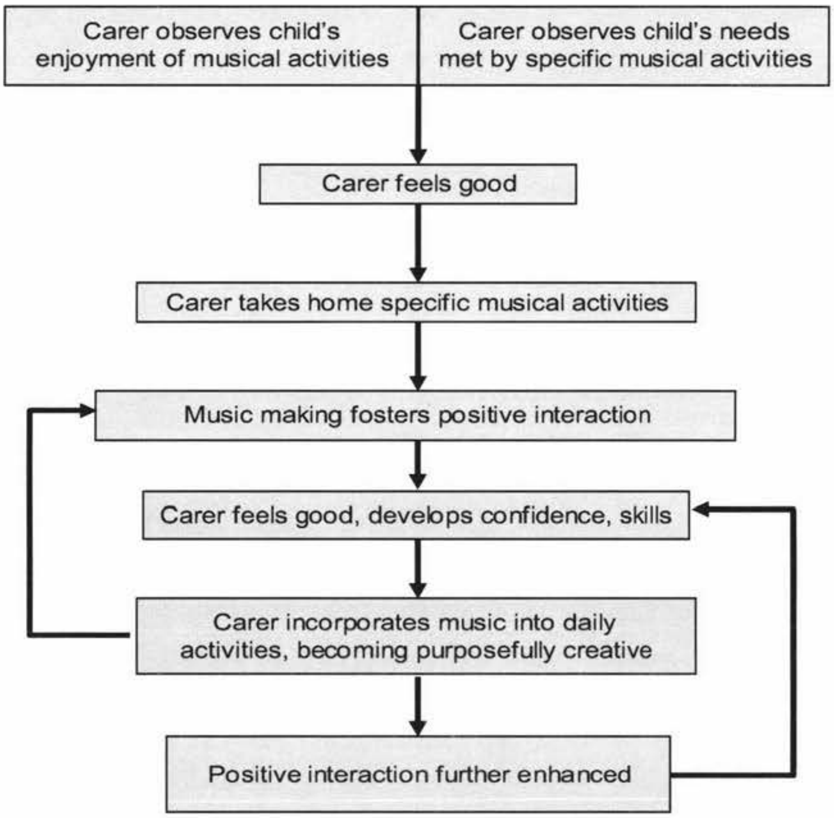
Music Therapy as an Instrument of Interactive Intervention

Interaction intervention is, therefore, well-understood to be central to getting the types of benefit sought by programmes like those offered by WEIT. But as also noted already, there is relatively little research on the role that MT might play as an instrument or tool specifically focusing on interaction intervention. This is especially surprising in the light of the interview responses which bring out quite strongly the effectiveness of MT as a tool of interaction intervention. One such example was reported by Leanne (Case #2). Leanne's son needed daily physical stretches and she found the use of music enabled her "to do the really hard repetitive work with Garth" and it "just made it fun and it helped me to relax and enjoy and that whole attachment and bonding came together" (L. 58:04).

The interview responses indicate that MT as an instrument of interaction intervention does not change the basis character of the dynamic cycle illustrated in Figure 2. The use of music as an agent of change, and as an agent of effective interaction, still requires adaptation, learning, and acquisition of confidence and skill, with positive feedback central to this process, "It is a two way process. Garth is very responsive to music so by incorporating music into our daily activities a strong parent-child relationship has developed" (written).

One can detect from the interview responses many instances where such positive feedback was associated with the carer's observation of the beneficial use of music, and subsequently with their own use of music. Consistent with other verbal and written feedback I have received over the years, all four primary carers involved in this study reported having gained new insight into how music activities enhance many aspects of their child's development. They also commented on how much pleasure their children got out of musical experiences, which is in line with Archer's (1995) and Shoemark's (1996) reported survey results. These 'feel good' moments made the carers more relaxed and confident. They began to participate more with their children at WEIT, and they began to take home specific music activities, "I can see the huge impact it [MT] has ... especially in the relationship like me, and Garth and the family, and the other kids and the social skills that come with it" (L. 35:01). The implementation at home of strategies that they had seen to be successful in giving their children pleasure as well as achieving developmental goals during their WEIT sessions in turn fostered positive interactive experiences, "We find ourselves going home singing these songs ... you just get them in your head and you sing them, so everything's fun" (J. 1:07:37). These experiences are illustrated in Figure 3 below, showing a similar cycle of positive interactions to that discussed earlier in relation to Figure 2, with a generalisation of the process beyond the therapy centre (a generalisation that will be discussed in the next section).

Figure 3 Evolution of carer's experiences with music therapy intervention



The use of music to foster a beneficial evolution in relationships was at a comparatively early stage for Jacqui and Eva, who had had only ten sessions at the time of the study. Sonya and Leanne had had more time to develop confidence in exploring using music in different ways. They had become more creative with their music-making and reported using it as part of their everyday lives. Music was the basis of many shared positive carer-child interactive experiences. These experiences were further strengthening their relationship with their children.

However, there was one aspect of the MT programme at WEIT that could have been detrimental to the carer-child dyad which needs to be noted – the initial opening circle time (group MT). When facing up to their first day at WEIT each carer reportedly experienced anxiety, some feeling it more intensely than others. This was a 'reality check' as they met other families with children with special needs. Group MT at the beginning and end of a two-hour individualised EI programme is an important part of the WEIT structure. While it sets out to provide a stable and comforting aspect of the programme, combining all the therapies and providing a holistic sense of intervention and support, it initially acted for some as a reinforcer of their anxiety.

Because of its positioning at the beginning (and end) of sessions, group MT is the first contact when beginning the WEIT programme. By being obliged to enter the group circle time, first-time participants find themselves facing other carers and their children with disabilities, and in all four cases this highlighted their situation in a way that contributed to the carer's initial discomfort (even though they had sat in on a circle time on a visit prior to enrolment). Participating in singing and action songs may have also contributed to an uncomfortable degree of exposure of their already fragile selves. Perhaps going directly into an individual therapist's room would have been less public and less worrying. Such an approach could be seen as just another individual professional appointment amongst the many they had already had.

However, in each case the carer observed their child enjoying the music activities. The carers could see developmental benefits occurring whether they were social, emotional, cognitive and/or physical. This is consistent with Archer (1995), Shoemark (1996), and Waterman (2000), in whose studies carers recognized the benefit of incorporating music in their children's EI programme. The carers at WEIT felt good about their children being involved in MT, and as a consequence began to feel, over time, more comfortable themselves in both the group and individual MT sessions. This increase in comfort lead to greater participation, and also a strengthening of the peer group support network.

Generalisation of Developmental Gains Outside WEIT

The discussion thus far has focused on therapeutic intervention and results in terms of carer-child relationships and interactions, making no distinction between intervention in the centre-based context and the home context. As the literature suggests (Goodfellow, 1986; Mahoney & Bella, 1998; Ramey & Ramey, 1998), maintenance of progress achieved within the institutional setting does not occur unless the carers assimilate advice and strategies given, and continue with the programme at home. However, the effectiveness of implementing pertinent aspects of the EI programme at home depended largely on how the implementation was carried out, on the nature and quality of the carer-child interactive experience. If the carer adopts the strategies for implementing the IDP goals and the strategies for engaging in positive constructive interactive experiences, there is more chance that gains will be sustained (see Box 2 in Figure 2). Comments by participants in Cases #1 and #2 reveal that they observed sustained gains outside the EI centre and that they regarded these as resulting from their committed efforts to generalise aspects of the EI programme into the home environment. Efforts like these are clearly aided by interaction intervention.

All four carers talked positively about the strategies they were exploring and implementing outside the WEIT setting, and were well aware that using effective strategies would benefit both their children and themselves, "The different therapists have shown me what to do and I've been working on that at home" (S. 6:24). Such perceptions agree with Mahoney and Wheeden's (1997) findings that the more we can enable carers, the less dependency there will be on professionals and the more confident the carers become in their own abilities to meet the needs of their children.

The Effect of Different Programme Durations

The length of time participating in the WEIT programme differed in each participant's case, and the ensuing results are another aspect of interest to the researcher. Even though the number of cases sampled in this study is small, there is still evidence to support the research of Mahoney and Wheeden (1997) that early entry into EI programmes is beneficial, and the longer the involvement, the better. This evidence can be seen when comparing Cases #1 and #2, with Cases #3 and #4.

The positive outcomes for the first two cases (Sonya and Leanne) appeared to be more established than for the latter two cases who had only ten weeks of EI involvement. Both Sonya and Leanne experienced weekly multi-disciplinary EI services from when the children were infants. These services would continue until their children started school. Cases #3 and #4 are slightly more complex. Often children on the autistic spectrum and with Fragile X syndrome are not diagnosed until after they are three years old, by which time several years of stress and misunderstanding within the carer-child relationship have elapsed. Thus, although the programme is still family-focused and multi-disciplinary in nature, the delay of diagnosis is a complicating factor. Another unfortunate delay to the best practice tenet of 'as early as possible' is often out of the carer's control, for example, a waiting list at WEIT. Within the last twelve to eighteen months, three EI centres in the local area closed down because of financial problems. WEIT then became the only EI centre-based service provider within a 500 kilometre radius. Such restrictions affected the admission times for both Case #3 and Case #4, and the ensuing carer responses.

However, even though these two cases only had a relatively short period receiving EI services (their children will be attending school when they are five years old) they indicated in their interviews many positive views about the EI services that concur with research findings and with Figure 2. Even after only ten sessions there appeared to be a positive change in the carers' reported sense of well-being and their attitudes to their immediate future arising from their experiences at WEIT. The ability to incur change even over a short period of intervention concurs with the short term studies of Oldfield and Bunce (2001).

But does a difference in length of involvement in an EI programme affect the nature and quality of carer-child interactions? More specifically, how does this translate into the nature and quality of the use of music as a tool for interactive experiences in the home environment? This is of interest to this study as the main objective for a music therapist in EI should be to become redundant in the process of working with each carer-child dyad. This objective is reached when the primary caregiver has the knowledge and confidence to use his or her own voice, body, and music resources (that is, to become capable of the intuitive musicking described by Small, 1998), to successfully engage with their child under differing circumstances. This gain in confidence takes time and will influence the carer's efforts in implementing EI strategies when at home.

If involvement in MT in EI aims at creating a new awareness in carers about how they themselves can initiate music-making experiences to foster positive interactive experiences with their children, how do the responses of the four participants reflect this? There is an interesting contrast here between the two participants who had a lengthy exposure to MT and the two participants who had only ten sessions. Those who had fewer sessions, or less exposure, used structured music relatively more than those with longer exposure. For the latter, Cases #1 and #2, improvised music was used relatively more.

It appears that carers initially try out at home specific activities that they have participated in or observed or they use particular recordings as the music source. Over time, and as clearly voiced by Sonya and Leanne, they became more confident and creative in their own music-making. This was a result of them becoming aware of the benefits of making up songs, chants, and using various musical techniques to encourage positive and constructive interactions as part of their every day lives, and to encourage skill learning.

For Jacqui and Eva, after only a short exposure to MT, the primary sources of music intervention at home were tapes, CDs, or specific action songs from WEIT. Eva, however, reported how she observed different interactive techniques that were effective in decreasing anxious behaviour. An example of the techniques mentioned was non-verbal interactive play between the music therapist and her daughter, and she was beginning to explore some of these at home herself. In addition, Eva was recently creative and successful with her own invented 'toilet' song.

The move to greater creativity could be a consequence of having had more MT sessions, or it could be that the child's nature and degree of disability have a bearing on the use of creative and improvised music versus the more familiar structured music. Structured music, once familiar, is predictable, and both Jacqui and Eva have children with high anxiety levels, children who by nature of their disability find change difficult to cope with. It seems that knowing that specific music can bring both the carer and child into a 'comfort zone' is an important tool for the carer. For example, Gene could now leave a place in a regulated emotional state knowing he could have his CD on in the car; Pippa knew that "Dancing Mum" got Mum to put on some music and they could share a happy time together.

The improvised use of music becomes most effective when the carer understood more how musical expressions meet emotional states. This is remarked upon by Leanne:

> Music therapy gives me day to day skills that I can use creatively as a mum when helping Garth with his daily activities e.g., I sing a song when helping Garth to put his shoes on or when brushing his teeth. These can be challenging tasks for Garth as he sometimes dislikes sitting still and sometimes he does not like his face being touched. Music helps Garth to complete these tasks and this makes both of us feel good. (written)

But within their creative use of music they added a structure to the immediate situation. Two further examples, each with a different intent, illustrate this point:

1. Music as a tool to help Garth regulate his emotions:

> It's [music] been very grounding and motivating to work, and to be able to engage Garth on a level where he's going to engage in like a helping working relationship, it's when he can't vocalize, it's a really good grounding platform to work on to get the other skills. (L. 36:17)

2. Music as a means of stimulating James towards learning a new skill:

> James' coordination wasn't very good and we've been teaching him ball skills and it wasn't very good but it is now; we do it to music. We do throwing the ball and rolling the ball to music and yeah it works every time. (S. 32:10).

The difference here, too, is that the carers gained confidence over time in using their own voices and body language as an effective tool when engaging with their children. Jacqui and Eva, after only ten MT sessions, still relied mainly on the music resources created by others.

Both Jacqui and Eva had not known their children's diagnosis for long. They were still learning about what it all meant and were now beginning to 'look at things from a different angle'. This understanding of their children meant looking and listening to them in a different way (as described in the literature review, pp. 31-32), trying to become more aware of what made their children anxious and learning how to decrease that anxiety by increasing control of their own responses. Both observed their children feeling comfortable and freely expressive when working with the music therapist. Both were still absorbing strategies used in this interactive process.

It is difficult to compare the participants of children who are on the autistic spectrum with those who are not. This is compounded by the fact that not only did Jacqui and Eva receive a recent diagnosis (within the last month and twelve months respectively at the time of the interview) but that these children had four years of a stressful relationship with their carers prior to the diagnosis. It may be that structured music provided a prop as they came to a new understanding of their improved and developing relationship.

On the other hand, Sonya and Leanne had been given a diagnosis early on. They were able to develop their relationships with their children with more knowledge and support from WEIT services when their children were at a younger age.

Summary

To summarize the comparison of the caregivers' responses when they are supported in a centre-based EI programme involving MT, it can be noted that:

- the intensity of personal pain for the carer seems to diminish
- they become ready to learn
- they perceive music-making as an enjoyable experience
- they perceive music-making as having a positive impact on many aspects of their children's development
- they become more confident and creative in using music in every day activities the longer they are involved in MT in EI
- they modify their own behaviour to foster positive interactive experiences with their children
- they feel better about their personal situation after being involved in a centre-based EI MT programme
- they have a more positive relationship with their children after being involved in a centre-based EI MT programme

These findings confirm my observations as to what can occur when families are involved in MT within an EI programme. But there were some aspects across all four transcripts that the researcher had not expected. What was surprising about the four interviews was:

- how much the carers wanted to tell their story in full (as mentioned in Reissman, 2002), and relay their moments of anguish
- how dramatically the carers had changed from anguish to 'feel good' subsequent to their involvement in EI
- the extent to which the carers had become more proactive and positive in their endeavours
- how the carers had positive, yet realistic goals
- how the carers liked being informed, or 'taught' a way of working independently with their children
- how, after ten sessions, the carers seemed to rely on the more 'structured' music activities whereas…
- after more than twenty sessions, the carers were more confident in using music more creatively in every day situations

Each interview conveyed a sense of moving towards positive interactive experiences using music. Each of the participant's experience seemed to follow the path set out in Figures 2 and 3. However, each of the participants reached this stage in different ways, through different experiences, depending on:

- how old the child was when diagnosis was made
- how old the child was on entering WEIT
- how long carer and child had been at WEIT
- the nature and degree of the child's disability
- the carer's personal circumstances

Limitations of Procedures

Clearly this study is context-bound. The therapists at WEIT work closely together, have ongoing discussions before and after the two-hour sessions, adjust intervention strategies accordingly, and are very aware and respectful of individual differences and ongoing change in the children and within each child's family circumstances. These issues relate to those discussed by Greenspan and Wieder (1998) and Roffey (2001). Each family enrolled at WEIT receives individual SLT, EIT, physiotherapy, and group and individual MT. The group MT facilitated by the music therapist involves all the therapists and five carer-child dyads.

The present staff members have all been employed at WEIT for several years, are very familiar with the MT procedures, and work as co-therapists in the group circle time both at the beginning and end of sessions. They are all comfortable using their voices and bodies in music and movement. This particular group of therapists provides an environment specific to the dynamics of each therapist's personality and professional expertise. The group dynamics are influenced by their presence and by the nature of their involvement. From the researcher's point of view, and evidence for this is supported by the transcripts, the team at WEIT is inclusive, nurturing, and fully supportive of the MT involvement in the programme. In other words, these results may not generalize to situations where the dynamics of the team are not so conducive to such team involvement, or to situations where the multi-disciplinary approach involves only individual sessions and none of a group nature.

The participants in this study have been interviewed about their experiences within the context of this WEIT programme.

Interview process

When relationships with a therapist have developed over time, it is more than likely that interviewees would give responses in order to please the therapist-interviewer, and so the researcher chose not to conduct the interviews as a way of avoiding possible bias. However, since the interviewer was not a music therapist, some pertinent comments made by the participants may not have been fully explored or noted.

The interview is a communicative event between two human beings. What transpires depends on what each participant brings to the interview, the choice of what to say (Riessman, 2002) and what to respond to, and the quality of the rapport developed. Furthermore, the individual differences of the participants (e.g., personality, relationship to child [e.g., mother, grandmother], personal social/emotional histories, personal comfort zone when talking of feelings or relationships) impacted on the nature and content of the narratives (Miczo, 2003). As Reissman (2002) points out, "Meaning is ambiguous because it arises out of a process of interaction between people: self, teller, listener and recorder, analyst, and reader ... all we have is talk and texts that represent reality partially, selectively and imperfectly" (p. 228).

A single interview was chosen because of time constraints and the fact the subject of study was a sensitive issue (Johnson & Clarke, 2003). However, a single interview may lead to further thoughts arising after the event. In this study carers were offered a chance to add to their interview, if relevant thoughts emerged post interview. Over the few days following her interview, Leanne wrote down further thoughts she wished to have added to her transcript.

The interviewer for this study, in her attempts to avoid leading with her questions and in her desire to be empathetic to each participant's situation, did not sustain a consistent wording of questions across all four interviews. Indeed it may not have been sensitive to restrict the questions to a set pattern, when the carers conditions were so different. This had consequences for the analysis of the data. In retrospect the use of a pilot interview with other carers may have helped to establish a more consistent interview approach (Murray, 2003). Nevertheless, the exploratory survey (Archer, 1995) and notes made of less formal discussions with carers provided material for the framing of general questions to guide the interviewer.

Transcription limitations

In transcribing an interview verbatim many aspects of the communication process are necessarily omitted. A transcription does not record tonal quality of voice, the pacing of responses, body gestures, facial expressions (eye gaze, nods, smiles, frowns), breath quality and meaning of silence (Poland, 2003). This might affect the accuracy of interpretation.

Prior music experience of participants

The carer's personal experience with music prior to MT in EI may have influenced how comfortably they were able to use music with their children. In the four cases presented, not one participant had any formal musical training. All had received the limited experiences of general school music-making activities, mostly in their pre-teenager years.

Other influences on the results

MT is an integral part of the multi-disciplinary approach at WEIT. In turn, the other therapies and therapists play a major role in the success or otherwise of the MT programme. Thus, any changes in carer-child relationships may not necessarily be attributed solely to MT but to the multi-disciplinary nature of the overall EI programme. Nor can one rule out the influence of the music therapist's personality and style of intervention on the success or otherwise of the MT intervention. It is not just in the music itself, but in the interactive process of the music-making experiences, that changes may be initiated.

Implications for Further Research and the Study's Contribution to Music Therapy Literature

The carers in this study, by telling their story have begun to fill a gap in the literature. There is currently insufficient published material on the topic of MT in EI, especially as it relates to the emerging trends of what constitutes best practice in EI, that is, parental involvement with a focus on the parent-child relationship. In telling their stories the carers have exposed an important niche in both the MT and EI literature. The interviews raised issues that warrant further research:

- what constitutes best practice in EI with respect to the therapeutic services offered

- how therapeutic services are implemented in differing settings
- the practical implementation of family-involved intervention in centres and home settings
- the effects of training in family systems, and relationship-focused intervention for therapists
- the benefits of home-based versus centre-based EI if individual sessions only are offered

The writings of Baird and Peterson (1997), and Campbell and Halbert (2002) also noted the need for more specific research in these areas.

Further areas to be examined, related to MT, that arose from this study are:

- a comparison study examining the benefits of home-based versus centre-based where individual MT sessions only are offered
- a comparison study examining the benefits of home-based versus centre-based where group MT is also offered in centres
- which therapies have the strongest influence on social/emotional growth
- longitudinal studies designed to evaluate the long-term effects of MT in EI
- more comprehensive evaluation of whether the length of involvement in MT in EI impacts on the degree of creativity and confidence carers feel about using music in everyday situations?

There is also the issue of nature and degree of disability and how this affects the EI service provision. Sonya (Case #1) commented that she accepted James would be behind his peers academically when he started school, but that he would definitely be socially ready "he will fit in in the social way". This supports the findings of Hauser-Cram et al., (2001) that for children with Down syndrome the impact of positive carer-child interactions is greater on the social and communication skills than on cognitive skills. I would like to suggest, however, that, with an improved carer-child relationship, a child's positive well-being on entering school will impact on his motivation for academic achievement within his or her own ability potential. Further research could tease this out – MT in EI may not influence the natural trajectory of the cognitive development of a child with Down syndrome, but it may well improve the child's quality of life by contributing to his or her developmental potential and independence.

The sample of participants was small for this study. It would be interesting to see whether, by interviewing a larger sample, the findings of this study stand up to further scrutiny. It would also be interesting to see if the flow diagrams developed as a result of this study would generalize to other populations of families with children with multiple special needs who are involved in EI programmes. If the programmes are home-based, or centre-based, but not involving a MT, then would the flow diagram, Figure 2, differ in any way? If both these diagrams generalize to other centre-based EI MT programmes, then it would seem this information could be used in EI centres, to consider the level of carer participation, and the strategies used for effective and efficient implementation of services.

Conclusion

It is interesting to relate the situation of each of these four cases to Greenspan and Wieder's (1998) list of functional emotional skills (see p. 17 above) which the authors state are important foundations for further development. In light of the analysis of responses of four interviews it seems that MT contributes an important role in nurturing the acquisition of these skills through positive interactive experiences. It is evident from the comparison of the grouped responses in this study that music-making fosters positive interactive experiences, a 'feel-good' situation for both carer and child, which in turn and over time, seems to strengthen their relationship.

Each of the participants has a greater understanding of how music-making experiences can enhance positive interactive experiences with their child. Each of the participants now feels more confident in modifying their own behaviour, their voice, body language and communication intent in order to maintain a constructive engagement. The changes in relationship with their children that the carers perceive after having been involved in MT are reported as positive, nurturing, and fun. The changes within themselves relate to the assimilation of new strategies, of new ways of looking, listening and engaging with their children.

Mahoney and Bella (1998) question how one knows EI services are enhancing the ability of families to nurture and care for their children. Similarly, in relation to this study, how does one know changes in carer-child relationships of the form represented by the positive feedback loops illustrated in Box 2 in Figure 2 are actually happening? Likewise, how does one know such changes are the result of interaction intervention and not of growth through general life-experiences? One can never know absolutely, but a significant number of pointers are present from the participants' transcripts and presented in the analysis of grouped responses. Statements from the carers' experience support the view that the more one builds on the carer's own strengths and abilities, the better the carer-child relationship (Figure 2). Such a view is strengthened when MT is included as one of the strategies of intervention.

