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Relationship-based early intervention services for children with complex needs: lessons from New Zealand

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Abstract

Purpose:

This qualitative study aimed to explore parent and professional view and perceptions about the key characteristics of a relationship-based EI service for children with complex needs.

Methodology:

A case study is reported of a relationship-based early intervention service for children with complex needs in New Zealand. This qualitative study involved 39 participants (10 children, 11 parents and 18 professionals).

Findings:

Parents appreciated the knowledgeable, well-trained professionals who invested time in getting to know (and love) children and families and family practices, worked together in harmony and valued the contribution that parents made to their child's progress and achievement. Professionals described the key characteristics of the service in terms of the range of therapies offered by the service, the focus on a strengths-based and family focused approach, play-based assessments, acceptance and value of family practices (including responsiveness to Maori and bi-culturalism), appropriate and respectful places to meet and greet families and work with children, and recruitment and retention of humble professionals who identified with the ethos of the model. Observable social processes and structures within the delivery of the model include respectful professional interactions and relationships with children and families, integrated professional working, effective and timely communication

between professionals and families, pedagogy of listening, waiting and personalisation, engaged families and actively participating children.

Policy and practice reccomendations include:

. A systematic review of literature on EI programmes and services that hold as their core aim to build relationships between parents and children as a foundation to emotional resilience, well-being and long-term mental health.

• A centre-based model of EI that recognises parents as children's first and most enduring teacher rather than decontextualised programmes than risk devaluing children's and parents competencies is recommended for EI services in the UK.

Key words: Relationship-based early intervention services; complex disabilities; complex needs; integrated working; families; ecological approach

Introduction

The benefits of early intervention (EI) have been well documented (see Guralnick, 2005; Heckman, 2006). EI programmes can prevent risk factors from exerting negative influences on children's development (Field, 2010; Marmot, 2010; Munro, 2011; Allen, 2011), EI can not only minimise delays, but other secondary complications as well (Guralnick and Albertini, 2006). The importance of parents' contribution to their child's education cannot be underestimated (Carpenter *et al.*, 2015). Pretis (2006) argues for a common set of principles to guide EI services. These would include but not be limited to inclusion, child and family-centred activities and empowerment.

In England the rights of young children (aged birth to five) with developmental delays and disabilities are embodied within The *Children and Families Act* (Department for Education/Department for Business, Innovation and Skills/Department for Work and

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Pensions/Department of Health and Ministry of Justice, 2014) and the Special Educational Needs (SEN) Code of Practice (DfE/Department Of Health, 2015). At a local level, EI services are determined by Local Authorities who are obliged to communicate to parents what their local offer comprises in terms of the model of delivery, professional support and parental partnership. Under the Act, parents of children with severe and complex needs and who have an Education, Care and Health Plan (ECH) can choose how and where their child is supported in terms of mainstream or special education. However, Blackburn (2014) found that in practice the choice for children with severe or complex needs is often restricted by practitioner knowledge/training and setting resources. Consequently, most children with severe and complex needs attend specialist school settings that have early years units.

Children with mild to moderate needs in England are usually supported in mainstream early years setting, sometimes combined with specialist assessment support such as Child Development or Language Support Centres organised by charities such as ICAN. Co-ordination and communication between settings, parents and professionals is often a challenge where children attend mainstream or combined settings (Blackburn, 2014).

Whether children attend specialist school settings, mainstream or combined settings, their intervention runs the risk of being decontextualised as families do not generally participate in their therapy and education interventions alongside them, except in the case of home-based services such as Portage (a home-based play service that aims to develop parental capacities to play with their children in order to promote children's development) or play therapy which are often delivered in isolation from other therapy services and have the potential to isolate parents in the home. Communication and co-ordination between therapy services can often be distant and disjointed (Blackburn, 2014). This view is supported by Robertson and Messenger (2010) and Lamb (2009) who argue that the most significant challenges for England in delivering EI provision for children with disabilities have been:

- Maintaining effective communication with all parties involved;
- Developing a clear understanding of roles and responsibilities between professionals
- and families;
- Maintaining a high level of professional specialism;
- Developing trust between families and professionals and inter-professionally;
- Focusing on outcomes;
- Empowering parents and families.

Aims and objectives of this project

Taking this into account, a search for evidence-based international best practice in relationship-based, family-centred EI services was undertaken and the Champion Centre in New Zealand (NZ) identified as an interesting model of EI provision, especially in light of the focus in NZ on sensitivity to biculturalism and children's rights in policy and academic research (Foster-Cohen and van Bysterveldt, 2016). The Champion Centre model is underpinned by five principles and based on a social ecology model (Bronfenbrenner, 1979). These are that the service is relational, family-centred, strengths-based, ecological and reflective.

