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A Trajectory of Relationship Development for Early Intervention Practice for Children with Developmental Disabilities

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Abstract

Background: Collaboration, through multiple complex relationships between families and professionals, is integral to Early Intervention (EI) practice for children with developmental disabilities (DD). The purpose of this study was to explain the processes involved from the multiple perspectives of all those involved in the team.

Methods: A Grounded Theory methodology was used. The sample included 5 young children with developmental disabilities, 6 parents and 17 professionals from an EI team. In total 31 interviews were carried out. Through an iterative approach to data analysis, the processes of the EI relationship were explored.

Results: The process of the EI relationship emerged from the data. The relationship process happens through an overlapping five stage developmental trajectory which includes: 1) initiating, 2) experimenting, 3) intensifying, 4) integrating and 5) transitioning.

Conclusion: The role of relationships between professionals, children and their parents in successful EI disability services is paramount. The EI relationship is a complex interdependent one which requires a roadmap of explicit stages, which can facilitate all involved in the relationship to work together. This study provides this roadmap in the form of a developmental relationship trajectory. Understanding the key factors, within each stage of the developmental trajectory, supports positive relationships between professionals, children and their families, thus positively influencing the outcome of EI practice for children with DD.

Keywords: Relationship, early intervention, child, disability, grounded theory.

Introduction

The premise of this research study is that while much is known about the value of relationships in family-centered practice insufficient attention has been paid to this in the context of Early Intervention (EI) service provision and practice for children with developmental disabilities. Guralnick (2001) defines early childhood intervention as a system designed to support family patterns of interaction that best promote child development. EI systems involve multiple complex, personal and professional relationships. These relationships may include child with developmental disabilities, their parents and service providers (Kelly and Barnard, 1999), families and service providers (McWilliam, 2010; Paige-Smith and Rix, 2011). Carpenter (2005) acknowledged that, within a family system, patterns of interaction may vary and is dependent on their support network. Within EI practice, there is an expectation that parents and professionals collaborate and form a partnership, which has been shown to be a potential predictor of the success of intervention (Kelly and Barnard, 1999; Paige-Smith and Rix, 2011; Office of the Minister for Children and Youth Affairs, 2007). Thus collaborative relationships underpin EI disability services (Matthews and Rix, 2013; Bridle and Mann, 2000) and are key to enable the child with developmental disabilities to reach their full potential (Yung, 2010). Therefore, these collaborative relationships require deeper exploration.

Although all relationships are different, Guerrero et al (2011) identify that it is helpful to consider relationships from a developmental perspective. A relationship-

based approach to EI involves all domains of development (Weston et al, 1997; McCollum et al, 2001). Guerrero et al (2011) define interpersonal relationships as relationships between individuals who mutually influence each other and share some degree of behavioural interdependence within repeated interactions. Lee et al (1990) define emotional closeness as existing when there is a sense of shared experience, trust, enjoyment, concern and caring in a relationship. Relationships within EI between the child with developmental disabilities, parent(s) and the professional(s) may be defined as close and interpersonal. Within EI research, establishing positive, trusting relationships between professionals and families takes time and their value in intervention is understated (King et al, 1998; MacKean et al, 2005). Understanding these relationships is fundamental and although interpersonal relationship models have relevance within EI practice, they have not yet been considered within EI service provision.

Initially, families may be hesitant and ambivalent about beginning EI services, whereas professionals may be eager to share their expertise (Fialka et al, 2012). Within the family life cycle, transitions such as changes in family characteristics, interaction and function occur (Turnbull et al, 2005). When unexpected changes occur, such as the birth of a child with a disability, parents' emotional responses to these transitions may vary (Turnbull and Turnbull, 2001). These varied emotional responses may be explained through understanding the four dynamic stages of adaptation for parents where feelings can come and go (Miller, 1994). Rolland (1994) provides a family systems-illness model explaining that relationships with families are developmentally orientated and interactions change at different points in the illness and disability trajectory.

The concept of children developing in an environment of relationships in early

childhood is a fundamental one (Shonkoff and Fisher, 2013). A variety of models exist to explain the developmental nature of relationships within a person's life.