A comment of a primary caregiver was a stimulus and prompt for this study. I quote:

> Music has become a very natural way to respond to our child's initiatives and a very positive way to interact with him. It has been a major contributor to building a bond between him and me. At times, often in fact, I felt I was

> imposing activities on our child, be they physical, cognitive etc., and I became a therapist not a mother. Through work with our music therapist I have learnt, am learning, to respond to our child, to provide activities in a fun way he will enjoy and consequently the mutual enjoyment has built our relationship.
> (Survey response, from exploratory survey reported by Archer, 1995)

Participant #2, Leanne, articulated remarkably similar sentiments, which were representative of the views expressed by the four participants in this study:

> Music therapy offers gentle therapeutic holding for parents and children. This was particularly important for me in the early days when I was feeling anxious about Garth's prognosis and being a mum to a child with special needs. Music therapy helped me to better manage my stress levels, work through grief and feel confident about my parenting role. Music therapy fostered the relationship I have with Garth and it is a two way process. Garth is very responsive to music so by incorporating music into our daily activities a strong parent/child relationship has developed. (L. written)

These views were expressed nine years apart by two carers who have never met. They indicate an important role for MT in EI programmes.

It has been shown in this study that MT has the ability to be an effective mode of intervention in the lives of families who have children with disabilities. In light of this, it seems highly desirable to have MT as one of the professional multidisciplinary services offered as part of EI best practice.

Appendix 1: Description of Syndromes

Sotos Syndrome

Sotos syndrome is a genetic condition that causes rapid physical development in the early years of life.

- Head circumference, hands and feet may be large in comparison with the rest of the body.
- Muscle tone is low and there is delay in motor, cognitive, social and language development.
- Difficulties with self-esteem and with peer and family relationships can be as a result of these children looking much older yet acting much younger than their chronological age.
- As receptive language is usually further advanced than expressive language, frustration is also often an issue.

The comparison physical, cognitive and communication gap with peers is not as marked as the children get older, with many adults being within the normal range of intellect and height. However coordination may be a persistent problem through into adulthood. Individuals with Sotos syndrome may also exhibit certain behaviours such as:

- phobias,
- aggression,
- obsessions,
- autistic-like behaviour, and/or
- attention deficit disorder.

Down Syndrome

Down syndrome is caused by a genetic abnormality of the 21st chromosome (trisomy 21), some instability, or mosaicism, of other chromosomes, and the addition of an extra chromosome.

Down syndrome is the most common cause of intellectual disability, but the degree of disability is wide ranging. There are also often medical complications that generally arise in the early years such as:

- congenital heart disease,

- gastrointestinal problems,
- constipation,
- respiratory difficulties, and
- visual and auditory problems.

Muscle tone is usually low and this affects feeding (exacerbated also by the protuberant tongue), and also influences the global delay in motor, speech and social development.

Autism

Autism is a brain disorder that typically affects a person's ability to communicate, form relationships with others and respond appropriately to the environment. Due to difficulties understanding interactive experiences, many children with autism exhibit the following behaviours:

- appear aloof and isolated, in their own world, inaccessible
- avoid eye contact
- indifferent towards surrounding social interactions
- start developing language, then stop and lose it
- become fixated with specific objects
- have rigid patterns of thinking, difficulty generalising
- low tolerance to change, high levels of anxiety
- can engage in stereotypical or self-stimulatory behaviour such as rocking or hand flapping
- through heightened sensitivity, show an intolerance to certain sensory stimuli such as sound, smell, taste, touch, texture
- become aggressive seemingly without provocation
- lack imaginative play skills

Children with autism who have language often use it in unusual ways, and often without contextual relevance. Echolalia is common where children echo back a spoken phrase, without necessarily getting meaning from the words.

The body language of a child with autism does not necessarily match his/her emotional state, and the tone of voice not necessarily indicative of his/her immediate feelings. They generally have difficulty reading and understanding the body language, tone of voice and facial expressions of others.

Even though autism does not necessarily indicate intellectual impairment, the impact of autistic behaviours will have a marked influence on the realization of a child's language and intellectual potential. This impact will differ from child to child, on the severity of the disorder, and on the understanding and management of such behaviours in the context of the child's family and community life.

In some cases, autistic children can show a sense of brilliance in a particular area such as memorizing pages in a phone book, or playing a tune on the piano after hearing it once. However such skills are rarely functional or generalised.

Fragile X Syndrome

Fragile X syndrome is so named after the link was made between particular intellectual disabilities and associated behaviours, and the finding of a 'fragile' site on the X chromosome. This was in the late 1970's, and then in 1991 the gene that causes Fragile X syndrome was discovered. Reliable DNA testing is now available. Fragile X syndrome is the most common inherited cause of intellectual impairment.

Common attributes of people with Fragile X syndrome:

- boys affected more severely than girls, girls often shy and withdrawn
- learning problems (wide range in affected ability)
- challenging behaviour, inattentive, easily distracted, impulsive, overactive
- autistic-like features: difficulty relating to people, avoidance of eye contact
- poor self regulation, extremely anxious
- ongoing speech and language difficulties
- physical features include a largish head and prominent ears

Cerebral Palsy

The term cerebral indicates something to do with the brain; the term palsy refers to something wrong with the control of muscles or joints in the body. Therefore cerebral palsy describes an injury to the brain resulting in a lack of normal control or development of muscles. This injury could occur before, during, or shortly after birth.

The nature of cerebral palsy differs depending on the site and severity of the injury. Muscle tone may be:

- too high, that is, the muscles have difficulty relaxing (spastic cerebral palsy);
- too low, that is there are difficulties in controlling muscle movement (ataxic cerebral palsy), or
- a combination of both (athetoid cerebral palsy).

The degree and whereabouts of the injury will also determine what areas of the body are affected:

- quadriplegia is when all four limbs are affected;
- hemiplegia, when one side of the body is affected, and
- diplegia is when either it is just the legs, or when the legs are more severely affected than the arms.

Appendix 2: Information Sheet for participant carers

Massey University

Information Sheet for Parents

Parent's perception of significance of early intervention music therapy on parent/child relationship

A Research Project

As you know I am the Music Therapist at the Wellington Early Invention Trust (WEIT). This year I am also undertaking some research as a Massey University student studying for a Masters Degree.

The research is to be based on my work at WEIT and is looking at the effects of music therapy on the parent/child relationship.

You are invited to take part in this project. After reading this information sheet, please contact me within the next 7 days with your decision. If you choose not to participate in the study this will not in any way affect your involvement in the WEIT programme.

The names of parents who agree to participate will be put into a hat for random selection. I am looking for one parent/caregiver from 2 families who have been at WEIT for 10 weeks, and one parent/caregiver from 2 families who have been at WEIT for over 20 weeks to be interviewed.

If selected there will be some open-ended questions for you to respond to during an informal interview. Debbie Mair will be the interviewer, and this interview will take place at WEIT, but outside your usual session time – there will be no disruption to your involvement with the programme at WEIT. It is envisaged the interview will take no more than an hour. Child-care will be available if required.

The interview will be recorded. You may ask for the recording to be stopped at any stage during the interview.

I will be transcribing the interview and collating it for analysis.

You will have access to the audio recording for up to 7 days after the interview, at which time, if you do not wish the information to be collated, the recording will be destroyed.

All material is confidential and you can be assured that you and your family will not be identifiable in any reports. The audio recording will be destroyed at the end of my degree assessment.

I will be happy to discuss the results with you, and will have a written copy available.

If you have any questions please contact me or my research supervisor, Dr Robert Krout (details below).

This study has received ethical approval from the Wellington Ethics Committee. It has also been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 03/107. If you have any concerns about the conduct of this research, please contact Dr Pushpa Wood, Chair, Massey University Human Ethics Committee: Wellington, telephone 04 8012794 ext 6723, email P.Wood@massey.ac.nz.

Before participating in this project there will be a consent form for you to read and sign.

I thank you for taking the time to read this.

Christine Archer

May 2003

Researcher
Christine Archer
Music Therapist
Wellington Early Intervention Trust
79a Copeland St, Lower Hutt.
Ph. 04 567 4082

Supervisor
Dr Robert Krout
Music Therapy Programme Leader
Massey University
College of Design, Fine Arts, and Music
Wellington.
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Appendix 3: Consent form

Massey University

Consent form.

Parent's perception of significance of early intervention music therapy on parent/child relationship

A Research Project

1. I have read and I understand the Information Sheet dated May 2003 for volunteers taking part in the study designed to look at the effects of music therapy on the parent/child relationship. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given. I reserve the right to ask further questions.

2. I understand that taking part in this study is voluntary and that I may withdraw from the study at any time and this will in no way affect my participation in the WEIT programme.

3. I understand that my participation in this study is confidential and that no material which could identify me or my family will be used in any reports on this study.

4. I have had time to consider whether to take part.

5. I know who to contact if I have any questions about the study.

6. I give permission for the interview to be audio recorded and I have the right to turn off the tape at any stage during the interview.

7. I understand the interview audio recording will be destroyed at the completion of Christine Archer's degree assessment.

8. On the understanding that my or my family's identity will not be disclosed I give permission for statements made in the interview to be retained by Christine Archer for educational purposes, including presentation at professional conferences or inclusion in a professional journal article. I understand that the data will remain in the control of Christine Archer at all times.

9. I would like Christine to discuss the outcomes of the study with me.

YES / NO

I ....(full name of parent or guardian)
hereby give consent to take part in this study.

Signature ....

Date..

Researcher
Christine Archer
Music Therapist
Wellington Early Intervention Trust
79a Copeland St, Lower Hutt.
Ph. 04 567 4082

Supervisor
Dr Robert Krout
Music Therapy Programme Leader
Massey University
College of Design, Fine Arts, and Music
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Appendix 4: Guidelines for Interviewer

Background information:

- Description of child: socially, emotionally, cognitively, physically
- Family setting
- Reason for enrolling at WEIT ('the Trust')
- How old was child when entering WEIT?

Relationship:

- Tell me about your relationship with your child before you were involved at WEIT?

- Tell me about how you felt when:
    1. you began at WEIT
    2. you began the group music therapy sessions ('circle time')
    3. you began individual music therapy sessions

- How do you feel now about your involvement in:
    1. the WEIT programme
    2. circle time
    3. individual music therapy sessions

- Do you think your relationship with your child has changed since you have been involved in the early intervention programme at WEIT? If so, in what way?

- Do you perceive these changes as only happening at WEIT, or do they generalise into your family life outside WEIT session times?

- Do you think involvement in Music Therapy has had any impact on other members of the family, e.g., other parent, siblings?

Triggers:

1. What do you think have been some of the triggers that have stimulated this change in relationship:
   in group circle time
   in individual sessions

2. Has the Music Therapist contributed to this change? If so, in what way?

General:

- What would you say to other parents who were about to begin Music Therapy sessions?

- On reflection, would you wish anything to be different as regards the Music Therapy programme at WEIT?

Appendix 5: Transcript #1[9]

Interview #1: Sonya (S), primary caregiver to James (J)

James' mother = K
Interviewer = D
Manager of WEIT = Sara
All other people = OP

Date:	Monday 14 July 2003 (school holiday time)
Time:	1.15pm
Venue:	music therapy room at WEIT

D turned tape recorder off at conclusion of interview.
Sonya continued.
D had dilemma of wanting to turn tape recorder back on, but had put closure to interview process.
After Sonya left, D wrote down what had transpired post-interview – see end of transcript.

Transcription of Interview

:10	**D:** Right…ok, we'll basically it'll be good to maybe start with some background information on James, so just looking at, if you could just tell us about your family unit, I guess, and you know just thinking about maybe the changes to the unit
:40	**S:** When he was born, his mum came and stayed with us and I virtually looked after him from day one. K, his mum, had a lot of problems, and she eventually moved out, and I kept an eye on things, and I eventually went and got him and brought him home with us and um that's where he's been ever since. He's living with his nana and granddad
1:18	**D:** And there's no likelihood of that changing?
1:20	**S:** No
1:24	**D:** I guess another good thing would be for you to tell us about James, His social skills, his learning skills, and his emotional...stability
1:40	**S:** James as he is now, lots of social skills, um he's a real people person, (laughing) bit of a character, um and he's doing really well, um yeh he's going to kindy, and he really loves it, and yeh he's doing really well, we're teaching colours at the moment, being doing that for a while, and we think that he knows them but he chooses not to use them and when you ask him he goes, "no way" 'cos he doesn't want to know, but I've caught him out several times…we went away on holiday and he was interested in all the big trucks up in Rotorua you see

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[9] Following Poland's (2003, p. 279) approach, the following symbols are used in this transcript:
"xxxx xxxx" denotes words or passages that cannot be deciphered
CAPITALS denote strong emphasis
"-" indicates speech has been interrupted
References to "the Trust" are to be interpreted as references to WEIT

	and he was saying "oh big truck", and then all of a sudden he'd say "big red truck" and then he looks at me as if 'oh no, I've said the colour y'know, that's the type, that's what he is like
2:50	**D:** And um obviously he's got some words if he is saying sentences like that
3:00	**S:** Some, he started gabbling, and you couldn't understand him, but now, it's the words are coming out and you can understand and he's saying sentences now
3:10	**D:** Wonderful
3:12	**S:** Yeah he's doing well
	D: And obviously physically he's up and mobile
	S: Yes he is yeah
	D: Doing all the -
	S: Yes running around , jumping, yeah , he's doing all of that (chuckling)
	D: Great, yes, that's wonderful. I guess looking at, thinking that when James first came to the Trust, can you sort of remember the reason why you came to the Trust?
3:42	**S:** He came to the Trust when he was really young, three months old, yeah, and I think was at that stage because his mum was young, and the hospital actually referred K here
	D: Did you look at other places or did you just y'know -
4:06	**S:** No we didn't, 'cos we had a choice, but we came here and we just chose here straight away
	D: Can you remember what you liked like you sort of like to make you choose?
4:22	**S:** Oo, um, I think it was 'cos when we came we met um Sara [manager of WEIT] and she took us through everything and um he had a um what's it called a, that lady that comes around with a, ah -
4:44	**D:** Developmental, neurodevelopmental therapist?
4:50	**S:** Yeah, that lady and she came with us and it was her that really talked to us afterwards and said, y'know, this is a good place and, yeah, 'cos we were still learning 'cos we didn't know anything, when you've never had anything to do with anything like this, you know you don't know, and she was really good.
	D: And I guess now, looking back -
5:10	**S:** They're just fantastic here, yeah, all of them they're just great, you can …see James has just come along so far yes getting just getting that input once a week yeah, but it has helped him
	D: Yeah that's great…good to know what age James started at the Trust, yes he was very young
5:90	**S:** We were just lucky then because now there's a waiting list, and I think we were just lucky.
	D: Um I guess in regards to just y'know looking at your relationship I guess with James at the Trust, um, you know can you think about just sort of maybe how that's y'know assisted you?
6:24	**S:** It has 'cos since James has been coming I've been coming every week with him and the different therapists have shown us, shown me what to do and I've been working on that at home, yeah, we have a lot of time at home, and it's like the speech therapy and coming into Christine's ring music and they sort of go through and show you what to do and that's how I've been carrying on with James, yep
	D: You've been able to find that easier then to be able to carry that through at home?

7:06	**S:** Yes I do 'cos they're really easy people to talk to and y'know everybody's fabulous
	D: No that's good and you said you do a lot of work at home. Do you y'know daily is it you try and incorporate it?
7:22	**S:** Every day, yep yep everyday we do, sometimes it's only for a short while just depends on the day, other times, on a wet day we'll just spend all day just playing and learning things and, yep, I do spend a lot of time,
	D: Yeah, that's wonderful. I guess one of the other things is that, y'know I guess if you think about how you felt when you first started at the Trust, y'know just that initial coming to somewhere new?
8:00	**S:** Mmmm I remember I was a bit nervous 'cos you didn't know what to expect and what the people were like and yeah um, yeah that's all I remember really. I was quite nervous, but everyone made you feel at ease and -
	D: James' mum came and -
8:18	**S:** She started coming yes in the early days she was coming, yes, 'cos she doesn't drive so I had to come down and bring her yeah
	D: But now you, is she still coming now?
8:30	**S:** No she doesn't come at all
	D: And I guess looking more at the structure of the Trust, I guess getting some thoughts from you on the music circle time that they have
8:50	**S:** Yes I think um I think the music part has worked really well for James because he does everything to music, y'know you can teach him things to music, ummm, we can even make, he's learnt how to say his own name and recognize his own name and we've done it through music, and Christine started that on the piano, 'cos when he comes here he goes straight to the piano, and Christine has done his name to music, so when we go home I carry that on, I don't play the piano but we just do the music and we just do the music and um, we carry it on and he will say his name, after a while he will say his name
	D: And he would say it through a song?
9:42	**S:** Yes, always through a song, y'know but if you asked him what his name was, he'd go 'no way', he wouldn't say it at all, but if you did it to music then he would say it yep.
	D: And can you think of, are there any other good examples like that where you have felt music has helped James to progress?
10:06	**S:** Um he likes the drums, um. Christine does a thing on the drums with him going fast and then slow and then waiting and he has progressed there. First of all he'd just bang away, but now he will go the fast and slow, and he'll wait which has taught him that you can do things fast and do them slow but you've got to wait, that was a big achievement for James too, 'cos everything was like vroom, straight in
	D: Can you think of how you've been able to carry that across at home? Have you been able to do that?
10.46	**S:** Yes I've been trying to get him to stop running because he's got a bit of a problem with his hips at the moment, and when he's running his legs are going out and he's falling over all the time, and with the fast, slow and waiting we can say to him now, now stop James and wait and don't run so fast
	D: He understands?
11:24	**S:** He understands, and another good example is at the crossing, at the zebra crossing, 'cos I've been, he's going to school soon, so I've been teaching him the

	zebra crossing. When we go to kindy we always go across the crossing, and y'know we've got the waiting and, y'know you can't go fast, you've got to walk and so it's helped him there too.
	D: That's great yeah, and obviously James enjoys music.
11:54	**S:** He just, yeah, that's his favourite, music's his favourite thing, he's always got a music toy, or he's humming or something, he's always got music in his head (laughing)
	D: Yeah no that's good that he gets such enjoyment out of it, and then I guess just looking at the individual, 'cos you had individual sessions with Christine, how do you…found I guess thinking back to the early days when you first started, how did you find coming in on to the one-on-one sessions, can you remember how you felt?
12:36	**S:** Yeah I think it was really good, um, at first you don't know what to make of it, and 'cos he was so young he couldn't do anything anyhow, but then we used to always sing to him, like, Christine used to say just sing to him and talk to him, so we used to do that um, I don't know if that's what started him off with his music thing, but he's always done that, always done the music thing, and we've always talked to him and sung to him
	D: Yeah that's great, and as a little baby did you find music, um I guess music's such a good tool for lots of things, to comfort him
13:40	**S:** He was such a perfect baby, I mean he never cried, y'know you didn't know if he was hungry 'cos he never let you know, at three months he was just perfect, yes, no but we still did sing to him
	D: That's great. I guess just talking about the now 'cos you've been at the Trust for a number of years now, um just looking at your involvement in WEIT and the actual therapy sessions um I guess just looking at what have you got out of the individual therapy sessions
14:22	**S:** I've got a lot of enjoyment plus a lot of education skills (laughing) out of it, because I can go and teach James now, y'know they've shown me how to teach right from three months right up to now, um yeah, with his, well in every way, his speech and um the physiotherapy, and music and the early intervention teaching
	D: So you've found it has equipped you with skills...know how to present activities to James
15:00	**S:** Yes definitely has, 'cos I go to my other grandson, he's three now, and I go to him and see where he's at
	D: Wonderful, yeah you've sort of got a baseline
15:22	**S:** Yeah it's a, no, it's been really good
	D: That's great. And I guess looking at now in the circle time, do you feel, 'cos I guess y'know, you've talked about James in the circle time in the early days, what do you think he gets out of it now?
15:38	**S:** Oh he loves his circle time. He mimes, he's going through, he's been going through for quite a while miming everything and for a while there we were a bit worried because he wasn't talking and he would just mime everything but you could tell that he was miming the right words to the songs and um, I spoke to Christine about it and she said it will come, don't worry, and I'm thinking when's it going to come 'cos he just wouldn't talk, and then all of a sudden it did come and now at circle time he's there and he's singing away and doing the actions

	D: And he's singing the words to the songs?
16:10	**S:** No, not necessarily, some of the words but um yeah it's just a lot of noise, he hasn't got that great a singing voice either but he enjoys it, and the actions, he does all of those -
	D: So he's a definite participator
	S: Oh yes (laughing)
	D: That's great (laughing), and I guess looking at now, just the individual therapy time with Christine in particular, you know what sort of things do you think he is getting out of that now?
16:70	**S:** Well I think he's getting a lot out of it, 'cos he remembers, when we go home he remembers the songs and the things that you do 'cos he goes to his room and he'll, he'll get something that we've used in the music sessions and um Christine for a long time has been reading this book to him, you know, Hot Rod James, now he'll go and get one of his books and he'll call it Hot Rod James and he's going zoooom, yeah, so he is taking it in
	D: And he's initiating when he goes home to do that
	S: Yes he is yeah
	D: That's wonderful, very good um, I guess y'know just looking at um your relationship with James, and I guess thinking about the early days, and now, y'know do you think, um being involved at WEIT, has that changed your relationship at all, from sort of your relationship with James?
17:40	**S:** With James, um, yes I suppose it has, 'cos he lives with me now and we've got more time, um 'cos I gave up my job and that to be with James um, yeah and I suppose that I've got more time to do it with him, um yeah, I suppose it has
	D: So you gave up work?
18:26	**S:** I gave up work so I could spend time with him 'cos I was determined that he was going to be able to do things when he went to school, I've really spent a lot of time, and it's paid off
	D: It is paying off, so you've been able to see the progression?
	S: Oh yes definitely
	D: I guess um just looking at some of the um, you've mentioned some of the way that your relationship has changed, I guess can you think about how much change in regards to everyday, the things you do every day, in regards to the things you do with James, outside of the Trust?
19:22	**S:** Um everyday things (laughing) well -
	D: Your routines?
19:28	**S:** There are routines, my husband and I our routine went out the window, y'know we were like, we were up and off, we both worked and we went out and had a social life and y'know we went away quite a lot and um yeah we don't, it's changed that way 'cos we don't really go out and we don't go away unless we take him with us, yeah so it has changed dramatically, but that's fine
	D: Right and you're happy with that?
20:04	**S:** Yeah yeah 'cos I was absolutely devastated when we were told that we had a Down syndrome 'cos I didn't know a thing, I didn't know anything about them, I'd never come in contact with one, yeah and I knew nothing, so I had to gather all the information and I went to the Down Syndrome Association, so I got to know a lot of things and we just decided, well that's what we're going to do
	D: And obviously you sought out information to know more about Down syndrome, it's always y'know, information can be good -