The objective of this project was to visit the Champion Centre in order to interview professionals, observe their interactions with children, talk to families and gather information about the work undertaken at the Centre that could be translated to a UK context to work with children with complex needs. The objective was to capture effective and best practice within an interdisciplinary context that could be mutually beneficial for all stakeholders concerned with children with complex needs. Research questions included:

- What are the views, understandings and reported practices of professionals working within a relationship-based early intervention service with children who have complex
 needs?
- 2. What are the views and perceptions of parents/families who use the service?
- 3. What are the observed practices of professionals and key physical and social resources in a relationship-based EI service for children with complex needs?

Background to the Champion Centre

The Champion Centre in Christchurch, NZ is one of four EI services in Canterbury for children aged birth to six with severe and complex delays and disabilities. The Centre provides relationship-based EI services on a centre-based integrated therapy approach that values children's strengths and family practices. The programme is offered to children from birth to school age who have significant delays in at least two areas of development. Children who attend the Centre have a wide range of special needs. These include developmental challenges as a result of Down syndrome and other genetic disorders, cerebral palsy, extreme prematurity, epilepsy, developmental dyspraxia, autism and brain injury. Five principles underpin the service, these are that the service is relational, family-centred, strengths-based, ecological and reflective.

Small group sessions are attended weekly by families at the Centre. At each session the child is seen individually by a core therapy team of a physiotherapist (PT) or occupational therapist (OT), early intervention teacher (EIT) and speech and language therapist (SLT). A social worker is an integral part of each team. When the child is three years of age, an education support worker (ESW) joins the team to support the child in their community early childhood centre. Children's learning and development is extended through the provision of specialist programmes (including music, play, and computer supported learning), in addition to the

"core" therapy team. Specific therapy is available for children who have feeding, sensory, behavioural and relating and communicating difficulties. As the child approaches school age, the team assists the parents/caregivers in their preparation for inclusion in an appropriate school setting. This "wrap-around" service includes visits by a dietician, podiatrist, and visual and hearing resource specialists, Early Childhood Centres and schools.

Methods and ethical considerations

Data collection methods included observations of nine children at the Centre during their intervention sessions and interviews with their parents. A past parent whose child had previously attended the Champion Centre was also interviewed. Therapy staff and the senior leadership team were interviewed and Centre documentation reviewed and analysed. The project was approved by the Faculty of Health, Education and Life Sciences Ethics Committee at Birmingham City University. Participants were selected by professionals at the Champion Centre to represent a range of the children and programmes delivered, and on the basis that the children and their parents were sufficiently robust to participate.

All interviews with parents were conducted at the Champion Centre with the exception of one interview where parents chose to be interviewed at home. Interviews lasted between 20 minutes and 55 minutes. Parents were asked about their child's successes and celebrations, challenges in daily life, the families' support network, parents' aspirations for their child's education and inclusion in society and employment, as well as any concerns about these aspects. They were also asked about their perceptions of the Champion Centre and its relationship-based approach. Interviews were professionals were also undertaken at the Champion Centre and professionals chose to be interviewed in teams according to the particular programme in which they worked rather than individually. Professionals were asked about aspects of interdisciplinary working, working with families, their aspirations for children and families and their perceptions of the characteristics of a relationship-based

approach to EI services. Professional group interviews lasted between 40 and 70 minutes. All interviews followed a semi-structured interview schedule that allowed time and opportunity for participants' reflection on their experiences whilst providing sufficient structure to ensure that the research questions were addressed.

Observations followed a narrative written record as the researcher wanted to record naturally occurring events that followed children and families' participation in their EI activities (Hobart and Frankell, 2004). When triangulated with interviews with parents and professionals and document analysis of children's individual plans, this provided rich data on children's experiences within the programmes available at the Centre.

All participants provided informed consent and were reminded of their right to withdraw before interviews and observations commenced. Observations required ongoing monitoring of children's wellbeing and comfort levels at all times and sensitivity to their privacy and anonymity. Children's identities were protected by the use of pseudonyms. Data were stored securely on University equipment.

Data were analysed thematically in order to reduce bias. Research questions identified *a priori* themes and thereafter emerging themes were identified. Qualitative content analysis provided the opportunity to organise, condense and categorise data through a process of interpretation of and inference from participants' original expressions. Frequency counts of themes from interview transcripts or observation records allowed both common and discrepant themes to be identified. This was an inductive process rather than being theory guided and deductive. A process of reducing and clustering to form initial codes or subcategories that described followed. The unit of textual analysis was an extract from a transcription or a narrative written record from an observation with factual connection to an idea and issue. After initial codes had been identified in data of two or three transcripts.

codes were compared with each other according to similarities and differences to determine which data "look alike" and "feel alike" as suggested by Lincoln and Guba (1985: 347).

