

Scope (Aust) - Case Studies

Case Studies

The following case studies are from Scope's West Metro Therapy team and the names have been de-identified.

Case Study 1: Language barrier to NDIS planning

A mother is taking care of 3 adult children with complex disabilities. Under the bulk funded system, she was seen regularly by an OT who was supporting her with getting equipment, vehicle modifications and overall care. English is a second language for the family. When the planner meeting happened, the mother was not able to articulate the need for an OT and there is no therapy funding within her plan. So, she has been left without any therapy to help navigate the needs of her 3 children. This underscores the need for planners to know to ask questions and get a full sense of needs. Are interpreter services offered?

Case Study 2: A family with complex issues and how they were supported to engage with our Early Childhood Intervention Services

Tim was referred from the central wait list in 2012 at age 3½. He was diagnosed with a syndrome that resulted in him having Global Developmental delays. Prior to Scope meeting the family, Tim and his younger sister had been in the custody of their father and occasionally saw their mother, who had an addiction to heroine. Child Protection was involved. Following a particularly severe bout of domestic violence – which Tim and his younger sister witnessed – the children were placed in foster care. At the time that Tim was allocated a place with Scope ECIS his mum had very recently been granted full care of the children. Freda (Tim's mum) had substantial involvement with:

- Child Protection workers (including drop in visits without notice)
- Housing workers
- She was ordered to attend meetings with her parole officer which included random requests for her to present to be tested for narcotics
- She also had to attend a chemist daily to fill her prescription of methadone.

Freda did not own a car, money was tight. Freda's self esteem was low, she felt very guilty about her previous lack of care for her children, she was overwhelmed at Tim's needs, she had no confidence in her parenting skills and she was truly very busy with all of these demands on her.

It was very difficult to make initial contact with Freda. She did not answer her phone to numbers that she didn't know, she did not respond to text messages, and she did not check her mail. When the attempts through these channels had failed contact was made by two workers (for safety) simply arriving at the home and knocking on the door. Freda answered and the workers were able to describe ECIS services and how they might be of value to her. She was able to ask questions about why her son presented as he did, about how she might support him to speak, to use his fingers for finer tasks and to develop core body strength. We also got to notice what Freda was doing really well – and to point this out to her. She said that no one had ever complimented her before and she

Scope (Aust) - Case Studies

found this a little overwhelming – but that it gave her the seed of a belief in the possibility that she might succeed.

After this visit the Key Worker was able to catch up with Freda and Tim more often – but there were many cancellations, or worse, times when I would confirm by text that I was leaving the office and would arrive in 30 minutes, receive a confirmation text from Freda, and arrive to find she wasn't there. There were many times when I would ring her number over a period of weeks without her answering or returning the call – but eventually she would ring me – full of remorse that she hadn't called. One day I arrived for a scheduled appointment and she apologised that she'd been ordered to present for a blood test and would have to cancel - I offered to drive her to the appointment – we had such a great talk on the way about respite and childcare and how she could be sure to get her children there more often. Driving her to the shops for a coffee became a sure-fire way of her remembering our appointments – usually.

Over the 2 years that Tim spent in the ECIS program:

- He (and his sister) attended childcare 5 days a week (previously his mother had struggled to get them there – but then struggled to manage them all day at home).
- During visits, Freda learned to make play dough, and paints and how to engage in play activities with these materials along with common household items to strengthen his fingers.
- He had regular Speech pathology and Occupational Therapy sessions – often at childcare – Freda would often catch the bus to attend the sessions so that she could implement suggestions at home.
- Freda learned that Tim's disability didn't mean that he couldn't learn – but that the messages could be delivered differently so that he understood – she also learned the importance of consistency and her own body language.
- Strength Based conversations supported Freda to learn how to play with her children, and that it was ok to say no and to manage behaviours firmly and still be a 'good' mum
- Freda's self esteem improved and with this her willingness to take risks regarding going out and about with her children.
- Freda developed the confidence to speak to staff at childcare – she had previously believed others would judge the way she looked and had felt shameful. Previously she had dropped the children off and picked them up and without engaging with staff. With newfound confidence she could now pass on and receive relevant information concerning her children and advocate positively for them.
- When selecting a suitable school for Tim, Freda made appointments with and met with the principals of several local schools to determine which would be most suited to Tim's needs.
- Freda attended necessary enrolment meetings and provided information, reports from Scope and Tim's pediatrician.
- Freda arranged for Tim to receive ongoing speech pathology once he started school.

