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Above and Beyond:

Exploring outcomes and practices of Scope Southern Region

Early Childhood Intervention Service for children with
disability

Erin Wilson

Robert Campain

Scope and Deakin University, August 2011
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ISBN
# Contents

<table>
<thead>
<tr>
<th>List of Abbreviations</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>6</td>
</tr>
<tr>
<td><strong>Section 1: Introduction and Methods</strong></td>
<td><strong>22</strong></td>
</tr>
<tr>
<td>Chapter 1: Introduction – background and context</td>
<td>23</td>
</tr>
<tr>
<td>Defining early childhood intervention</td>
<td>23</td>
</tr>
<tr>
<td>Scope Southern Region Early Childhood Intervention Service</td>
<td>24</td>
</tr>
<tr>
<td>The project</td>
<td>28</td>
</tr>
<tr>
<td>The historical development of early childhood intervention</td>
<td>30</td>
</tr>
<tr>
<td>The Victorian early childhood intervention context: the Victorian Government policy and directional statements</td>
<td>31</td>
</tr>
<tr>
<td>Conclusion</td>
<td>36</td>
</tr>
<tr>
<td>Chapter 2: The research project</td>
<td>37</td>
</tr>
<tr>
<td>ECIS effectiveness - the need for empirical research</td>
<td>37</td>
</tr>
<tr>
<td>International and Australian empirical studies</td>
<td>38</td>
</tr>
<tr>
<td>Research questions</td>
<td>40</td>
</tr>
<tr>
<td>Timeframe of research</td>
<td>42</td>
</tr>
<tr>
<td>Methodology</td>
<td>42</td>
</tr>
<tr>
<td>Data collection methods</td>
<td>43</td>
</tr>
<tr>
<td>Data analysis methods</td>
<td>50</td>
</tr>
<tr>
<td>Structure of the report</td>
<td>51</td>
</tr>
<tr>
<td><strong>Section 2: Outcomes of Service Delivery</strong></td>
<td><strong>52</strong></td>
</tr>
<tr>
<td>Chapter 3: Identifying outcomes</td>
<td>53</td>
</tr>
<tr>
<td>Defining outcomes</td>
<td>53</td>
</tr>
<tr>
<td>Outcomes for children</td>
<td>55</td>
</tr>
<tr>
<td>Outcomes for families</td>
<td>56</td>
</tr>
<tr>
<td>Methods for measuring outcomes</td>
<td>57</td>
</tr>
<tr>
<td>Implications for this research</td>
<td>58</td>
</tr>
<tr>
<td>Chapter 4: Outcomes for children from Scope Southern ECIS</td>
<td>59</td>
</tr>
<tr>
<td>Introduction</td>
<td>59</td>
</tr>
<tr>
<td>What outcomes are examined?</td>
<td>59</td>
</tr>
<tr>
<td>Research methods to collect data about outcomes for children</td>
<td>60</td>
</tr>
<tr>
<td>Research methods to analyse data about outcomes for children</td>
<td>64</td>
</tr>
<tr>
<td>Results</td>
<td>66</td>
</tr>
<tr>
<td>Conclusion</td>
<td>73</td>
</tr>
<tr>
<td>Chapter 5: Outcomes for families from Scope Southern ECIS</td>
<td>75</td>
</tr>
<tr>
<td>Introduction</td>
<td>75</td>
</tr>
<tr>
<td>What outcomes are examined?</td>
<td>76</td>
</tr>
<tr>
<td>Research methods to collect data about outcomes for families</td>
<td>76</td>
</tr>
<tr>
<td>Research methods to analyse data about outcomes for families</td>
<td>79</td>
</tr>
<tr>
<td>Results</td>
<td>80</td>
</tr>
<tr>
<td>Conclusion</td>
<td>86</td>
</tr>
<tr>
<td>Chapter 6: Satisfaction with Scope Southern ECIS</td>
<td>88</td>
</tr>
<tr>
<td>Introduction</td>
<td>88</td>
</tr>
<tr>
<td>Satisfaction as an outcome measure</td>
<td>88</td>
</tr>
</tbody>
</table>
Chapter 7: Enablers to outcomes

