

Relationship-based early intervention services for children with complex disabilities: Lessons from New Zealand

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The Champion Centre, located in Christchurch, New Zealand, provides a relationship-based early intervention (EI) service for children with complex 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. It advocates for children with disabilities through training and research. The author visited the Centre recently on a Winston Churchill Memorial Trust Fellowship.

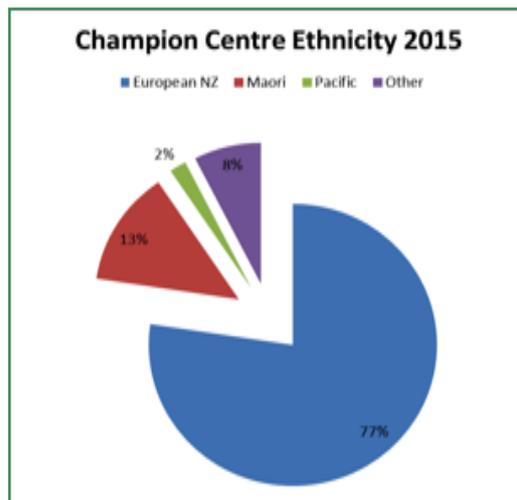
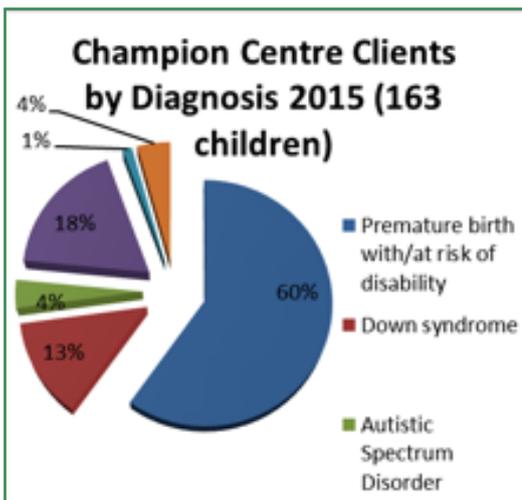
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The Champion Centre programme is offered to children from birth to school age who have significant delays in at least two areas of development. Children who attend the Centre have a wide range of special needs including developmental challenges as a result of Down syndrome and other genetic disorders, cerebral palsy, extreme prematurity, epilepsy, developmental dyspraxia, autism and brain injury. Children who participate come from predominantly European NZ heritage; however, approximately 13% are of Maori heritage and 2% are of Pasifika heritage.

informed parents/caregivers. The programmes are underpinned by five principles. These are that EI services should be:

- Relational
- Family-centred
- Strengths-based
- Ecological
- Reflective

An integrated, individual therapeutic programme is developed for each child by the Team with the family/*whānau* (Maori word for extended family). The programme is based on an understanding of



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

human development and on the New Zealand Early Childhood Curriculum, *Te Whāriki* and is carried out through a combination of hands-on therapy and generalisation/extension activities at

the Champion Centre and by the family/*wbānau* in their home/community. The Centre operates in accordance with the Treaty of Waitangi and with ongoing requirements for bi-culturalism in all educational settings.

The Treaty of Waitangi (Māori: *Tiriti o Waitangi*) This was signed on 6 February 1840 by representatives of the British Crown and Māori chiefs. It recognised Māori ownership of their lands, forests and other properties, and gave the Māori the rights of British subjects. The Treaty is generally considered the founding document of New Zealand as a nation.

The model used at the Centre 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.

Infants from birth to around two years of age attend the Baby Programme. The Middle Years Programme is for children two to four years of age after which they join the Transition to School programme. There is also a monitoring programme for children born prematurely and the Relating and Communicating Programme for children whose main difficulty is being in relationship with others and who are often highly anxious.