Altman and Taylor (1973) propose Social Penetration Theory, in which self-disclosure increases as people develop their relationships within their life. Knapp and Vangelisti (2005) expanded this theory by identifying five stages, that couples and friends go through to move from strangers to close relational partners. While these models focus on intimate interpersonal relationships, models also exist to explain professional - client relationships. Within the field of disabilities, Fialka et al (2012) propose three developmental stages in the relationship between professionals and families from 'Colliding and Campaigning' to 'Cooperating and Compromising' to the 'Creative Partnering and Collaborating'. Although models exist to support our understanding of relationships, none are specific to the unique context of relationships within EI disability services. In essence, relationships are fundamental and understanding the uniqueness of the relationships from the perspectives of all involved will positively inform the development of effective EI practice.

This study aimed to explore children's, parents' and professionals' experiences of EI disability services. Furthermore, the researcher aimed to develop a conceptual model of factors to facilitate and inform EI practice.

Methods

Based on the diversity of how EI services function and the heterogeneity of the client population who use the services in the country where the study took place, qualitative exploration was needed to understand the processes within EI from the perspectives of families and service providers (Sandall et al, 2002; Creswell 2007). A grounded theory methodology was used because the researcher wanted to cover contextual

conditions and understand their possible impact on the phenomenon of the study. The use of multiple data sources not only enhances data credibility (Patton, 1990), it adds multiplicity of perspectives and “truths” (Strauss and Corbin, 1998; Corbin and Strauss, 2008). Strauss and Corbin’s (1998) model of grounded theory provided clear procedural steps for data collection and analysis. Two university ethics committees approved the study and the data was collected in 2012. The ethical considerations included informed consent, opportunity for the child to express assent, confidentiality and opportunity for participants to withdraw at any stage of the research process.

Participants and Recruitment

Five EI teams within two regions in the country (one urban region and one rural region) were invited to take part in the study and one team accepted the invitation. The team, in the study, was part of a bigger non-governmental organization with an active interest in research. The team provided an EI service for children aged from birth to five years with developmental disabilities. This team’s ethos was one of family-centered practice (Dunst, 1995), following the Team Around the Child approach. The Team Around the Child approach is defined by Limbrick (2007) as ‘an individualised and evolving team of the few practitioners who see the child and family on a regular basis to provide practical support’ (p. 3). The professionals had regular meetings called Team Around the Family meetings. A purposive approach was employed to sample the team, which included families and professionals (Creswell, 2007). The gatekeeper, who was the team leader, was asked to select parents, children, between the ages of 2 and 5 years, and professionals based on the criteria that all participants were part of this particular team. Further sampling occurred as categories emerged from the data (Strauss and Corbin, 1998).

The final sample included five children with developmental disabilities, six parents and seventeen professionals. The child and parent participants (outlined in Table 1) were from different families. All families were nuclear families. The professional sample included four Nurses, three Speech and Language Therapists, three Physiotherapists, two Occupational Therapists, one Social Worker, one Care Assistant, one Family Support Worker, one Dietician, one Psychologist and one Team Leader. Thirteen professionals worked fulltime and four worked part-time. Professionals worked on the team between 2 and 15 years (average 5.4 years). Six professionals had worked in EI in other organizations between 3.5 years to 10 years (average 6.9 years).

Insert Table 1 here

Data Collection and Analysis

In total, 31 interviews were carried out. Interviews with the adult participants were semi-structured. Interviews with the professionals took place at their place of work, and parents' interviews took place in their homes as did data collection with child participants. Multiple methods were used to facilitate the participation of the five child participants, who had disabilities (Authors, 2014). Clark and Moss's (2001) framework for listening was used to guide the data collection process. The multi-method process involved interactions with each child, use of a Microsoft SenseCam (Hodges et al., 2006), SenseCam images, pictures, Talking Mats (Murphy, 1997), and general observations. Each interview and interaction were audio recorded and notes

were taken during and after the observations. The complete transcriptions of each audio recording were imported into the Nvivo software package (version 10) to support qualitative analysis. The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging data from the research field. Strauss and Corbin's Grounded Theory method of analysis helped the researcher to fracture or break the information down into themes and core categories through open, axial and selective coding (Strauss and Corbin, 1998). To establish trustworthiness of the data Lincoln and Guba's (1985) criteria for qualitative research; credibility, transferability, dependability, and confirmability, was used through strategies such as peer debriefing, peer checking, audit trails and member checks. In keeping with the view of Corbin and Strauss (2008), the findings present the theory with limited quotations in order to explain the conceptual message (p.319).