Results

Details of children and parents who participated in observations and interviews are shown below in Table 1 below.

INSERT TABLE 1: Table 1 Details of children and families who participated

Generally, young infants from birth to approximately two years of age attend the 'Baby Programme'. The 'Middle Years Programme' is for children aged approximately two to four years of age at which time children join the Transition to School Programme in readiness for school.

Details of professionals who participated in observations and interviews are shown below in Table 2. All interviews were conducted at the Champion Centre. Interviews last between 40 minutes and 90 minutes. Professionals were asked about interdisciplinary working, their perceptions of the Champion Centre and its relationship-based approach, challenges in delivering the Champion Centre model and their professional aspirations for children. In addition to this, the Senior Leadership team were asked about the strategic direction and sustainability of the Centre.

INSERT TABLE 2: Table 2 Details of professionals who participated

Interviews with parents

Children's Success and celebrations

All parents reported successes and celebrations for their child which can be categorised into two broad categories of communication and gross motor development. Five parents discussed

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successes in one or both of these areas. Four parents were pleased their child was able to understand more and/or express themselves with more clarity and four parents also noted the significance of their child's physical milestones as being memorable. This included walking for two children and crawling and running for one child each. The remaining three parents were satisfied with any and all progress and could not identify any particular developmental milestone as being more memorable than others:

They're all memorable because everything he does is an achievement. He has Prader Willi, he's not supposed to be able to do any of these things so... it's just exciting every time he does something. Everything he does is because of him being here and because I do everything with him at home. I use here as a motivator, I want him to achieve so I can go back to the Champion Centre and surprise them.

Children's challenges in daily life – including family support available

Nearly all parents described challenges for their child in daily living. Three parents mentioned communication as the main difficulty for their child and in addition to this one parent also mentioned anxiety and another mentioned support needed with physical skills. Two parents each mentioned significant difficulty for their child with gross motor and one with fine motor skills. Two other parents reported their child's difficulties with hygiene routines and feeding were particularly challenging. The mother of the youngest child stated that her daughter was not experiencing any significant challenges currently. However, she was aware that this may change over time as her daughter matured and that her daughter needed ongoing monitoring.

The majority of parents had a network of friends and family who lived within reasonably close proximity and who were able to support them emotionally and practically. Five parents included other parents who attended the Champion Centre in their network of friend and family support. One (past) parent stated that wider family members do not always understand their emotional needs, especially when children are first born/diagnosed with a disability. She

highlighted the benefit of knowing parents through the Champion Centre who could empathise and relate to their experiences:

Both sets of parents found it difficult to cope with our emotional needs at the time in terms of coping with our grief. They couldn't understand why they couldn't come to the hospital, why they hadn't held the baby, but we hadn't held her, she was sick, in an incubator. That's why it was good to know other people having the same experience and good to be with other parents at the Champion Centre who had the same experiences.

Key characteristics of relationship-based EI services

Parents identified a number of key characteristics that they valued in a relationship-based EI service. Five parents mentioned the importance of experienced, knowledgeable professionals who teach parents to teach their children. Four of these parents recognised that this helped to prepare their child for school. Four parents each stressed the significance of professional support for the relationship between parents and children in showing parents how to relate and play with their child, as well as professionals knowing the child/family well enough to do this. Three parents stated how useful it was to have the support of other parents who were experiencing the same challenges and difficulties. Two parents appreciated professional recognition of their contribution to their child's ongoing progress and one parent stressed the value of feeling that "you're not doing it alone."

Key characteristics of the Champion Centre

In describing the most important characteristics of the Champion Centre, all parents mentioned the social support available to families and the benefits of the integrated approach taken by professionals to scaffold children's learning and development.

Here it's all interlinked, since she started coming here she's just come so far in her development. One person will say oh she needs help with this and another will say oh I can help with that and they piece it all together.

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One parent compared the integrated approach of the Champion Centre to her previous experience with another EI service, which she reported as being quite disjointed. She wondered whether her child would have made the significant progress that she has if she had continued with that service.

Six parents appreciated the way in which the interventions supported family life and noted the importance of professionals acknowledging how hard parents worked at home to support their children as well as the importance of consistent regular visits to the Centre:

I love the fact that you come once a week and all the therapists see her and work with her and then they all meet and discuss her and everyone knows everything about her.

