

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

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## Summary of findings

### Context

For children at risk of or identified with developmental delays or disabilities Early Intervention (EI) services can alter developmental trajectories significantly. Current EI services in the UK run the risk of devaluing families' contribution to children's learning and development and children's varying competencies and strengths. The objective of this project was to visit the world-leading Champion Centre in New Zealand to learn about its relationship-based EI services for children with complex needs. The aim was 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 developmental delays and disabilities. The Champion Centre programme is provided in a centre-based model of service, in partnership with parents, and in accordance with international best practice. The programme is offered to children from birth to school age who have significant delays in at least two areas of development and is underpinned by five principles. These are that the programme is relational, family-centred, strengths-based, ecological and reflective.

### Main findings

All parents interviewed were able to recall celebrations and successes in terms of their child's development. Parents held high aspirations for their children's inclusion in education, employment and society. Parents reported challenges in daily living for children that ranged

**"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." (A parent)**

from communication to motor development, daily living and challenging behavior. 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. This highlights the role of peer support for parents in reducing stress factors that might disrupt relationships with their child and the benefits of a centre-based model of delivery.

Characteristics of the Champion Centre relationship-based EI services that were valued by parents included professionals empowering parents to support their child in the context of family life as well as preparing their child for formal education. They 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. This included listening to and responding sensitively to children and parents.

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 outside the Centre was also perceived to be important.

**“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.” (An SLT)**

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.

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 young people with disabilities. At the most profound level, there was the aspiration that the service could *“change brains for parent and child.”*

Observable social processes and structures 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.**

Recommendations for UK policy and practice include:

- A scoping study to assess the viability of an EI co-ordination service that provides a point of entry for referrals for children at risk of/identified with developmental delays and disabilities and their families, taking into account the Canterbury model of Health and Education working collaboratively together under this umbrella. The aim would be to promote an ethos of informed choice about EI services in a way that empowers parents and reduces family stress.
- A scoping study into the feasibility of an Early Intervention Teacher post-graduate qualification that recognises the additional child development, pedagogical expertise and interdisciplinary practice required to work with children with complex needs and their families. This would include models of teaching, learning, delivery and subject content and include contributions from the European and International community on Early Childhood Intervention as well as the Champion Centre.

- Funding for 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 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.
- Consideration of the concept of nationally approved Specialist Service Standards that identify the features of effective practice for specialist services for children, young people and families.



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## Abbreviations

<b>ASD</b>	Autistic Spectrum Disorder
<b>BCU</b>	Birmingham City University
<b>CP</b>	Cerebral Palsy
<b>CoP</b>	Code of Practice
<b>DS</b>	Down Syndrome
<b>EI</b>	Early Intervention
<b>EIT</b>	Early Intervention Teacher
<b>ESW</b>	Education Support Worker
<b>GDD</b>	Global Developmental Delay
<b>MOE</b>	Ministry of Education
<b>NZ</b>	New Zealand
<b>OT</b>	Occupational Therapist
<b>PT</b>	Physiotherapist
<b>TA</b>	Teacher Aide
<b>SEN</b>	Special Educational Needs
<b>SLT</b>	Speech and Language Therapist
<b>UK</b>	United Kingdom
<b>WCMT</b>	Winston Churchill Memorial Trust



## 1. Introduction

The many benefits of early intervention (EI) for children, families, and communities where adequate resources are available have been well documented (see Guralnick, 2005; Heckman, 2006). The United Nations has adopted two international human rights treaties that, when taken together, articulate the human right to EI for infants and young children with disabilities. These treaties, the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), also describe the standards by which all States Parties can guide the development of programs, services, and laws necessary to comply with the Conventions.

EI programmes can prevent risk factors from exerting negative influences on children's development (Field, 2010; Marmot, 2010; Munro, 2011; Allen, 2011). For children with intellectual disabilities, EI can not only minimise intellectual delay, but other secondary complications as well (Guralnick and Albertini, 2006). Given the wide variability in the nature and quality of EI programmes internationally, Pretis (2006) argues for a common set of principles to guide them. These would include but not be limited to inclusion, child and family-centred activities and empowerment.

Currently 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 Pensions/Department of Health and Ministry of Justice, 2014) and the Special Educational Needs (SEN) Code of Practice (DfE/Department Of Health, 2015). The Early Intervention Foundation (<http://www.eif.org.uk/>) assesses the evidence in terms of impact and cost of EI. However the Foundation is not specific to Early Childhood and there is a focus on decontextualised programmes that risk devaluing family practices and children's varying competencies.

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. In theory 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 settings which is 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 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.

The emotional and practical considerations of raising a child with a developmental delay or disability are discussed in Carpenter *et al* (2015). However it is important to acknowledge the range of emotions experienced by parents (from joy to grief, denial and shock) which are largely contingent upon their own emotional resilience and resources (including family/community support), the nature and degree of disability experienced by their child and how obvious or ‘hidden’ the disability is, tolerance and acceptance by community and cultures they live in and financial and practical support provided by EI services.

## **2. Aims and objectives of this Fellowship**

Taking this into account, the objective of this project was to visit the world-leading Champion Centre in New Zealand (NZ) to learn about their relationship-based EI services for children with complex needs. The aim was 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 disabilities. The objective was to capture effective and best practice and build international relationships within an interdisciplinary context that could be mutually beneficial for all stakeholders concerned with children with complex disabilities.

## **3. Methods and ethical considerations of undertaking this Fellowship**

Given the complex nature of the model, I considered it important to immerse myself in the Centre for a lengthy period in order to fully understand the social and physical processes and structures that underpin delivery of the model as well as socio-cultural dimensions of Christchurch where the Centre is located. Therefore the majority of my visit to New Zealand was spent in Christchurch/at the Champion Centre.

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. I also visited the mainstream community pre-school of one of the children who, like most others over three, combines attendance at the Champion Centre with attendance at a community pre-school. Therapy staff and the senior leadership team were interviewed and Centre documentation reviewed and analysed. The visit was undertaken in September 2015.

In the balance of the trip, I visited a number of special schools in Auckland and Hamilton to widen my knowledge of the education provision in New Zealand for children with disabilities and had meetings with a Ministry of Education Educational Psychologist and Specialist Teacher. In addition I had the opportunity to present a Prestige Lecture at the University of Canterbury <http://www.education.canterbury.ac.nz/seminars/> and two seminars to interdisciplinary professionals in Auckland and Hamilton. However this report will mainly focus on observations and discussions undertaken at the Champion Centre due to time and space constraints.

The project was approved by the Faculty of Health, Education and Life Sciences Ethics Committee at Birmingham City University. 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 have been protected by the use of pseudonyms. Data were stored securely on University equipment and analysed thematically in order to reduce bias. 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. However, the researcher was encouraged to build relationships with families in accordance with the overall ethos of relational pedagogy that inheres within the model.

#### **4. Theoretical assumptions**

This project is underpinned by a number of theoretical beliefs and assumptions held by the researcher about children's development. Firstly, the influence of interactions between developing children and the environment(s) they inhabit on their learning and development is acknowledged. More importantly, the plasticity or potential for change in children's development is recognised. This suggests the concept of the engagement of an active child with their environment and a view that the application of intervention can improve the course and context of development (Bronfenbrenner, 1974; Lerner, 2002) allowing the study of what is development to what could be development (Bronfenbrenner, 1993).

Bronfenbrenner's (1979; 1993) bioecological model acknowledges that children grow and develop in a social and cultural context influenced by the bi-directional interactions and relationships within and between the environments they inhabit. Their learning and development is therefore socially and culturally constructed through interactions and

relationships with others in environments where meanings and languages are shared, as summarised by Bronfenbrenner (2001: 6965):

Over the life course, human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving bio-psychological human organism and the persons, objects, and symbols in its immediate external environments. To be effective the interactions must occur on a fairly regular basis over extended periods of time.

However, Bronfenbrenner did not closely define the proximal processes within relationships that promoted sustained interactions noted to be fundamental for children's socio-emotional, communication and cognitive development (Brazleton and Greenspan, 2000). Specifically he did not describe the characteristics of social interactions between caregivers and children that provide the stimulus for development, such as maternal sensitivity.