Introduction

Research methods to collect data about the enablers to outcomes

Results

Conclusion

Chapter 8: Barriers to outcomes

Introduction

Research methods to collect data about the barriers to outcomes

Results

Conclusion

Section 3: The Process of Service Delivery: Family Centred Practice

Chapter 9: Defining Family Centred Practice

Exploring the literature

Implications for this research

Chapter 10: The nature and extent of Family Centred Practice in Scope Southern ECIS

Introduction

Research methods for collecting data about the understandings of and extent of family centred practice

Research methods for analysing data about the understandings of and extent of family centred practice

Results

Conclusion

Chapter 11: The use of Family Service and Support Plans

Introduction

Research methods for collecting data about engagement with Family Service and Support Plans as an element of family centred practice

Research methods for analysing data about engagement with Family Service and Support Plans as an element of family centred practice

Results

Conclusion

Section 4: The Process of Service Delivery: Transdisciplinary Practice

Chapter 12: Transdisciplinary practice - exploring the literature

Defining transdisciplinary practice

The challenges of transdisciplinary practice

The need for evidence

Implications for this research
<table>
<thead>
<tr>
<th>Chapter 13: The degree and type of transdisciplinary practice and the effectiveness of resources and supports for it</th>
<th>174</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>174</td>
</tr>
<tr>
<td>Research methods to collect data about the degree and type of transdisciplinary practice and the effectiveness of resources and supports for it</td>
<td>175</td>
</tr>
<tr>
<td>Research methods to analyse data about the degree and type of transdisciplinary practice and the effectiveness of resources and supports for it</td>
<td>178</td>
</tr>
<tr>
<td>Results</td>
<td>179</td>
</tr>
<tr>
<td>Conclusion</td>
<td>195</td>
</tr>
<tr>
<td>Chapter 14: Confidence, experiences and preferences of therapists in transdisciplinary practice</td>
<td>197</td>
</tr>
<tr>
<td>Introduction</td>
<td>197</td>
</tr>
<tr>
<td>Research methods to collect data about the confidence, experiences and preferences of therapists in transdisciplinary practice</td>
<td>198</td>
</tr>
<tr>
<td>Research methods to analyse data about the confidence, experiences and preferences of therapists in transdisciplinary practice</td>
<td>199</td>
</tr>
<tr>
<td>Results</td>
<td>199</td>
</tr>
<tr>
<td>Conclusion</td>
<td>204</td>
</tr>
<tr>
<td><strong>Section 5: Discussion and Conclusions</strong></td>
<td><strong>205</strong></td>
</tr>
<tr>
<td>Chapter 15: The bigger picture</td>
<td>206</td>
</tr>
<tr>
<td>Introduction</td>
<td>206</td>
</tr>
<tr>
<td>Reflection on research methods</td>
<td>206</td>
</tr>
<tr>
<td>Discussion of key findings</td>
<td>213</td>
</tr>
<tr>
<td>Conclusion</td>
<td>225</td>
</tr>
<tr>
<td><strong>References</strong></td>
<td><strong>229</strong></td>
</tr>
<tr>
<td><strong>Appendices</strong></td>
<td><strong>238</strong></td>
</tr>
<tr>
<td>Appendix i: Parent Survey (2007 &amp; 2008 version) - Scope Southern Region ECIS Research</td>
<td>239</td>
</tr>
<tr>
<td>Appendix ii: Family Service and Support Plan</td>
<td>250</td>
</tr>
<tr>
<td>Appendix iii: Review of FSSP Outcomes and Process document (as attached to FSSP)</td>
<td>253</td>
</tr>
<tr>
<td>Appendix iv: Therapist Survey</td>
<td>254</td>
</tr>
<tr>
<td>Appendix v: Record Sheet - Manual Usage</td>
<td>256</td>
</tr>
<tr>
<td>Appendix vi: Parent rated impact of ECI service on life areas (from annual Parent Survey)</td>
<td>257</td>
</tr>
<tr>
<td>Appendix vii: Parent rated impact of ECI service on parenting capacity (from annual Parent Survey)</td>
<td>258</td>
</tr>
<tr>
<td>Appendix viii: Percentage of parent response on each item organised by domains of family centred practice</td>
<td>259</td>
</tr>
</tbody>
</table>
List of Abbreviations