Scope (Aust) - Case Studies

As a result:

- Tim’s vocabulary and articulation improved such that he was able to comfortably communicate with his peers and adults.
- Tim was confident to play on equipment in the park and at school alongside other children.
- Tim had learned to ask for help, tell others to stop when needed, and share his toys in appropriate ways.
- Freda developed the confidence and skills to play with her children, encourage their efforts, and to teach them a range of skills. She also learned to take her place in and engage with others in the community in which she and her children lived.
- Tim commenced at a local primary school with funding organised through the Program for Students with Disabilities on day 1 of Term 1 – complete with a uniform organised by his mum.

There were many professionals involved with this family – ECIS was different. Freda was not compelled to engage nor was she compelled to follow our ideas. The fact that she chose to work with us, and that we had the space and time to engage with her at a pace she was comfortable with – and that cancellations weren’t a catastrophe – allowed her to take control and responsibility for Tim’s development. Although I have not had contact with her since Tim started school (as is the nature of block funded ECIS) I expect that she will continue to use the skills that she learned over this time to the ongoing benefit of both of her children.

The above is an example from my caseload that I feel provides a good example of engagement of more complex families in service. I have de-identified, but otherwise told the framework of this case.

Case Study 3: ECIS and a hard to reach family

1 year old girl with developmental delays, breathing difficulties (has a tracheostomy which requires frequent suctioning and full breathing support overnight), swallowing difficulties and tongue malformation. She spent the first 6 months of life at the Royal Children’s Hospital (RCH).

When ECIS started, family often did not turn up to appointments at RCH and was not engaged with Maternal and Child Health Services. Family were not following hospital recommendations about appropriate food/fluid for child’s safety. Child seen by ECIS is youngest of 7 children, both parents are originally from Somalia and father often “goes away” for long periods (months at a time). 1 sibling is pre-school aged, and all others are at local school. The mother reported that she did not know who to ask so she just ignores appointments or letters if she can not attend an appointment.

Since ECIS input (12 months); RCH Complex Care Service is linked with a Key Worker who supports mum to understand appointments and re-schedule if she is unable to attend. The Key Worker often attends with mum so she can help to ask the questions she has, and help understand the

Scope (Aust) - Case Studies

recommendations being made. The child is linked with a Maternal and Child Health Nurse and receives an enhanced service (which means they now have home visits rather than needing to attend the clinic). Mum is linked with Salvation Army who is helping with clothing, school equipment and food for all the family. Mum is following recommendations for food/drink for the child; the previous recommendations given by the hospital did not take into account how the family eat (sitting on the floor sharing food in the middle) and the home environment. The ECIS Key Worker changed these after sharing a meal with the family. The child has now improved so much that she no longer needs modified food. The Key Worker also supported the child to trial a speaking valve, so is able to vocalise and say words using her tracheostomy.

Most recently, the mother informed the ECIS Key Worker that the landlord had given the family 90 days notice to move out as he was planning to sell the property. The father is currently away, unclear when he will return. The mum had already contacted the Salvation Army support service who was allocating a care worker to find a new property and help with moving/costs etc. It is a shame that ECIS does not actually measure this...but it is a massive achievement that the mum is now familiar with services and has the confidence to contact the right people to help her when she needs help, without the ECIS Key Worker!

Case Study 4: An at risk family who had not engaged with services previously

Charlotte was referred to Early Childhood Intervention Services by her pediatrician following identification of concerns regarding her speech and social skill delay. Prior to the initial home visit, the OH&S Home Visit Screening Tool was completed over the phone by one of our team members with the assistance of a Vietnamese telephone interpreter. During this phone call, it was identified that Charlotte's father had a complex mental health history. At the time of the OH&S screen, he was in inpatient care. For this reason, it was agreed that the initial visit to meet this family would be conducted by their assigned Key Worker and ECIS Team Leader.