INTERDISCIPLINARY PROFESSIONAL WORKING AT THE CHAMPION CENTRE

Professionals at the Centre work in partnership with parents/caregivers to provide a family-focused, strengths-based EI programme. For families attending the full multi-disciplinary programme, small group sessions are held weekly 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, 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. Specific therapy is available for children who have feeding, sensory, behavioural and relating and communicating difficulties. As the child approaches school age, the Team assists the parents/caregivers in their preparation for inclusion in an appropriate school setting. Children born prematurely with no major developmental challenges attend weekly until they are four months corrected and then go onto a less frequent rotation of visits, provided their development is tracking within acceptable limits.

Although professionals join the Champion Centre with training appropriate to their discipline,

post-experience training is conducted within the Centre. The Director attributes the success of interdisciplinary professional working at the Centre to a number of factors:

- Recruitment of new staff involves discussion of complicated scenarios to determine whether applicants consider children's development holistically, contextually and empathetically.
- Staff are recruited on the basis that they demonstrate high levels of empathy, insight and reflectiveness in their practice, and are able to look beyond their own professional discipline.
- There is constant discussion about children's development between professionals and professional teams.
- Low turnover of staff results in consistency of approach and a synergy of understanding between staff about children's development.
- Flexibility allows any professional to lead teams and be the family's key contact lead worker, according to families' preferences and practices.
- Professionals from diverse disciplines within the Centre attend post-experience training together.

PARENTS' PERSPECTIVES ON THE CHAMPION CENTRE

The parents whom I met at the Centre identified a number of key characteristics that they valued in a relationship-based EI service:

- A service provided by experienced, knowledgeable professionals who teach parents to teach their children
- Professional support for the relationship between parents and children – being shown how to relate to and play with their child
- Professionals who know the child/family well
- Professional recognition of parents' contribution to their child's ongoing progress
- Approaches that help prepare children for school
- The support of other parents experiencing the same challenges and difficulties
- Feeling that 'you're not doing it alone'.

All parents spoke highly of the social support available to families and the benefits of the integrated approach taken by professionals in order to scaffold children's learning and development.

Here it's all inter-linked. 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, 'I can help with that,' and they piece it all together. (Mother of a child aged two years, six months with developmental delay)

Parents appreciated the way in which the interventions support family life. They spoke of the importance of professional acknowledgement of how hard they work at home to support their child and the fact that professionals are non-judgemental about their child and family routines/practices. They also appreciated having 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.
(Mother of a child aged four years, six months with Down Syndrome)*

Parents felt that they were helped by staff to 'navigate' medical issues and parenting and child behaviour concerns, and that children were not rushed to reach developmental milestones. They were touched by the compassion and love shown by professionals to both themselves and their children:

Just being supported emotionally. Many times chatting to the staff, you would leave in tears, but I needed that. (Past parent)

PROFESSIONALS' PERSPECTIVES ON THE CHAMPION CENTRE

The professionals at the Centre listed a number of essential components of a relationship-based EI service. All talked about the importance of understanding the family's journey both prior to and during its engagement with the service. It was described as 'crucial' that parents should have to relate their child's early experiences to professionals only once and that this should occur within the parents' own 'safe space', usually the home setting. Professionals also mentioned the need for honesty and empathy and to respect families and each other.

They felt that an Early Intervention service should:

- Work with parents to enhance their ability to support their child and where necessary help them to learn to love their child.
- Remove 'roadblocks' to parent/child relationships so that children with disabilities can experience joy.
- Acknowledge and respect diverse family structures/processes and interactions.
- Identify and build on children's strengths and embody an empathetic approach to families.
- Employ professionals who love working with families rather than solely with children.

They all noted the importance of an interdisciplinary approach underpinned by regular, effective communication between professionals and between professionals and families.

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. (Champion Centre Director)

They felt that families benefitted hugely from the Centre's strengths-based approach that extends to research undertaken at the Centre

and the methodologies adopted to support it. For example, assessment of children is always play-based and measures for research are chosen for their capacity to offer immediate feedback to parents and therapists about children's progress.