Results

Two hundred and eighty five codes emerged from the open coding phase. The researcher distilled these codes during axial coding and 15 categories emerged. Through constant comparative analysis, reading and interpretation an understanding that the process of the EI relationship happened through an overlapping five-stage developmental trajectory (figure 1) emerged. This trajectory, specific to EI disability services, draws on Knapp and Vangelisti's (2005) model and proposes a new fifth, transitioning stage, within the EI relationship. The trajectory acknowledges the importance of relationships in facilitating positivity within EI practice for children with developmental disabilities. The five stages of the relationship are outlined and described.

(insert figure 1 here)

Stage 1: Initiating Stage

At the beginning of the relationship parents wanted and needed support and this is an important factor in this 'getting to know you' stage. The key elements within this stage for the participants included: referral, suitability, introduction and assessment. There was a referral process to access the EI team, which was a requirement for all families. Suitability for the service required meeting criteria before assessment. In some cases, unsuitability for the service occurred following initial assessment. Referral to the team was dependent on diagnosis; for example, some families joined the team from birth, following a developmental assessment, or transferred in from another team.

Introduction to the team in the study, involved an initial home visit by the team leader. Families and professionals met for the first time at a team based assessment meeting. Parents reported that this was challenging for them as they did not know what to expect and did not know the people they were meeting. Not all parents could recall this event. Single discipline assessments also occurred and some parents, when feeling unprepared, found these challenging also. Parents perceived that the assessment experience was easier when the person conducting the assessments had commenced a relationship with them and their child and when parents understood the reasons behind the assessment. Professionals recognised preparation existed for families for certain assessments, for example, psychological evaluation.

Stage 2: Experimenting Stage

In the context of EI this stage refers to getting started, developing the relationship development and setting boundaries. Professionals supported new parents to the service and were acutely aware of giving good impressions to families. During this stage, therapy and/or home interventions commenced with the family. Parents did make first impressions of the intervention, team, and professionals. Professionals tried to distinguish between their own professional and personal boundaries when interacting with parents. Both parents and professionals reported feeling 'awkward' during interactions.

'If you are aware of roles and what somebody's job is then you won't be confused, you can engage and question appropriately' (Parent 2)

For professionals, feeling part of the team led to good working relationships and feelings of relevance. For example, being named on a report led to professionals feeling included. Some parents viewed themselves working with the team, whereas others saw themselves as part of the team. At this stage of the relationship all participants made decisions about their level of involvement. Concern and lack of clarity arose at this stage in relation to roles and expectations, for example, *'Therapists haven't time to see everyone all the time'* (Parent 4) and it was unclear if professionals were *'Expecting parents to be therapists'* (Professional 5).

Stage 3: Integrating Stage

During this stage of the relationship, closeness developed between the child, parents and professionals. All participants felt a togetherness where they were not alone, felt united with someone and felt supported to continue the relationship. The participants acknowledged each other and acknowledged the disability. For the professional, this stage facilitated the feeling of being part of the team. Feelings of

acknowledgement and acceptance led to sharing of information between professionals. During this stage, professionals also acknowledged parents, their opinions and views and in turn parents and children felt listened to. Furthermore, parents' acceptance played a role during this stage as a realization occurred for parents of their child's level of skill and the level of service being offered. Subsequently this realization facilitated acceptance of their child's disability, acceptance of the child's level of ability and setting of realistic expectations of achievement. Additionally, parents' ability to accept advice and information also influenced the development of closeness. Professionals highlighted that some parents attended appointments and '*disengaged*' emotionally and mentally for different reasons. Some professionals identified that some children '*disengage*' due to being '*therapied out*' as a result of engaging with other services outside the organization. For children, there were mixed feelings about therapy activities. Child 4, was interested in doing all the therapy activities whereas for Child 1, therapy activities were not fun.

Families sharing information and being open, together with professional openness to change, facilitated the relationship. Professionals acknowledged that goal setting needed to be linked to parents' expectations and interests of the child and needed to be realistic. Children shared how they communicated, indicated their interests and shared what activities they were involved in. The children were active participators in their activities. Their level of participation in these activities varied and was dependent on their abilities and on the context of the activity. Being aware of how each child communicated and being able to interpret the child's communicative signals facilitated interactions within activities and services. The children could show their likes and dislikes and make choices. Parents disclosed to the team leader when they felt unacknowledged in the goal setting process. The Team Around the Family

meetings were seen as *'the glue'* that kept the professionals together, allowing professionals to share information, decide goals, air concerns, discuss issues, and decide a care plan. Parents knew that this collaboration existed; with some wanting to be directly involved while others didn't. One professional noted that it was *'a discussion around the family'* rather than a team around the family meeting and suggested that families should be involved.