20:48	**S:** Yeah I got a lot of information, I got some from the net as well and -
	D: 'Cos have you received support from outside?
21:10	**S:** Yes, we used to go to Down syndrome things quite a lot, but we don't now 'cos they have coffee mornings and he's in kindy and yeah, weekends he's been going and staying with his mum and his dad [live separately], so the weekend events we haven't been going to -
	D: But there has been support there?
21:26	**S:** Oh yes, yes, they call every now and again. Sara calls me now and again to see how James is doing, and I know some of the other mothers who have got Down syndrome children and I keep in contact with them
	D: Yeah no that's great, yeah it's important to keep -
21:47	**S:** Yeah well it is, and especially as there's a couple of little friends of James that used, were coming to the Trust, and they're off, gone to school now, yeah so we keep in contact 'cos I want to know what they're doing at school now and how they're getting on, so I can help James to get there
	D: Yeah, oh no that's good to just have that little network that's just that little bit further down the track
22:08	**S:** Yeah we said we would keep in contact so -
	D: Great, and you met them through the Trust?
22:13	**S:** I met them here, yes
	D: Right, so you've had a similar experience -
22:22	**S:** Yeah no that's been a real help having that 'cos um, I can see that they're doing some things that James is not doing but James is doing some things they're not and so we're comparing, y'know see how we can help
	D: That's great. Um having been involved with music therapy do you think there has been any impact on any other members in the family in regards to I guess what you've learnt here, and you know, maybe taking it home?
22:54	**S:** Oh yeah, yes I've taught me other grandson, I've taught him some sign language and he knows the songs that we sing here so when I've got both of them we can all do the songs and the actions, yeah and my husband too, he's had to learn (chuckling) sign language and he's had to learn the songs so that we can have sing song times
	D: Great, yeah that's really special
23:24	**S:** And we have, and my other grandson, we have his parents too, we've got the family, my sister and her little one, so I've pulled them all in, the signs, mainly to the songs and to the signs for eating and hello and goodbye and y'know just the basic signs
	D: Yeah that's really important for James isn't it
23:56	**S:** Yeah yes it is, so I've been teaching them as well
	D: (laughing) That's very good, and what about his kindy? Do they -
24:02	**S:** No, James is different at kindy, he will not sign
	D: Oh he won't sign?
24:07	**S:** No he will not sign, no, and if you start signing to him he'll go "no way" and he'll run away and he'll, the 'other kids don't do it so I'm not doing it' and there's a couple of songs that they sing there that are the same as here and he won't do the actions 'cos the other kids don't do them, so that's that's good though 'cos it shows you he's observed them and he's seeing 'they don't do it so why should I, yeah I think that's really good, it's progress
	D: Yeah

	S: Yeah it's funny though (laughing)
	D: So he's really wanting to do the same
24:43	**S:** Yeah you go in and all the names are in on the table and y'know you say to him "find your name" and he goes 'mmm' and he looks and I say, what is your name and he goes, 'no way' and then picks the name up and puts it on the hook (laughing), yeah he's funny
	D: But he's obviously recognizing
25:08	**S:** He knows what his name looks like yes he definitely does
	D: And obviously music has been a good tool for him
25:14	**S:** Music has done it for him, if he could have learnt everything to music, even his maths, everything done to music, he'd learn it
	D: Yeah wonderful, um yeah I guess just looking at what you've got out of music therapy I guess it would be good to sort of know if you were talking to a new parent, to someone who was thinking about coming to the Trust, can you think about maybe what you'd sort of say to them or -
25:50	**S:** Well I actually did do that for a little baby boy who has just started here. I know his mother through a friend, and she was quite devastated when she had a Down syndrome so I said oh get her to ring me, so she rang me up and we had a chat and I told her about the Trust and she said that she had just joined here too and that they couldn't get in for a while and they got him in once a fortnight I think for a while, but now he's full, once a week, and um I talked to her about it and told her what happened here and what was going on and that, and I think that really helped her, 'cos she's rung me a couple of times since and yes she's really enjoying it yeah
	D: Can you remember some of the things like did she ask you questions or did you just sort of -
26:52	**S:** No I just sort of told her about um, she asked me how long James had been going and y'know how's he doing and I actually took James up to see her, she said oh I would love to see him, y'know I'd love to see what he's doing, y'know, she's curious as to know what A [child] is going to be doing at James' age, so I took James up there and yeah it was good and she got a lot out of it
	D: Yeah it's really important isn't it
27:28	**S:** It is, I think um 'cos she's quite a young mother too and she didn't know what to expect so I think that helped her
	D: Sonya, I was just thinking about how much involvement does K have, James mum, does she -
27:48	**S:** She has him most weekends, ah but just for a day and a night and then I go and pick him up, and that's enough, it's enough for her and it's enough for James too, he's ready to come home
	D: And does, is K familiar with what's being worked on here?
28:12	**S:** Oh yes see I keep her up to date with everything that he's doing, all his appointments, everything he does at the Trust
	D: So you just show her what you've been doing
	S: Yeah I do
	D: Great, yes I guess it's good to know on reflection 'cos you've been here for a number of years, um what do you think would be, is there anything you would have liked to have received through music therapy or any of the other sort of disciplines, is there anything you would have liked to have gotten more of or, or differently?

28:53	**S:** No I don't think so, I think that they've just been marvelous here, I don't think they can do anymore, I know there was um talk of some mothers wanting more sessions, longer sessions but they can't physically do it, they just can't do it, y'know they've got waiting lists, and they just can't do it. I mean, if they could it would have been good to get that little bit extra, but then they are so approachable here that you can just go and talk to them any time, you can ring them any time about anything, any concerns, yeah that's been good support.
	D: You've obviously found that the length of the sessions that James is having at the moment seem to be that you think it's enough for him?
29:43	**S:** I think it's enough for him yes, especially 'cos he goes to the kindy in the morning and then he's got the afternoon down here.
	D: No that's great. Is there anything y'know else that you would like to sort of share with me in regards to y'know just your thoughts on the Trust, or um, anything else that you would like to add?
30:15	**S:** I just think it would be tragic if it ever closed down. Where would you go, y'know to help these children, um because there isn't anywhere else, the others have all closed down now, haven't they, there isn't um, where would they go, it would be tragic, it would be back to the old days where you just locked them away and y'know, that that was horrible
	D: But no it's great that James has got so much out of coming to the Trust
30:46	**S:** He has definitely. Well I wouldn't have been able to teach him 'cos I wouldn't have known what to do
	D: So you found that by coming weekly that's really, you've been able to see it, and see what you need to do.
31:05	**S:** And then they tell you each session they tell you what to work on during that week, and um, I do a lot of time with him, and yeah most, most times the next week when he comes to a session he's been able to do what he was doing the week before and couldn't quite get there, and yeah especially with the music, just like, just singing all day long, walking round the house doing 'stupid songs'
	D: They're not stupid songs
31:40	**S:** Anybody who comes to the door must think, gosh he's crackers because we just sing all day long so -
	D: You just said before that if you could have a song for every skill that James would definitely be….so it's really great that you've, that you know the importance of using music
32:10	**S:** Yes well even his coordination 'cos James coordination wasn't very good and we've been teaching him ball skills and it wasn't very good but it is now, we do it to music. We do throwing the ball and rolling the ball to music and yeah it works every time
	D: So it's a really motivating…isn't it
	S: Yeah it is, it is
	D: That's great. O.K. well um I guess if you've got nothing else you want to add then, I think the prompts that Christine has given me are pretty much covered so I think we could finish it there and
	S: Alright, good
	D: Thanks for coming in
	S: Oh you're welcome
	D: Oh it's lovely to hear how James is progressing
	S: Yeah yeah he is progressing

	D: It's wonderful
	S: Yes he's a real character that one (laughing)
	D: He's lucky to have such a dedicated Grandma
32:58	**S:** Oh I was determined and I've got my goal, I've achieved my goal, 'cos he's ready for school
	D: I was going to say, what was your goal?
33:10	**S:** My goal was for him to go to school and be able to fit in. I know he won't be able to do the work that they do. I've been down to his school and watched the five year olds -
	D: Oh great
33:24	**S:** Yeah that's another thing I have done. I spent a morning down at his school watching the five year olds to see what they're up to, and I know James is, he's not near them, but he will fit in in the social way, he will definitely fit in
	D: And obviously for you that is an important part of his development
33:48	**S:** I think because he watches other children, he's always watching what they're doing, and he tries everything that the other kids are doing, especially at the kindy
	D: So he wants to copy?
33:58	**S:** He wants to copy, y'know the kids are climbing and I'm having a fit but James is climbing and jumping off things. Two months ago he couldn't do that
	D: Wow that's great.
34:10	**S:** You know, so yeah, he's watched and watched, and we watched him at the kindy, he's watching these kids going up and down, up and down and jumping off, and he's just sitting there with his little hands up (gesturing) and he's watching, must have thought, well I can do this, and off he went
	D: Give it a go
34:30	**S:** Yeah, first of all he went to the end and went splat y'know and (laughing), but they had the things down so they can't hurt themselves, but first of all it was just like drop off the end, but now it's proper jumping
	D: So he's just kept practicing
34:55	**S:** That's something he's learnt here too, the jumping
	D: Great
34:58	**S:** Yeah, so I think he's ready for school, the social…he'll watch the other kids doing the work and I think it won't be long before he'll be able to do it
	D: And I guess emotionally you feel he's coped with um, 'cos I know obviously he's living with you and mum's in the picture
35:26	**S:** Yeah his mum and his dad are in the picture, and he knows, he knows where he lives though.
	D: Yeah yeah, and so emotionally he's developed a relationship with you as his primary caregiver?
35:38	**S:** He has yeah, he's ready to come home after a day, yeah wanna come home
	D: That's wonderful. Alright then we'll finish there and thank you
35:46	End of interview

Summary of information Sonya shared verbally with interviewer after the recorder was stopped. This was verified by Sonya.

- Sonya mentioned being daunted by school approaching in November but feels James has good social skills to help him fit in with his peers.
- Sonya and [husband] are teaching adults with Down syndrome how to Rock n' Roll.
- When doing ESW work Sonya was able to apply a lot of what she's learnt at the Trust, and through James, to the children she supported.
- Sonya would hate to see the Trust ever close as it is so supportive to the families and so important for the children's development.
- Sonya has joined IHC because she and [husband] won't be around forever and she wants to know that James will be looked after because K may have difficulty thinking about what James may need in the way of support in the future.

Appendix 6: Transcript #2[10]

Interview #2: Leanne (L), primary caregiver to Garth (G)

Interviewer = D
Garth's father = Rob
All other people = OP

Date:	Wednesday 16 July 2003
Time:	10.15am
Venue:	music therapy room at WEIT

Transcription of Interview

:12	**D:** Ok well it's good that you were able to come in Leanne to help Christine, that's great, um. Well it's always really nice to have a bit of background information on Garth. I guess it will be really nice to hear about Garth's early days when he first came into the world, and y'know up to now really
:34	**L:** Ok well he was born at thirty five and a half weeks, and um he was a really difficult delivery, um I had to be induced, I was in labour for 50 something hours, 55?, yeah my waters broke spontaneously but I never established labour so I ended up being induced and there was a ventouse delivery, and he went straight to special care baby unit at Hutt Hospital, um he was given antibiotics, um and then on day two, the consultant came and saw me and said "I've heard a loud heart murmur and we want to do some more tests, and then, so he was born on Wednesday night just before half past six and by Friday afternoon we started getting information about him having congenital heart defects, so we were in special care baby unit in Hutt for about eight days and then we transferred into neonates in Wellington, because um we were actually living in Wellington, but my care had started in the Hutt, um and he needed more um special care and we just wanted him to be close to family and that would be I think, first of all Friday we transferred and then on Tuesday morning we were flown up to Greenlane [hospital], and when we were in neonates he started getting ahh having a lot more difficulties with breathing like when we were in special care baby unit he had a couple of desaturations and oxygen levels dropped down to the 70's...and then when were in neonates in town that got worse, he was having clusters of oxygen desaturations in the 40's and 50's. He had an apnoea and ah had to be resuscitated by bag and mask and they did cranio ultrasounds there and they though he might have had early obstructive hydrocephalus, umm and what else, lots of things, um they did lumber punctures, they did blood screens, metabolic screens, he had lots of jaundice, he was under lots of phototherapy, he was already on diuretics then to try and help, 'cos sometimes the oxygen

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[10] Following Poland's (2003, p. 279) approach, the following symbols are used in this transcript:
"xxxx xxxx" denotes words or passages that cannot be deciphered
CAPITALS denote strong emphasis
"-" indicates speech has been interrupted
References to "the Trust" are to be interpreted as references to WEIT

	desaturations and bradycardias... And his heart rate dropped. So they were doing lots of treatments and lots of tests and then we were up in Greenlane, we were up there for five, five and a half weeks, I know, it's not like being home with a baby after 3 days, all those things just like out the window, so we were up in Greenlane for five? Yeah, no five weeks, we were in ward 9, went up to ward 9, they did more echo cardiagrams there, they confirmed there was a large hole in the ventricles, a smaller hole in the atrium and the little patent ductus arteriosus duct that usually shuts off when a baby's born, was still open, so he sort of had blood shunting everywhere. Um he had two more apnoeas up there in ward 9, that needed bagging [resuscitating by bag and mask], then he was specialed, because when he was in neonates he was in one of the front rooms and he got so sick he was in ICU for the last two days before he transferred up to Greenlane, and then, on ward 9, he was specialed for two days and then on the Saturday, um he got really really sick, um over the space of a few hours, I mean he went into like sceptic shock this horrible grey colour, um, his heart rate went really high, his respiration rate was like over 200, he was really really sick um and we were transferred to ICU about midnight and they were doing bloods and Garth was just like grey, he's this awful grey pale floppy rag doll lying in my lap and they couldn't get bloods from him, and the anaesthetist is coming up and trying to get femeral blood and he's just lying there not flinching and I knew sick boy and we went down to ICU and he was in there for three and a half weeks, um he was on a respirator for most of that time. They queried whether he had necrotizing enterocolitis when we went down because Saturday he got really sick, he, because he was being nasal gastric fed he couldn't breast feed, he had a lot of green bile coloured mucus coming out of his mouth, come out the nasal gastric tube, so they did blood screen and it came back he had E col: and blood screens...um so...(big breath, chuckling)
	D: He had a rough start
5:04	**L:** He had an extended right hemicolectomy at two weeks of age, he hasn't had to have a colostomy, they tested him for cystic fybrosis, but that came back negative because we had had a lot of trouble with mucus, the fluid on his lungs even in ICU, but they extubated him once to get him off the respirator prior to his heart surgery but he couldn't handle it and they had to give him adrenalin and reintubate him and try and get him as well as they could, and I mean he was on dopamine, he was on adrenalin, he was on, he had like eight pumps going, so early days he had a really really hard start. So two weeks of age he had the right hemicolectomy, and he was incredibly sick, I mean his tummy got really shiny bloated, distended, um and then he had a period of trying to get well again and then he got another sepsis from a catheter in his um, subclavian so he was on another regime of antibiotics to treat that and then they were just having to do increasing increasing support to get his heart pumped, and then he had heart surgery when he was a month old, and he went through it well, it went really well the surgery, he had a cardiac respiratory arrest after the heart surgery and had to be resus, full rescusitation for that, um, and then he just gradually got better. He stabilized, he had to have drugs for the junctional tachycardia after surgery for a while and then he just gradually got better, and then back up into ward 9 for a few days and I began to notice then blank spells...he had a CT scan of his head and that showed up he had hypoxic brain injury. He had bilateral cortical infarction and possible

	in the occipital lobe as well, there was low grade hypoxic changes throughout his cerebral cortex and it showed up some structural abnormalities, as well the ventricles were enlarged and I think the sylirian fissures were wider than you would expect for his age. So from that I was told in ICU that he would have difficulties with learning and movement, and in the time we were in there as well we were seeing one of the specialists who deals with syndromes and I had sort of thought that there was not something not quite right with Garth when he was born 'cos he was really long and he had these really big hands and big feet and his face, his head was really big and, a gorgeous boy but there was something different about him, his eyes he had a really high narrow arch palate and I was sort of thinking, ohhhh, something not right and they sort of said he some sort of soft dysmorphic features up there but couldn't actually pinpoint them, they tested him velocardiofacial syndrome and that came back negative um and then they just sort of said oh he's got some soft unusual features with his face. Then we came back down to neonates, (laughing) um, there's lots um ...and we were there oh I guess for about a week. We were in hospital for two months before we came home. Um he came home on the apnea monitor which he had for six months. Um, I mean once he had his heart surgery and his other surgery done um he stopped having the bradycardias....well the heart problems went and he stopped having the breathing difficulties, they all ...gradually, so he came home on the apnea monitor. He's been back into hospital a couple of months after he came home for query seizures 'cos I sort of noticed when he was on, like after he had all the surgeries and just before he discharged back down to Wellington, he'd be a bit blank – you know he was not responsive, he'd kind of lie there but just kind of blank spells, stary, and I'd think oh don't tell me he's got cortical blindness, and don't tell me he's autistic or, y'know you hear all those sorts of things and I'd think oh Garth where are you and he'd just kind of disappear on me and he was doing that and he started having these shuddering episodes where his arms would extend out and his legs and he would kind of shudder, and he was having, he would take a long time to feed, um and so he came and he was tested he had an EEG and it all came back normal, all the background things were fine so no seizures, um and then his neurological exam came back abnormal with his tone, and that's when he started talking about cerebral palsy with him and he was really stiff as a baby, he actually slept in a hammock 'cos he was quite stiff um and he did this sort of unusual posturals at times, turn his head and arching and those sorts of things and that kind of went on, and then that actually got better but I was still worried as a mum 'cos he wasn't really smiling when Rob or I would come into the room there wouldn't be that recognition of his mum or dad or the smiling – he didn't actually start smiling 'til about four or four and a half months um and we were seeing a neurodevelopmental therapist who would come and visit us at home a couple of days a week, um, and that was like twice a week and then it gradually went to once a week and then um, yeah
	D: So with all your hospitalization and I guess a rough start, how were you, how was your relationship with Garth in the early days?
11:17	**L:** The early days I felt I was in a tumble drier with a bag of rocks, absolutely traumatized – I'd see my son be resuscitated three times, I'd see him blue black and purple, lifeless and thought I was losing him, and it's like, that was really incredibly hard, I mean there was all this medical intervention, we were

	in ICU, we were in hospital, my kind of picture being home with my healthy baby within three days had just gone totally out the window and not only did I have like a baby with all these medical problems I also thought there was something else, there was cerebral palsy and then I was thinking (breathing in) y'know ongoing tests and it was hard. It was really hard, um having all the medication and follow up, and just a lot of intrusion. And to be able to have, spend that time with a baby, and just not even being able to breastfeed. I was expressing milk and then I got so stressed I couldn't, I mean I just dried up and then I couldn't do it, um that got really hard, that was hard.
	D: So he was continued to be gastronasal -
12:26	**L:** Nasalgastric, um in the time he was in ICU, he was intravenously fed, um
	D: Ok and what about when he came home?
12:34	**L:** Came home, he was being breastfed and also nasalgastric, um?…no he wasn't they took the nasalgastric out I think, gosh I'm just trying to remember now. Um 'cos he had the team used to come round and visit. I think I was, no he was being bottle fed, he was being bottle fed, but it was taking up to an hour to get a feed in, really really slow, um yeah, and I would try and breast fed as well, doing breast feeding and bottle feeding and expressing
	D: And did you feel as though you sort of got the bonding once you got home?
13:26	**L:** Once I got home, it was like thank goodness I'm home, I'm home, yeah. Once we got home it was a lot better yeah yeah
	D: Wow, that's just amazing
13:41	**L:** So it was a really difficult early start
	D: You've progressed forward
13:47	**L:** Progressed forward, that's a long time ago (laughing). He's done so well from early days when he was stiff and these blank spells and I'm thinking jeepers Garth where are you, and I'm holding him and he would be blank
	D: And that's a worry to any parent
14:05	**L:** And it's like what's this all about, yeah, and that got better, I mean he started doing the smiling things, he started playing with toys, and bringing them up to his mouth. Um he was late with sitting, late with walking. He only started sitting up when he was about 12 months I think, between 10 and 12 months, and then he took his first steps when he was about 18 months old. Yeah
	D: But he's got there
14:36	**L:** He's got there, and he's just -
	D: You want to celebrate that
14:39	**L:** Yeah yeah, at xxxx he'll go off like a rocket actually, he goes through these periods where he just goes zoom, he goes ahead in leaps and bounds
	D: Does he have a diagnosis?
14:51	**L:** He does. He has Sotos syndrome, he was diagnosed with that when he was thirteen months old. He was seen by genetic services in Wellington and they did histories, and photographs and things and bone xrays and things. They can't actually test for it but just from his clinical presentation and his facial appearance, like his eyes are wide apart, the outside corner of his eyes go down a little bit – he's got a really, he's got an adult's size head now, and he's only three, um and he's got a really high forehead, he's got receding hair line, little chin, high narrow arched palate. His teeth came through really really

	early. All of those things in combination with everything else. Soto syndrome has low muscle tone so they actually think he's got cerebral palsy in the background then this Soto syndrome over the top, because he was really quite stiff as a baby then his muscle tone's changed. And it went quite floppy. And, not, yes sort of a little bit floppy, but he lots of trouble getting his arms up above his shoulders, and things. Doing lots of stretching, he's quite tight in his pelvis, his hips and his legs. Um that's just gradually improved.
	D: So, Garth's family. Just thinking about your family unit. Who's around Garth to sort of y'know, in his life at the moment. What's your sort of family setting?
16:26	**L:** There's me, and there's Rob and there's Garth at home. Um, the rest of my family are scattered around the country. I have a sister in New Plymouth and a sister and brother in Auckland
	D: So when you went up to Greenlane you had family up there to?
16:43	**L:** No no I was up there on my own. Rob would come up, he came up for the surgeries and then he had to come back down for work. Oh, yeah
	D: I'm sure it's, yeah, it seems so long ago but actually I'm sure it's very fresh in your mind
17:06	**L:** Yeah, it's not too bad, it's a bit in the background, it's in the background now. Yeah 'cos when he's…xxxx doesn't need to have follow up the cardiac surgeons now 'cos he's fine. It's ok he just has six monthly follow ups with his pediatrician and he was having six monthly follow up with his surgeon for follow up for his tummy, it's xxxx but that's all fine now, he's got ongoing problems with constipation but we just manage that
	D: So you obviously looked at attending the Trust. What made you sort of, did you look at different places? What made you decide to sort of go down to looking at early intervention services for G?
17:55	**L:** Ah, I think it was just such a stormy beginning with Garth and the support had been incredible like I came back to Wellington and then the homecare team would come round and check on Garth, um, and we also had GP the neurodevelopmental therapist, um and she actually gave me a booklet on early intervention services, and then talking with her and talking with OP, Garth's pediatrician, sort of looking at where to from there, and then I began looking at conductive education. I guess when Garth was about six months of age I looked at that then I looked at the CCS places, Gillies Ave and then I looked at here, and then I chose to come here
	D: Can you think about what made you choose to come here?
18:48	**L:** Oh yeah (laughing) I know why, conductive education I think …was…ah, um had some really good concepts but I don't think it's overall therapy was um a good package for Garth because they only had a speech language that visited say once every two weeks, and I just found it a bit too structured, with it's physical therapies it was quite harsh and rigid. They were doing like toilet training, they were doing, it was a little bit too much, a little bit too early.Y'know Garth isn't even…on a potty, and it just didn't feel right. And I mean I really like the physiotherapy and the muscle, the physical side of things there, but as a total concept programme for Garth I thought he need more and just needed something a bit softer, yeah it was bit too rigid, and also I found, oh I found it really hard that some of the children there like a lot really disabled, like couldn't hold their heads up, and yeah and I though oooh it was hard for me, yeah, it was too hard for me being in that sort of