Maternal sensitivity is a central concept used in theories relating to attachment and bonding and early mother-child interactions, the most important tenet of which is that social and emotional development is contingent upon an infant developing a relationship with at least one primary caregiver. This primary caregiver is usually but not necessarily a maternal figure. Infants form attachments to any consistent caregiver who engages in sensitive and responsive transactional, bi-directional social interactions with them. According to Cassidy (1999) the quality of the social engagement is more influential than the amount of time spent in interaction. Ainsworth *et al.*, (1978) defined caregiver sensitivity as the availability and alertness of the caregiver in well-timed responses to the child's signals, consistent with a degree of control and negotiation of conflicting goals. Account is taken of the individual characteristics of both children and caregivers, as well as the influence of the context of interactions, and the differential afforded by the same parent to different children at each age and stage of their development. A feature of sensitivity for pre-verbal infants is the question of whether or not mothers treat their children as if they were "intentional agents" (Meins and Fernyhough, 1999: 364) with a mind of their own and therefore communicate intentionality at the earliest stages of development. Mind-mindedness characterises social interaction involved in early caregiver-child interactions, and in particular, the proclivity of a mother to treat her child as an individual with a mind from an early age. Sensitive adults attribute intent to an infant's early vocalisations by interpreting the possible meaning of infant behaviour and vocalisations (Meins and Fernyhough, 2006). Therefore in order to understand what an infant is trying to communicate in their early babbling and coos, is necessary to recognise that the infant is actually *intending* to convey some message. In other words, when mothers listen and respond to their infant's early behaviours and vocalisations, they demonstrate mind-mindedness (Meins, 1997). They perceive these vocalisations as intentional communication rather than inconsequential utterances without agenda or meaning, and interpret them using past knowledge of the child and concurrent gestures (Meins and Fernyhough, 1999). These early social interactions are important as children internalise them over time. This is the process by which the development of all higher mental processes occurs through the co-

construction of an active child and caregiver making meaning of shared experiences (Vygotsky, 1978).

These concepts are important to recognise and acknowledge in the delivery of EI services. If early relationships are disrupted or compromised due to parent/child characteristics, then interventions that seek to address this would seem to provide efficacy. Professionals who care for and support young children in educational settings might also relate to children (especially infants) in this manner, demonstrating the concept of ‘professional love’ (Page, 2014).

## **5. The early intervention service provision in Canterbury, NZ**

Christchurch is the principal City of the Province of Canterbury in NZ. EI services for young children (aged birth to six) in Canterbury that are funded by the Ministry of Education (MOE) and are delivered by the Ministry of Education itself and by three NGO services (of which the Champion Centre is one) subcontracted by the Ministry of Education. Entry into the Champion Centre (and other EI services funded by the MOE) is via the Early Intervention Co-ordination Service (EICS) which acts as a single point of entry following referral by paediatricians for all four services in the Christchurch region (see Appendix A for details of the four services).

When children are born or diagnosed in infancy/early childhood with developmental delays and disabilities that are significant enough to qualify for multi-disciplinary EI services, paediatricians refer the child and family to EICS. The clinical representatives of all four of the services that make up EICS then make offers to families based on capacity and child needs. The EICS coordinator then informs the families of the choices on offer and invites them to choose the service that best suits their needs. In making their offers to families, providers try to ensure that no family is waiting more than a month for a service.

The aim of EI provision is to ensure that all children with delays and disabilities can reach their full potential and no child “falls through the cracks”. Compulsory education in NZ commences at the age of six although children are entitled to attend school from their fifth birthday and the vast majority of parents choose this option for their children. If children with significant needs attend mainstream school, they are entitled to support under the Ongoing Resourcing Scheme (ORS) which funds teacher aide (TA) and specialist teacher support.

All specialist services for children and young people across the age range funded by the MOE must follow the Specialist Service Standards (MOE, 2006) which aim to ensure consistent quality specialist provision for children and young people with SEN. A cyclical process that provides principles of practice from access and delivery through to reflection is promoted. The standards reflect the MOE’s goals of:

- Excellence in teaching,
- Community engagement, and
- Quality providers to achieve the best possible outcomes for all children and young people. (MOE, 2006: 12)

Principles for practice include:

- Coordinated and collaborative
- Active participation of children
- Consistent with government strategies
- Evidence-based
- Engaged families/whānau
- Outcome focused
- Ecological approach
- Culturally affirming
- Preventative
- Inclusive

Compliance with the standards is maintained by means of three-yearly on-site reviews carried out by teams of senior Ministry of Education Special Education professionals, augmented by participation from the NGO sector, schools and parents.

## 6. Background to the Champion Centre

The Champion Centre provides multi-disciplinary EI services for infants and young children with significant disabilities and their families. The programme is offered in a centre-based model of service, in partnership with parents, and in accordance with international best practice. Research and advocacy underpin this.<sup>1</sup>

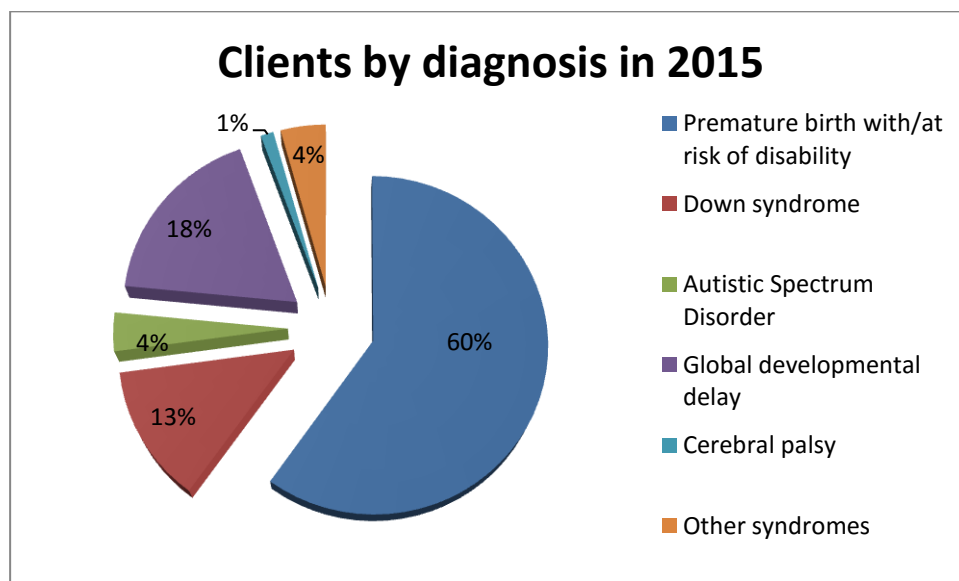


Figure 1 Percentage of children who attend the Champion Centre by diagnosis/condition in 2015

Source: Champion Centre Annual Report for the financial year ending 30<sup>th</sup> June 2015.

<sup>1</sup> There are two strategic goals reported in the Champion Centre's Strategic Plan 2015 – 2020. These are: 1. To provide long-term sustainability of the Champion Centre service for infants and young children with disabilities; 2. To advocate for children with disabilities through training and research.

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. Figure 1 shows the percentage of children by primary diagnosis in 2015 among the 163 children in the service. Children who participate come from predominantly European NZ heritage, however, approximately 13% of children are of Maori heritage and 2% are from Pasifika heritage

### **Delivery of the programme**

A full description of the principles of the Champion Centre EI Service can be found on the website <http://www.championcentre.org.nz/>. Briefly, the website and programme information state that the service is based on the philosophy that all learning occurs in the context of healthy relationships between the infant or child and those who live with and love them. The Service operates from the perspective that every child, no matter what developmental challenges they face, will learn and grow through the intervention of skilled therapists and informed parents/caregivers. The Champion Centre programmes are underpinned by five principles to successful EI services. These are that EI services should be relational, family-centred, strengths-based, ecological and reflective.