Stage 4: Intensifying Stage

This stage of relationship development involved families supporting themselves, getting support from their extended families and involved parents supporting other parents. Frequency of contact, along with trust, respect between participants led to good working relationships within the team. At this stage all involved had acclimatized to the relationship and familiarity developed. For child 4, his mother commented that:

'It (therapy) became very familiar to him. The hello song at the beginning..'

With familiarity, reciprocity was evident whereby all involved worked in harmony with each other, adapting and making changes to accommodate others and themselves. Professionals also made changes to improve the service. Becoming acclimatized to the relationship allowed the realization to unfold that it takes time for changes to happen. When professionals knew each other well and knew families well, they could anticipate how the child and their parents would engage and interact. Confining factors to the intensifying stage in the relationship included: negotiation and continuity of care. The negotiation involved discussions around scheduling and coordination of appointments and prioritization. Negotiation linked to the adaptability of all involved and the influence of the people involved in this negotiation process.

Prioritization involved discussions around whose needs and wants come first, for example, parents' or professionals', or the child's or families? Continuity of care included frequency and consistency of appointments and service.

There was a willingness to learn and work together and plan together to meet the child's needs. Togetherness was very important and for parents '*knowing*' that the professionals were '*behind you, supporting you and helping you*' to meet the child's needs. The Occupational Therapists, Speech and Language Therapists and Physiotherapists recognised that for success within their interventions home support/intervention was needed and felt confident that the home support provided the opportunities for parents to carry out the therapy goals. The professional set the goals in relation to their area of expertise, however, they were embedded in established structures, routines, and child's interests within the home. It would appear that this process was inconsistent as it was '*down to each individual case*' (Professional 8) and '*dependent on the needs of the child*' (Professional 16).

The professional tried to '*find a balance*' between expert driven goal setting and parent driven goals and child's interests. There were times when some parents felt that professionals shared goals via reports and that the parent was informed of goals. Some parents were not aware or didn't know the goals for their child. There was the possibility that professionals were also unclear, as goals were not detailed explicitly:

'We would make our own kind of observations and try to work out our goals from that' (Professional 9).

Stage 5: Transitioning Stage

This stage refers to the ending of the relationship, moving on and transitioning from EI professionals to those in school services as the child enters primary education. For some parents transitioning from EI was fraught with angst and fear,

'Feeling of being cut off' (Parent 3)

'Losing a comfort blanket' (Parent 4)

Professionals acknowledged that it was a challenging time for parents as strong bonds and relationships had been formed between families and professionals. Positivity was also illuminated through the data in relation to the transition from EI, with some participants looking forward to the future. Transitioning also involved moving to another professional within EI, for example, changing professional when a child reached three years created the feelings of 'loss' and a parent recalled 'crying' when her child was transferred to another professional because they entered preschool education. Some very smooth transitions happened where professionals worked jointly with the child and their family before the transition. However, there were also feelings of uncertainty, anxiety and conflict, which arose for all, involved. Families became familiar with the system and the professional they were working with and then it changed. Some professionals also found it difficult to let a child go when they were moving to another therapist within the service. Planning for this stage within the team featured mainly for professionals as they planned for the transition for the child from the team to primary education. They prepared children through a school readiness programme, planning meetings for schools to help school staff facilitate a child's smooth transition to education. Parents were also leaving the team and there was little reference to preparing the child's family for the transition.

Discussion

This study discovered a trajectory of relationship development for the child with developmental disabilities, their family and the professionals within the EI relationship. This trajectory was found within a team setting, based in a country, where family-centred practice was the underlying philosophy. Theories of informal personal relationships by (Altman and Taylor, 1973; Kelly et al, 1983; Knapp and Vangelisti, 2005) and models of professional partnerships within disability (Fialka et al, 2012; Miller, 1994) support his trajectory. The pivotal role relationships play in EI disability services is well supported (Carpenter, 2005; Shonkoff and Fisher, 2013).

The intimacy of the *Initiating Stage* in an EI relationship links theories of both personal and professional relationships together (Knapp and Vangelisti, 2005; Fialka et al, 2012). Families share details, allowing their lives to be explored by professionals. This is the beginning stage of supporting parents as advocates for their children with developmental disabilities by arming them with information, encouragement, and optimism (Miller, 1994). Professionals helping families feel prepared and knowing what to expect, and sharing information will facilitate the development of trust at this stage (Paige-Smith and Rix, 2011). Yung (2010) stresses that professionals and families need to have high quality conversations.