	environment having spent two months in hospital and all that trauma and then yeah, so I decided not that and then I looked at Gillies, and ….ah, it just didn't seem to be as organized. Um, yeah, it's probably ok, I just looked at it on a wrong day, then go back another day it might have been different, but the day I went and had a look at it, I mean it was ok, but then when I looked a the Trust here it was just very professional, very organized, well organized well integrated, um, and it offered a really comprehensive range of services that I thought would really help Garth, and help the family really, so we were lucky to get in here 'cos there's a waiting list
	D: So you've been with the Trust for how long?
21:37	**L:** Nearly two years, two years in August. And also at that time we looked at CCS but I think they were going through lots of problems, changes with their management and the whole thing and I think it all kind of spilled down to the centres and they were a bit chaotic
	D: And obviously you've been very happy with the Trust if you've been here for two years.
22:05	**L:** Yes, yeah, I think it's amazing, I wish it was available five days a week for all the families, to have a service like this because I mean it was so good getting the support at home with Garth and then to come to a centre like this was more and better than what I had at home so it's like consolidating all the early work that I had, the work I was doing with Garth and then to come here just consolidated that and did more and better and
	D: So in the early, so when you first started at the Trust can you just sort of remember about how you felt maybe those first few sessions?
22:46	**L:** I wanted to run away (laughing). For me it was just a shock and the acceptance of having a child with special needs y'know and coming, and yes it's just all that fight or flight xxxx or do I, for me, I mean Garth was fine, he loved it, for me, it was hard for me to come in, it wasn't all like that, it was just um it was quite ground, I mean it was very grounding in a way too, to have the expert knowledge and care and to put a plan in place to say this is where we are now and this is where we can go in six months
	D: Do you think your attitude has sort of changed from when you first started here to now?
	L: Towards?
	D: Just towards um I guess Garth's development if you like, maybe your relationship with G, and your interaction with him?
23:51	**L:** Oh yeah, I've just got a lot more skills um in how to help him as a mum, really, to help him with his development, with the challenges he's had, um like with his muscle tone problems, his coordination and balance, speech, 'cos his language is very delayed, and he's not talking, yet or if he does something 'cos he has dyspraxia as well, um, it's yeah, it's learning for me, it's having the skills to know how to help him the best. Um, and to help, particularly sometimes like he gets frustrated 'cos he can't get his words out, I mean, his receptive language is very good, he understands, but he can't express himself, he has difficulty, he can't get his muscles to work properly, but using lots of really neat things like he uses pictorial exchange communication and he can use like music to help kind of express himself, he loves music
	D: Leanne, when you say he uses music, how does he use it?
25:04	**L:** He'll point and he'll want music tapes, music CD's he'll want music videos he'll know and he'll sit there and listen, and he'll dideebob away to

	them and he'll …. Um so I think emotionally it helps to settle him, um and he uses it in a rhythm in a way like sometimes I'll sing songs when he's on his bike or when we're walking like big steps, little steps, and when we're out walking we do big giant steps along the footpath, and it just helps him get into a rhythm
	D: Great, very good yeah it's great to be able to incorporate it into the natural sort of what's happening for you as a family
25:47	**L:** Yeah just do it day to day things um and even like when he's in the bath and we do things like that, we do hand things, exercises and just incorporate into normal day to day things so it just normalizes it more, it's not so scary
	D: And you mentioned emotionally, that it helps to soothe him, calm him, is that, do you sing to him when he's upset?
26:12	**L:** Yes, yeah, I sing, yeah he's got a little song, Garthy-boy song (laughing) and just the little things like twinkle twinkle, um and some of the other little action things like he loves little mousie brown up the little candlestick like when he gets frustrated I can just distract him with things like that,um or wind the bobbin up, he loves those sorts of things, and you can see him like with his motor planning and dyspraxia it will come out in the most weird and wonderful times, he must be sitting in the shopping trundler and he's doing wind the bobbin up and he's pointing to the ceiling, and he's stretching, and all that sort of stuff is there for him, but it's an amazing resource, amazing, I mean it helps me as a mum to feel good about what I'm doing um, yeah, so it's like a two-way thing, it just helps us to work together more to do his programme. It helps W.
	D: So dad certainly y'know, he knows what he needs to do, because he obviously -
27:18	**L:** (laughing) yeah he does xxxx -
	D: But obviously he sees the value in -
27:30	**L:** Oh yes 'cos W's come here a couple of times too and he just comes home and he goes wow, wow what they do there is just amazing, just wow, yeah
	D: So you find it quite easy to sort of what you're shown or what you see here, you find it quite easy to incorporate that into home life?
27:52	**L:** Yeah yeah, I just try and do it, day to day things or um early days when he had a lot more difficulties, I mean I just had to deal with set exercises when he was quite stiff and that. I just used to do that. When we are I have music on in the background, just nice relaxing music and I do that
	D: Do you think in the early days you sort of saw music as a tool for Garth to learn music, to learn skills?
28:30	**L:** yeah as a tool, I use it, even before he was born I used to put my little xxxx own for him, (laughing) it helped me as much as Garth, but um, yeah, I've always used it. I used to play music a lot when we first came home, even when we were up in Greenlane.um, there were other families up there that had their little portable CD's and were playing music to babies, soothing, different music. Um I think it's been an incredible tool, it's something that Garth has really been able to use and use it well. He just seems to relate, whether it's because his language is late coming, but he can, he works with it. You see it moves him, and it motivates him, like with his drumming and his like, the hediho elephant songs you can get those sorts of things going and he gets into a rhythm 'cos sometimes he goes, and getting him to change his energy levels from fast to slow, he can use music in songs and things to help him to

	regulate, to centre
	D: So when you first started at the Trust, was he as interested in the music then as what he is now, or do you think that's developed?
29:48	**L:** It's probably developed although I find it a bit hard to tell because of his motor planning he would, he's very much he'll sit and listen and watch, and he'll still like sometime, eh you can see him he just can't ooooh, he just can't quite get the motor planning, and then he loves it and then he just smiles and he's happy, um but yeah it's the action, cos he yeah, he's trying to get his body to it, but I just know from the expression on his face, he loves it, and when he does I mean he's -
	D: So the circle time, I guess thinking when he first started did he, what was he like in that sort of setting, did he sort of you know enjoy -
30:32	**L:** He did, in circle time, he was a xxxx (laughing) little bubby, he did enjoy it, he would sit and watch again a lot um, sometimes he gets, it was getting him to concentrate I think 'cos he would kind of get up and he'd want to move round 'cos before he could walk he would kind of sit there and, yeah sitting and watching, taking it all in.mmm you can see the eye contact, he was watching everything but still not joining, but he was really stiff with his shoulders and that and you had to do lots of stretching and stuff for him, um but it certainly has grown
	D: And what's he like now in that particular circle -
31:24	**L:** He's starting to do twinkle twinkle and he can do diamond shape which is huge, and then he just couldn't, wasn't using his hands and that before, he's not sure his hands at the end of his arms, like he's a little bit defensive, tactile defensive at times, and I've found that hard, yknow, trying to help him and he's like don't touch me sort of thing so that has developed and got better, so I'd say music has definitely helped in that 'cos it motivates him to do the work himself um. So that's getting easier, and now he's quite boisterous (laughing), still his motor planning is coming together
	D: But he's still yeah obviously loving it
32:08	**L:** He loves it, he kind of sits there and he squeals with delight and he'll anticipate things and he's pointing up to the radio he wants the music to go fast and then he squeals, it really helps him vocalize
	D: That's wonderful, and what's he like with the other children in that circle time
32:27	**L:** Um, he's watching, he's like passing the sticks around, he will pass them on, that's got better. His ability to do that in a more organized way has got better, um, he watches the other children and sometimes he tries, he tends sometimes to go close to people so I am having to model to get him to do that a bit more socially appropriate, um he very much sits back and watches.
	D: Does he like that sort of something when you say he goes up, does he like that sort of social -
33:04	**L:** Yeah he does, he squeals, he's really seeking xxxx and play with other kiddies he'll go up close, and he will try and engage them, um it pulls on my heart strings sometimes ,'cos he can't talk, he'll go up and then he'll run away, saying come and catch me, to try and engage kiddies like that,
	D: So that's his way of yeah, come and play with me
33:25	**L:** Or playing peek a boo, or sort of hide and run and squeal, and yeah
	D: So he's using all his skills

33:32	**L:** He's using all those to try and get the interaction going, yeah, he'll go up and he'll give people something. He's really good at sharing. Um he'll share, um books and things, um a ball. He's done so amazing. Initially he couldn't even, he'd hold onto a ball and he was that stiff in his muscles, he couldn't even, you'd have to lift his hands off it to get it, now he can throw it, so he'll kind of do things like if he's around other kiddies and he's got a ball he'll kind of throw the ball to see what will happen
	D: Yeah that's really good. Just knowing he can use objects to get interactions as well, that's a -
34:16	**L:** And he'll use his voice, he can, I mean he'll vocalize, he'll make a kind of'mm, a high calling noise or with me and Rob in particular he'll come and get us, use his hands, he'll actually come to us, if we're sitting down and he wants something, he'll come and get us come with me and then he'll show, show us what he wants, he might go to the fridge and you'll open it up and he's pointing to what he wants, and trying to getting him to use his pictorial exchange book as well for those
	D: How did you feel I guess in the early days doing the circle as a parent you ah obviously need to be quite participatory, y'know, how did you feel about that?
35:01	**D:** Umm, oh, initially it was like, oh, OH (laughing….) because special needs is just a whole new ball game, never been exposed to it before. Um and for me I found it really, it's like uh, yeah holding on to my breath, and as soon as the session's over it was out the door, y'know so for me it was a challenge, and now now I love it, now it's ok, not scary, it's ok it's,(laughing) and I can see the huge um the huge just help and impact it has really, um yeah, y'know specially in the relationship like me, and Garth and the family, and the other kids and the social skills that come with it
	D: So you obviously think music has helped you in your relationship with Garth
36:12	**L:** Oh yeah
	D: And can you sort of think in what way -
36:17	**L:** Um, well emotionally it's been very grounding and motivating to work, and to be able to engage Garth on a level where he's going to engage in like a helping working relationship, it's when he can't vocalize, it's a really good grounding platform to work on to get the other skills. Um yeah to help get him to work, to vocalize, to make choices, to help him to think cognitively, to make choices and things, and socially…yeah I just think it helps bring everything else together for him, really, y'know cognitively, emotionally, and just physically, I mean it's been a tremendous help with getting him to stretch, doing the stretching exercises, and just like in the early days, particularly sort of the repetitive stuff we had to do, 'yknow
	D: Which is really important
37:18	**L:** Which is really really important and the music has just been essential really to get through that hard time, 'cos it just, I mean it does, it works with all the other therapies and they all, and on it's own it works well and then having to do all that other hard start it just makes it a lot easier, and you can see the benefits 'cos Garth is progressing, and he's progressed so well
	D: And you sound like you're a very wonderful mother, puts in all the input -
37:54	**L:** It's hard but then I think, y'know we've got to give him his best shot, he's had such a hard time and I need to be able to sit down and look him in the eye

	when he's fifteen and say hey, we've done a good job y'know, and he's doing so well, I mean he's just such a happy boy. And he tries really really hard, he's really struggling sometimes, just with his motor planning, um and he's good, like the frustration and that, when he gets frustrated, and he'll have like a little like hissy-fit, but he's quite easy to distract and I often use music with that, y'know come on 'hot rod Garth' let's get on your bike vroom vroom, and he picks himself up and he's off, and then 'hot rod Garth' goes fast on his bike, and then he can ride and then just get him to slow down again and it helps him to feel ok, it's ok to be angry, it's ok to be frustrated, and we can use this to work and work it through and it's all right
	D: And you feel comfortable using it out in the community now
39:00	**L:** Oh I do, it was hard initially, in the early days it was, and just that whole acceptance and coming to terms with him and a child with, y'know and then 'cos Garth has Sotos syndrome he's big and he's in size 5 pants, anything from size 6 to size 8 clothing tops and people look at him and thinks he's a lot older so expect more from him so yeah, I just get on with it. I get a bit excited, sometimes I have to slow myself down, in the supermarket it's like Garth would you like the strawberry yoghurt or the chocolate, and I just get a bit excited and try to get him vocalizing and he'll squeal and people kind of look, but you know he tries, he tries really hard
	D: It sounds like you're so good at integrating it into your every day life
40:01	**L:** Yeah every day
	D: And how have you found the individual sessions in here with Christine? I guess in the early days, can you think back to how you felt about coming in here, having that individual one-on-one? How did you find that sort of setting?
40:24	**L:** Oh that was a long time - (laughing)
	D: Do you remember how he was, when he was having that sort of one-to-one?
40:36	**L:** One-to-one, yeah 'cos he was quite kind of, getting him to concentrate was the challenge in the early days um and he was quite stiff in his legs, with his muscle tone and the motor planning, um, it was a real challenge, but he loves the piano, the guitar, and I could just see, I mean for me as a mum I found it hard, 'cos the whole kind of concept of having to come to a place and do stuff, but for G, I could see, you just see his facial expression, although he couldn't kind of move his hands and he couldn't talk you could just see his face watching and engaging, and really interested in the piano and the playing and the drums and hiding the toys, and then he would start to learn to sign and sign cat and dog and hiding the toys and starting patting and getting the rhythm going, and I could see it helped him, um develop more an awareness of what was happening around him, his body, and spatial things, um yeah, gosh early days it was a long time ago
	D: And obviously now when you have individual sessions -
42:07	**L:** Because he was just kind of sitting on the floor then, he wasn't even kind of walking
	D: And how do you find it now?
42:17	**L:** Oh I love it, I want to do more (laughing), I want to come every day, I really xxxx. Yeah, it's amazing tools and experience to be given as a mum to be able to take home and have it in the family
	D: And that's what early intervention's all about, getting the skills to -

42:48	**L:** You just kind of, yeah doing the stuff at home
	D: Sounds like you are a very dedicated and wonderful mum. Now I'm looking and seeing what we've covered. We've sort of talked about your family life, you've sort of mentioned how you've incorporated into home. Um I guess one of the other things, is like do you think the music therapy in particular has had sort of an impact on I guess Rob is it? Him being able to, I guess 'cos he's been here and being able to see just how music works for Garth, has he been able, felt comfortable with I guess doing similar things to what you do?
43:28	**L:** He does, yeah he does, 'cos when he was here a couple of weeks ago, I said, how did you find the first morning group session, he says fine he says he loved it. I said what was Garth doing, was he doing the hand action things, he said he's doing a bit and he 's sitting and watching. He feels comfortable doing that sort of stuff. Um and he sees the benefit and the progress that Garth is making with it. Um yep, like at home in just trying to get Garth to vocalize like he's at, often he tries to talk more first thing in the morning or last thing at night when he's in bed. (laughing) And Rob will often go to him at night and he's good, Garth loves, he's got teddies, he's got three teddies that he adores, he's got his favourites that sit at the back of his bed, and he twiddles and he goes and he goes 'te-dy' te-dy and then te-dy and Rob will go te-dy, da-dy, and just trying to get more control of his muscles so he uses that and twinkle twinkle and things, he'll do that yeah, and action things and 'high fives' and 'high fives' and 'low fives' and make it into a fun game, and just make a point of when he leaves the house, of waving goodbye saying goodbye Garth and getting Garth to wave I mean, in early days he couldn't even wave, he can wave goodbye now more often than not, he can wave goodbye, he can sign thankyou, he can do 'red' he can go 'smart', um doing a lot more things, and using the music with that it just kind of I xxxx, it just tends to help him to relax, and it comes through, he sorts it out more, he gets a bit more organized. Um yeah. I just see the change in him when he goes, gets upset, and I sing a song or do some action things and his whole demeanor changes
	D: That's a pretty powerful tool
45:52	**L:** Which is yeah it's like wow, y'know it's like wow Garth, you've got something here that you can do. You haven't got all these awful behavioural problems, you've got actually tools that I can use and Rob can use, and y'know Garthyboy understands
	D: And as you said music is such a good distracter for him, and it's with you all the time isn't it, it's not as though you need to bring something in your bag
46:21	**L:** No, no, driving in the car and I'll say Garth you've got 'dog' and y'know and he can do that dog (signing), or do, yeah
	D: I guess you know having the individual sessions with Christine, do you think she has sort of y'know equipped you with sort of the knowledge of why music is such a tool to be used?
46:58	**L:** Oh yeah, just to help Garth with his um motor planning, challenges, concentration, coordination, and getting a rhythm really getting him to regulate his energy levels 'cos sometimes he'll get quite static, and now, I mean a huge change in Garth like from the early days when it was uncoordinated, sporadic, haphazard, and now he can beat along with the drums, he can change energy levels and go stop and he'll stop, now, he comes into the room, Christine can show him a photograph of the drums, he knows

	exactly where they are, he'll go across, and sometimes he will anticipate before the sticks photograph comes out, he's up to the drawer pulling the drawer out choosing the sticks he wants, I mean that's huge from early days and he knows what they're for and he's getting ready to go and sometimes he'll sway, his body will sway with it rhythm as well and that's huge, y'know for a little boy who was really still… he's done remarkably well and I think the music therapy has helped enormously with that and with his confidence, and particularly doing some more work on his facial muscles like little action songs like 'grandma' and really getting him to focus on where the sounds and noises are coming from and putting his hand underneath….it's better when Rob when he does it and he can feel the vibrations and those sorts of things and he gets to understand sensations in his body and muscles and where the noises and things originate and come from. Um so those sorts of things are important and action songs like the o o o, and the ar ar ar, and Garth watches, he really watches when you are doing these songs and things with him and he tries himself, I mean like the other day he'll just come out with something out of the blue like the other day, we go for walks every morning, and he loves knocking on doors and we were knocking on the big red one on the surf lifesaving club on the foreshore and I say, oh no-one's home Garth, and he goes, 'oh oh' and he's doing that calling 'grandma' y'know and that's the music and he's going 'oh oh' and he's vocalizing and that's like wow, what a rocket , our Garth, y'know, so I mean I can just, can just imagine that that's just going to get better for him, or he'll get more control and yeah
	D: Do you have friends, or even other families here who have just started with the Trust, do they sort of ask you about y' know about music therapy, and why, do you feel as though you could say to them why music is so great?
50:00	**L:** Oh yeah
	D: I guess do you have friends that ask why do you use that, I don't know -
50:09	**L:** You know I was talking to a friend yesterday and she was saying I have always wondered about music therapy and how it sort of complements the other therapies, people don't know about it, and what do you do, and now I can say, look we do all this stuff and y'know this is why we do it, and this is how it helps Garth and this is how it can work, y'know , and you have your set goals and it's um on the developmental thing, for Garth I can see how he's made huge advances really, um, from early days
	D: Sounds like your attitude to music particularly from the early days of being uncomfortable to now being such …to being able to use it, you've made huge progress yourself in that your attitude to music has obviously grown
51:17	**L:** It has, I think that being in a, having to come to a place, yeah and do this sort of stuff was yeah it was like awrrr, it was hard initially and now it's ok
	D: It's no longer out of your comfort zone 'cos you're doing it so often, so it's totally comfortable for you, which is great
51:45	**L:** I don't come in and run away (laughing)
	D: That's good. Does Garth, does he attend a pre-school or kindy?
51:57	**L:** He starts kindy middle of August. I've looked at different pre-schools in that we have moved, a couple of them a few times as well, he'll be starting kindy for two afternoon sessions to start with. And he does riding for the disabled which he loves
	D: Do they use music at riding?
52:19	**L:** Um they, ah, we make little songs like color matching, doing the rings on

	the posts, and the ducks, and doing the signing, wobble wobble wobble, quack quack, I mean do a bit of that with him, just sort of improvise and add it in, um butterflies and things and different things that they have in buckets on the drums and shooting balls into hoops and things, um yeah
	D: That's great. OK -
52:56	**L:** Yeah we sort of use it with the balls, but yeah, not, not a lot
	D: Ok, um I guess just on reflection is there anything um that in regards to Christine's sort of session or programme at WEIT is there anything that you would like to see, or that could be done differently, is there anything in regards to that that you would like to comment on, 'cos I guess we're always looking for, to ask people how can we improve, how can we improve what we are delivering?
53:41	**L:** Just being able to have it available for more families. It's just such a wonderful service. To hear that there's families on the waiting list, it's heart breaking really, because, being able to come to a place like this, it's just invaluable really. I find all the sessions hugely important really, and I was thinking I could say come every day but I don't think you need to come every day because what I learn here I take home with me and we have the individual development plan so once a week's fine, and y'know, yeah, I just take everything home
	D: And you use it daily by the sounds of it
54:30	**L:** And I use it every day at home and got goals and things to work with like Christine works out the individual development plan for Garth and we've got goals to work towards, and he doesn't mouth the drumming stick anymore, um, you know he's got colour recognition, he can concentrate, his concentration's improved remarkably
	D: Right, which you really need, you need that don't you
55:00	**L:** Because the hardest thing for Garth is sitting, that's been the huge big kind of challenge, cos, to get him to sit, and I find the music engages him, and he'll sit, um, and he'll kind of sit and participate, that's what I've noticed is quite remarkable for him, grounding, and he'll settle and he'll sit and he's watching, and he may not be able to get his motor skills, but he's sitting, um he's wanting to do things, and he is, he's doing more things
	D: Wonderful. Is there anything else that you would like to sort of add, that you can think of that you can add as part of this interview? Is there anything that you would like to share, or I haven't asked you or -
55:55	**L:** Um, no I just think um incredibly lucky to be able to come and participate in a programme like this, yeah, um ah I mean I think if I had chosen other options, I don't know that Garth would have done so well like conductive education y'know, yeah, the comprehensive approach and integrating really yeah everything um -
	D: It was obviously good for you to look around and see what, so you knew what was out there, you made your choice and it sounds like it's been a wonderful choice for you and Garth to come here
56:39	**L:** Yeah, I think he's done really well
	D: And you've still got another -
56:47	**L:** Yeah I know, he's only just turned three
	D: It sounds like he's doing very -
56:53	**L:** Yes, oh he can run, he's running, he's jumping, rides his bike, I have to

	run to keep up with him on his bike. No he was a little boy who was stiff sleeping in a hammock, y'know and it is stiffness in his muscles. I mean he had difficulty feeding himself, he can feed himself now, and sometimes he kind of forgets what he's doing but, I mean he can do it, he can do it, and I just think the music has helped integrate and put everything together with the physiotherapy, I mean it just complements them all, y'know if I'm doing the teaching things with him at home and his pictorial exchange system with him, I mean it's yeah, music just cuts across the board with all of them, I think they work together and the physio particularly the physio in the early days doing a lot of repetitive stuff, it was um , it made it a lot easier having the music there, to be able to use that with it
	D: Yes, because obviously he was finding it really hard to do, so by complementing with something that he just loves
58:04	**L:** Yes, and it makes it fun, y'know and xxxx it's like in the early days god it's like all this work to do, how do I be a mum there's all this stuff to do and it [music] just made it fun and it helped me to relax and enjoy and just that whole attachment and bonding cam together. Y'know from having two months in hospital and all these other admissions with pneumonia and things and then it [music-making] could just pull it together
	D: Yeah it's obviously a wonderful bond for you and Garth, yeah 'cos you obviously use it a lot I can tell
58:39	**L:** Yeah, he just responds really well
	D: Terrific, have a scone, but we've pretty much finished our interview, I think we've covered everything now. He sounds an amazing little individual -
59:01	**L:** Yes he is, he's a good boy
	D: He was very happy when he came in the door
59:07	**L:** He is y'know
	L: He's really easy, he's very busy, but he's an easy boy
	D: That's just great considering his rough start
59:24	**L:** He's come ahead in leaps and bounds now
	D: But it sounds like it's been, you've put in a lot of effort too
59:31	**L:** Yeah, well I stopped working, I chose, I actually resigned and xxxx doing some casual work and then I thought no, no, no I couldn't do both, I just decided no, to stay home
	D: And you've been comfortable with that decision
59:51	**L:** Yeah, entirely, best decision, best decision I made really and just to see Garth doing so well
	D: It's evident isn't it
	L: (laughing) it's fun, yeah a lot of fun
	D: Yeah that's great, oh well we'll go and find Garth and Christine and see what they've been doing
1:0:20	End of interview

Extra information that Leanne shared post interview.

Leanne wrote the following:

Why did I choose WEIT?

The music therapist, Christine Archer, came highly recommended by other health professionals who work with children who have special needs.