An integrated individual therapeutic programme is developed for each child by the team with the family/whānau (Maori word for extended family). It is based on an understanding of human development and on the New Zealand Early Childhood Curriculum, Te Whāriki. It is carried out through a combination of hands-on therapy and generalisation/extension activities at the Champion Centre and by the family/whānau in their home/community. The Centre operates in accordance with the Treaty of Waitangi, signed in 1840 between Maori and the British Crown, and with the ongoing requirements for bi-culturalism in all educational settings.<sup>2</sup>

Professionals at the Centre work in partnership with parents/caregivers to provide a family-focused, strengths-based EI programme. For those attending the full multi-disciplinary programme, 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 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

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<sup>2</sup> Christchurch has a small percentage of Maori in the general population compared with elsewhere in NZ - 7% compared with up to 90% in other areas. However, as mentioned above, 13% of children attending the Centre are of Maori heritage



inclusion in an appropriate school setting. Children born prematurely with no major developmental challenges attend weekly until they are four months corrected and then go to a less frequent rotation of visits, provided their development is tracking within acceptable limits.



*Figure 2 Champion Centre*

The model of delivery is based on ecological theory (Bronfenbrenner, 1979; 1993) and recognises the influence of the multiple integrative influences on children's learning and development over time. It achieves ecological validity through the systematic incorporation of the child's family and home life, early childhood centre and finally school into the child's programme. This "wrap-around" service includes visits by a dietician, podiatrist, and visual and hearing resource specialists, Early Childhood Centres and schools. Details of the programmes and parents' journey with the Centre can be found in Appendix B and C.

## **7. Results**

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



*Table 1 Details of children and families who participated*

<b>Age/Gender</b>	<b>Diagnosis</b>	<b>Programme</b>	<b>Ethnicity</b>	<b>I/O</b>
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

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. There is also a monitoring programme for children born prematurely and the Relating and Communicating Programme is for children whose main difficulty is being in relationship with others and who are generally also highly anxious.

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.

*Table 2 Details of professionals who participated*

<b>Team</b>	<b>Participant Job Titles</b>	<b>Type of Interview</b>	<b>Number of professionals</b>
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 therapist/team leader, early intervention teacher, computer specialist, family support worker, music specialist, physiotherapist, play room co-ordinator	Team Interview	7

## 7.1 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 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.”



*Figure 3 The music therapist works with a child and his mother on standing*

### **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."

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."



*Figure 4 A child playing while his mother talks to professionals in the Baby Programme*

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.



*Figure 5 A child bonding with his father in the music room*

### **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:

"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. The mother of the youngest child was also more concerned with the immediate future and did not express concerns about the long term future due to her daughter's age.

## **7.2 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.



*Figure 6 A child learning about reading and language in the Middle Years Programme with her mother and early intervention teacher*

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, which can sometimes be challenging as described later. As well as working with other agencies to ensure effective delivery of the Service, the Centre offers training to other professionals about aspects of child development such as prematurity, thereby extending the professional knowledge that inheres within the model to the general community. Working in collaboration with other EI providers in the area is fundamental to sustainability and ensuring quality across the sector.

### **Key characteristics of relationship-based EI Services**

Essential components in relationship-based EI services suggested by professionals were extremely varied. All five 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

In describing the key characteristics of the Champion Centre, 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.<sup>3</sup> 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.

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<sup>3</sup> The Champion Centre conducts research about children’s development with parents using a series of questionnaires that focus on everyday functioning. The results are available to parents and professionals at the Champion Centre and show the impact of EI, and of the efforts of children and their families to learn, on children’s development over time.



*Figure 7: L to R: Clinical Practice Manager (and SLT), Champion Centre Director, Family Services Manager (and psychologist)*

### **Challenges in delivering the Champion Centre Model**

Inadequate funding was deemed by all professional teams as the most significant challenge in delivering the Champion Centre EI service. For therapists, there were concerns related to pay and career pathways and it was stressed that sustainability and consistency of the workforce relies on professionals employed at the Centre holding quite altruistic values in terms of their work with children and families. For the Centre Director the lack of adequate funding had implications that are related to significant effort being required to raise sufficient funds to meet the shortfall between the cost of delivering the service and the funding provided by the government as well as concerns related to staff employment and careers:

“There’s a frustration that we’ve been filling the gaps and joining these services up with private funding, filling the mortar between the bricks for the last 35 plus years. I keep saying to people, come and have a look and see what it’s like, see how it works.”

This is especially challenging considering that funding derives from a number of government sources including the Ministry of Education, the Ministry of Social Development and the Ministry of Health. Grant terms vary in the time-scales and terms upon which they are given, making long-term planning complex.

In addition to funding concerns, some professionals also mentioned the challenge and importance of communicating with other agencies outside of the Champion Centre, especially when children transition to school. The emotional aspects of delivering the service as well as the tension of balancing the needs of children with the needs of families, which do not always operate in harmony, were also described as challenging by one professional each. One professional stated that parents themselves do not always understand the Champion Centre service which has the potential to place the therapist-parent relationship at risk.

By contrast, 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**

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. Following this, 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. The Centre Director explained that children often enter the Relating and Communicating Programme with a diagnosis of autistic spectrum disorder from their paediatrician and transition from the programme without the diagnosis. In addition, often parents understand

their own difficulties in life by being enabled to understand their child's difficulties allowing them to reflect on their relationships through life. As stated by the Director "with the current focus on neuroplasticity, we can change brains for parent and child."

### 7.3 Observations

Nine children were observed in their EI sessions (three children attending each of the EI Programmes) with accompanying family members as shown in Table 4 below.

*Table 3 EI programmes and sessions that children were observed in*

<b>Child</b>	<b>Programme</b>	<b>Sessions Observed in</b>	<b>Family Members Present</b>
9 months (F)	Baby Programme	EI Teaching, Physiotherapy Speech and Language Therapy	Mother
11 months (M)	Baby Programme	EI Teaching, Physiotherapy Speech and Language Therapy	Mother
18 months (M)	Baby Programme	EI Teaching, Physiotherapy Speech and Language Therapy	Mother and paternal grandmother
25 months (F)	Middle Years Programme	Play Therapy, Group Music, Physiotherapy, Playroom, See and Learn	Mother
27 months (M)	Middle Years Programme	Music Therapy, Computer Room, Speech and Language Therapy, Visiting Vision Impairment Specialist	Mother and maternal grandfather
30 months (F)	Middle Years Programme	Early Intervention Teaching, Playroom, Speech and Language Therapy, Music Therapy, Play Therapy	Mother and paternal Grandmother
48 months (M)	Transition Programme	Computer Room, Music Therapy, Playroom, Outdoors with Physiotherapy, Speech and Language Therapy	Mother
54 months (F)	Transition Programme	Computer Room, Play Room, Physiotherapy, Early Intervention Teaching, Speech and Language Therapy and Music Therapy	Mother
60 months (M)	Transition Programme	Music Therapy, Computer Room, Occupational Therapy, Speech and Language Therapy and Play sessions	Father

### Physical processes and structures

The Champion Centre is located on the site of Burwood Hospital, where there is a separate car park and entrance to the Champion Centre and a formal but friendly reception area. The Centre is divided into discrete areas for music therapy, computer supported learning, each of

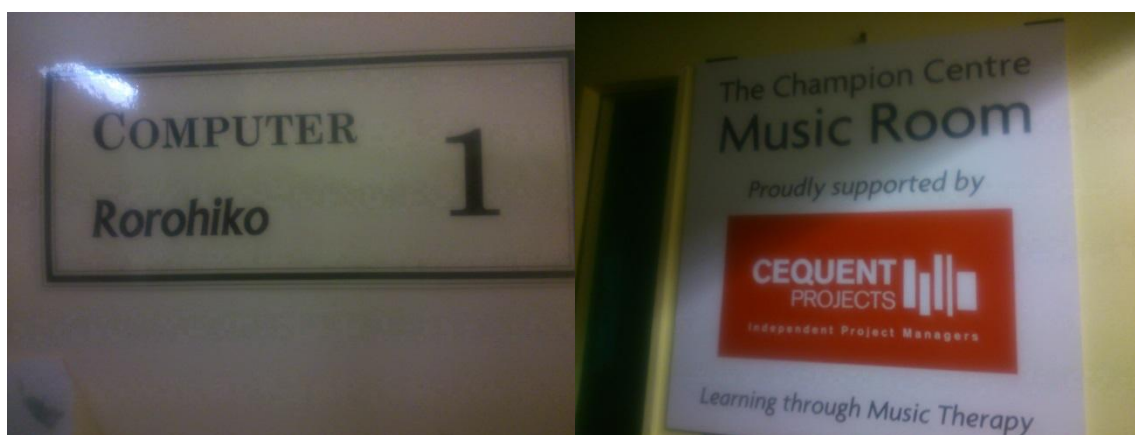
the main programmes, the relating and communicating programme, play rooms, a family kitchen, sensory outdoor play area, and quiet rooms for sensitive discussions with families.