Four parents mentioned the value of well-trained knowledgeable professionals employed at the Centre who know their child well and understand their needs, whilst three parents appreciated the fact that professionals were non-judgemental about their child and family routines/practices. Two parents stated that when their child was attending the Middle Years Programme they found it more difficult to determine and identify their child's progress than was the case for the Baby Programme and Transition to School programme. One parent each mentioned the benefit of the play-based approach where children were not rushed to reach developmental milestones, the frequency of the therapy sessions and the compassion and love offered by professionals to parents and children:

The care that extends beyond their subject matter, so just being supported emotionally and many times chatting to the staff, you would leave in tears, but I needed that.

One (past) parent described the mediating role of staff in helping parents to "navigate" both medical issues and parenting and child behaviour concerns and another stated that her husband was delaying a work promotion as it involved moving to another District. She said

they felt so strongly that their child was benefiting from their son's participation at the Champion Centre that this was more important than increased wealth or career prospects.

All parents reported that once they had selected the Champion Centre as their preferred EI provider, their place and enrolment was confirmed almost immediately and not longer than two or three weeks. All parents also reported that they were fully involved in their child's learning and development at the Champion Centre and valued this aspect of the service.

Parents' aspirations for their children

Parents' aspirations for their children were described in quite concrete and specific ways. For example all parents talked about aspirations for their child's success and progress in mainstream education and gaining necessary teacher aide support to facilitate this. Further to this two parents wanted their child to access tertiary education, which for one parent was motivated by a desire for his son to achieve vocational qualifications and have meaningful employment. For the other parent, her aspiration was motivated by her desire to demonstrate to health professionals the unnecessary conceptual limitations they had placed on her son:

I want him to go to University and do all the things that doctors said he wouldn't be able to do.

One parent hoped that her son would be able to enrol at primary school fully orally-fed (rather than tube fed) whilst another wanted her daughter to be involved in everything and have everything she needs. Gaining the necessary life skills to be independent was important for one parent whilst the parent of the youngest child hoped her child would not experience any long-term disability. One parent noted the relational benefits of having a child with learning difficulties in terms of her child's learning being a shared experience between parent and child due to the intensive teaching required for her daughter to learn new skills:

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My other children would seem to learn things and you wondered how, but with O it felt like you did things ten times more but you could look back and say we did that together, it was so satisfying when she did things that way.

Parents' concerns about their child's inclusion in education, employment and society

For four parents, their concerns about their child's inclusion mainly related to the availability of adequate funding and resources being available for their child to be fully included in mainstream school. Two parents expressed concern about their child's ability to form and maintain friendships in school, whilst another was concerned about his son's safety due to lack of appropriate fencing at his chosen school. By contrast one parent was concerned that her daughter's unusual behaviour was manifesting in increasingly obvious ways that were not understood by others. One (past) parent was concerned about her daughter's long-term independence and care needs. She wondered who would take responsibility for this when she and her husband were no longer able to do so. One parent stated that she had learnt over time to focus on the immediate future rather than worrying about the longer term future.

Interviews with professionals

Interdisciplinary working within the Champion Centre Model

The Champion Centre Model was described by professionals as a "partnership with families" with an interest in parents' well-being and parents' goals in terms of their relationship with their child. This means observing development of the "whole child" and ensuring that all aspects of the child's development are progressing well. The way in which professionals at the Centre work together was conceptualised by staff in terms of how they learn with and from each other in that each professional examines children's development and family processes from their own distinctive professional perspective. This perspective is respected by other professionals within the model. However, each distinctive perspective forms one part of the whole perspective and the overall perspective is both holistic and consistent.

It is absolutely key that I work alongside people who understand neurological systems different from the way that I would have understood them through speech and language. So when I talk about the way every child communicates, I mean that across the developmental spectrum. Instead of seeing a child's response as being good or bad I see it as a response. This has been helped to grow by working alongside people like psychologists who have their own lens through which to look at the child, which has adapted my lens and image.

In addition to this, the model was described as complex, evidence-based (theory to practice) advocacy building, reflective respectful and collaborative.

Interdisciplinary working with professionals outside the Champion Centre includes working with a wide range of professionals (for example paediatricians, community services, specialist teachers, social workers, assistive technology providers) from the family's enrolment into the Centre, during their ongoing participation within it and at the point of transition to school.

Key characteristics of relationship-based EI Services

All five professional interviewee groups talked about the importance of understanding the family's journey both prior to and during their relationship with an EI service. It was described as "crucial" that parents should only have to relate their child's early experiences to professionals once and this should occur within their own 'safe space', usually the home setting. Also suggested by three professionals was the need to respect families and other professionals', honesty and empathy. Suggested by one professional each was the importance of:

- Working with parents to enhance their ability to support their child and helping them to learn to love their child.
- Removing "roadblocks" to parent/child relationships so that children with disabilities can experience joy.