WEIT's two-hour programme for parents and children begins with a group music session. Each child plus parent then attends individual sessions with different therapists with a short morning tea in the middle. Everyone then comes back together and the programme finishes with a group music session.

No other early intervention centre offered such a well-facilitated, comprehensive and professional therapeutic service. Music therapy facilitates and fosters the parent-child relationship through the group and individual therapy sessions. Children learn active and passive participation skills in the group music. They learn about things having a beginning and an end. They learn to socialize, communicate, share and anticipate with turntaking. They have fun, especially when learning about motor skills and co-ordination. The warm up exercises in the music group help the children to settle (helps me as a mum too) and this improves their concentration for learning.

Music therapy offers gentle therapeutic holding for parents and children. This was particularly important for me in the early days when I was feeling anxious about Garth's prognosis and being a mum to a child with special needs. Music therapy helped me to better manage my stress levels, work through grief and feel confident about my parenting role. Music therapy fostered the relationship I have with Garth and it is a two way process. Garth is very responsive to music so by incorporating music into our daily activities a strong parent-child relationship has developed.

Music therapy complements and augments the other therapies at WEIT e.g., speech language, physiotherapy and early [intervention] teaching. Music therapy motivates and empowers Garth to participate in other therapies e.g., sitting, starting and finishing an activity can be a challenge for Garth. Using music during his early learning session helps Garth to concentrate, engage in a meaningful way with others, and complete the task.

When Garth was a baby I needed to do daily repetitive physio exercises for him as he had a limited range of movement in his limbs, shoulders and trunk and his muscle tone was stiff. I had been shown exercises by the visiting neurodevelopmental therapist and by the therapist at Conductive Education which I explored as an option for early intervention for a short time. I would often have gentle lullaby music playing and/or I would sing to Garth during the exercises. So, music fostered our relationship and enabled me to do the really hard repetitive work with Garth. Best of all, we could have fun while doing the work.

Music helps Garth to express himself. It validates his feelings and gives him confidence. It helps Garth to regulate his breathing (mine too). Through music Garth becomes more aware of the energy in his body. He becomes more aware of his muscles and how to coordinate them. This all helps his spatial awareness.

Music therapy helps Garth and I to celebrate his successes. It helps us to work together and this promotes opportunities for learning for both of us.

Music therapy helps me to be more aware of my behaviour and language and how to work more therapeutically with Garth.

For example:

1) the importance of slowing down my actions to allow Garth the opportunity to practise his motor skills

2) the importance of speaking in a calm and well modulated voice.

Music therapy gives me day to day skills that I can use creatively as a mum when helping Garth with his daily activities e.g., I sing a song when helping Garth to put his shoes on or when brushing his teeth. These can be challenging tasks for Garth as sometimes he dislikes sitting still and sometimes he does not like his face being touched. Music helps Garth to complete these tasks and this makes both of us feel good.

When Garth becomes frustrated with either having to complete a task/activity, difficulties in talking, or difficulties in getting his muscles to work in the proper sequence then music therapy is an invaluable intervention. I can mange Garth's behaviour by using songs and actions to help validate his feelings. Music helps Garth to explore constructive ways of expressing himself and dealing with his feelings of frustration. Music helps to distract Garth when everything has become too overwhelming and stimulating for him.

Emily Perl Kingsley's short story "Welcome to Holland" describes our journey beautifully. Music therapy helped me to "catch my breath" and this has undoubtedly had amazing effects on the relationship that I have with Garth. Italy and Holland both have music and that is the wonderful thing about music therapy – it normalises the whole experience.

Appendix 7: Transcript #3[11]

Interview #3: Jacqui (J), primary caregiver to Gene (G)

Interviewer = D
Gene's father = M
Manager of WEIT = Sara
All other people = OP

Date:	Thursday 11 September 2003
Time:	7.30pm
Venue:	music therapy room at WEIT

This is the second interview with Jacqui.
Technical problems of the recording equipment foiled the first interview.
Jacqui agreed to be re-interviewed.
Jacqui was recovering from the flu and nasal congestion, so some words were difficult to transcribe.

Transcription of Interview

:40	**D:** Well thanks again for coming today
:42	**J:** No problem
:43	**D:** And um yeah obviously we'll start the interview and it'll take, it'll be similar to what we talked about last time, um so yeah it would be good to hear about Gene, just tell us about what he was like as a baby through to I guess today really
1:01	**J:** Basically, conceiving him, right through, I mean -
1:03	**D:** I guess when he first arrived, what he was like as a little infant in regards to your relationship with him, how he responded to you, any...yeah I guess just his story really
1: 20	**J:** Basically he came on his due date, a healthy wee boy, well yes, a healthy wee 7lb 9 he was, boy, yeah on his due date so...the labour went well, everything went well, um so yes, it was a little boy, and yeah, he was a great baby and he slept through from two weeks old, yes, no, he was an excellent, an excellent baby, um yeah and everything just floated along and everything was fine and he was a content little thing and we just sort of basically ...yeah like he didn't really have, I didn't really have any concerns that young, I mean, as a, as a... probably up to six months old he was sort of pretty much sleeping and eating like most newborn babies sort of do, and looked around and smiled and did all those normal sort of things, um....probably... um....not that it was probably a concern but he probably started crawling ah... he must have been 11 or 12 months old, 11 or 12 months old, he sat up at a normal sort of age um

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[11] Following Poland's (2003, p. 279) approach, the following symbols are used in this transcript:
"xxxx xxxx" denotes words or passages that cannot be deciphered
CAPITALS denote strong emphasis
"-" indicates speech has been interrupted
References to "the Trust" are to be interpreted as references to WEIT

	and did all those sort of things. He wasn't terribly mobile but because he was so content and Plunket [infant healthcare system] always said to me, y'know he's content and he'll crawl and walk like, she always said to me that from the word go, like just because like if y'know he was on the floor and there was toys there but if there was something more closer to him he would be quite happy with that opposed to ah being inquisitive and wanting to crawl over and find something different he would have been quite happy just with what was -
3:00	**D:** Immediate
3:01	**J:** Immediate distance from him and that was fine, I mean, y'know that wasn't never really, y'know he still went and he rolled and he y'know he was still doing all those sort of things, he just wasn't really, he wasn't I guess wasn't so much mischievous more than anything, he was just content basically and um, so then he started crawling and he crawled just normally, like on all fours, um didn't bum shuffle or anything like that, and same thing, he got where he wanted to and, never thought anything of it, and um y'know and he'd get up on furniture and -
3:38	**D:** So he was doing all those typical milestones that -
3:42	**J:** Yeah he was, yeah like I never really, I mean I sort of thought, like our daughter, she walked at nine months, so I mean but she was to the extreme the other way, so I mean not many children walk at 9 months, so she did, she was, and there's 9-and-a-half years difference, so as much as I could remember what she did, y'know it wasn't like she was only a year or two difference that those memories are very vivid in your mind…um so when I mean as I said yeah, for him walking, like he didn't walk 'til he was oh just a couple of days under 18 months, just over 17 months old, and, that seemed really late to me but because I had daughter who walked at nine months, but then everyone was sort of saying oh y'know I had other friends whose children who were walking so at 15, 16 months so I wasn't still then I wasn't hugely concerned, I mean like, I mean I sort of thought oh he's a late walker, but everybody sort of said oh he's a boy, y'know and he was content and he was happy crawling and so I wasn't concerned as such I just sort of thought oh yeah, y'know when people say to you 'oh mine didn't walk 'til 19 months, mine didn't walk 'til 20 months' so it wasn't something I was concerned about as such, I just thought he was just a… cruisey really, but then…um but then, oh, no, backtrack myself a little bit actually, when he was littler, when he was about 12 months old, we did notice like whenever he sat, um he always liked to cross his legs, so yeah, so that was a concern, that, well not so much of a concern, well it was really 'cos I did notice it, and like when he was in bed when he would sleep and things like that he would always lie with his trunk….more, no I shouldn't say his legs, his ankles like across like that (demonstrating) opposed to yeah like that just with his ankle type things, and that was one of his very comfortable positions like um even sitting wise of if I was feeding him or things like that he always liked to have his, and people used to joke about it like it used to be quite obvious y'know he liked, and I would like open, go like that (demonstrate) and he would just instantly put them back like it was obviously, I always sort of thought it was a comfort thing and then when he was about 12 months old or so, I sort of thought, oh no, I hope this isn't stopping things because he did like doing that um and then I sort of thought hope there wasn't anything wrong with his hips so it was more I was sort of thinking hips more than anything and um, so that's when we took him to OP and he checked him

	out and said that no he was fine that they had x-rayed his hips and everything and his hips were fine, that he was sort of flexible and things like that but there was nothing to worry about basically, but he wanted to see him again when he started to walk, so at 18 months when he started to walk we took him back and when he did, when he finally was up on his feet, he was quite externally rotated, Charlie Chaplin type walk um so then, but he still y'know walked, he was walking still in a normal motion but he was just like rotated to this degree opposed to his feet um so we took him back to OP, and same thing he checked him over again and said no that… he was still ok and basically that yeah he was still ok but he did walk in a Charlie Chaplin type manner um but his hips were normal and everything was basically normal as such, I mean he was rotated but he felt that a lot of that might have been through choice, opposed to um that was the way he felt comfortable walking like they couldn't, there was nothing to medically as such that they felt they could correct or y'know that they felt was -
7:38	**D:** There were no bones sort of -
7:41	**J:** No yeah so like he's an orthopedic surgeon and he felt there was sort of nothing, like his hips were fine, his knees were fine, his knees down to his ankles were more where he felt that, and I actually walk slightly rotated, and he just sort of, y'know thought of thought it was just, no he was far more severe than me I mean he was like 75% rotated so he was quite…one of his legs was worse than the other, but they were both, y'know, and when he sort of ran he would run almost like a penguin type thing a woah (demonstrating) opposed to a motion like a stride, um but this was still early I mean he was only just walking at this stage so you sort of felt that that would y'know, that that would correct itself, and he said to us that he felt that by the time he was four that he would be a lot better…um
8:37	**D:** So how were you feeling then, you sort of taken him back the second time and they were just saying look everything's fine
8:44	**J:** Well at that stage right when he started first walking I probably wasn't, I was sort of thinking well maybe he y'know it will be, but as the months sort of got a few months on when he was walking more steadily and y'know more freely opposed to that learning type process, I knew then that something was wrong, like I just yeah like little things like as you say if you went up and jumped off the deck which our deck's only this high (demonstrated) well he wouldn't actually jump off the deck as such, um he would come to the end and then sit down and hop off or when he um little things like I could tell he was having difficulty and I believed that it was because of the way his legs were and it was stopping him from doing things like we live in a two storey house and he would go up the stairs um which at that age probably wasn't too bad, I mean, he was going up, as the months went on I noticed he was still doing it he would sort of go up one foot at a time, bringing the other foot up to meet it opposed to 'bang bang bang bang' (demonstrating alternating stepping), like this type of thing and on the slide, we've got a slide and I noticed he would climb up the stairs, he would climb up the stairs and would hold on but when he got to the top he used to sort of, you could tell it was awkward for him like most kids would just fling his legs through and down they'd go, and he was getting to the top and he would get one leg up but he would almost struggle and a lot of times I would have to go and help him, like try and bring the other leg through um so I knew then it wasn't a choice issue like this wasn't

	something he was just choosing not to do, yeah, he was, and then of course I felt that it was starting to hinder him because he knew that he couldn't complete these tasks by himself so it was almost stopping him doing some of these things -
10:38	**D:** So would, so would he be reluctant to go up the slide?
10:41	**J:** Yeah because, unless I was sort of there or he'd call for me he probably wouldn't have done it on his own because he knew that he would struggle to do it, um yeah, so he just, and like he still now, and I mean what he's nearly five at Christmas, he still can't I mean like if you put him on this table [small form in room approximately 10cm high] he wouldn't be able to jump off two feet at a time, like land on two feet, no he would go down on one like one bang,…he still struggles with that now, ah but then I, just different things he was doing, um I just thought, no this isn't right like y'know and they all said no no just y'know he'll get there and it's like no, he, he's not doing this because he doesn't want to, it was more an issue that I found he was struggling to do it so um that's when I decided to get a second opinion and we went to…I can't remember his name….I just read it on the doctor's file the other day too…um head pediatrician at Wellington hospital and um xxxx was his name I think but don't hold me to that, and um...with a, a um appointment with him and same thing when we got in there he felt that he, they x-rayed him again, he was about two-and-a-half by this stage, um they x-rayed him, again his hips were normal and basically that the rotation was coming from the knees down um that they felt that he chose to walk that way and that he was still within the range but one end of it, um I'm like well I disagree but, he felt no, that that was the case and that they wanted to see him again when he was four, oh in a years time which was about three-and-a-half at that stage, or two-and-a-half at that time but he would be three-and-a-half…yeah, which he may have been a little bit older than that…um so they, he said he wanted to see him in a year because he was externally rotated and he said that when he was in double figures like 11, 10, 11, 12, type thing that they could operate from the knee down, break this bone down here and reconnect it so his feet turned this way, but they wouldn't do that 'til double figures but he said that, even if they did all that and straightened this bone so it went down that um he could get out of bed and still choose to walk in his comfortable position and it would all be a waste of time because if that's the way he just chooses they feel that that was a comfort and in a way people walk all different ways, if he chooses to walk that way that the operation would do nothing anyway, so it was….cop out really, and um so he wanted to see him in a years time, so over that year so then I, we came home and I was still really disillusioned by all this because I still felt I was hitting my head against a brick wall basically and that no one was really listening to me and that there was still this problem um so we went home, and same things were happening over and over again like I could just see him struggling and I thought no…no… this just, this isn't within the range thing, this is, and the older he was getting the more noticeable it was getting
14:10	**D:** Was he, was Gene showing, was he showing any sort of I guess emotions in regards to when he would attempt something?
14:21	**J:** Um yeah I think more, sometimes out of frustration a bit, but I think he would tend to more, it was making him probably reserved than outgoing because he knew he was struggling to do it and keep up, um so each sort of month basically as this gap was getting y'know, he was getting older to me I

	just felt the gap was getting bigger, was getting wider, um and so we just, so I thought well no, this still… I don't care what they say this isn't right, this still isn't right but y'know just watching him and I could just tell so um he went to Barnardos [pre-school daycare centre] at that stage in the mornings, so OP [supervisor] at Barnardos said to me um, they noticed it like y'know that just different things, more the attempting things, just struggling a bit to um achieve those things, like even riding a bike, I mean well he didn't ride a bike then because I guess that holding your feet on the pedals going into that motion was just -
15:28	**D:** Just too hard
15:30	**J:** Yeah it was too hard for him, so she recommended child therapy, with OP [physiotherapist] and OP [occupational therapist] in Pharazyn Street, and so we went and met them, and they were just wonderful, like straight away they said like they had never seen a child so badly rotated um that he was like about 75 degree rotated and they just couldn't believe that two orthopedic surgeons had said that that was within the range and was ok and not even recommended any sort of therapy for it, they just couldn't believe it, they were just blown away actually, and um even not to recommend physio or just any sort of y'know -
16:18	**D:** So how were you feeling when they said that to you?
16:21	**J:** Um…relieved almost, because finally someone was listening to me, finally, I mean I had taken him to two doctors who were highly, highly qualified doctors, surgeons basically and were telling me nothing was wrong and I knew there was, so, as hard as it was, it was, it was finally….Finally somebody can see what I can see and is listening so it was a huge weight off my shoulders, a huge relief really um that yeah that I wasn't just going crazy and he wasn't just a boy that was y'know there was more to it than that, so we started a um a 12 week session with them, oh it was going to be 10 weeks, but because there were only two weeks to like Christmas so we just carried on with -
17:16	**D:** So he would've been? -
17:18	**J:** He would've been, this was before last Christmas so coming up to four um yeah he was four last Christmas so and we worked up to that Christmas, like the beginning of that school term so this was sort of like October, November, so yeah he was approaching four and um they were wonderful, they just, we went, basically and like they explained everything that was going on and what was happening was that um he was getting y'know like from 0-6months, and 6-12 months of milestones and he was getting sort of like 80% of his milestones opposed to reaching to 100% and then it was time to click onto the next step of milestones but he was getting himself far enough that he was getting to the next stage but before completing what was going on, and when they, y'know it was just these basic things that you just don't, you just take for granted really, that children do and sometimes you don't even realize that they are sort of doing them because they just, they just do them, and it just happens, and you don't just realize, and because he was almost fooling us that he was getting to that 80% sort of mark, enough to like y'know he was crawling, so of course then his little body was I guess was telling him ok I can go to the next step but he really wasn't quite ready to and um, but he was getting himself there but then of course as he was getting older those milestones were then becoming wider and they were catching up on him basically, and um so they went right back to basics and balance and just um get him to do, it was all fun things, like y'know it was nothing sort of hard, it was going right back to

	basics, I sometimes wondered what on earth they were doing it for, but they all had a purpose, and they really worked well, um they really really helped him, he came out of there a different child really, um well with motor skills definitely like just his confidence and even, and his feet literally, you could see them coming, I mean like they said they hoped to get them to sort of 20 – 25% so that was sort of coming back around 50% and they really did I mean it was, um, yeah, it didn't happen over night but you could definitely by the end of those 12 weeks he was oh absolutely he was doing things that he wasn't even remotely going to be able to achieve 12 weeks earlier, and really did, yeah just going back to those basics, and he didn't like to um, touch, it was going right back to touching everything like messy things, he wasn't fussed on like shaving foam, or like different feelings different, all those sort of things so they took him back, right back to um basics, walking across beams, climbing up steps, and y'know by the end of the 12 weeks he was going up our stairs at home like this (demonstrating alternating feet) and, y'know which was a huge achievement from a child that was going up like this, and um jumping off, but he was riding a bike and just yeah, I mean it was just amazing really what they did with him, and then they, they were the ones that noticed that like, I mean I don't know whether I, I shouldn't say I was so wound up, I mean his speech was there, but y'know he was saying words and 'Mum', 'Dad', y'know, and he was saying things enough and I guess we were so engrossed with getting the motor skills side of it right and all, that I don't know whether, I shouldn't say I didn't notice, but well I probably didn't, I mean the same thing he was probably fooling us enough -
21:07	**D:** I was just going to say doing the 80%
21:10	**J:** Yeah fooling us enough with that that at this stage, as I said he was probably about three-and-a-half, so, he was saying enough that, he was speaking, y'know and things like that that you just, y'know, and that, but OP and OP [at child therapy clinic] noticed and said that they felt he needed some speech therapy and I guess y'know they started putting it all together like between the motor skills come fine skill come everything y'know put the connection that the dye was there probably all over opposed to just one area um so we yeah, so that's when they had got in contact with Sara [manager of WEIT] and recommended here [WEIT] so that was um our next xxxx. We never heard of, y'know we never really had anyone that had needed help like as such like that so we didn't know and so that's when we came over and we met Sara and come for a session, a y'know look and everything and that was the beginning of -
22:19	**D:** Coming to WEIT
22:20	**J:** Coming to WEIT yeah
22:22	**D:** Do you remember when OP and OP [at child therapy clinic] sort of started to mention to you that they felt it was more of a global delay, do you remember how you felt then?
22:32	**J:** Um I guess I probably, when I say I didn't, well I wasn't really naïve to it because I knew it was there, but I knew there was probably delay in his speech, I didn't really, between his motor skills and his speech I didn't sort of pick much else as being wrong, if you know what I mean, I didn't sort of think of as an overall picture that there was more to it, I just sort of thought um speech, y'know like two different things, but two things that were just quite simple sort of thing, I didn't probably think of y'know any total development delay as

	such, um M's sisters both had speech when they were children, um for different reasons, and I sort of thought oh yeah, speech, yeah I didn't probably…yeah….realize to the degree of it at that stage, um I think I was just sort of so relieved that someone was listening to me about his motor skill type things and y'know that was working that, I was almost excited I'm thinking ah yep, we have to get on to this, and and I guess even over those 12 weeks, which three months I mean it's quite a long time, um the, it was getting more obvious that his speech and things weren't right, y'know which as I said in three months, I mean I look at three months ago and three months now and I mean at that age is a huge developmental time, and so at the beginning of that, when we started probably going there, but it wasn't as obvious but as those 12 weeks went on it was becoming more obvious, yeah, those 12 weeks were, y'know were starting to become a six month gap or 12 month gap opposed to y'know just something that we thought he was just -
24:32	**D:** So I guess just thinking about, like you've talked about Gene from sort of y'know from when he was a little infant up to sort of four years of age. Your relationship with him, how do you think it's been through that, that course of -
24:46	**J:** Oh he's definitely Mummy's boy, without a doubt, mind you, that's probably because, I mean I'm the home person, M works full time um so I obviously spend a lot more time with him, um I probably tend to overcompensate for him which mothers probably do, and I, I could see him struggling so, I'm going to cry, I was going to be braver this time um (crying and laughing), supposed to be brave, um
25:24	**D:** Just take your time…
25:25	**J:** Yeah, I guess I could see it and I mean I was probably in a lot more circumstances than M was like just general during the day going off to other friends and their children and seeing him struggling, and you do tend to overcompens…I mean, I probably do whether it's a good thing or a bad, and I try not to sometimes, and I am getting more aware of that that sometimes he probably does have to learn for himself but as younger, I'm going back to that age and not realizing probably what I realize now um it was different, y'know I probably did tend to y'know and, and whether I was right or wrong, he probably did rely on me because he knew I was probably his other set of hands or um of that type of thing, um so, yeah, we're very very close, but mind you we're a very close family anyway and um M's a great father and he's hands on with him y'know when he's not working, but as I said obviously I'm the, yeah, I'm the -
26:38	**D:** You're the primary -
26:39	**J:** Yeah, at that stage I was with him 24/7 basically so yeah he knew that, um as I say that if I'm not there, that was fine, y'know but yeah, he was definitely, probably would be a mummy's boy opposed to… back then anyway, think they might be a little bit different but I still is that now I think that with mothers and sons and children always have a bond anyway that they're a bit more unique in that you're at home with them all the time…um, so no, I mean, yeah it was half and half as much as half of me was realizing that there was a problem, the other half was that too that I was finally getting something done about that problem so… um… y'know so there was quite a lot of mixed emotions really…um
27:32	**D:** Yeah, understandably…so you've started at WEIT, you've been here sort of 8 – 10 sessions haven't you and um I guess y'know it would be good to hear

	about when you had those first one or two session, coming into WEIT and coming into the group circle time, what were sort of your feelings on that?
27:56	**J:** Um…it was really good like I, even the first time I came um like I was always, it was really welcoming and it was never a scary environment or anything like that, um, reality check was probably y'know like all of a sudden I started to probably realize that there was a more going on with Gene than what I had probably realized, um, so that side of it for me was probably a bit harder because, all of a sudden I just from this I thought a walking problem and a bit of a speech problem, um there was more, there was a bigger picture there that I had to, not face, because I probably, I sincerely probably didn't realize that there was anything, well I say that, I mean yeah, I mean, I… as I said as opposed to looking at a overall picture I was looking at as in separate identities, y'know as I said a walking problem, a speech problem, without thinking what was -
29:06	**D:** Putting the connections together and -
29:07	**J:** Yeah, so um when we came here, like I mean it was just fantastic, I mean like I knew instantly that it was the right place, like we didn't have to look, I mean we didn't look anywhere else, I mean we came here, we got wonderful feelings, vibes and instantly knew we needed to look no further, um and it was going to be great for him, um. When he first started, we came on a fortnightly basis um and no it was really good, and the first session I mean it was wonderful and they are so welcoming, and so friendly, and I mean it was just great, but it was a reality check, not from them but just the whole realizing that yeah that y'know that it was but it was just fantastic, I mean they're just, they're just incredible ladies, I mean…oh I'm going to cry again, they are, they're just wonderful, they're just unique people and they are (crying)…. they're fantastic, so…. they basically…. M probably found it a little bit hard because we alternate um so we all realize what's going… hand in hand, and we can all put it into him so we try to alternate what we do pretty much in the time when he's not stuck at work so we try to alternate Fridays because now he's on a weekly basis um and even then we still alternate, um yeah I mean I guess for a male it probably a bit…. he felt the same as me, it was wonderful and incredible people and that, but for him it was a reality check too that there was a wider thing going on here, um no he did really well, he, he, yeah he, I probably like to think I fitted in, and he did too, but males are different than females and fathers are and as much as, I mean he loved coming and he always wanted to come so it was never like y'know he didn't want to or he was pushed into it, I mean it was always a choice thing that he wanted to do too, um but he felt the same thing and it was just….yeah…I mean we just …it was just amazing and …um yeah it was just everything about it was really good, just that reality, short reality check those first couple of times, um y'know, realizing our son basically did need help, and y'know but on that hand, as hard as that was to really come, not come, well yeah I guess come to terms with that he did y'know have trouble, did need help on the other hand it was very comforting to know that we were here with them (crying) and they were the perfect people to give it to us so as much as you were facing one issue, it was great that we have…y'know and we were really really lucky and we knew that, that we had the right place and y'know and they just treated him (talking and crying)… and they still do…. and me and M… and I just like we have xxxx xxxx really and that he's special and they care about him and yeah, it's great