Case Study: Jasmine

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. Jasmine is nine months old and has a diagnosis of developmental delay and asymptomatic cytomegalovirus 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, paediatricians at the hospital where Jasmine was born were concerned that symptoms she was displaying resembled withdrawal. Her adoptive mother stated that she had chosen the Champion Centre in preference to other EI services partly as a result of recommendations from friends who had used the service previously, and also because she felt that a Centre-based service would provide socialisation benefits for both Jasmine and herself. Jasmine was pre-verbal at the time of my visit, and was working with her therapists on imitation, new sounds, hand-eye co-ordination and social referencing. Jasmine's mother has a close relationship with and frequent support from her partner's parents as well as friends.

CELEBRATIONS AND CHALLENGES

Jasmine's mother stated that as Jasmine's diagnosis was 'uncertain' and her level of delay unknown, she was thrilled that Jasmine appeared to be making progress along the developmental path. 'The fact that she's doing something new every week is awesome.' She and her partner had been made aware that difficulties for Jasmine might not be immediately obvious or become apparent for some years, but she felt confident that any delays in her development would be identified early so as to ensure the best possible outcome.

JASMINE'S MOTHER'S ACCOUNT 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. She appreciated receiving regular confirmation that Jasmine was within expected developmental parameters. She particularly valued being listened to by professionals and their non-judgemental approach:

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 for the family as a whole.

She liked the way that each discipline integrates with the others and works to create a truly cohesive learning environment. She reported feeling fully involved in a very hands-on way in her daughter's learning and development and valued the explanations from professionals about why particular activities were being offered.

ASPIRATIONS FOR JASMINE: INCLUSION IN EDUCATION, EMPLOYMENT AND SOCIETY

Jasmine's mother aspires for her daughter to thrive in mainstream education and to succeed in her chosen career. She is confident that the Champion Centre is helping her to achieve the 'base skills required to reach milestones going forward'.

CONCLUSION

The Champion Centre's relationship-based EI service for children with complex disabilities places parent-child relationships at its heart. Professionals recognise that early relationships

between caregiver and infant have the potential to promote emotional resilience and positive mental health. A high value is therefore placed on working with families to support children's holistic development within the context of family processes and interactions.

The author was funded to visit the Champion Centre by the Winston Churchill Memorial Trust under their Early Years Prevention and Intervention strand of Fellowships. A full description of the principles of the Champion Centre EI Service can be found at <http://www.championCentre.org.nz/>.

REFERENCE

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International Guest Lecture: Dr. Susan Foster-Cohen
Bio-psycho-social consequences of premature birth: family and professional partnerships in early intervention

The Faculty of Health, Education and Life Sciences at Birmingham City University warmly welcome you to an International Guest Lecture from the Director of the world-leading Champion Centre in New Zealand

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The short, medium and long-term impacts of **premature birth** on the infant, the mother, the family and their educational and social communities are the active subjects of research in a number of academic fields. Such research is revealing trends and likelihoods of developmental, educational, mental health and social consequences of prematurity that can, and must, be addressed in early intervention. Particularly difficult, however, is predicting which children will have which, or any, lasting consequences of their prematurity. This presents a challenge for health, education and social welfare practitioners to translate the research evidence into the best support for each child, the families that raise them, and the teachers that educate them. This talk will review the bio-psycho-social consequences of premature birth and then describe the multi-disciplinary support provided to children born prematurely, their families and their teachers at The Champion Centre in Christchurch, New Zealand. It will focus on the challenges encountered in assessment, monitoring, and intervention; and the importance of developing families as 'advocates for life' for their children.

Dr. Susan Foster-Cohen is the Director of the Champion Centre and Adjunct Associate Professor at the University of Canterbury. She is engaged in active research into the outcomes of parent-partnership interventions at the Centre. She has also been a member of a research team at the University of Canterbury exploring the long-term outcomes of prematurity, with a particular focus on communication and language development. She has held academic positions in universities in the UK, USA, France and New Zealand and has published widely on language development in both pure and applied journals and books.

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