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 as shown in Figure 8 below:



*Figure 8 Visual Timetable of morning sessions for parents and children. The photos of are of the physiotherapist, early intervention teacher and speech therapist respectively.*

Therapy rooms are clearly labelled enabling children and families to become familiar with rooms and sequences of interactions within them as shown below:



*Figure 9 Computer and music therapy rooms at the Champion Centre*

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***

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. The level of interpretation of infants' pre-verbal signals and signs required a degree of sensitive mind-minded (Meins and Fernyhough, 2006) caregiving from professionals towards children. 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 such as tissue boxes combined with tinsel or tissue paper 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*



*Figure 10 Early intervention teacher and physiotherapist work collaboratively with a child on his motor skills in the Baby Programme*

Collaborative, integrated and interdisciplinary working was observed to be the most consistent and strongest theme in delivery of the programme. This was so profound that when observing professionals, prior knowledge of their professional background was necessary to discriminate the therapy being delivered. 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. All professionals used songs for transitioning into and out of therapy sessions to signal to children when something was ending and something new beginning.

### *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’s 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.

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*



*Figure 11 A child working on her motor skills in a physiotherapy session with her mother*

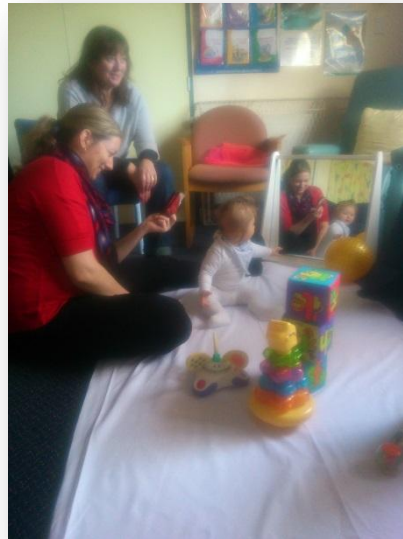
The programme was observed to be one that relies on engagement from families and active participation of children in their sessions. Families are empowered and enabled to engage at the level that is comfortable and appropriate for them according to their own psychobiology. For example during music therapy 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.

## 8. Case studies <sup>4</sup>

### Case Study 1: Jasmine



*Figure 12 Jasmine with her mother and early intervention teacher in the Baby Programme*

#### Background

Jasmine is an only child and lives with her adoptive parents in a river town in North Canterbury. Her adoptive parents are of NZ European/South African heritage and she is nine months old. Jasmine is diagnosed with developmental delay and asymptomatic CMV infection. Jasmine currently attends the Champion Centre with her parents for weekly sessions in the Baby Programme. She has been attending the Champion Centre since she was six weeks old

Jasmine's birth mother was an intravenous drug user but had abstained from using for some time before she became pregnant. Even so, there were concerns by the paediatricians at the hospital that the early symptoms Jasmine was displaying resembled withdrawals. This had not been confirmed at the time of this project by the hospital, but genetic testing and MRI and ultrasound scans had been instigated. Her adoptive mother stated that they had chosen the Champion Centre in preference to other EI services partly due to recommendations from friends who had accessed the service previously and also because they felt that a centre-based delivery would provide socialisation benefits for both Jasmine and herself.

Jasmine was observed at the Champion Centre in early intervention teacher, OT and SLT sessions. She is pre-verbal, and at the time was working on promoting imitation, new sounds, hand-eye co-ordination and social referencing.

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<sup>4</sup> Pseudonyms have been used in the case studies in order to protect children's identities in accordance with BCU ethical guidelines.

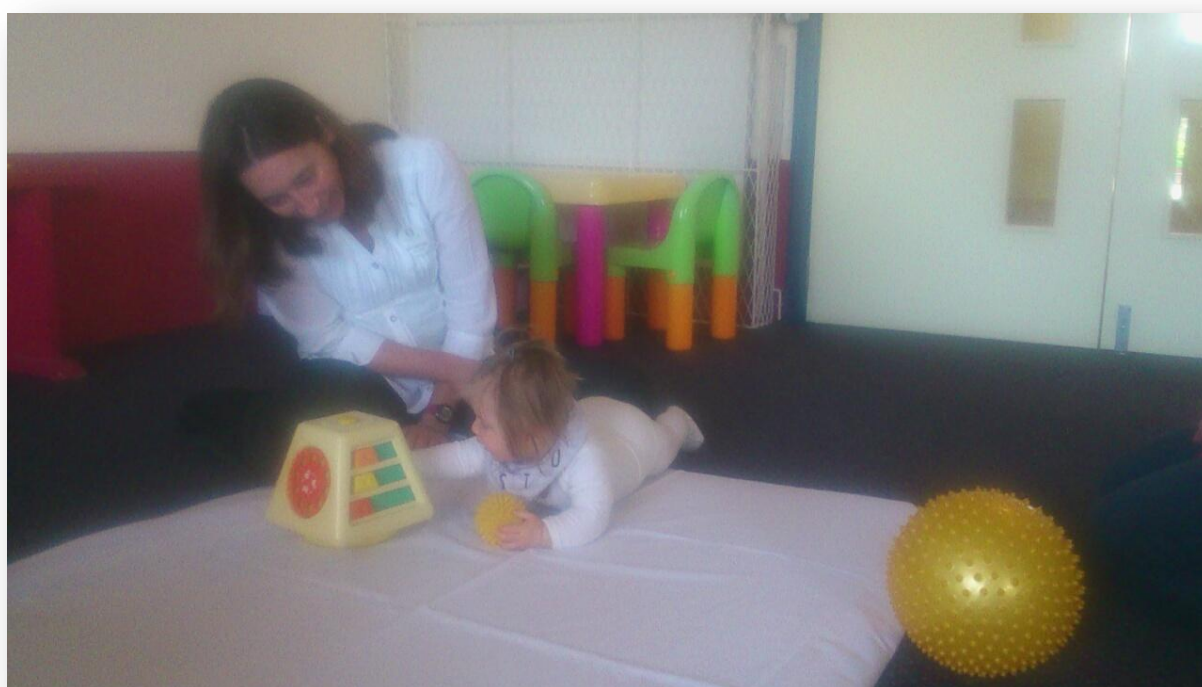
Jasmine's mother has a close relationship and frequent support from her partners' parents as well as friends. Her partner's mother lives locally and visits the family at least four times a week. The family is also supported by Plunket<sup>5</sup>, a neonatal outreach nurse and the family doctor in Belfast.

### **Celebrations and successes**

Jasmine's mother stated that as Jasmine's diagnoses was an "uncertain entity" and her level of delay unknown, they were thrilled that currently she appears to be making progress along the development path and "the fact that she's doing something new every week is awesome." However, she acknowledged that she requires careful ongoing monitoring due to her diagnosis.

### **Challenges**

Jasmine's mother reported that they had been made aware that delays and difficulties for Jasmine may not be obvious or become manifest for some years to come. However currently there were no significant challenges or difficulties in daily living that impacted upon family life.



*Figure 13 Jasmine with the Physiotherapist at the Champion Centre*

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<sup>5</sup> Plunket nurses are part of a nationally funded service of registered nurses with a speciality qualification in Well Child/Tamariki Ora nursing. Plunket kaiāwhina and community karitane (including Māori and Pacific health workers) are educated in a wide range of parenting and health issues to give extra support to family and whānau.