32:30	**D:** It's good that you've got such good support
32:34	**J:** Yeah oh, absolutely, I mean sometimes I don't think… how could I ever do without them I mean how far they've brought him, how he's changed and um, over the weeks that he's been coming here is just amazing, I mean, family notices it, my sisters, his speech, his communication, everything I mean it's just obvious to everybody how much this has helped him, I'm in no doubt about that
33:08	**D:** So you've seen development in all areas?
33:11	**J:** Oh huge amount of development, I mean I look back um to the beginning of the year, and I mean and even just M's been away, he was away in America for five weeks um he's been back two weeks, and even he said in that five weeks of him being away, just that, he said he just couldn't believe the difference, like it's, it's very obvious the difference, just his whole um, his whole personality, his outgoingness, um he's a friendly little boy anyway, he's very social, more around adults, um he loves people and he does, and he's very but, and I've always believed and I've always said, I mean he loves kids too but um, and he loves to play with them, he does, but I've always felt that he's more struggled on that side of it because of his communication um and I've always said that um that I believe that he's wanted to get out there and he's wanted to do and because first with his mobility he struggled a bit so he couldn't keep up basically, um and with his speech, um, as well as, what he says he actually says very well, like he speaks, I mean you'd understand every single word -
34:31	**D:** Right, so it's really clear -
34:33	**J:** Oh very clear, he speaks very clearly but he has trouble like with what you and I are doing the back and forth -
34:41	**D:** Two-way conversation -
34:42	**J:** Two-way conversation um so if you were to say something to him, he sort of, he often repeats you or um comes back with the same that he feels comfortable with because his little brain finds a struggle to, he knows what he wants to but to the reply of it but actually what he says, he's, he speaks, I mean there's nothing wrong with his speech as such that way, um so, but just even that, how much that's come along over the last y'know few weeks is just amazing, I mean, even I notice it, I y'know, what people take for granted, y'know the other day he's talking to me and he was actually answering me, and oh him and M were in the car and M's got a phone that you hang up and y'know they can talk out on the loudspeaker on, and y'know, I picked him up from kindy and I said how was kindy 'good mummy' and I said what did you do "I did a painting for you" y'know he was actually, for 3 or 4 sentences he was actually replying to me, and afterwards I hung up and I thought wow, y'know I would never got that long ago as much as he would say to me when I got home, I did a painting for you, but if I said to him....his replies would be… he would have it but just not in that general flow of conversation, um and I hung up and I thought wow, I mean like, he was actually, we were actually having a conversation, y'know, and um I thought yeah it was just, mmm it was just amazing, and I think that is what's happening with children, in kindy now too, like he has an ESW in kindy with him, 5 mornings a week, OP [ESW], and he's incredible too, he's actually fantastic with him, and um, and like I think his social skills with the children has improved so much too because of the whole mixture of being of what's happening here is helping that so that the

	children are taking a bit more time with him and he's managing to socialize with them better so his whole um, y'know communication with children, I mean the whole overall picture has changed so much, so much, um and thanks really to here, 'cos I could never have done it without, I mean, I didn't even really know where to start, I mean, as much as I knew, and that was the thing like he would repeat himself to me, and as much as he would say something he would just be repetitive and find a saying that he would be (en)grossed with and like if he walked in here now the first thing he would say to you would be 'where's your car?', he's obsessed with cars, but instead of sort of saying hello, how are you, he would say, and he would want to talk to you, but he would know his opening line would be 'where's your car?' because then he knows that that would get you talking to him and that would start the communication going and he does that, so he knows, and I mean, he's a bright little boy in a lot of ways, he's got an incredible memory, um he'll recite a book to you like books at home that we read to him, like several books, he'll like he brought one in for Christine, the Little Yellow Digger, and he'll read it to you and, Becky's Surprise, y'know things like that, he'll remember a book from start to finish, and he'll recite it to you pretty much -
38:12	**D:** Word for word
38:14	**J:** Pretty much, I mean he's, it's, like that he's good and I mean he'll tell you the alphabet and he'll count to 20, and for all those sort of things, he's good at, um… but then he's yeah, like he, so that basically when he started here they I guess which I didn't know but obviously [the therapists] had their meetings and they discussed what they suspect might be the cause of what's going on and things like that so they, Sara recommended that we see a pediatrician, which is what we did, OP [pediatrician] at Hutt hospital, and um we went for a xxxx xxxx, maybe eight weeks ago, and OP suspected that it was Fragile X, um which I had no idea what that was or had even heard about it at that stage, um so yeah so that was a bit of a learning thing for us too, trying to figure that all out, and I had suspected that he had signs of like mild autism, like I didn't know a lot about autism but just different things I started to wonder, and then that's when he explained that Fragile X and Aspergers are very similar in sign, signs-wise, that they show similar symptoms, so, he was really good, he discussed a lot of things with us, and he was really good with Gene, and basically came to the conclusion that he suspected that it was one or the other. He had suspected Fragile X so they did DNA testing on him to test for that, so we went back two weeks ago and they found that that was positive so he had been -
40:06	**D:** Diagnosed -
40:07	**J:** Diagnosed with Fragile X, so then, yeah that was kind of, it was that mixed emotions all over again really, so it's been a roller coaster in a way, but um, as much as it was hard to ok finally there was a name to this and finally that y'know I guess all the other times y'know when you start seeing him achieve some of these milestones you start to just sort of think maybe there was just y'know a slight delay, and one day he's going to wake up and y'know -
40:42	**D:** He's caught up -
40:43	**J:** Yeah, y'know that this was going to happen and whatever, but then I guess for that, I came out of there probably really quite flat um half of me was pleased to know that finally there was an answer for this, and there was a reason for this and it makes you understand things in a different light, and the

	other half was sort of like a reality check that there was actually a problem… that we had to address, and, and half of it was, y'know I had mixed feelings for the fact that it was good because I knew then that I fought for this and y'know so if xxxx, well yes I'm glad because I did fight for this and we have found out the problem and thank God he's here and we've got help for him and the best possible help we could ever ask for, um and y'know and like all those sort of things, a comforting side of realizing that there was a problem, um, but yeah, so that was sort of mixed emotions for a few days. M took it extremely well actually, um, whether because I didn't, or I shouldn't say I didn't, because that's not quite, y'know the reality of it probably knocked me but he sort of y'know very optimistic, and ok this is how it is and now this is what we got, we go forward and we do about it which he's right but, um and then you sort of start to feel a bit guilty and you start to think all those other things y'know, typical, typical, y'know, did I do this? (crying) and y'know all this type of thing, but… no a week later I do actually feel better about it (crying and laughing), xxxx xxxx, so that's basically where we're at on that side of it, so now yes he has been diagnosed with Fragile X and um, but it is comforting because a lot of times like, I look back a year ago and one of the signs of this particular syndrome is anxiety and dealing with big groups and that's probably one thing I did really notice um that… like a year ago if we walked into a room of people or we walked into a different situation he would find that very hard to deal with and just shy off and go all, I shouldn't say silly, but I guess that's a word y'know and start performing and I, y'know you sort of think oh God, y'know don't be silly mate, c'mon, and you don't realize that, what he's going through and I just whatevers, not being naughty but y'know, c'mon we just we'll deal this, this is how it is, and let's just do this, get on with it, y'know, and um (choking back tears) where now, I know it's not that, and you do look at things differently you do deal with things differently. We went to a fish and chip night at kindy last Friday night and um, we walked in and there was the morning kids as well as the afternoon kids and probably fifty parents and um, y'know, we walked in and as soon as we walked in with our fish and chips, and… he came to a halt, pretty much at the gate, and um, 'I'm not going', not that he didn't want to go, I knew he wanted to but there were several lots of our friends in there that were sort of probably in the middle of this group or y'know whatever, and we sort of like..c'mon then let's go in and…I....and he was quite happy and he wanted to sit at the back and eat his dinner so that was fine, we have a whole better understanding of it, a year ago I probably would've said c'mon let's just and you do, I didn't realize that that was 'cos half the time he would be fine, and y'know so I just didn't realize that was what was happening, so we sat back, I mean we just sat over, I just tried, to probably from here to the piano (indicating distance in the interview room) from the next group of people and but that was fine, he was in his comfort zone, and we looked at it and we dealt with it, and we sat there and we ate our dinner and um, they had a magician inside and there was no way he was going in there, but that was fine, because I mean there was probably 75 children and probably as I said 50 adults all confined in this room, I wasn't fussed on that situation let alone I mean, and he was, no way he was going to deal with that, but that was fine, I didn't push it, whereas I said once upon a time without the understanding maybe I might of um or sort of push him a bit further and try to get him to do it anyway, um so we didn't, he waited outside, and then a couple

	of the kids came out, and, that was fine and he started playing with them and then he just, he just gets in that zone and he's fine and like he just, he felt comfortable then, and then once it finished all the kids came out and they had lolly scrambles and he was great, he went off and did the lolly scramble thing and y'know he was just way into his own comfort zone and once he's in that he's, he's perfect, and y'know as I said one, when the doors were opened and all these kids started coming I sort of thought......y'know we'll see, but he was great, they went off and they got lollies, it was dark at this stage, y'know, it was pitch black and they had there torches and he was really really good, so it's just...now it's all learning and realizing that the way we have to y'know, we did it the right way, we walked out of there thinking well that was y'know that was good, we understood this and we've learnt from this, and this, ok, this is how we have to go about it but it ended up a lovely night, he had a really nice time..where, y'know as I said, in a different situation, and with less understanding, that same case might not have ended up -
46:36	**D:** A bit stressful for him -
46:38	**J:** Yeah and so we just have to look at things in a bit of a different perspective than um y'know how I would've in a different scenario
46:51	**D:** So you started at WEIT and Gene's part of the group circle time, how's he going there I guess in regards the group?
47.06	**J:** Yeah, he's, the group at the beginning he, right up until probably two weeks ago I'd like to say, two or three weeks ago, um he wasn't too, like the first several weeks, um he would like want me to sit next to him and I would sort of, and that was fine though, that was ok so because I would participate and sit down and do what they do as well and that was fine but he liked to know that I was probably I was...there, and so then slowly after the first few weeks were gone I sort of tried to not to sit next to him y'know just maybe one person away, or just from you (indicating distance from interviewer) to me away, just enough to be there but just not be right next to him, and I sort of like would try to sit in front of him opposed to beside him, so we just sort of gradually worked my way around and...he's very observant, like he doesn't like to participa...well, y'know, he's not a child, as soon as you put attention on him, forget it, can't do that don't ever bring attention to him like that, because otherwise he just gets the same thing, now I realize it's just a whole anxiety thing that I think he feels like the whole worlds coming in on him and we've learnt you just don't do that, I mean, praise him in a different way but just, y'know and um, Christine's wonderful like she realizes that too and at the front of the class y'know like she knows, and she's really good as she gets eye contact with him and he watches and he's funny because as much as he didn't participate in those sort of things there, he would sit, oh he was quite happy just to sit there and he would watch Christine and take it all in and when we got home he would sing the songs on the way home in the car, so like he just took everything in, absolutely, he would sing the songs, the whole way home, like I'm like you little rascal, you sit there and sing them in front of everybody, but he wasn't, I mean he didn't, that was fine, but I knew at least he was really observing and it was, more was going in than what met the eye, like he was, yeah and he would come out with all these songs at home, and it's really cute actually, and then the last few weeks, he's actually started to do some things and participate and like you can see probably for a couple of weeks you could tell that he wanted to do, he'd give the odd little pat on his knee and y'know

	and he would, and he's not done, he's done really well over the last couple of weeks actually, he's y'know he's not full on but he is, he's starting to and y'know he'll touch his head and bend down and do his, and he is, he's really, he, and y'know we [Mum + Christine] give each other little eye…and I just, the same thing, if he found that I was sort of (non verbal gesture)...we just carry on and let him do it, and yeah if he thinks that the attention is not on him like that he's um fine, so no, he's really, he's really, he is, it's really beneficial and it's really been very helpful for him that way and he loves music, he really actually relates to it, I believe, um and when we come into the room [for individual MT], I think that's the one thing I like is that he gets a bit of both, like he gets um, that first bit of group, that group learning to deal with a small, a group situation where he's going to have to do things in front of other people and put himself into those situations, but it's just a nice size group that it's not overwhelming for him, 'cos as much as sometimes he doesn't participate, he's not overwhelmed or anything by it, he just takes it all in and he does because he knows all the words, he knows the actions and he'll go home and he'll do the honk honk and the beep beep, and he knows them, and then I like the fact that when he comes into Christine's room, he's full on, xxxx the drums and he's over there getting the drums and y'know he just, he's a whole different child being brought out in a whole different, y'know he just loves coming in here, and the piano, and he knows where the sticks are and he'll go into that drawer and she's got lots of different sticks that are different colours and different patterns but he'll go through them and he'll pick, he knows which two match um and he just loves it, he absolutely loves it, even when he's maybe not having such a good day in the other rooms um, he'll snap when he gets in here and I don't think we've, I mean to be quite honest I don't know whether we've really had a y'know a dreadfully bad day, I mean most days in this the music area are really really good, um it just seems to bring him right out, and he's learnt just the whole method of the teaching of it of the, like um he's not good at waiting, I mean his patience level like if he wants to talk he wants to talk then and there if he wants a, he hasn't really concepted the 'we have to wait and you listen' y'know like that type of thing, like she does it all with music and he doesn't even realize that he's doing it and I truly believe it's helped a great great deal with that um like we'll sit down the three of us and we'll blow on horns, and it will be Christine's turn, then Mummy's turn and then Gene's turn, and the whole concept of him learning the waiting without realizing that he is waiting, and, and he does, and he's done it SO well, like it's just amazing, and you put that same thing into a different situation and I don't think y'know he would, like if we go into OP's [EI teacher] room sometimes y'know she'll get ok we'll do that book next, or no, we're doing that book now, like y'know he's got no concept of it where I believe with the music he looks at it in a whole different, it really just puts at a different angle that they don't realize that it's, how they're learning, and he really is and then we'll get on the drums and it will be mummy's turn, and he sits on the waiting chair, and then Gene has a turn, then I sit on the waiting chair, and it's just this whole teaching him of just every day skills that are brought out by doing that, and he just absolutely loves it
53:30	**D:** How do you find um I guess y'know what you are working on here, how do you find being able to do that at home?
53:39	**J:** Um good, because we just do it like, he definitely loves music, like even

	like with videos and things like that he's not a child that will sit and watch like um….um like a normal video, don't want to say a normal video, like or Beethoven or, like just with a storyline on it you won't get him sitting there watching things like that or cartoons, he's not the sort of child, like it actually has a story line, when you putting it with music on, High Five, Wiggles, or anything like that, and he'll sit there and dance and sing along, so it's definitely, definitely that's what he likes um, any sort of music like that he really enjoys like, we went through a stage whenever we had to leave anywhere um we could be at nana's house or my sisters or someone's friends house, whenever we had to leave he didn't like that but I mean it's the same thing again, I've learnt now too that y'know it's when they explained it out to me that when we say we're going it all of a sudden it's like well his mind, it goes, y'know with this anxiety thing going on and the way it works in that his mind runs a hundred miles an hour and where are we going? How are we going? And all these sort of things and how we have to explain it all out to him but he um would perform basically, lose the plot, basically when it was time to go so we, so now I have CD's in the car and he knows that was our way of almost 'bribing' y'know ok we say goodbye now and when we get to the car you can have the CD on, so we've been listening to Christmas carols since August, (laughing), hey he loves, he gets the High Five Christmas Carols and other ones too now as well, but yeah so he quite happily 'bye bye' and off we get into the car and 'I have my CD on now', and that was our way of trying to, y'know music came in by helping him because he loves it, and he would go out and say goodbye and lose the fact of y'know the other anxiety of leaving into going to wherever, so things like that definitely
56:07	**D:** Can you think of any other sort of ways that you use music at home?
56:11	**J:** Ah when he goes to bed, he always, and has always um he has a Winnie the Pooh thing and um always he goes to sleep with music and even if we are somewhere else y'know like I mean he's quite happy to sleep in a bed anywhere if we're at M's mums or wherever, and he will always ask for music, whether, no matter what sort of music it is, it doesn't have to be pooh bear, but he wants, um whether it be a music box, whether it be another wind up toy, um he always likes to go to bed with music, absolutely, and always has, and he will always ask for it like even in the middle of the night sometimes when we get him up to go to the toilet and when we come back in and even though it's dark and he's still half asleep, if you go to walk out, 'want pooh bear on' like y'know he always asks for music, so it's obviously a comforting thing to him um and a relaxing thing because he, he yeah definitely -
57:15	**D:** And you mentioned before about his sort of levels of anxiety, do you use music in those situations?
57:23	**J:** Yeah like I said the anxiety when we leave, we will definitely do it, and um like um when we try to deter the situation like um when I realize that he's panicked about something, we go and we listen to, Christine has done us a great tape of the birdie song which he actually does wonderfully, and um and so instantly if I say to him well let's go and put a CD on, or a tape on or a video on or wiggles, it's something that, he will, it pretty much snaps him out of it
57:58	**D:** So you're obviously able to use that to just move him on -
58:02	**J:** Yep, yep just straight away yeah, send him into a direction and nine times out of ten it works unless something there's another reason for it and he's tired

	or, but then if he's tired, he'll ask to go to bed and he'll still ask for his music so it's, yeah if you offered him a CD or anything like that he'll just run for it (laughing)
58:24	**D:** And so, what are the sort of signs that you know, how do you know that that's worked, what does he sort of show?
58:30 59:10	**J:** Um oh instantly, it's like Jekyll and Hyde really, like he'll go from um like I wouldn't say, oh yeah sometimes it's throwing a tantrum, I guess, that's how I would explain it, um, crying and he'll go to bite me and I'm always the one that he takes it out onto and I probably because he knows, well he doesn't get away with it with me, but he knows even if someone else has pegged him off, I'm the one that cops it, um and, he's going through a stage lately that he'll, he doesn't bite me but he'll bite my clothes, when I say that he doesn't go like, he won't bite um like he wouldn't go bite my arm, but he would grab my top with his teeth and you can tell it's just a sheer uuhhh (big inward breath), and he does it, like he doesn't just come along generally he does it when he's in a situation when things have got him too overwhelmed, and I've learnt that as well 'cos when he first started I thought oh not you like we won't have any part of that, and it does and do, the whole picture starts falling into place and he does, it's definitely in an overwhelming situation where it's just… he gets um…. beside himself and he will, he'll go to get my clothes and he'll bite them or um he'll hit me and he'll swear, and he knows there's certain words that, he knows, and he has a couple of favourites, and he'll just say it to me and I y'know go through act normally stage and like 'but I said that' he'll say to me, like y'know and I'll say 'oh that's alright, that's fine,' like y'know like 'cos we went through the punishment stage put him in his room, or put him on the stairs and none of that worked, none of it! Absolutely none of it works! And um y'know I was about hitting my head against…. and he knew it was getting a reaction, he knew that he didn't really want to say it, he knew instantly and that whole uhh (breathing in) situation that it was going to get me, get the attention that he was seeking basically and um as I said we tried everything, so now, instantly I'll turn him around. So he'll go from that sort of child to um if I just say, come on let's go and do this and put a CD on and put your Wiggles on, and within y'know 'oh I get it I get it' [inferring Gene's thought] instantly sort of turn flips (clicking fingers) just like that, yep yep yep
1:01:05	**D:** And when the music's playing does he -
1:01:07	**J:** Um no he'll, yeh he just like for example if I put a video on, um he'll just sit or stand in front of the TV and he'll dance and sing and I mean, he's just as happy like y'know you would never have known that two minutes earlier that he was doing what he did but I had to laugh tonight actually because he, we're just having a new kitchen put in the house, in our house, and the old one and everything else out of the kitchen is in our main lounge, and all the old cupboards and everything, I mean everything has just been put in there until it's just all sorted, until the new kitchen's all put in so we can sort it out, and so the drawers and everything and our CD rack is (chuckling) actually in the corner and like all the old cupboards with everything still in them because the other ones are put in this weekend, it's just all around, so it's like a jungle gym in there and I thought to myself tonight, he's, or today, he's awfully quiet, and I thought he's y'know it's not often that happens, so I go looking for him and well he had climbed over all these obstacles and I don't how he did because it was a heck of a job and he had got right to the corner, to the CD rack, and here

	he was going through all the CD's looking for his CD's. So like, he'd made, I mean, if you told me five minutes earlier that he would have got over there I would have said 'no way in hell he could have got over there, because of what he had, there was the benches there was everything and he got over there...and he was over, in the CD rack just with all the CD and y'know he loves just even hold them like just y'know, yeah yeah so he's yeah, you could put him that situation and it just abso, instantly like, as I said it's not sort of a like a five or ten minute calm down period, it will change him.
1:02:55	**D:** Right….wow
	J: Absolutely
1:03:02	**D:** So I guess coming from, now that you've been at WEIT for ten weeks or so, how do you think that's changed your interactions, or your relationship with Gene?
1:03:11	**J:** Um, good actually, because I believe it, I mean, we have a better understanding of what his needs are, um, why he's like the way he is, um and how to deal with it, um which, y'know I think we've learnt as much from this as what Gene's learnt….absolutely, like it's definitely not just been a Gene thing as such, I think the whole family has learnt from them and how to go about things in a different way of teaching him, um understanding him, just yeah,…it's been, it's been a huge learning curve and I don't know how I would ever have managed without it, looking back now, I wouldn't even want to think about life without this place…I mean it's really made a huge huge difference in our lives, no doubt about it, and even for me, I'm just, as well as, yeah for both, for all of us but for child and parent, um I always thought that I always consider myself, I like to think a good parent like y'know, um but just understanding things sometimes and looking, and just doing things in a different way that I would never have known how to do before
1:04:36	**D:** Or thought about -
1:04:38	**J:** Or thought about doing um, going back to y'know just doing, the whole learning perspective in such a basic way that's right under you that you just don't realize because you take for granted, um and it's oh it's just been huge, a huge, huge thing for all of us, absolutely
1:05:01	**D:** I was going to ask you too, how do you feel about, y'know, you in this, in the individual sessions, how do you sort of feel about being part of that as well as sort of your input in the group circle time?
1:05:14	**J:** It's good 'cos like I said, I think that I get a lot out it, as well as Gene does, um, the way of teaching him, um showing him and just getting across to him and um everything. I think it's as beneficial for me as, as for him, absolutely.
1:05:41	**D:** And so do you remember how you felt about those sort of first couple of sessions in the individual ones with Christine in the early days?
1:05:41	**J:** I've, yeah, I did, I never ever um…. I never ever sat here and thought oh my god what am I doing? Well y'know like sometimes you think (breathing in and chuckling) uh God, I never ever, like, from the word go that was something that I never ever felt like I um she's so outgoing and she's got such a wonderful personality um she's just y'know she gets in there, she just sings I mean it's like… she's…nothing else matters if you know what I mean, um at first all I could think was wow, I wish I was that, y'know I mean I can't sing to save myself so that it's she can, but y'know I just sort of thought wow it was just second nature to her, and that's what I felt, it was just so natural, you know what I mean like she wasn't, you didn't walk in here and think she had picked