In April 2016, after several unsuccessful attempts to speak to Charlotte's mother over the phone to schedule a date and time, myself (as Charlotte's assigned ECIS Key Worker) and my Team Leader attended an initial home visit to meet Charlotte and her family. The pre-booked Vietnamese interpreter met us at the family home. The visit was unable to proceed on this day as we were informed by Charlotte's grandmother that neither parent was home. It turns out Charlotte's mother was required to attend a medical appointment for herself and had forgotten about the scheduled visit. Contact was made with Charlotte's mother over the phone to schedule another time for the initial home visit, which was conducted a short time later. Upon arriving at the family's home for the second time, it was discovered that Charlotte's father was home from hospital. It was apparent very early on during the visit that he was unwell and it was not safe for the visit to continue for the full duration.

Engaging 'Hard to Reach' Cohorts
An NDIS Implementation Taskforce Workshop
Friday 10 February 2017



Scope (Aust) - Case Studies

When asked, Charlotte's mother stated she believed that they were safe in the presence of her husband. Before myself, my Team Leader and the VITS interpreter left the home, Charlotte's mother reported that she had been living in Australia for 10 years, and during this time she had not been offered or received any assistance from any services or individuals. Charlotte's mother reported feeling very isolated and incapable of accessing community supports. She had not been able to access English lessons due to the fluctuating state of her husband's mental health and the necessity of being home to care for her children at all times. Arrangements were made with Charlotte's mother to meet over the coming week in a community location.

A strong rapport and trusting professional relationship was developed between myself, my Team Leader and Charlotte's mother. Charlotte's mother also advised that she felt a sense of comfort and trust in the Vietnamese interpreter we had been assigned during the home visit, so it was agreed that he would always be requested for the community visits. Charlotte's mother reported feeling gratitude that support was being offered by Scope/ECIS, however due to personal circumstances still found it difficult to consistently attend scheduled community visits. Prior to each appointment I sent Charlotte's mother a text message in simple English, with a reminder of date and time of each visit. A range of extenuating circumstances that arose resulted in many visits needing to be cancelled and re-scheduled at late notice.

The safety of Charlotte and her family quickly became the top concern and priority for us, and our time was spent linking Charlotte's mother in with appropriate support services who could offer her, Charlotte and her other children support, counselling, refuge and safety in the case of an emergency. Despite best efforts to introduce Charlotte's mother to these services, she did not follow up with any services independently. When this was discussed in further detail, Charlotte's mother advised that she did not trust new people and only felt comfortable discussing her situation with myself, my Team Leader and the VITS interpreter. It was agreed that meetings would be attended by Charlotte's mother and myself, to assist her initial engagement with these vital support services.

Regular follow-up was required on my part to ensure that engagement with these services was maintained. For financial reasons, Charlotte's mother was unable to make phone calls from her phone, so did not return any missed calls. I was required to frequently call services to explain this situation to them and request they repeatedly make attempts to reach the family. Scope's ECIS services were responsible for engaging a wide range of additional services, including council, kindergarten, emergency services and a women's refuge. For safety reasons, the family was eventually required to leave their family home and move out of the area into an undisclosed location.

Despite several unsuccessful attempts to initiate contact and engage with this family, the service provided by Scope and ECIS ended up being critical to this family's safety and wellbeing and highly valued by the family.

Scope (Aust) - Case Studies

Case Study 5: Early Childhood Intervention Services and a hard to engage family with many cancellations

Key Worker was working with a family where parents lived with maternal grandparents, and money was tight as Dad worked only shift work. Client was a 4 year old boy, Timmy, with autism, who was non-verbal, not toilet trained and difficult to engage. Mum was hesitant to enrol him in mainstream early childhood programs due to his high needs and difficulty with communication. Mum was kind and caring, and welcoming of support but socially isolated and was not active in seeking services. Mum frequently cancelled home visits and did not seek out rescheduling, but was happy to agree to meet if the Key Worker contacted her. After establishing that the Timmy needed more opportunities to explore play materials and interact with children, the Key Worker supported Mum to explore childcare options by attending tours with her until Mum felt comfortable leaving Timmy for half day sessions in a childcare kinder program.