### **Perceptions of the Champion Centre**

Jasmine's mother stressed how reassuring it was to attend the Champion Centre with her daughter and learn about child development. As a result of this she felt that she knew the stage that her daughter should have reached and received regular confirmation that she was within expected developmental parameters. She particularly valued being listened to by professionals and their non-judgemental approach to working with families stressing the emotional impact of this on family life:

“Arriving at the Champion Centre each week is like getting a massive hug. It almost feels like coming home at Christmas. There's no judgement. There's always someone to listen if you need to talk. The support is fabulous – both for Jasmine and with the EI team and the Social Workers for the family as a whole.”

Jasmine's mother particularly likes the way that each discipline integrates with the others and works to create “a truly cohesive learning environment.” She feels confident that any delays or difficulties in Jasmine's development will be identified early and effectively supported to ensure “the best possible outcome.” She reported feeling fully involved in a very “hands-on” way in her daughter's learning and development at the Champion Centre and valued the feedback and explanations from professionals about why particular activities were being offered.

### **Inclusion in education, employment and society**

Jasmine's mother hopes that her daughter will not experience any long-term or severe learning difficulties and aspires for her daughter to thrive in mainstream education. Subsequent to this she hopes that she will succeed in her chosen career and currently does not have any concerns that she will not be able to achieve this, stressing the role of ongoing monitoring for children at the Champion Centre. She is confident that the Champion Centre is helping her daughter to achieve “base skills required to reach milestones going forward.”

## Case Study 2: Emma



*Figure 14 Emma in the play room at the Champion Centre*

### Background

Emma is the middle child of three and lives with her parents and siblings in an urban area of Canterbury. She is of NZ European heritage and is two years; six months old. She has been diagnosed with global developmental delay with particular difficulties in personal, social and gross motor parameters. Genetic testing has been carried out but nothing specific has been identified to date. Emma had initially been assessed by the Ministry of Education (MOE) as being at a 9-12 month level developmentally at 22 months old and there were difficulties in both receptive and expressive language. Emma's mother stated that her daughter also found it difficult to express affection saying that she was "not one of those children that you can just grab and hug." Emma relies on routine and when this is absent or her normal routine changed, she becomes anxious and overwhelmed. She also has erratic sleep patterns and sensory processing difficulties. Emma's mother stressed the difficulty of having a child with an "invisible disability" in that Emma's difficulties do not manifest in her physical appearance. In addition she has observed Emma's difficulties becoming worse over time:

"More and more she is hand flapping and the repetition and kicking is getting worse. She is a beautiful child and so infectious but you see more when she's with her peers in that she's very different. She has a great personality, but she is different."

Parents have the support of family nearby (mum's sister and paternal grandmother) and a wide friendship network. However, they do not have any close friends who have a child with Special Needs which Emma's mother reported as being difficult as she felt that other people did not understand Emma's behaviour.

Emma currently attends the Champion Centre for weekly sessions in the Middle Years Programme. She has been attending the Champion Centre since she was two years old after transferring from another EI service. Emma's mother reported that she had found the other service "disjointed" and in contrast to the centre-based service at the Champion Centre the service was delivered in the home fortnightly. She expressed concern about the rate of progress for her daughter if this service had continued. However, following an assessment by the SLT from the MOE Emma's needs were highlighted as being more complex than originally perceived. This resulted in the family being offered the opportunity to engage with one of the multi-disciplinary services (via EICS) and the family chose the Champion Centre. Emma's mother described the decision to transfer to the Champion Centre as a "no brainer" especially since the Champion Centre EI service included music therapy which "calms Emma.. she loves music and sings a lot."

Emma was observed at the Champion Centre in early intervention teaching, playroom, SLT, music therapy, play therapy. She also regularly participates in OT and physiotherapy, but this was not observed. At the time of the observation, Emma's learning outcomes and long-term goals included independent dressing, bilateral skills, joint attention and focus, generalising matching skills, and achieving single leg stance. Emma's current specific learning goals included the following, grouped under the headings of the New Zealand early childhood curriculum, Te Whāriki:

#### Wellbeing

- Independently remove her trousers.

#### Belonging and Contribution

- Transition willingly to new activities with visual support.

#### Communication

- Name family members.
- Will consistently point to/indicate 15 named items/people on request (one at a time).

#### Cognition and fine motor

- Open a variety of containers using two hands.
- Share a whole book with a familiar adult.
- Match a range of objects.

#### Sensory processing and gross motor

- Go up and down steps with a single leg stance.
- Climb the ladder up to the trampoline at home.
- Tolerate two different deep pressure activities.
- Tolerate two different messy play activities.



*Figure 15 Emma with her mother, SLT and maternal grandmother at the Champion Centre*

### **Celebrations and successes**

Emma's mother was able to describe successes for Emma at home and at the Champion Centre. At home she particularly remembered Emma learning to walk two days before her second birthday. This was significant because previously she had "knee-walked" or been carried by parents, which made it difficult for her to interact with her siblings and peers at home and in social spaces such as playgrounds

"For her to be mobile means she can be happy and independent. We can take her to a playground and she can run around and be happy. If everyone else is running around, she can do the same. So actually it's just given her the independence so it makes her less frustrated."

At the Champion Centre her mother was particularly satisfied with Emma's progress in communication skills. Since attending the Champion Centre Emma's mother had observed rapid progress in her daughter's level of understanding, use of language and motivation to express affection, all of which she attributes to the routines and therapeutic approaches offered at the Champion Centre:

"We've noticed a big change at home in that when we ask her to do something, she understands a lot better. Since she started coming here, she's just come so far in her development. Before she didn't even say "mum" and now she does and that's very special. Now she wants to come and cuddle you more and I think that's coming with her understanding more and us understanding more about where she's at."



She can now categorise and generalise which means that she can identify that the word “daddy” only applies to her own daddy rather than all men. In addition she now knows her siblings’ names, which has helped with family relationships. Emma’s mother qualified this statement by saying that her daughter was:

“... still Emma and still has her quirks and condition. She’s a really smart girl but things just get jumbled inside. But we know more about how to get more out of her.”

### **Challenges**

Emma’s mother reported challenges for Emma include being socially and emotionally a lot younger than she is. She can also become easily over-whelmed and anxious and relies on sleeping with parents to be content at night. This means that going out to social groups such as Tumble Time requires preparation and management to monitor her emotional regulation.

### **Perceptions of the Champion Centre**

Emma’s mother was particularly appreciative of the way that staff at the Champion Centre had helped her to understand her daughter and to talk to her in meaningful ways that enabled Emma to understand others better. She described the non-judgemental manner of well-trained professionals as contributing to a “top quality education” for her daughter. She also described strategies suggested by the Champion Centre such as using simple instructions and key words to scaffold Emma’s receptive language. In addition to this the integration of all of the therapists under one roof that Emma can access weekly and the joined-up conversations that occur between professionals so that “everyone knows everything about her” were perceived by her mother as beneficial.

Although Emma’s mother was confident of the benefits of all of the therapies offered to her daughter, she felt that Music Therapy was particularly beneficial because Emma responds well to tone and pitch in segmenting other people’s speech. She also feels that music is beneficial for Emma’s emotional regulation as she finds it calming. However, she stressed the benefits of all of the therapies and the integrated model employed by the Champion Centre as well as the model of empowering parents to help their children at home and throughout life saying “they’re teaching us to teach Emma.” Emma’s mother reported being fully involved in all aspects of her daughter’s learning and development at the Champion Centre and that this transferred to family life, stressing that it was a “huge learning curve for the whole family.”

### **Inclusion in education, employment and society**

Emma’s mother is hopeful that Emma will go to mainstream primary school alongside her typically developing peers and be “not too far behind” them in terms of development. Emma’s mother has aspirations for Emma that include living independently. She acknowledged that she might need support with this and with finding and sustaining employment. Her overall aim is for Emma to be included in everything and she expressed determination that she was going to “push for her to get as much as she can have” in terms of support and assistance, both practical and financial:



“Just because she has special needs doesn’t mean she can’t have everything, she’s very clever in her own way.”