In EI, the *Experimenting Stage* is a deeper one than that in personal relationships proposed by Knapp and Vangelisti (2005) and is linked to the Co-operating Phase identified by Fialka et al (2012). Uncertainties continue at this stage and all participants further explore and share their expectations, establish boundaries and share roles and responsibilities. Family-centered practice reflects an enabling model of helping, where the skills of families to care for their child with special needs are fostered (Dunst and Trivette, 1996). However, from the data it is unclear if the decision-making process was based on parents' wishes or on their levels of interaction

or engagement in the relationship. This study also found that professionals expected parents to interact in a particular way during intervention. For example, to actively engage in therapy sessions and carry out home activities. Other studies also found that professionals expected parents to take a lead role in their child's intervention, even if this was not the parent's wish (Espezel and Canam, 2003; MacKean et al, 2005).

Hence, parents may be compromised by their experience of EI. Professional expectation of parent engagement is also highlighted by Matthews and Rix (2013) and Bridle and Mann (2000) highlight that parents are forced to compromise if they wish to engage with services and in turn this can create difficulties with their relationship with their child.

To facilitate the *Integrating Stage* of the EI relationship it is important to understand how families and professionals want to engage together. Parents and children want to engage, but how they engage may be different. During this stage, professionals can gain a deeper understanding of a child's interests, skills, interaction style and motivation. Professionals also gain a deeper understanding of a parent's roles, motivation, involvement, and interaction style. Parents may have different commitments outside the family routine, which may impact their flexibility (Carpenter, 2008; Turnbull et al, 2007). This study highlights that the parents' level of interaction may be dependent on their levels of motivation, acceptance, familiarity, personality, confidence, and dependency. Previous studies highlight that difficult times or the emotional stance of parents can influence their level of interaction (Rolland, 1994; Turnbull et al, 2005). As Miller (1994) noted when parents are armed with knowledge they can determine their own level of interaction. Hence, parents learn from the earlier relationship stages what to expect and how they can be involved.

Closeness is key to all relationships (Lee et al, 1990) and is key in the Integrating Stage. People communicate to become closer to one another, to feel less isolated. It could be perceived that the Team Around the Family meetings, used by the professionals in this study, are for the professionals to plan and share information. They perceived these meetings as '*fundamental*'. In turn, the professionals develop closeness. This raises the question if parents knew what was involved and if time was allocated for them to be involved would they too see the Team Around the Family meeting as fundamental to the relationship? Therefore, using the information developed from the Initiation and Experimenting Stages, the Integrating Stage can facilitate and implement interest-based child learning opportunities within the context of their everyday activities (Dunst et al, 2010). At this stage of the trajectory, this would allow for children, parents and professionals to collaboratively devise a plan that reflects the child's and families' priorities and strengths along with measurable, obtainable goals (Bruder, 2010).

The *Intensifying Stage* in EI includes frequency of contact, which is also a feature of both Fialka et al (2012) and Knapp and Vangelisti (2005) models. Edelman (2004) stresses that the impact of EI is dependent on practitioner expertise and on the quality and continuity of the personal relationship between the service provider and family. Familiarity fosters anticipation of somebody's reaction and interaction and one adapts their interaction to suit the situation and the partner in the conversation. Altman and Taylor (1973) and Guerrero et al's (2011) support this view whereby individuals mutually influence each other and that the interpersonal communication is dependent on who is in the relationship. In practice, limited therapy time and limited frequency of contact due to organizational factors results in lack of continuity and impacts on meeting needs. Furthermore, professionals with increasing caseloads and

administration duties may lack the time necessary to become familiar with each other and develop synchronicity and collaborative ways of working. Within family-centered practice one of the outcomes is empowerment of parents and children (Dunst, 1995) and if empowered they will not feel overly dependent on professionals (Andrews and Andrews, 1986).