	up a book and was like ok today I have to teach from this page or, it was just such a um….yeah it just from, basically from her heart, from her heart and just a whole, and I think that's what blew me over so much, you know what I mean, like a lot of teachers can come across and you, a lot of people can teach anything but they can't teach in a way that it gets across and she does, and that's what I find very special about her, is that is not a um, yeah, it's just a whole… gifted, she's a very gifted person, and she shows that with everything she does
1:07:33	**D:** So you feel comfortable with the singing and partaking?
1:07:37	**J:** Yeah and they have to put up with me (laughing) but yeah I do, and I mean yeah, when I first walked I mean it's not like I didn't feel uncomfortable, but like there were songs I didn't know, actions you didn't know, so you have to sit there, and, and you do, and they do it in such a neat way that they are catchy and as I said, we find ourselves going home singing these songs, 'cos they do, you just get them in your head and you sing them so everything's fun and it's a real um, yeah the kids take onto them, well I say that speaking of Gene, Gene certainly did, so, you do, each week you learn a bit more, and you start to learn the actions and Christine had made us tapes up and written out the words and so y'know we'd go home and y'know we'd put the tape on, which was the music side of it, and we'd all sing and y'know and that was really really helpful too, so now, yeah, so now I'd like to say I know, well enough that to get me by (laughing) on most them.
1:08:38	**D:** Does M, has M told you sort of how he felt about coming into the individual sessions or the group time?
1:08:45	**J:** Yeah, he pretty much feels like I do, um as I said, the beginning I think he probably struggled a bit more but whether that's just a whole male thing um reality of the whole thing and um, but he was always, always felt it was very positive, but it was just a whole adjustment thing for… I think males, I don't know, I don't know if males do find it, maybe they do find it harder than females, but no I mean, I don't know how he does 'cos we're never here together, but I have spoken to Sara and she says that he does wonderfully now, like, and like y'know of course they notice it in the first few times, but like they say it's like most y'know parents that come in and realize there's so much to take in the first time, there's not only the reality of meeting new people and learning their way, it's the reality of realizing that's something's not, y'know, something that your child is needing so I think it's a very mixed emotions but as I say I couldn't find better people to deal that with, and help us accept and get on with that and, and teach us than that than they are here, I mean, as I said I just couldn't say more of them, and I'll start crying again……..they are, I mean yeah, it is, that side of it, that side of it was, when you have so much going on, and to deal with, that was something we never had to deal with as such, y'know, and I mean I guess and it's hard for them too they have new people coming in, new children, new parents, um I guess y'know you don't stop and think it's equally hard for them, they probably sit there sometimes and do these things in front of ..y'know, of them, so but they do and as I said it is such a natural way that's how I would describe her in that way, it's just not forced…
1:10:51	**D:** Is there anything you would like to have done differently, or is there anything you would like to have as part of the sort of therapy you receive at WEIT?

1:11:03	**J:** There's not really, um, I really like the way the group session for that first part in the afternoon, then I think it's great they go individually and then I think it's great they finish off that way [with group MT]. Honestly, I can honestly say there's probably nothing that I would change in that way, I mean, I say that from my child's point of view and I think it's great for him to be in that group thing, but I also think that if he was in the group ALL the time, he may not benefit the same, because he's not, at the moment, such a group child, but he's learning, and he's definitely come along so it's the best of both worlds for us, he's learning that, and benefiting, and he is, and you can see him each week and I, I get excited when I come here now 'cos I just to see how he's going to react on that particular mat day, um but then he does very well like one-on -one, he definitely likes that too, so for Gene, I wouldn't change a thing, I think that it works very very well, um, in that way
1:12:11	**D:** You have obviously friends and relatives that you obviously talk about what you do with Gene
1:12:17	**J:** Yeah absolutely
1:12:18	**D:** How do you talk about Gene in WEIT, how do you sort of -
1:12:22	**J:** Um, we're very very open, and I think that's half, ah for me personally, or us, that's a huge part of our dealing with Gene is that it's a very open spoken about thing, 'cos as much as we, and we talk to our friends a lot about it, and mind you they can see the change anyway, so they find it amazing because they're actually without as much being here they are seeing how much he's coming along um because I believe that if that what they are told and understand, that's, that's helping Gene in itself
1:13:00	**D:** Yes, definitely
1:13:01	**J:** 'Cos it's…when people understand something they have, and it's like us, y'know when we are understanding and you realize what's going on, people look at things in a different way, and they have a different understanding about things opposed to just thinking, 'oh look at him, why is he doing that' y'know, and people do think like that but then some, when people don't understand, or don't realize like even sometimes in the supermarket if he decides to stack an act [tantrum] in the supermarket, um, y'know people look and, but when people do realize, um and like everybody knows we come here on Friday and we call it 'Sara's house', or early… he actually does call it early intervention now, but for the longest time he always considered this Sara's house and um yeah, he talks about it too with them, like 'I go Sara's house today', and y'know, so he's very open with it as well, um, but no, we do, we talk, and they're really interested, y'know like what we do, and how the system works, and, they're very supportive, and, I think that's what friends and family are all about anyway, but ours are and so they show as much interest by discussing y'know how we're go about and we do music, and we do y'know fine skills and y'know, and the group sessions, and like we discuss and they 'ah wow, he just, he wasn't doing that x amount of weeks ago or just his conversation, speeches, and things like that just everything, speaking is just um… so they can see the um the rewards -
1:14:44	**D:** Which must be really nice for you as a parent to hear parents saying 'wow, Gene's doing this now' or -
1:14:52	**J:** Yeah, and I mean I can… comfortably in myself too….I can sit back and think…. feel comfortable with what I'm doing for my son, and I think that's really important, for me it is, is that, ok, um with fragile X I guess too, y'know,

	I sort of think it would have been nice to have found out earlier, and been on top of this earlier, but then I think, y'know I fought for this and over the last year we've had OP and OP [at child therapy clinic] and with WEIT, so I thought a lot of it's not been wasted, y'know like I have, y'know then I think well we're a lot luckier than a lot of people 'cos a lot of people don't realize about this until school, y'know like 6, 7, 8, time age when they're struggling and um, but I sit back now and, I had this discussion with a friend last week actually, and she said to me, but you got to be lucky she said because you've done all these things and he's had all this help, he's got an ESW in kindy, you've fought for all this and, and had this, she said he's a lucky little boy really, she said because you've done, y'know he's got a lot more than what a lot of people might have just brushed it off and sort of thought oh, just y'know, a boy or just y'know slower or whatever, she said, but… in myself I'm comfortable with that now that I have got good, the best help that I think y'know, at the moment what he needs and what he's getting with what they've done here for us organizing his ESW, putting him into kindy, um the first term we were there, he started right at the beginning of the year – he probably struggled a bit socially um he sat on the corner, he didn't deal with mat time at all which now I understand why, um, he yeah, so y'know at the time I didn't, I
1:16:59	thought oh no why…y'know I'd drive to kindy just cringing because I knew as soon I walked in there he would um at that time I would have thought stack an act, um, y'know he'd just not lose it but just y'know I never knew what sort of reaction I was going to get whether he was going to come up and bite at my clothes or whether he was going y'know do what as much as we talked about it with him that y'know you have to sit on the mat 'til the kindy teacher says 'it's time to go now, y'know, ten weeks and it never happened, I mean it just every day, and I would just drive to kindy about in tears thinking (breathing in) y'know and I would go at the beginning at mat time thinking at least I don't have to have all these parents looking at me thinking god, you know like, I sort of thought oh maybe I'm doing something wrong and you start doubting yourself and you're thinking what am I doing that could be different, so we went through the coming early and then they started, and then we came here and Sara got an ESW in there with him which was OP for the first term and things just started changing, and now with OP there, now I go there and like before as I said if this is the mat (using table to demonstrate) and the teacher's down there, he would be on his own just literally right in this corner, the closest point to where I walk in that door, where now he's right up in the middle of the kids um and waits and when I walk in he just, y'know, from this transition he got a little bit closer and then I'd go to walk in the door and he's go to stand up and he knew he had to wait and you can tell it was such a huge thing for him, like this was, I mean what other parents just walk in and you just
1:18:41	for granted that your child just sits there and waits and that's…y'know you could see him and he wanted to get up where now he just sits there and he just looks at the teacher and he'll look at me and if she's reading a book or something he'll wait for the book to be finished and now I mean I love it – it's just what having an ESW that they've organized for me has done for him is just amazing – like it's fun now and I go there excited and can sort of talk and um y'know he'll wait and it's just oh he's just a transformed child when it comes to that and they've taught him all that by having um by putting someone in with him and realizing that I mean which is a huge, huge step for him

1:19:32	**D:** It's really good that you've yeah that you're seeing the progress
1:19:37	**J:** Oh, absolutely, and that's, I think that's what's kept it all going really, and there has been and, I guess I look over a short amount of time too and the progress, it's…it has been quite remarkable, it really has been, and I think that's, that's why we are probably on such y'know that high and xxxx xxxx xxxx norm because there really is rewards for what's been xxxx the rewards are really, y'know -
1:20:09	**D:** But obviously you as parents are putting in, y'know, you're obviously doing the hard work at home as well to -
1:20:15	**J:** Yeah but as I said I think that's what we've got out of here too is just the whole, a whole different approach and outlook and way that I'd like to think y'know I find myself thinking two or three steps ahead of myself all the time where, I, by the time I probably not realizing but just I wasn't programmed to think like that and I, and you don't because it's just not what you do xxxx, having these explained to you and taught to you um, yeah I definitely believe my outlook is, y'know I find myself just um y'know prepping him a day or two ahead of times and just working through so it's, I've definitely learnt a great deal in that way
1:21:14	**D:** Yeah, that's great, it's what early intervention' all about really
1:21:19	**J:** Yeah it is and it's just incredible how it has helped us, um with that, and yeah as I said they're just amazing they really are, an exceptional group of people, and absolutely just dedicated to what they do, and to me that's quite amazing to find y'know to come here to one house and go into different rooms and find that sort of quality of people, dedicated um people in one house, it's just -
1:21:56	**D:** It's great that you've got that really good supporting feel that you're getting what you need for Gene
1:22:03	**J:** Absolutely, absolutely, in every area and I really couldn't say this should different or that should be different…that's… from my heart I really could not say I would change any part of it
1:22:22	**D:** Um is there anything that you'd like to just add at this stage, is there anything else that you'd like to say that you feel we haven't, I haven't asked you, or we haven't covered?
1:22:37	**J:** Um…don't think so...
1:22:40	**D:** I guess the other thing is, how do you think, how do you feel on reflection, has this interview been different from our last one?
1:22:47	**J:** Um I thought it would be harder…like when...I guess when we did the first one it was probably just a week out of me finding out about Gene, so I was probably in a bit more…when I say that as I cried tonight, I didn't really think I was going to cry tonight ...emotional, but um and I sort of thought y'know so I guess, and you didn't know a lot about Gene, so I guess it was quite easy to sit here or sit there and tell you about a child who you didn't know anything about so when I found out that it hadn't worked, I was ...not worried, but I sort of thought….ohhh…how do you sit, to say it all over again which you had already once, that how could I do it but I actually haven't found it that hard, I haven't shut up really since (laughing), but…no…I was more worried that…I wanted to…um I wanted it to come from my heart and I wanted it to be… how I really felt, and I sort of thought, I hope that that does come across because that is really how I feel, um…and with the first one I think that to me I felt that that did come out that way and then, so that was my only concern about doing

	it again was just that fact that I wanted, but I actually haven't found it a problem (laughing) so I hope it came across alright too because I really, once I started talking I actually y'know, as much as you've heard it before, I…I really -
1:24:23	**D:** But even though you say I've heard it before you always get different -
1:24:27	**J:** You come across….yeah…you get a whole different….all over again
1:24:32	**D:** I certainly don't think I've listened to…to the same -
1:24:35	**J:** I sort of thought – here I am telling you the same story all over again but, um so that was the only thing that worried me that I didn't wanted it to be, I wanted it to be from my heart and that's how I felt that it should've been and that was my only concern, but as I said, well naturally, I felt yeah it's gone really well again, I mean, I 'm quite happy with the way it's gone this time as well, um as you say it's probably just got a slightly different angle, but it's just yeah yeah, so I've talked your ear off for the last hour (laughing)
1:25:10	**D:** No no, that's cool (laughing). No it's just nice hearing your stories
1:25:21	**J:** It certainly um, it makes you appreciate life in a different way and not take things for granted, and um I guess sometimes having a child that um…is more special needs, or does have a developmental delay um, the rewards can be as great as sometimes the effort that goes into them which I think is, y'know, it's quite special in it's own way as well...but no, he's a wonderful child and he's a great little boy
1:26:02	**D:** He sounds a wonderful -
1:26:04	**J:** He is and as much as some days you think oh y'know, whoa, it was a tough day, y'know you hop into bed and y'know and you think hey life could be a whole lot worse, there's people worse off than us out there, and y'know, even though he might have been a little monster for the last two hours before you put him to bed and y'know he'll hop into bed and then you'll walk out the door and he'll say to you 'I love you mummy' and y'know you just walk out and all that just disappears y'know, he'll always come up with something, or he'll come along and smooch and or something, and hey that's, we've got a heap of challenges and this is just another one really and y'know…I see light at the end of the tunnel, and I think …now we're onto it and we know and we're there to, y'know -
1:26:25	**D:** Make a difference
1:26:58	**J:** Yeah absolutely, I know we'll get there, it's just um the xxxx xxxx xxxx but I have no doubt that things will be fine, but it just, it's going to be one of those y'know that just needs a little bit more than… but half the battle is knowing, and that's…. a huge thing….for everybody
1:27:30	**D:** Yeah, ok well we might finish the interview there, and thankyou for coming in
1:27:34	**J:** Thankyou
1:27:35	End of interview

Appendix 8: Transcript #4[12]

Interview #4: Eva (E), primary caregiver to Pippa (P)

Interviewer = D
Manager of WEIT = Sara
All other people = OP

Date:	Wednesday 5 November 2003
Time:	11.30 am
Venue:	music therapy room at WEIT

Situation with participant at time of interview: Out of 13 sessions Eva had been present for 10 sessions, Pippa's father for three. Marriage separation was taking a turn for the worse with Eva informing us a week prior to the interview that she intended to move, with their two children, out of the area, to a place where she had close extended family connections. Pippa's father was not at all happy.
Eva arrived for the interview, cell phone in hand, requesting she answer it if it rang during the interview; she was in the middle of selling her house. It did ring as the interview was about to begin. It did not ring during the interview.

Transcription of Interview

:00	**D:** Thanks Eva for coming in -
	E: That's alright
	D: And helping Christine with her thesis. Um I guess it's always good to start with just a um an introduction about Pippa
	E: Yep
	D: That would be really good to just hear about her, I guess, story if you like, from when she was a baby through to the present
:18	**E:** OK, um, Pippa, I mean like I um I can even say like she was, I was induced at thirty eight weeks with Pippa and um they thought that she was going to be a very small baby and um there was a lack of fluid around her, I didn't seem to be replacing the fluid around her, so they thought that an induction would be the right way to go…um a pretty straight forward birth, um when she came out she did have to be suctioned, and she did go into a special care unit for two nights at Hutt Hospital, because they felt that she had a lot of um…that stuff um that had to be suctioned out and had to be cleared and um she was drying up and she wasn't feeding, so um, yeah so she came into the world with a bang (chuckling) and um… then…she was never an easy baby, she screamed a lot…um, she was reflux, she never slept, um what else about Pippa… and at 11 months she got whooping cough, even though she was immunized, she got whooping cough, there was a little mini epidemic happening in Eastbourne, I don't know if you remember that, that was quite bad, and so she got whooping cough, and then she

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[12] Following Poland's (2003, p. 279) approach, the following symbols are used in this transcript:
"xxxx xxxx" denotes words or passages that cannot be deciphered
CAPITALS denote strong emphasis
"-" indicates speech has been interrupted
References to "the Trust" are to be interpreted as references to WEIT

1:51 2:43	needed grommets when she was a baby as well, and um, she still continued to scream and not sleep, and um, I always felt there was something not quite right, I just got a feeling with Pippa that there was something going on, she sat late, she crawled late, she walked late, um it wasn't until she was about two that I really noticed that she wasn't talking and I would um raise this with people and they would say, no just wait, and wait, and um...rang up the Barnardos [pre-school daycare] centre and they, they decided to call in um special education to get her assessed and yeah she was about a year-and-a-half behind, and then we went to see OP [pediatrician] this year, March of this year and she was diagnosed with um autism, at the mild end of the spectrum...um, yeah and also I suppose another thing to note, um her father and I separated when she was two-and-a-half, so, I think she's had y'know kind of a rough start to her life, it's been sort of full on, and Pippa...where Pippa is at now, yeah, I'd say she behaves like a mildly autistic child, um, the most noticeable thing about her is her speech and her meltdowns, yeah...yeah
3:14	**D:** So you mention, so...being such a difficult baby how did you, your relationship with Pippa, how do you think that -
3:24	**E:** Um, well it's quite funny because I bonded immediately with Pippa and I didn't really bond with my first child and also I um I suffered post natal depression with both my children, not as severely second time because um mental maternity health were sort of on my case, yeah I was monitored. Um...it was very stressful yeah, and I think um with what was going on around her as well with um the marriage not being so great as well it was probably not a great environment for her to be in
3:57	**D:** And now, now that she's older and -
3:59	**E:** And now that's she's older and it's um y'know she's four-and-a-half so it's been y'know two-and-a-half years that we've been separated but things still aren't great. I really still don't believe that um she's in a great environment um for her disability... and we, I am planning on moving down south at the end of this year, so, which will take her away from her father, but I think it's going to give her that stability and that routine that um that she really needs and -
4:32	**D:** And so, obviously she's got um, a sibling?
4:35	**E:** She's got an older brother [R] who is eight-and-a-half
4:40	**D:** And what sort of relationship do they have?
4:47 4:56	**E:** Um...R struggles with her, um...um, she adores him, but won't let him near her or do anything for her. I, it's, it's me basically, I'm sort of like her world really, um...yeah but no, they do, they love each other but they, I think they behave like normal siblings to be honest (laughing) -
5:08	**D:** (laughing) xxxx xxxx typical moments
5:13	**E:** Yeah, R will say I don't want an autistic sister, and I say well she might not have wanted a big brother so (laughing) y'know, he does struggle with it, but um, I do have, um y'know look I've got a lock on his door, and so he's allowed to have Pippa-free time, and I don't feel that I want to put them in the same school because that will put a lot of pressure on him, he needs to be away from her, she's hard work, he needs to be away from her
5:40	**D:** Right, yeah, yeah, and it's obviously good that you've, that you've thought that through and that's what you feel's right for -
5:47	**E:** Oh absolutely -
5:48	**D:** For Pippa. So you mentioned you had a diagnosis in March, how did you feel about that?

5:57 6:11	**E:** Relieved…yeah, but um, it took a year to get there, um, y'know there's all those other issues going on being separated, and I kept on saying to my ex that there's something not quite right here, and it was just, and I didn't feel like I was being listened to, um y'know people would say she will catch up but I just new she was getting further and further away from the mark and um, the y'know the screaming, the meltdowns, yeah, as she got older it was becoming apparent that there was something up with her…relieved…um very sad, a bit of grieving, xxxx xxxx a bit of acceptance, um…but having, I grew up with a um ah my cousin who's quite, severely Asperger's, so um, sort of xxxx -
6:49	**D:** xxxx an understanding of, yeah -
6:51	**E:** Yeah, and how their world works, and, xxxx, um yeah… but relieved, and then just decided that, ok, well what can we do? yeah
7:02	**D:** So then you….how did you find out about the Trust?
7:06	**E:** How did I find out?….um… how did I find out about the Trust? I think I remember just receiving all this information and I think there was a brochure in there about the Trust and just ringing around and um, getting hold of Sara [manager of WEIT], and speaking to Sara about it, and -
7:24	**D:** So did you look at just the Trust or did you look at other options that -
	E: Special education, um…..yeah, no, yeah, we, um registered with Autism New Zealand, they gave you a lot of help about what was um, the help that I was entitled to… but just didn't really know what to do and that was why it was so great um striking someone like OP and she just said y'know basically blah blah blah, and um, then I, I went on the waiting list but um, it was great because I rang OP and said look, I'm on my own, I'm really starting to struggle here, things are really starting to feel like I'm getting out of control, so they got me in here as, as soon as they could, which was fantastic
8:12	**D:** That's great, so you've been here roughly attending 10/12 weeks? sessions?
8:19	**E:** I think so (laughing)
8:22	**D:** How did you, how did you find y'know coming in for those first couple -
8:26	**E:** Completely overwhelmed. I, I remember sitting here thinking, they probably think I'm nuts… I couldn't even speak… completely and totally overwhelmed, y'know, and Pippa was completely and totally overwhelmed as well. I remember just sitting in the corner and someone just handing me a cup of coffee and going 'it's going to be all right, it's like this for the first time for everybody' and I was thinking…and part of me was like that fight or flight response, I just wanted to run and then I thought 'no I have to stay', and um it was terr, honestly it was terrible the first session it was just horrible and I made Pippa stay right to the end, she was like holding on to my leg like begging me to go home, and I said no no, we have to stay, and just exhausting, but …I knew it was good….yeah it was just a, just a bit of a shock, and to see um other parents and other children in a similar situation, it was good in knowing that she could come here and behave as badly as she wanted to (laughing) and nobody even looks sideways
9:41	**D:** And so, obviously, um how did you find the group music time because that's, that's how they start the session, how did you find that?
9:49	**E:** Yeah, like Pippa loves her music, she really responds well to music, um she still, when we're there she still clings to me, um but I know that she loves it, she's always got like one eye out there sort of like, oo oo what's going on, and um, yeah I, I enjoy it, I think it's um I think music is great for Pippa
10:13	**D:** And obviously, how, what's she like in the individual sessions with