• Acknowledgement and respect for diverse family structures/processes and interactions.

• Love of working with families rather than working solely with children.

Key characteristics of the Champion Centre Model

All professionals noted the importance of an interdisciplinary approach which was underpinned by effective and regular communication between professionals and between professionals and families. This was thought to rely on inter-professional respect and a degree of humility from professionals towards each other and the families they support:

The team meetings are absolutely the core. Where a single person visits the family or assesses a child, what are they going to do with that information – write it down? But how do they decide what to write down…here they're talking to each other. They've all seen the child. Somebody will have a little piece that they would never put in a report, but somebody else will have a little piece and suddenly there's a synergy of understanding.

Further to this, the importance of the range of therapies being accessible to families in one location was noted by all three of the programme teams, as was the frequency of delivery and time given to children within their sessions. Also mentioned was the importance of professionals adopting a family-focused approach including building partnerships, relationships and trust with families. Identifying and building on children's strengths, meticulous attention to detail, as well as adopting an empathetic approach to children and families were also deemed necessary.

It's the hardest thing to walk through these doors...often we have a huge amount of grief and then it's about making a cup of coffee, supplying tissues and listening.

One aspect of this was the professional response to Maori and ways of "being together" that acknowledges and respects bi-culturalism. The focus on a strengths-based approach extends to research undertaken at the Centre and methodologies adopted to support research. For example play-based assessment approaches are utilised and measures for research are chosen for their ability to allow immediate feedback to parents and therapists about children's progress.

In addition to this the Centre Director identified the structural processes that needed to be in place such as an appropriate building that can accommodate necessary equipment and nurturing therapy spaces in a welcoming environment. Recruiting and retaining professionals who identified with the aims and ethos of the programme and were committed to its sustainability and longevity were described by her as crucial for survival of the Service and can be challenging as described below.

The practice manager was concerned about meeting child and family needs in the context of a "more isolating and less nurturing world" She explained that this places pressure on parents to cope with increasing demands to be "good parents", which can be more challenging when parenting children with disabilities. This is especially the case when maternity/paternity leave and pay remains at a low level which has the potential to disrupt parents' ability to have the time to get to know their child in infancy:

I would challenge the Government to think about the value they place on infants and little children, the value they place on the family and upskilling, enabling and empowering parents to be parents. If we could have a different way of valuing infants and family in the context in which they grow, the job that we do here would look quite a lot different.

One dimension of this hostile world that was raised by a number of professionals was the increased pressure on families and child development arising from the Christchurch Earthquakes in 2010 and 2011. Professionals reported that anxiety is quite often a factor in the environmental influences on children's development which they felt was "epidemic" in Christchurch with the pre-natal experience contributing to family anxiety.

Professional aspirations for children and families

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Professional aspirations for children were conceptualised within the context of families, communities and society and social models of disability. For example, all professionals hope that children will function at the best of their ability and competency within the context of school and employment. Professionals described the different ways in which they aspired for children to be valued. This included:

- To be understood by those who love them and others and to understand something about themselves.
- To be valued for who they are, not restricted by a 'label' or other people's definition of a particular condition.
- To have a voice.
- For parents to know their child and to believe that there are no limits to their future potential.
- For parents to become advocates for their child's condition and to change societal perceptions about disability.
- For parents to fall in love with their child.
- For the parent/child relationship to reach its full potential.

Professional aspirations for children and families focus on concepts of humanity and human potential. For example, although professionals described the benefits of the service for children with complex needs, they also perceive the benefits for children with moderate needs in the capacity to "turn their lives around" by enhancing their developmental trajectory.

Observations

Nine children were observed in their EI sessions (three children attending each of the EI Programmes) with accompanying family members.

Physical processes and structures

The Champion Centre is located on the site of Burwood Hospital, where there is a separate car park and entrance and a formal but friendly reception area. The Centre is divided into discrete areas for music therapy, computer supported learning, each of the main programmes, the relating and communicating programme, play rooms, a family kitchen, sensory outdoor play area, and quiet rooms for sensitive discussions with families. Children's sessions are organised on a rotation basis according to children's learning plans and current targets. The plans for the morning sessions are agreed between staff collaboratively and communicated by means of a visual display on whiteboards. However, there is flexibility to allow for changes and unplanned events. On arrival at the Champion Centre in the morning, children and parents are provided with a visual timetable to enable them to predict the format of the morning. Therapy rooms are clearly labelled enabling children and families to become familiar with rooms and sequences of interactions within them. The combination of clear visual support and clearly labelled therapy areas means that children and families can navigate their sessions independently. Professionals are always vigilant to children/families who might need support moving between sessions, for example where children find transitions difficult or parents have younger siblings to manage as well as the child participating in sessions and therefore need practical assistance with equipment and handling.