In this regard, her mother felt that Emma’s experience at the Champion Centre was helping her to be the “best that she can be.”

## Case Study 3: George



*Figure 16 George in the play room at the Champion Centre*

### Background

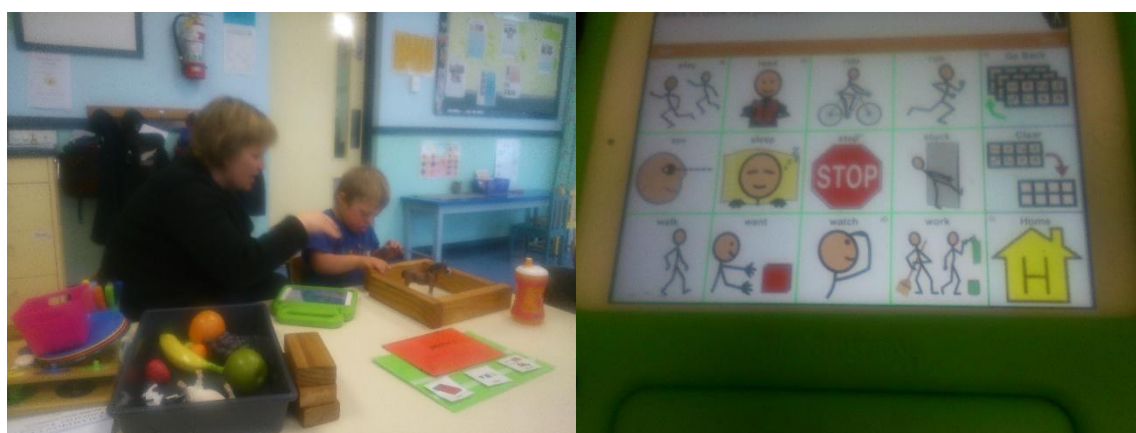
George is the eldest child of three and lives with his parents and two younger siblings on a dairy farm in a rural area, some 40 miles from the Champion Centre. He is of NZ European heritage and is five years old. He has Down Syndrome (DS) and has associated learning difficulties although he does not have any of the associated health difficulties such as organ damage. However, he had early feeding difficulties and spent some time in NICU<sup>6</sup> during his early infancy at which time he was naso-gastric tube fed.

George currently attends the Champion Centre with his parents for weekly sessions in the Transition to School programme. He has been attending the Champion Centre since he was two months old. His parents chose the Champion Centre over other EI services due to the centre-delivery model which they felt would be beneficial for themselves as well as their son. They identified benefits for themselves in being able to talk to other parents of children with DS and share experiences. Perceived benefits for George were in socialising with other children at the Centre and receiving specialist intervention from a range of professionals every week in a manner that was integrated and delivered in one location. He also attends a mainstream playgroup and is supported there by an education support worker (ESW) from the Champion Centre.

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<sup>6</sup> A neonatal intensive-care unit (NICU), also known as an intensive care nursery (ICN), is an intensive-care unit specialising in the care of ill or premature newborn infants.

George was observed at the Champion Centre in music, computer supported learning, OT, SLT and play sessions. He communicates using words, gesture and signs which are augmented with a tablet as shown below:



*Figure 17 George uses a tablet and signs to augment his verbal communication*

At the time of the observation, George's learning outcomes and long term goals included increasing toileting awareness, increasing independence in self-help skills, increasing attention to task, increasing expressive communication skills, increasing fine motor skills, and increasing understanding of number, extend balance and co-ordination. George's current specific learning goals (in Te Whāriki categories) were:

#### Health and well being

- Use the potty at regular intervals.
- Take his shorts off before bath time.
- Put a rolled up T Shirt over his head.

#### Belonging and contribution

- Attend to and complete an activity.
- Continue/extend use of 'sign names for familiar people putting hello and name together.
- Improved compliance with following a request/instruction.

#### Communication

- Will label emotions (happy, sad) using sign or POKD (pg 23a and b) (visual communication cards and books)
- Increase his navigation skills in POKD/iPad – to be able to find places and activities page sets i.e. 2-3 page turns (with physical support)
- Increase his awareness of loud/quiet voices.

#### Cognition and fine motor

- Snip a strip of paper using spring loaded scissors.
- Match pictures of groups of 2 and 3.

#### Sensory processing and gross motor

- Use a 3 wheel scooter.

Although it had been suggested in pregnancy following a scan that there was a possibility of George having DS, a subsequent scan confirmed that the likelihood of this was 1/500. It was therefore a shock for parents to discover that George had DS when he was born. However, parents have a wide family and friend network who live nearby, which they felt contributed to their ability to manage family life. The community of other parents of children with DS whose children attend the Champion Centre with their son was a highly valued source of support. They also suggested that the obvious physical signs of DS combined with wide societal knowledge about the condition meant that people were generally tolerant and willing to “make allowances” in a way that they might not for less obvious and less understood conditions. They felt that this also contributed to the provision of Government funding for children with DS being more easily accessible than was the case for “hidden disabilities.”

### **Celebrations and successes**

Parents were able to describe successes and celebrations for George’s learning and development both at home and at the Champion Centre. However, they reported that because George’s development was “so gradual” they had difficulty remembering some of his earlier developmental milestones and tended to focus on the more recent and significant ones as described below.

Parents’ most memorable celebration of George’s learning and development at home related to his physical development, specifically running. This was significant because:

“It showed a level of co-ordination and strength and balance.. and it means he can now compete with his younger brother, chasing a ball... it opens up a lot more things for him and it’s good for his confidence.”

As far as his successes at the Champion Centre are concerned, his parents particularly remember him learning to ride a trike and learning to draw faces:

“It was a battle to get to him to hold a pen but once he started being interested, now he’ll do it on the screen or on paper and he loves it.. when he started liking drawing and he started drawing faces, he did it all the time.”

### **Challenges**

Parents also reported the challenges for George in daily living that mostly related to communication. They said that although he is slowly progressing in communication development, they had poor recall of any his early communication milestones. Listening to and following instructions is a particular challenge for George and parents have sought help from the Champion Centre psychologist in this regard who has explained that his difficulties relate to compliance and audio-visual response understanding. To support this, the psychologist has provided his parents with visual resources that are designed to scaffold George’s receptive language. His inability to express himself in a way that others can understand manifests in frustration and distress for George and his parents.



*Figure 18 George baking at home with his parents and younger brother*

His parents explained that George relies on routines and he functions well when he is fully occupied in meaningful ways. This means that he is happy and regulated when he has routine household jobs to employ his time such as folding the washing or emptying the dishwasher.

### **Perceptions of the Champion Centre**

Parents particularly valued the support and professional knowledge offered by the staff, particularly in the first two years (The Baby Programme) and later in the Transition to School Programme as George prepares for transition to school:

“The couch time with Jan in the first two years was invaluable...but now it’s things like George needs the school fenced off and we wouldn’t know where to start with that in knowing who to talk to. They just know about that and how to get the funding... and knowing what things to engage George in to activate his learning, things I take for granted or wouldn’t know to look for such as the way he climbs steps.”

Parents said that they felt fully involved in all of George’s activities at the Champion Centre which had contributed to parent-child bonding and relationships. This was something that George’s father particularly valued as he and George have a very “special bond.” Recently he had attended a ‘Dad’s Night’ at the Champion Centre where he had enjoyed talking to other Dads and sharing experiences. Parents described benefits of the ongoing monitoring and feedback from staff on George’s progression and the impact of this on family life,

stressing how motivating it was for them to know that he is progressing in areas where they do not feel skilled and knowledgeable themselves to assess, such as forming letters.

They value the role of the ESW in facilitating the transition into school by providing a bridge between pre-school and school, integrating George into the school environment in a stepped approach.

### **Inclusion in education, employment and society**

Parents expressed their concern in relation to George's education and future inclusion and employment in terms of his communication and issues related to safety:

“My main concern is around safety, the school has to be fenced before he goes... his lack of verbal communication and his ability to communicate with peers is a concern.”