After about six months the family cancelled a few home visits, then did not respond to calls. The Key Worker persisted in trying to get in touch via calls and post. Childcare staff reported the Timmy was no longer attending childcare. After about 3 months Mum answered a phone call from the Key Worker, she apologised without giving a reason for lack of engagement and agreed to a home visit. When the Key Worker went to visit she found that Dad had left the family home, leaving them struggling emotionally and financially, as a result Mum had pulled Timmy out of the childcare kindergarten program because she could not afford the fees. Timmy's behaviour had escalated in this time, was sleeping throughout the day, and he appeared to be bored at home. The Key Worker was able to contact local council (in June) and arrange a priority of access kindergarten place immediately with fees waived due to health care card status (which Mum was not aware of). Key Worker was able to support an urgent application for additional funding at kinder, and attend kinder to support staff to work with Timmy.

Timmy responded well to the new kinder environment, wanting to join in all activities with peers. Kindergarten staff contacted Key Worker requesting ways to promote inclusion of Timmy in the group. Kinder staff used aided language displays with enthusiasm and soon found that Timmy was using more words to interact and communicate at kinder. Mum felt welcome and supported by kindergarten, and was able to discuss with them his strengths and needs in getting ready to transition into school the following year. Without ECIS, and the flexibility of the worker to support over different settings, manage cancellations, and persist in contacting the family, Timmy would not have attended any early childhood programs with had the opportunity to play and develop his communication with peers and teachers prior to starting school.

Case Study 6: A 'difficult to engage' family that had previously been engaged

Ben has a diagnosis of Cerebral Palsy, GMFSC III. Ben moved to the West Metro Region when he was just over 3 years old with his mother, Faye and infant brother. His mother had recently separated from her partner, who had D&A issues and had been violent towards Faye. Ben and his mum moved

Scope (Aust) - Case Studies

from a regional centre where he had been receiving ECIS (from a provider who had limited experience in children with physical disability) and Community Health Physiotherapy. Therapy and medical handovers focused on the fact that Ben missed appointments and his mother was difficult to engage. Pediatric medical services had discharged Ben due to non-attendance.

On her first session with our ECIS service, Faye reported that she would like to help Ben to walk, ensure his play is age appropriate and link with medical supports. Faye reported at this time that an application for a walking frame had been completed 18 months previously by the Community Health Physiotherapist. Ben presented as a very engaging and interested little boy. He had tightened hamstrings and adductors limiting his ability to stand and take steps independently.

Main achievements within the first six months of our service included:

Investigated what equipment had been applied for and concluded that no previous applications had been completed (including the walking frame application). Put in urgent referrals to SWEP and sourced Top Up Funds whilst trialing walking frames securing funds within 3 months.

Tried other equipment to ensure safety around the home, such as bath chair, and provide optimal physical performance, such as AFO's and leg wraps. Both this applications were deemed highest priority after re-applications to SWEP.

Referral to appropriate medical supports within Melbourne, this involved numerous phone calls to engage previous providers and ensure referrals were completed and phone calls to future providers to ensure referrals were completed and Ben was appropriately placed on the waitlist. Also supported mum with what she wanted from medical appointments and attended initial medical appointments with her.

Supported mum to apply for four year old kinder for Ben, involved discussing and encouraging mum in regards to application process and time frames.

A loan standing frame was provided to practice standing, whilst also encouraging cruising around house furniture. Since then:

- Mum has enrolled Ben in kinder and he has commenced
- Mum has been linked into necessary medical clinics.
- Ben has received appropriate equipment: bath chair, standing frame and walking frame.
- Mum has moved house and set it up independently
- Mum appears really confident with Ben and other service providers.