Social processes and structures

Observation data were analysed, coded and organised under the themes of respectful professional interactions and relationships with children and families, integrated professional working, effective and timely communication between professionals and families, the pedagogy of listening, waiting and personalisation and engaged families and actively participating children

Respectful professional interactions and relationship with children and families

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Families were greeted warmly and inquiries made as to their emotional state and wellbeing prior to sessions commencing. Professionals remained alert throughout sessions to parents' signals and cues as well as following parents' lead in terms of children's progress and achievements at home and aspirations for future development, putting family life at the centre of activities.

Observations of professionals working with children and their families in sessions revealed a high degree of professional respect for children and family's right to choice and consent. For example professionals 'invited' children to interact and participate. When working with infants, before moving or lifting them, professionals held out their arms/hands towards the child and waited for the child to indicate a response. The infant might do this by making eye contact to demonstrate participation, extending or raising their own arms to indicate consent or demonstrate by other subtle emotional or gestural expression that consent/willingness to participate was given. Only then did professionals move or lift the child. In addition professionals provided an ongoing narrative to their own interactions with children simultaneously relating and communicating with the child and modelling to parents the importance of talking to and with infants from the earliest stage. This level of respect and ongoing narrative was observed in all of the programmes. Children were provided as much choice within activities as possible, for example a choice of books or songs or instruments.

Professionals frequently used everyday resources that could be found in the home as sensory stimulus in preference to expensive toys, making it easier for parents to emulate practice they have observed within sessions to support their child in the home. This was only one example of frequent professional affirmation of parents' contribution to their child's progress. In addition, professionals frequently explained *what* they were doing with children and *why*.

Integrated professional working

Collaborative, integrated and interdisciplinary working was observed to be the most consistent and strongest theme in delivery of the programme. Often there was more than one therapy being delivered at one time, as professionals might work together in a session if this was deemed beneficial to the child/family targets. All professionals used the same language to talk (and often sing) to children such as "good looking", "good pushing" and used a total communication approach that integrated sign, pictures, gesture, speech and body language.

Effective and timely communication between professionals and families

Professionals were observed to discuss children's progress in the context of achievements and celebrations at the Champion Centre and reported successes at home from parents immediately after the morning's programme session. In addition to this there were ongoing conversations about children's difficulties and successes prior to sessions, during sessions and after meetings between professionals and families.

Pedagogy of listening, waiting and personalisation

A professional pedagogy of listening to children and families as well as waiting for them to initiate an interaction or respond to one was observed. Professionals adopted a listening approach to working with families and this was observed in a number of ways. For example in the monitoring programme for children born prematurely, the psychologist appeared to instinctively know to allow quiet pauses for parents to think about their questions and responses. In addition, professionals responded to comments that parents made about activities in the home and were observed to be attempting to incorporate family practices into sessions as far as possible. The ways in which professionals respected children's right to consent is noted above under the theme of respectful interactions and relationships with children and families.

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Each child's session was different, as therapists worked on children's individual learning targets that valued family practices and children's interests and preferences. Children's programmes were individual and tailored not only to their interests and family practices but also to other contexts in which they functioned or were about to function thereby promoting the notion of intervention being contextually appropriate. For example one child who participated in the Transition to School Programme worked on bat and ball skills in physiotherapy in readiness for school and also worked with toy animals in SLT in recognition of his rural and agricultural home life.

Engaged families and actively participating children

The programme was observed to be one that relies on engagement from families and active participation of children in their sessions. Families are empowered and enabled to engage at the level that is comfortable and appropriate for them according to their own psychobiology. For example during music therapy sessions, some parents actively led the sessions and the therapist followed them in leading their child's learning. Other parents appeared to prefer to watch their child participating and discuss progress with the therapist during and after the session. As shown in Figure 5 above, one child and his father were involved in a sustained melodic bonding session using a sound cradle to promote sensory regulation and relational harmony, with the therapist providing a musical narrative to the parent-child relationship.

Therapy sessions were observed to promote children's learning through movement and play and through active co-construction of knowledge with therapists and parents relying on emotional cues such as making and maintaining eye contact, mimicking, social referencing, motivating children to relate to others, cause and effect, symbolic play, matching activities and motor co-ordination. When triangulated with document analysis of children's individual plans, a focus on holistic development was apparent. For example children's plans were organised in the areas of health and wellbeing, belonging and contribution, communication, cognition and fine motor development and sensory processing and gross motor development and this focus on the whole child was observed in therapy sessions.