	Christine?
10:17	**E:** Um, she can start off quite resistant but then towards the end she's definitely leading the session, we definitely follow her, yeah
10:27	**D:** And how do you feel about sort of participating or -
10:32 11:09	**E:** Yeah good, good yeah, yeah I um, especially what I notice with Christine is that, um…Christine can pick up and put her finger on where, where Pippa is at very quickly and, and like she'll just say to me something like (lowered voice) 'we'll go non verbal, just go non verbal', and even by just by her, I've actually learnt a lot from that and I've, I've been passing that on to um like my parents and when Pippa is going "(paddy sound)", and they will be going 'what do you want?' and I will say 'just non verbal, just don't speak to her, just leave her alone, and things like that and, and I would only receive that information from participating and seeing how it works, and yeah
11:17	**D:** So how do you find what you sort of see here, how do you find then taking that and y'know using it at home, in the home environment?
11:28 12:00	**E:** Um…yeah sometimes I fi..sometimes I feel it's t..it's too much sometimes, too much with the, they see all therapists, they do the rotation, um sometimes I feel it's just a little bit too overwhelming for Pippa, that she feels the expectation and seems to react to it, but she loves coming here and she loves it, she loves it xxxx xxxx she's this real xxxx I'm here and (making excited sound), um, yeah I have taken a lot of stuff home but the biggest response that I see in Pippa is in here [music therapy room for individual session] and um with OP [SLT] on the computer with her, and in here I see Pippa display and recognize things like um fast and slow, and soft and loud and stuff like that and Christine does like (lowering voice) quietly and she'll try and say to Pippa now quietly and she recognizes that, and softly and yeah
12:33	**D:** And you mentioned before about her meltdowns, how do you, how do you manage those with her?
12:40	**E:** (coughs) how I manage them…here I am to tell…um...how I manage it, depending what (breathing out) -
12:51	**D:** Like are there any particular triggers that you've noticed –
12:54	**E:** Some, sometimes it, when there hasn't been enough information given to her, um and then I…but once she's gone into a meltdown, she gets quite xxxx, there's no coming back so a lot of times actually I just let her go, let her um scream it out and all the, if, if she's in the right frame of mind I can just grab hold of her and hold her tight and calm her down and say quietly (lowers voice) it's ok it's ok, yeah, and at other times I can't even get near her so I just actually let her thrash it out, yeah
13:27	**D:** Yeah yeah, just let her work through it, yeah, do you find, have you tried like, does mu, y'know have you tried music at, with those particular times or -
13:36	**E:** Um sometimes I wouldn't have access to it yeah… and she goes to sleep with um y'know the old music box with the ballerina -
	D: Oh yes
13:45	**E:** Yep she goes to sleep with that, and she loves her music, everyday we do dancing, everyday at home, she'll just grab me 'dancing Mum' -
13:55	**D:** Yeah, so is that, do you put, is that just you singing to her or do you -
13:58	**E:** Oh no we put on music and dance, yeah we dance around -
14:02	**D:** So music is yeah definitely a daily -
14:07	**E:** Oh yeah, absolutely, yeah…

14:12	**D:** Um….So I guess yeah other good things I guess would be to just sort of know from your perspective obviously before WEIT and now that you've started at WEIT, do you feel your relationship has changed again with Pippa -
14:30	**E:** Yep
14:30	**D:** Because of the sort of y'know skills I guess that you've picked up -
14:34	**E:** Yep, her tolerance level is, is much better, um yeah -
14:40	**D:** Right, tolerance, do you mean tolerance to sound?
14:44	**E:** Tolerance to -
14:45	**D:** Direction -
14:46 15:01 15:16	**E:** Anything just her general level of tolerance, y'know like things with um y'know 'one more and then it's finished' and things like that, her acceptance of things and, and learning that um, as you go along you do, you sort of pick up things that you've heard or talked about here it sort of comes to you….but um yeah, yeah I find her a lot easier to manage… I, I mean I'll be honest I still find coming here hard work, and um y'know sometimes I just do not feel like coming here and I know it's good but it is hard work, y'know…and sometimes I just would like to xxxx out the door and say 'xxxx not today, bye', yeah
15:35	**D:** And you're coming every week aren't you?
15:37	**E:** Um yeah and my ex husband comes every third
15:45	**D:** Ok, so you get a break for that -
15:47	**E:** I actually don't think it's a good thing to be honest, I don't, I think just yeah keeping it even and consistent is, is far better, um but um I'm not going to stop him from coming, it's his right, mm
16:02	**D:** Yeah and do you think…how's Pippa with that and say you're coming and then Dad comes, does she -
16:08	**E:** Oh no he'll just come with her, so I don't know, don't know, got no idea
16:16	**D:** And does he feedback to you -
16:18	**E:** No
16:19	**D:** No ok…….um, what else… we've talked about circle time, individual music time with Pippa, with the circle time now, have you noticed, obviously those first few sessions you mentioned she sort of y'know observed out of one eye, what's she like now sort of that 10, 12 weeks on
16:47 17:08	**E:** (coughs) She still um like when we do um dancing around I still have to carry her around, and she still won't sit beside me, she still has to sit on me, and we do like with the sticks, y'know she's right there in front of me and we're doing our things with the sticks and she, she will join in now, she'll do the odd one and then sort of like pull back, but she's, I, when, I think… she is participating but on her own level, yeah, so she's definitely with the group and like some weeks she'll just get down and hold onto the piece of lycra fine, and do the rainbow ring fine, other weeks no
17:25	**D:** Right, yeah, and have you, what's she like when you, do you sing any of the songs at home, what's she like when you do that at home, I guess just being in a different sort of, the environment's different -
17:42	**E:** Some days she'll go 'nooo' (in protesting voice) 'cos it's out of context, um but she loves that train song that they do here, and we do that at home, she'll set up the chairs and she's in the lead, and we have music on, so she, I have to follow and even when the song stops and you have to walk around I have to do what she's doing so, so she's got the whole concept of, but she wouldn't do it here last time, just wouldn't do it, but just sat and watched everybody do it

18:08	**D:** Right, oh it's good that's she's y'know doing that at home though, um…I guess the other thing is y'know when you're out in the community and I guess family friends, do you talk about, do they ask you lots of questions, about Pippa?
18:26	**E:** Ah, yep, yep
18:28	**D:** And do you, I guess, y'know talking about your week, and talking about the Trust, how do you sort of talk to them about what you, 'cos I'm sure they ask you what's it about?
18:39	**E:** Yeah they do, they know that, that I find it hard going, um and they go 'how was, y'know, how was WEIT this week?' and I go 'ohh' ('exhausting' chuckle], but y'know… without meaning to sound negative about it y'know it's all good because they can see changes happening, they do, y'know they do ask about y'know the different um therapists that she sees and what happens, and yeah, but yeah they know that um Thursday mornings is like 'ohh' (exhausted chuckle), by Thursday afternoon I'm pretty sort of shattered
19:17	**D:** And how do you handle when they ask questions about Pippa, do you find -
19:23	**E:** Just fine, yeah, just be direct and, I actually prefer people to ask questions, yeah
19:31	**D:** And what about her older brother, does he get questions asked of him?
19:37	**E:** Um yeah, um 'cos other kids can laugh 'cos she's funny, because what they think she's doing is funny and they laugh at her, he doesn't like that, he gets very protective and then he'll say, 'she's only doing that because she's autistic y'know' and things like that, so he knows about autism as much as we can tell him, and as much as he can understand
20:02	**D:** So you say you find he's got some phrases that he sort of he tends to use to answer?
20:10	**E:** Yeah, he'll just say 'my sister's autistic' and um it's quite funny, he'll do it to strangers and I love watching their reaction, and I just don't step in, I just go, and they go, 'well that's nice' (laughing), 'my sister Pippa, she's autistic', (laughing) yeah
20:34	**D:** And what support do you have as a family at the moment, obviously apart from the Trust, you mentioned the Autism Association?
20:45	**E:** I just get information from them, um Pippa goes to Barnados Centre in Petone, for three school days, because we've worked with a lot of um care, three days is the minimum, that's what works for us, any less doesn't work, any more does work, she could do more, but I like to, well I have to have her for Thursday morning, and I would like to have her for a day at home with her as well, um and um also getting respite through um…oh…what's the name of it, it's just changed -
21:24	**D:** Oh is it what used to be Access Management?
21:27	**E:** Yeah, is it Life, Life? -
21:29	**D:** Yeah, they've changed the name of it -
21:30	**E:** Yeah, they've given me a few days per year, um and that is up to me how I use that
21:38	**D:** And, and you do use that -
21:40	**E:** I do use it and y'know things like if I want to do something um y'know because I also have to be very careful who I get to look after Pippa, and I can pay people to do that, because I have this available to do that which is good, mmm, and what else um, no immediate family round me really, um good, good group of friends in Eastbourne that know Pippa, y'know, have known her since she was

	born, um but my parents both live in Te Horo and they both work so, yeah…it's pretty much yeah…that
22:25	**D:** Right…..ok…um … I guess um in thinking about y'know just the group music sessions and the um individual sessions is there anything that you would like to see differently or anything changed or is there anything in particular that you really love or in regards to how the music therapy sort of delivered or -
23:02	**E:** Um…no, I'm quite happy with the way it is, I mean they all love the um, when we, the goodbye that we have in the circle again, we all love that, um..no… I mean it's like Pippa is normally quite tough when she comes in but Christine always manages, by the end of the session it, every session's always ended well, yeah, so I'm really happy with the way things are going, like I say Christine just takes her lead off from Pippa to see where she's at, and she does that so well as well, which is what I really enjoy about her is that y'know she, she picks where Pippa is at and just goes right xxxx
23:49	**D:** Yep yep, and does Pippa cope ok with the length of session?
23:53	**E:** Yeah, she never quite, I think it's the expectation she doesn't cope with -
23:58	**D:** Right, yeah..that feeling of -
24:00	**E:** Yeah, but, she's happy to be here but she'll go into one room and it's just like oh now I've got to go and oh so oh, something else is expected of me, that's what makes her um flip out yeah….even though she enjoys every room, it's a yeah a feeling of something is, somebody wants something out of her, yeah, mmm
24:26	**D:** It must be quite tiring for you when she does flip out, just -
24:29	**E:** Oh yeah -
24:29	**D:** Going through with the strategies of what, how you're going to manage that -
24:33	**E:** Oh yeah, I had one, because we've just been down south on the ferry and um y'know she's been on the ferry since she was tiny, but yeah, she coped really really well…just gave her heaps and heaps of information in
24:45	**D:** I was going to say how did you prepare -
24:47	**E:** Yeah just talked about it like 'til it got really boring like just talked and talked and talked about it and um but we did have one incident on the boat in um in the kiddies area and she was lying down and she was kicking this little boy and she didn't mean to kick him, it's just that y'know with autistic children sometimes their limbs and that go everywhere, and um I tried to go over and sort it out and the, the child's father was there and he was trying to sort it out and, and at that point I didn't feel like saying, oh you know she's autistic, and it was not until Pippa gave the child one last whack with her arm that he picked his boy up and said (clapping hands) Um 'we're out of here, we don't have to be around people like this', and that's when I stepped in and said 'look um, she doesn't understand, she doesn't mean…she's, she's autistic', and I hated doing that, and then Pippa had a humongous meltdown, just…just oh it was horrible, um because she could feel like some tension, and she knew that it was centred around her so she really went into one so I just picked her up, put her under my arm and I just took her into the children's toilet and just put her down on the floor and just, I just sat on the toilet watching, just waiting, she just screamed herself out…um because y'know she was, on a boat, not in, not her environment, she was y'know… and um, eventually she calmed down again
26:16	**D:** Does she have particular things that y'know that she really likes?
26:20	**E:** Um…she's not really…really attached to one thing… yeah, I guess, I mean

	she's never like had a teddy bear or a blanket or, no, but she likes a variety of things, and then y'know like you think like 'oh I've got this, this will be a … and you get a 'no' and you think I was sure that was going to do it, yeah, but you just never know -
26:46	**D:** Yeah …does she have any strong dislikes…to anything?
26:51	**E:** Not um…not really, just clothes mainly, she's yeah, she just won't really wear anything else but pink, yeah, she's got this one, one top that I just I mean, one day, she wore it three days in a row (laughing) like during the day and to bed because… it wasn't worth the battle so I just left it on her yeah, that's about the only thing that's she's really really attached to is this one top
27:23	**D:** Ok...and obviously you find that sort of holding her, that sort of firm…she obviously calms down with that
27:33	**E:** Yeah, she's constantly on me, she's on me the whole time, y'know like that just blows people away, um, y'know, I have feelings I don't know how you cope with that but, she's on me, she's not touching me, she's leaning on me, she's lying over me, she's like standing, I mean if she was here now she would be right behind me with her arms around my neck, just she'd be on me
27:58	**D:** What's she like at Barnados and your, does she transfer those -
28:04	**E:** Yeah, they say (whispering) 'oh come Pippa let's have a cuddle' so yeah she will… and she is incredibly cuddly, y'know she -
28:15	**D:** But obviously she has that need to just contact as -
28:18	**E:** Yeah, but she will have her independent times when she will just go off for hours and do her own thing, yeah, she's capable of doing that
28:29	**D:** And when she goes and does that, what sorts of things would she go and do
28:32	**E:** Um, like she's got a dolls house and um, there's a xxxx xxxx xxxx like the um the Fisher Price figures, and she likes … she does a lot of role playing with them like they talk to each other and y'know there's a dog and there's a cat and they… so she does a lot of that….um she likes drawing…um, yeah, just and she likes xxxx xxxx she likes the little things
29:06	**D:** Yeah, that she can handle easily…yeah…um….yeah I guess we've covered most things that Christine's got as our questions…um..yeah…I guess, it would be good to note like I guess in the future, do you think much about the future, with Pippa?
29:35	**E:** I do, and with moving it's sort of a little bit uncertain, and leaving the Centre I know the biggest um… there'll be a void in the music therapy, that is the one thing that I can see that is really hard to fill, because I can go down and I can get speech therapy, physiotherapy, um y'know, occupation, I can get the occupational therapist to do some sensory work with her, but I can't get this, and Pippa being as musical as she is, and having that comment from Christine she says music is really in her and I can see it, the child has got amazing rhythm, yeah amazing rhythm, yeah um
30:21	**D:** So when you say rhythm, she picks up on -
30:29	**E:** Rhythm, and even just like banging and tapping to songs and, she's just got the rhythm
30:32	**D:** Does she hum or vocalize -
30:34	**E:** Yeah, she sings, she makes up songs, she...there's one area that she's really good is her colours, she knows all her colours and she'll just sit there and make up a colour song, like she'll just go around and be singing about the tree's green and that's blue and la de da (laughing)

30:49	**D:** Oh, very good
30:51	**E:** Mm yeah…so yeah she's a creative little soul, and um yeah so that, yeah… and what is good about the… this music therapy is that I have taken her to music groups before… but then there's expectations you see…and then she doesn't do what all the other kids do, and then that's not acceptable and then it becomes too much, too hard, yeah
31:16	**D:** Whereas I guess here the expectation is more just follow Pippa's lead -
31:20	**E:** Yeah, and she gets so much out of it, mmm, y'know she's not used to xxxx, and stand up, do this, and then do this, and then she's just going, don't think so, don't like that at all, so yeah, it is definitely one area I feel I xxxx xxxx xxxx (laughter)
31:43	**D:** Yeah, 'cos there are not a lot of, not many music therapists out there unfortunately, hopefully that will change -
31:49	**E:** Yeah, but y'know, just even to find somebody that maybe is musical, yeah, …I just, I don't know, it's something I think about but, y'know we do do, as I say we do a bit of singing and dancing at home, yeah, and um, we have fun y'know just with music as um, what she responds to, and some music just makes her completely shut down as well
32:16	**D:** Oh ok…can you give, can you think of an example?
32:21	**E:** Um…usually it's when we're just listening to the radio in the car and…yeah I think a lot of like um, she likes songs with sort of a good steady beat y'know, she really gets into that, her whole body is going, sometimes some songs that are just too full on, too much, she just 'blrrr' (demonstrating shut down) she just, like normally in the car she's like, na na na na (demonstrating happily moving to the rhythm) then there's a song and she's like this (demonstrating turning head away, thumb in mouth) shuts down
32:49	**D:** Right, that's interesting, yeah
32:52	**E:** Yeah, you can always tell the music she doesn't like…
32:59	**D:** Yeah, it's good that you recognize yeah, that's how she is, like -
33:04	**E:** Like a lot of the um sort of dance music type and I know that because my ex only plays all of that and she doesn't like it
33:13	**D:** Right, yeah, and so you said when she shuts, she just sort of turns her head away -
33:16	**E:** She just turns away -
33:17	**D:** And sucks her thumb
33: 19	**E:** Yeah…definitely knows that's xxxx xxxx, but y'know it's always as I said, coming in here like the last session was ahh (making high pitch stress sound) and y'know she wee'd on Christine's floor, just completely went into a huge meltdown and she's just beginning toilet training and she just lost it completely, but by the end of the session y'know we were both standing there with the drums, banging away, like she just loves the drums, she can really express herself on the drums, yeah, y'know…Christine has picked up on that right from the beginning, yeah and um, yeah it's always good to watch 'cos Pippa will lead like how she's feeling and Christine will start playing…if Pippa is "arghh" (demonstrating disturbed/aggressive sounds), Christine will start (same sound), and then Pippa will just quieten it down, Christine will just quieten it down and then Pippa will just 'ohh' (indicating an interactive gesture responding to supportive engagement), yeah, y'know she gets creative, she'll get the drums and go on the side of the drums and just do, just different things, yeah, so, she really

	does express herself when she comes in here
34:26	**D:** Yeah, and obviously y'know yeah wants to experience it as much as she sort of can find ways to do that
34:36	**E:** Yeah, she's like 'what will she [Christine] do if I do this?' [indicating Pippa's possible thoughts while engaged in interactive musical play with music therapist] (chuckling)
34:41	**D:** So do you tend to in the individual sessions, sort of sit -
34:44	**E:** I just sit back, yeah, yep
34:45	**D:** Does she -
34:46	**E:** I get, I get my own set of sticks and yeah, I join in
34:50	**D:** So she's not so um strong on wanting you to be involved, she's quite happy for you to sit back and yep
35:00	**E:** Especially when um when Christine gets the blackboard out with the chalk, yeah, and I can sit right back from her and Christine over there, and Pippa is making like marks and Christine will be doing like vroom noises, or d d d [indicating sound play responding to Pippa's energy on chalkboard], and Pippa just gets into that, she loves that…and she doesn't care if I'm here or not, y'know so -
35:21	**D:** And what about the other therapists with their individual sessions, does she want you to -
35:25	**E:** No
35:26	**D:** She's quite happy for you to just -
35:28	**E:** Yeah yeah
35:30	**D:** So it is good in that she's having that independent time sort of, yeah of physically not needing you to be so close
35:41	**E:** Yeah, but I am teaching her that, she knows, (chuckle) in the morning when I have breakfast, she will, she'll set up with a cup of coffee and toast, she'll hover and (hum hum hum) check my plate and as soon as I'm finished vroom she's off, so I am teaching her to say, when I say y'know 'beside mum, beside', 'sit beside me', and y'know that's something that they're trying to do here like y'know they'll put a mat out beside, y'know -
36:11	**D:** So it sounds like you've got some good y'know, you're finding ways to be able to really flow that into home as to how, what they're working on here, you can find ways to do that at home
36:23	**E:** Like I mean, I'm pretty sure Christine, I think she did mention about making up a tape for me and I can take it with me, and that will be great, and y'know I can set aside a part of a day when we can do that together and do some stuff, y'know just like looking at the drums now, and I was thinking we might get her a drum and stuff like that and -
36:49	**D:** Do they, does she participate in the music in Barnados -
36:52	**E:** Yes she does
36:53	**D:** She does, ok, and does it tend to be musical instruments or -
36:58	**E:** Yep, or just dancing to y'know like Wiggles or stuff like that, she does that -
37:05	**D:** Oh no that is, yeah, that's good, because sometimes, just being in a different environment, I was keen to know what she was like -
37:15	**E:** She's very comfortable there, very comfortable, yeah
37:20	**D:** Very good…um is there anything else that you want to say that I haven't asked you or covered, anything else that you want to tell us about Pippa?
37:34	**E:** Um…oh she's definitely benefited from coming here, y'know as I said in the

	beginning it was pretty overwhelming, yeah, I still find it hard (chuckling), I know that sounds negative, but I do, I find it's, I get quite mentally exhausted at end of day, um the end of the session, um, but yes, she's definitely improved, and that is one thing I will miss not having something like this to come to, but I'm glad that we've been here for the time that we've had, and know that, she can learn and that she's capable of that -
38:13	**D:** Yeah, 'cos you've seen her progress -
38:18	**E:** Yeah, yeah, and just having somewhere to come where everything is totally accepted, y'know absolutely totally accepted, and you can have a conversation (chuckling) and these kids are screaming and all of us are so used to tuning out and just whatever…and, and y'know sometimes it's quite good because you see other mothers come in and you look at them and you think, I know what kind of week you've had (chuckling) and it's also nice… yeah, 'cos I know if I ever walked in here one week and just said to them 'I can't do this anymore' they would just, y'know, I know that I would get support from that, and also with me moving they've been really really great and very supportive and as I said I'm sure Christine will give me lots of stuff to… information to take with me
39:12	**D:** I'm sure she will
39:15	**E:** I just feel really supported here, yeah…
39:20	**D:** Yeah, it's a great place
39:22	**E:** It's quite, I know this sounds terrible but it's quite good when other people come in, y'know, they're not really uncomfortable, but it's like this is their, y'know, this is the kids, this is their place y'know, coming into their turf, this is their, and yeah, it's good, it's good that they have something like that -
39:41	**D:** That's theirs
39:42	**E:** That's theirs y'know mmm, and that's also nice
39:48	**D:** And so um how are you going to prepare Pippa for not coming, do you think that will be a problem for her?
39:56	**E:** (big sigh) um… she'll ask about it because one week I was sick and she asked me all day, she'll ask for OP first [SLT], she seems to like, with Christine, it's like mmm no no no, but then she's absolutely fine when she leaves here, yeah, I think she will ask about it, but um I'll just…Pippa will cope with most changes if I'm there and her stuff's around her… so I think she will cope…just xxxx xxxx information
40:36	**D:** Yes, yeah, and as you said before, y'know, trying not to sound like a broken record but yeah, just going over it and over it, so that she really gets it in her mind -
40:48	**E:** In her head…I mean she's just been toilet training for over a week and and yeah, it's just fantastic, and little things like that really has helped her development as well, y'know, it really has, it's sort of, and she's so proud of herself, and y'know I can see that just pushing her along a little bit more as well, y'know because she's not going to be in nappies now, and people notice that she's in nappies, mm they do
41:22	**D:** That's a major achievement in a week
41:25	**E:** Yeah she's getting there…mmm that was my, that was my wish, my biggest thing on my wish list for the year was to get her toilet trained, four-and-a half years of nappies, it's wearing a bit thin (chuckling)…it was the right time, we tried a year ago before she was diagnosed and that was an absolute disaster and she regressed something shocking and, and I felt like putting it off because it was

	such a horrendous experience (chuckling) that I didn't want to go there, but it was the right time, and it was actually about Barnados saying 'c'mon Eva let's do it' so 'ok'
42:11	**D:** And… have you done anything differently than you did last time or do you just think it's just a maturation thing on Pippa's part that has made the difference, or do you think you have come at it from a different angle?
42:23	**E:** I came at it from a different angle and um, y'know I really told myself not to get stressed out about it and and we um like we talk about it and we like have a, we sing and we're going,.and we sing 'I'm going to the…toilet' and…so -
42:40	**D:** Good, ok so you've attached a musical sort of -
42:43	**E:** Yeah, and I make it fun y'know, I pick her up and I swing her around and we dance away to the toilet, 'cos otherwise it's no no no…yeah
42:51	**D:** Oh that's really good
42:52	**E:** Just trying make it fun and we do lots of jumping up and down and clapping and y'know
43:00	**D:** Yeah, that's really good, I hope, I'm sure you're going to get there, I'm sure of it
43:06	**E:** We will, absolutely, absolutely, there's no going back now
43:16	**D:** Well that, we could finish the interview there, if you're -
43:19	**E:** Ok, yep
43:20	**D:** Yep, and um again and thank you for coming in
43:24	**E:** No problem, no I think it's great that this is happening for Christine, it's good, she does an amazing job
43:34	**D:** It's a wonderful place
43:35	**E:** Mm we're very lucky to have it
43:39	**D:** Mm, yeah, it's quite unique really
43:41	**E:** It is quite unique…..just hope there's more of them round the country one day
43:50	**D:** Mm, yeah….alright [both getting up and organizing exit of interview]
43:52	End of interview

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