Furthermore, progressing through the developmental trajectory will allow for all participants to reach the Transitioning Stage feeling empowered, looking forward to the future and ready for another journey with a new team and onto the next phase of the child's life. The Transitioning Stage within this study equates with the last component, transition, of the developmental systems model (Guralnick, 2001). Due to the developmental trajectory of the relationship within EI, the relationship ends, in X country, when the child reaches 6 years of age or when he/she enters the primary education system. According to Guerrero et al (2011) close relationships are irreplaceable, provide fulfillment and emotional attachment. Rous (2008) developed a set of recommendations for transition for young children with developmental disabilities. Fialka (2006) suggests that in preparation for the 'goodbye' a checklist for the personal dimensions of taking leave should exist alongside the professional checklists. As families and professionals in EI are interdependent participants, they share resources, influence thoughts and behaviours, grow and learn over time and meet each other's needs (Kelly et al, 1983). This study recognizes the interpersonal and professional relationships that exist in EI.

Although this research was conducted in a rigorous manner supporting the trustworthiness of the trajectory of relationship development, it was based on one EI team in a particular cultural environment. The team involved in the study was keen to be involved and the team leader selected the participants. The authors acknowledge

that the research was carried out in one setting, however suggest that the setting could be viewed as common in relation to the service user group and team relationships.

Therefore, the findings of this study could prove to be transferable into other similar settings.

Conclusion

The role of relationships between professionals, children and their parents in EI is paramount. The EI relationship is a complex interdependent one which requires a roadmap of explicit stages, which can facilitate all involved in the relationship to work together. This study provides this roadmap in the form of a developmental relationship trajectory. While this model is presented as a linear process, the participants in the relationship may be at different stages of the model or children and parents may be at different stages with different professionals. This trajectory is a generic model, and may be used as a tool with potential transferability to other EI programmes. It adds to the literature on relationship development in the context of EI. This trajectory is all-inclusive, combining the views of children, parents and professionals. Equipped with the knowledge of the relationship stages combined with an awareness of what stage each participant is at in the relationship will let the EI relationship journey begin, progress and end smoothly. Further studies giving young children with developmental disabilities a voice, alongside parents and professionals, is required to develop research within the field of EI. Further research is required to test this theory of relationship development within other EI teams in the country and also within other teams internationally.

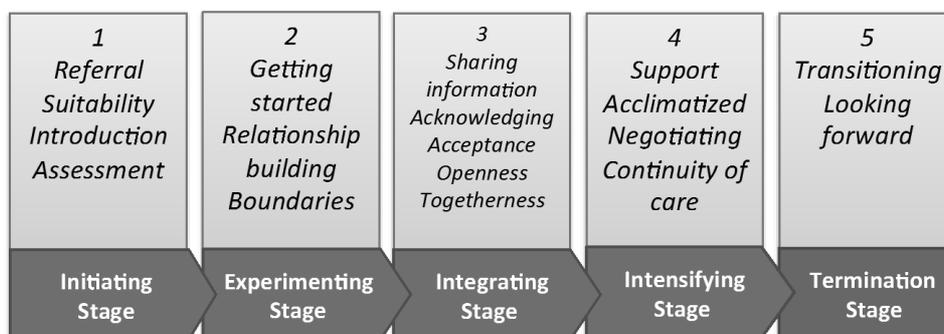
Table 1: Family Sample

<u>Family Representative</u>	<u>Child Gender</u>	<u>Age (years)</u>	<u>Length of time with EI (years)</u>	<u>Referral Age</u>	<u>Diagnosis</u>	<u>Education</u>
Child 1	Male	3	3	5 months	Down syndrome	Mainstream Preschool
Child 2	Male	3	3	4 months	Down syndrome	Mainstream Preschool
Child 3	Male	4	4	5 months	Physical and intellectual disability	Special Preschool
Child 4	Male	3	3	4 months	Down syndrome	Mainstream Preschool
Child 5	Male	3	3	4 months	Down syndrome	Not yet
Parent 1	Male	4	2	2 years	Physical and intellectual disability	Special Preschool
Parent 2	Male	4	4	3 months	Physical and intellectual	Special Preschool

					disability	
Parent 3	Male	5	5	6 months	Down syndrome	Mainstream Preschool
Parent 4	Female	3	3	4 months	Down syndrome	Not yet
Parent 5&6	Female	2	2	5 months	Down syndrome	Not yet

Figure 1: Relationship Stages in EI

Relationship Stages in Early Intervention



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Key Points

Families and professionals involved in EI practice will benefit from viewing their relationship from a developmental perspective.

Both interpersonal and professional relationships are evident in EI practice.

The trajectory of relationship development emerging from this study can be used as a tool to support EI practice.

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Understanding the key factors, within each relationship stage, may support positive relationships between professionals, children and their families, thus positively influencing the outcome of EI practice.

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