Discussion

This project sought to identify the key characteristics of a relationship-based EI, The literature located in the scientific fields of EI and psychology recognises the social and economic benefits of EI to change the developmental trajectory for children at risk of, and already identified with, developmental delays and disabilities (Guralnick, 2005; Heckman, 2006).

Interviews with parents at the Champion Centre revealed that they were all able to recall celebrations and successes in terms of their child's development and held high aspirations for their children's inclusion in school, employment and society. One (past) parent also described the relational benefits of her daughter's disability in terms of her progress being a shared journey between parent and child, rather than something that appeared to be automatic or innate as was the case with her other (typically developing) children. This could be a reflection of professional value placed on children's strengths by staff at the Champion Centre that has transmitted to parents over time.

There were challenges in daily living for children that ranged from communication to motor development, daily living and increasingly challenging behavior. Parents of children with obvious and well-known disabilities such as DS appeared to be more confident that their child would receive appropriate financial resources to support their inclusion than children who had not yet received a formal diagnosis or where the physical manifestations of disability were less obvious. Nevertheless all parents held high aspirations for their child's inclusion in school, tertiary education and engagement in meaningful employment.

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Most parents had a secure social network to support them in their parenting role including family and friends. Many parents also valued the support of other parents at the Champion Centre in terms of sharing similar experiences of raising a child with a disability which stresses the role of peer support for parents in reducing stress factors that might disrupt relationships with their child.

Characteristics of the Champion Centre relationship-based EI services that were valued by parents included empowering parents to support their child in the context of family life as well as preparing their child for formal education. Knowledgeable, well-trained professionals who invested time in getting to know (and love) children and families and family practices, worked together in harmony and valued the contribution that parents made to their child's progress and achievement were also important to parents. One of the key professional skills held by professionals that parents valued was the ability to listen and respond. The wide range of therapeutic approaches combined with a centre-based delivery offered by the Champion Centre were acknowledged by parents as contributing to both child and family socio-emotional development and ability to cope with challenges. In contrast to other studies (for example Lamb 2009, Robertson and Messenger, 2010), parents appeared to feel valued, empowered and viewed professional communication and working as integrated and supportive.

Interviews with professionals revealed that professionals placed the parent-child relationship at the Centre of their professional practice and viewed this as fundamental to ensuring progress for children across developmental domains. Also fundamental to their practice was interdisciplinary working that incorporated frequent communication and a culture of learning with and from each other. This was perceived to benefit individual professional development as well as the development of teams. Communication with other professionals and agencies was also perceived to be important.

Professionals attributed a wide range of factors to the effectiveness of the Champion Centre EI model. This included the range of therapies offered by the Champion Centre, the focus on a strengths-based and family focused approach, play-based assessments, acceptance and value of family practices (including responsiveness to Maori and bi-culturalism), appropriate and respectful places to meet and greet families and work with children, and recruitment and retention of humble professionals who identified with the ethos of the model. The concept of 'professional love' (Page, 2014) was alluded to whereby professionals acknowledged their own emotional attachment to children and families that extended beyond a desire to simply work with children.

Professional aspirations for children and families included acceptance and inclusion of children as well as meaningful employment and achievement in life. However, they also extended to aspirations for successful parent-child relationships in the hope that parents would become advocates for children and disability.

Observations revealed that the organisation of physical processes and structures empowers children and parents to navigate their sessions at the Champion Centre independently. Observable social processes and structures that inhere within the delivery of the model include a number of dimensions that can be categorised as:

- Respectful professional interactions and relationships with children and families
- Integrated professional working
- Effective and timely communication between professionals and families
- Pedagogy of listening, waiting and personalisation
- Engaged families and actively participating children

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The integration of the above dimensions results in a model that is underpinned by an understanding that emotional development precedes cognitive development (Brazleton and Greenspan, 2000) and a high degree of sensitive caregiving is required towards children and parents (Meins and Fernyhough, 2006). Consequently, for children to achieve the high aspirations that parents and professionals hold for them, they first need to believe in their own capacity to control the complex and sometimes hostile contexts that interact with their development. Core features of the model were the focus on theory to practice (informed by research), ecological validity, the ability to reflect and learn from each other, the experience of working closely together on commonly held objectives, and co-constructed values of child and family practice. These relationships are shown in figure 1.

INSERT FIGURE 1

Limitations

This study focused on professional and parent perceptions and views of one EI service in New Zealand. It is acknowledged that EI services should be designed for the social-culturalhistorical niches in which they operate. In addition the small number of participants further limits the potential for the findings to be widely generalized. However, taking this into account, there are important messages for EI service providers and policy-makers about relational pedagogy.