They were reassured that his experiences at the Champion Centre would prepare him for inclusion in school life and were pleased that the teachers and teacher aides had been learning sign language in preparation for George's arrival and also that his tablet would be useful in augmenting his verbal communication and signs.

In describing their aspirations for his future, they envisage George attending high school and tertiary education which they felt would most likely be of a vocational nature. They aspire for him to gain meaningful employment. They described his strengths in terms of a “good visual memory” and hoped that he would find a job that would use utilise his ability to predict and adhere to routines positively. They felt reassured that although “George will always be a little unique, society is a lot more inclusive now” so they were confident that George would always be included.

## 9. Discussion

This project sought to identify the key characteristics of a relationship-based EI service that might be important for EI services in the UK to consider. 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). Also highlighted in the psychology literature is the significance of relationships between caregivers and children to their holistic development (Brazleton and Greenspan, 2000) and the relationship between the multiple integrative contexts that children grow and develop in (Bronfenbrenner, 1979; 1993). This reinforces the value of an EI service that places parent-child relationships at the core of its pedagogy.

The Champion Centre in 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.

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. Only one of them described emotions of grief in relation to their child's disabilities. However the same (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.

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. At the most profound level, there was the aspiration that the service could "change brains for parent and child."

Reported challenges to the successful and sustained delivery of the model mainly related to full, long-term funding of the service to enable long-term strategic planning and government policy to support family life and child development, including those related to parental leave.

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

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, mind-mind 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. There also appeared to be a distinctive model of professionalism held by staff who worked at the Centre. Core features of this 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. This distinctive Champion Centre professional was observed to be a key characteristic of the model. These relationships can be seen in Figure 20.

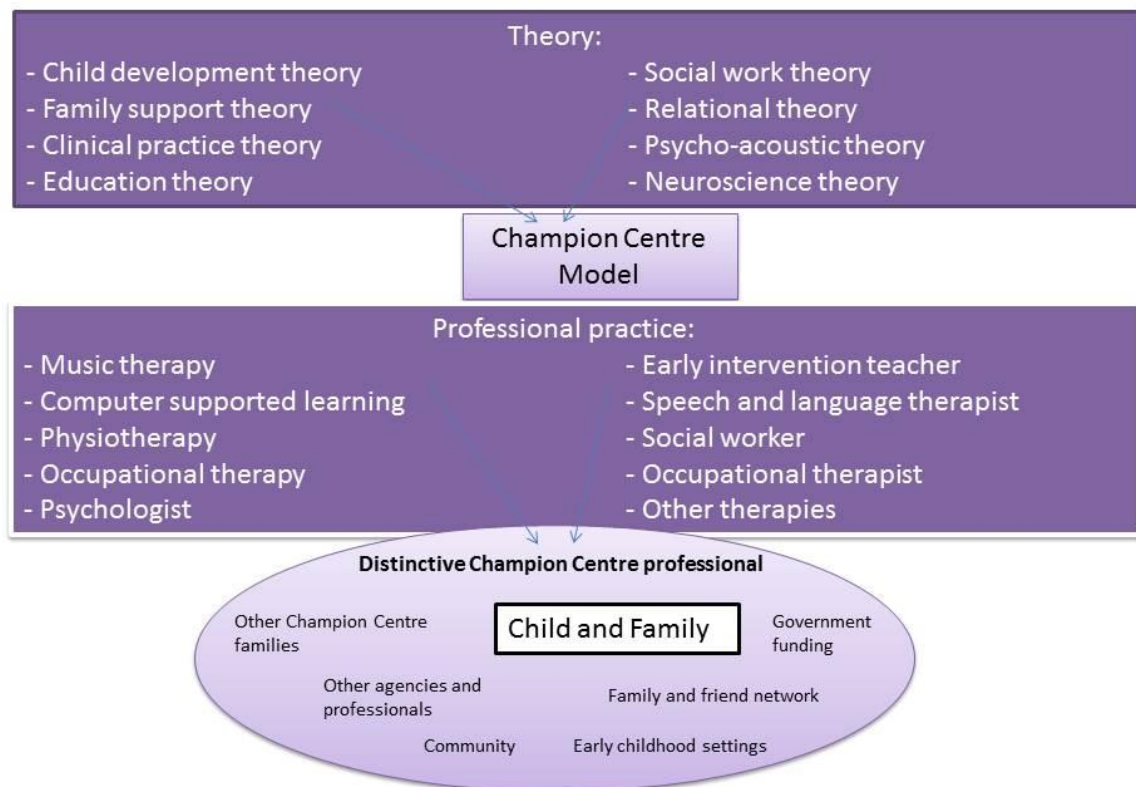


Figure 20 Champion Centre EI model

## 10. Conclusion and recommendations

The many benefits of EI services to support children with developmental delays and disabilities have been identified in this report. 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 family relationships and child development. The EI services in Canterbury, NZ demonstrate high levels of cooperation and information sharing between them (e.g., through EICS), which facilitates parental choice of service and facilitates movement between services in response to parent preferences.

Recommendations for UK policy and practice include:

- The instigation of a scoping study to assess the viability of an EI co-ordination service that provides a point of referral for children at risk of/identified with developmental delays and disabilities and their families, taking into account the Canterbury model of Health and Education working together under this umbrella. The aim would be to promote an ethos of informed choice about EI services in a way that empowers parents and reduces family stress.
- The instigation of a scoping study into the feasibility of an Early Intervention Teacher post-graduate qualification that recognises the additional child development and pedagogical expertise required to work with children with complex needs and their families. This would include models of teaching, learning, delivery and subject content and include contributions from the European and International community on Early Childhood Intervention as well as the Champion Centre. Of particular interest is the distinctive Champion Centre professional that arises from working in harmony with a range of other professionals;
- Funding for 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 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.
- Explore the idea of nationally approved Specialist Service Standards that identify the features of effective practice for specialist services should also be considered as a long-term aim.

The overall aim of these recommendations is to address 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.

## **11. Final notes to a Fellowship**

Since returning from NZ, I have been appointed as a Board Member of the European Association on Early Childhood Intervention (EURYLAIID) (<http://www.eurlyaid.eu>) and asked to the join Scientific Committee of an early childhood intervention conference in Poland. The findings from the Fellowship will be presented at two international conferences in 2016 (International Society on Early Intervention conference on Children's Rights and Early Intervention, June 2016, Stockholm and European Association of Service Providers for

Persons with Disabilities international conference on Hands-on Experiences of Early Childhood Intervention: from grassroots initiatives to international strategies', April 2016, Moldova. It is my hope that this will help to promote international acknowledgement of the UK as a contributor to the discipline of Early Childhood Intervention that focuses on contextual and relational EI for children with developmental delays and disabilities aged six and under.

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# APPENDIX A: Early Intervention Services in Canterbury, New Zealand