Conclusion

This paper has reported on a qualitative study of a relationship-based EI service for children with complex needs. The relationship-based, strengths-based, family-focused, ecological and reflective approach to working with children and families delivered by the Champion Centre

have been demonstrated to provide perceived benefits in terms of child and family relationships. The model provided by the Champion some of the key concerns identified by Pretis (2006), Lamb (2009), Robertson and Messenger (2010) and Blackburn (2014) of providing choice for children and families and empowering them, ensuring integrated working, developing trust and maintain high levels of professionalism and there are additional benefits of a centre-based approach in terms of peer support for parents. Professionals who work with children with complex needs may benefit from sharing therapeutic spaces and developing an interest in working to improve parent-child relationships in order to improve children's overall learning and development over the lifespan.

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Relationship-based EI services for children with complex needs

Tał	ole 1 Details o	of children and	d families	who participated

Age/Gender	Diagnosis	Programme	Ethnicity	I/O
9 months (F)	Developmental delay	Baby	NZ European (adopted)	Interview with Mother and observation
11 months (M)	Prader Willi Syndrome	Baby	NZ European	Interview with Mother and observation
18 months (M)	Feeding difficulties	Baby	NZ European	Interview with Mother and observation
25 months (F)	Down Syndrome	Middle Years	NZ European	Observation
27 months (M)	5q14.3 Deletion	Middle Years	NZ European	Interview with Mother and observation
30 months (F)	Developmental delay	Middle Years	NZ European	Interview with Mother and observation
48 months (M)	Global Developmental Delay	Transition	NZ European	Observation
54 months (F)	Down Syndrome	Transition	NZ European	Interview with Mother and observation
60 months (M)	Down Syndrome	Transition	NZ European	Interview with Mother and Father and observation
17 years (F)	Down Syndrome	Past parent	NZ European	Interview with Mother

Table 2 Details of professionals who participated

Team	Participant Job Titles	Type of Interview	Number of professionals
Senior Leadership	Director of Champion Centre	Individual Interview	1
Senior Leadership	Psychologist, Practice Manager, Director	Team Interview	3
Baby Programme	Speech and language therapist and team leader, physiotherapist, early intervention teacher	Team Interview	3
Middle Years Programme (Motor Disorders)	Physiotherapist/team leader, music specialist, early intervention teacher, play specialist, speech and language therapist	Team Interview	5
Transition Programme	Speech and language	Team Interview	7

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therapist/team leader, early	
intervention teacher, computer specialist, family support worker, music specialist, physiotherapist, play room co-ordinator	

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Characteristics of relationship-based ear	y intervention services	Resulting outcomes for children famili	es, communities and societies
Contextual and interpersonal	Individual and intrapersonal	Individual and intrapersonal	Contextual and interpersonal
 Legislation and QA for the recognition of the importance of a strengthis-based, ecological, relational, reflective, family-centred approach to provision of EI services Permission and opportunity to build relationships with and love children/families Recognition of balance between professional disciplinary aspecialism and shared interdisciplinary perspectives Recognition of the value of theory to practice In EI services Opportunities to give families time to talk with professionals and other families Opportunities for professional joint training Opportunities for professional development within the context of teamwork. Permission to support transitions within programmes, between professional school 	 Reflective empathetic approach Respect for family patterns, interactions and priorities Celebration of each child's (and families') strengths and competencies Ability to explain both <i>why</i> and <i>how</i> interventions are chosen and model to parents in an empowering way Enthusiasm to work with children within the context of families Ability to think contextually and hobisically about children Enthusiasm for the relationship- based model and ethos Motivation to engage in the programme long-term to ensure consistency of staff and teams Ability to take account of other professional disciplines 	 Professionals: Place parent-child relationship at the centre of programmes and individual plans Acknowledge and value the contribution of other professional disciplines Reflect critically on research and theory Be open to alternative ways to develop practice Value the development of teams balanced with professional develop matter evelopment Children: Progression and long term social and educational success Families: Parents know, understand and love their child Parent advocates Parental confidence (in themselves and their children) Perer support 	 Effective and timely communication between professionals and families Interdisciplinary meetings after El sessions to discuss children progress and development Pedagogy of listening, waiting and personalisation Responsiveness to family patterns, interactions, routines stressors and strengths Engaged families Actively participating childrer (and later young people) Knowledge transferred to fam and wider settings Community and societal understanding and tolerance Children (and young people) Widdisabilities make a positi contribution to community an society Inclusive, diverse, rich communities and societies

Figure 1: Applying relational pedagogy and professional love to early intervention services for children with complex disabilities These relationships are shown

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