	CCS Early Intervention	CCS Child Development	Champion Centre Early Intervention	Conductive Education Early Intervention	Ministry of Education, Special Education / Child Development & Therapy Centre (Beacon House)
Location	Home Based and in the child's Early Childhood Centre, Christchurch, Central and North Canterbury	Home Based and in the child's Early Childhood Centre, Christchurch, Central and North Canterbury	Almost entirely Centre-based at the Champion Centre, on the Burnwood Hospital site, with occasional home visits as needed.	Centre-based service located at Addington Primary School, 22 Brougham Street, Addington.	Primarily home based, and in the child's Early Childhood centre. Some assessment, intervention and parent training clinic based at both Special Education (SE) and Beacon House (BH)
Fees	None	None	None	None	None
Specialists involved	<ul style="list-style-type: none"> <li>According to the child's needs:</li> <li>• Early Intervention Teacher</li> <li>• Occupational Therapist</li> <li>• Physiotherapist</li> <li>• Speech Language Therapist</li> <li>• Child and Family Support Worker / Whanau Worker</li> <li>• Education Support Worker plus: Access to contracted consultants i.e.                             <ul style="list-style-type: none"> <li>• Psychologists</li> <li>• Advisors of the Deaf</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>According to the child's needs:</li> <li>• Occupational Therapist</li> <li>• Physiotherapist</li> <li>• Speech Language Therapist</li> <li>Consultations with:                             <ul style="list-style-type: none"> <li>• Child and Family Support Worker / Whanau Worker</li> <li>• Early Intervention teacher</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Core therapy team for every child:</li> <li>• Physical therapist or occupational therapist, speech/language therapist, and early intervention teacher.</li> <li>Additional specialists as child moves through programme: music, computer, play, and educational support worker.</li> <li>Additional support according to need from: psychologist, psychotherapist, feeding specialist, social worker.</li> </ul>	<ul style="list-style-type: none"> <li>None</li> <li>• Early Intervention Teacher</li> <li>• Conductor – specialist trained in Conductive Education. Trained to teach/educate children who have motor disorders and develop all areas: gross motor, fine motor, cognitive skills, communication/social skills, and self-help and life skills</li> <li>• Speech Language Therapist</li> <li>• Education Support Worker</li> </ul>	<ul style="list-style-type: none"> <li>According to child's needs:</li> <li>• Early Intervention Teacher</li> <li>• Speech Language Therapist</li> <li>• Psychologist</li> <li>• Advisory on Deaf Children</li> <li>• Karikawenga (Maori Liaison Advisor)</li> <li>• Occupational Therapist (BH)</li> <li>• Physiotherapist (BH)</li> <li>• Education Support Worker</li> <li>• Occupational Therapist (seating / wheelchairs/housing mods) (BH)</li> </ul>
Frequency of sessions	Weekly/fortnightly	Weekly/fortnightly	All babies, and children preparing for school, attend weekly. Children aged 2-4 generally attend fortnightly, but this may be weekly according to need. Each session is one to three hours long.	2-3 sessions per week dependent upon age	According to the Child's Needs: Weekly / fortnightly (SE) 12 week package, then review and monitor (BH)
Age range for referrals	0 – 4.5 yrs	0 – 12 mths	0-4 yrs	0 – 5 years	0 – 5 years (SE) 0-16 years (BH)
Possible time within the programme	0 – school age	0 – 18 mths	0- school transition providing child still meets service criteria. The EI team supports school transition.	0 – school transition. Early intervention team involved in transition to school process.	0 – school transition providing the child still meets the criteria. The SE EI team supports school transition. BH collaborate with SE therapists.
Seen individually or in a group	Individually  Special interest groups (e.g. Music, parent support) coordinated periodically in response to caseload needs.	Individually  May join a Special interest group	The child and their parent/caregiver have an individual session with each therapist in their team. In addition there is a group morning tea for parents, children and staff, and a group music session where this is appropriate. Up to 8 children constitute a group at any one session.	<p>Individual Programme</p> <p>All children have an individual programme developed in conjunction with families, CE staff and mainstream early childhood staff.</p> <p>Group Programmes</p> <p>All programmes are offered in a group setting of no more than 5 children. Programmes are adapted to meet the needs of each individual.</p>	<p>Individual Programme: All children have an individual programme, developed by the EI team, family/whanau and the Early Childhood staff. Child and family receive service at home, EC setting, and clinic. Individual physiotherapy, occupational therapy, provision of wheelchairs, equipment and housing modification.</p> <p>Group Programme: May access some group programmes, language and interaction groups using music. Group education for parents for dyspraxia and autistic children from Beacon House</p>
Any other key information	<p>Strong focus on trans-disciplinary learning with full availability of the therapists/specialists.</p> <p>CCS in addition offers general services to disabled children, youth and adults. It also has staff dedicated to supporting Maori whanau. In particular it offers:</p> <ul style="list-style-type: none"> <li>• Information, advocacy and support</li> <li>• Access to community recreation</li> <li>• Linkages to family-based respite care</li> <li>• Other youth and adult related services</li> </ul>		<p>Families identifying as Maori are offered the services of a Maori social worker. Other professionals that can be accessed through the Centre include: paediatrician podiatrists and dentists.</p>	<ul style="list-style-type: none"> <li>• One month "trial period" offered to all families</li> <li>• Computer/switching programmes at Burnwood Hydro Therapy Pool</li> <li>• Weekly horse riding session at Riding for the Disabled (dependent upon age)</li> <li>• Paediatrician runs clinics in the centre twice per year</li> <li>• Elmwood Visual Centre / Van Asch Deaf Education Centre visit children in the centre where required</li> <li>• CE programmes are also available for:                             <ul style="list-style-type: none"> <li>• Age 5 – 12 yrs at Addington primary school</li> <li>• Age 13 – 21 at Cashmere High School</li> </ul> </li> </ul>	<p>Parent Programmes: Hanen Language Programmes, "It takes two to Talk," "More than Words" (SE).</p> <p>Parent Education groups for dyspraxia and autism (BH)</p> <p>Computer sessions based on need (SE)</p> <p>Intensive behaviour programmes</p> <p>Appointments available in monthly clinics with developmental paediatricians at SE and BH.</p> <p>SE also provides ongoing specialist support in school sector for children eligible for ORRS, severe SL Therapy and severe Behavioural needs.</p>

## **APPENDIX B: Families' journey through the Champion Centre**

### **Programmes include:**

- Multi-disciplinary programmes once a week for 100+ children
- Support in Early Childhood Centres for around 50 children
- Feeding programme for about 6 children
- Relating and Communicating programme for around 12 children
- Monitoring programme for children born prematurely (approx 65 children)

### **Professionals who work at the Champion Centre:**

#### Core therapies

- Physiotherapy
- Occupational Therapy
- Speech and Language
- Psychology
- Early Intervention Teaching

#### Supporting therapies

- Play
- Education Support
- Computer
- Music
- Dietitian
- Podiatrist

#### Family support

- Social workers
- Psychologist
- Family Support Worker (Māori)

### **A parent's journey with the Champion Centre:**

- Pre-entry visit by a member of the Family Support Team to the family home.

- Starts relationship
- Collect basic information
- Sets the tone of the parent being listened to in their own environment
- Allows the movement to the Centre to be individually tailored.
- Before entering a programme
  - Informational tour facilitated by the same FST member
  - Explanation of how the programme works and chance to ask questions
  - Team leader at least telephone contact with the family before the first programme visit
- Entering a programme
  - Facilitated by the FST
  - Emphasis on engagement
  - Emphasis on the “expert” listening rather than telling.
- Ongoing work characterised by:
  - Close attention to the state of mind and body of the parent(s)/caregivers
  - Close attention to consulting parents through “wonderings” (also current research project)
  - Phone calls and discussion (sometimes home-visits) with parents on issues that are too hard/complicated to get into in programme time.
- Each transition between the Centre’s programmes as the child moves through the Centre is carefully prepared.
- The transition to school is carefully prepared
  - Every aspect involves the family: choice of school, timing of transition, pre-entry visits, liaisons with staff, the content of the transition report etc.
  - Centre staff remain a resource in perpetuity, and some families make significant use of them

## APPENDIX C: Weekly timetable of programmes

Day	Programme	Approximate age	Main diagnoses
Monday	Babies	Under 2	Mixed (early referrals)
	Feeding programme	mixed	mixed
	Middle years	2 - 4	motor disorders
	Transition to school	4 - 6	motor disorders
Tuesday	Relating & Communicating	2 +	Disorders of relating and communicating
	Transition to school	4 - 6	Down syndrome
	Transition to school	4 - 6	Mixed
	Assessment and Monitoring (+/- Plus)	Mixed (occasional and/or extra visit)	Premature (mild to moderate needs)
Wednesday	Assessment and Monitoring	Under 6 months corrected	Premature
	Middle Years	2 - 4	Mixed
	Transition to school	4 - 6	Mixed but ex R&C
Thursday	Babies	Under 2	Mixed genetic
	Middle Years	2 - 4	Down syndrome
	Middle Years	2 - 4	Mixed motor
	Relating and Communicating	2 +	Disorders of relating and communicating
Friday	Babies	Under 2	Mixed (late referrals)
	Middle Years	2 - 4	Mixed
	Transition to school	4 - 6	Down syndrome
	Relating and Communicating	2 +	Disorders of relating and communicating