ADD  Attention Deficit Disorder
AFO  Ankle Foot Orthoses
CSO  Community Service Organisation
DEECD  Department of Education and Early Childhood Development
DHS  Department of Human Services
DSD  Disability Services Division
ECI  Early Childhood Intervention
ECIA  Early Childhood Intervention Australia
ECIS  Early Childhood Intervention Services
EI  Early Intervention
FSSP  Family Service and Support Plan
GP  General Practitioner
ICF  International Classification of Functioning, Health and Disability
MOSS  Measurement of Outcomes of Services and Supports
MPOC  Measure of Processes of Care
NEILS  National Early Intervention Longitudinal Study
OT  Occupational Therapy/ist
SCS  Specialist Children’s Services
TD  Transdisciplinary Practice
WHO  World Health Organisation
Executive Summary
Overview of the study

This research project is an exploration of the early childhood intervention service (ECIS) provided by Scope Southern Region. The research seeks to examine the benefits and outcomes for families and children. In doing so, the project’s emphasis is on key practices such as family centred practice and transdisciplinary practice, while examining the enablers and barriers to providing positive benefits to families and children. The central question is whether the interventions are of assistance to families and children.

The research was commissioned by the Scope Southern Region Early Childhood Intervention Service in 2006, and involved researchers from Scope and Deakin University. The research seeks to address a number of key aims. These are to:

- Contribute to evidence about outcomes for families and children, and key practices of service delivery, in the field of Early Childhood Intervention for children with disability;

- Provide families and therapists an opportunity to participate in service evaluation and improvement;

- Develop and trial useful methods of data collection about outcomes measurement that may have wider application within the early childhood sector.

The specific research questions, along with a set of sub questions or topic areas are:

1. What are the outcomes experienced by children and families resulting from ECI services provided by Scope Southern Region?

   The research sought to identify and analyse:
the sorts of outcomes for children aspired to by families,

the level of achievement and types of outcomes achieved for children,

the level of achievement and types of outcomes achieved for families,

the extent to which service providers and families feel that needs have been met,

the level of satisfaction parents have with services received, and

the enablers and barriers to outcomes.

2. What is the extent of family centred practice in use within ECI services provided by Scope Southern Region?

The research sought to identify and analyse:

- how therapists understand family centred practice,

- how parents rate the extent of family centred practice,

- the level of parent involvement in Family Service and Support Plan development,

- the extent of therapists’ familiarity with Family Service and Support Plans.

3. What are the elements and practices of supporting transdisciplinary practice in the region?

The research sought to identify and analyse:

- how therapists understand transdisciplinary practice,

- the degree and type of transdisciplinary work undertaken by therapists,

- the resourcing and support of transdisciplinary work,

- the confidence, experiences and preferences of therapists working in transdisciplinary practice.
These research questions broadly address some of the key focus areas of the Victorian Government. Overall, key Victorian Government policy statements emphasise child outcomes and the fostering of relationships between children, families and community. General themes emphasize the importance of governments and services in working in partnership with families while supporting them in achieving positive health and developmental outcomes for their children. Social inclusion for children and their families, and the right for all to participate fully in the community, are key goals of the Government based on the recognition of human rights.

**Scope Southern Region Early Childhood Intervention Service**

Scope Southern Region provides early childhood intervention to families and their children with a disability or developmental delay from birth until school entry. The Southern ECI Service aims to work in partnership with parents and families to provide them with the knowledge, skills and support to meet the needs of the child, and to optimise the child’s development and ability to participate in family and community life. Southern ECI Service’s head office is located in the Melbourne suburb of Mordialloc, with another centre located in the South-Eastern suburb of Pakenham.

In order to provide an intervention service for their clients (up to 110 funded places on average throughout the study), the Scope Southern ECI Service is staffed by therapists\(^1\) in a range of professional disciplines including physiotherapy, occupational therapy, speech therapy, and psychology, as well as early childhood education. The service (incorporating both Mordialloc and Pakenham) employed approximately 16 therapists at any one time throughout the course of the project. Therapists predominantly worked individually, though there were occasions when they undertook joint visits (also referred to as dual visits) with two therapists working together with the child and their family. Also, the Pakenham service had a staff of three who provided group sessions at the centre as well as attending at people’s homes.

In 2006, the service moved to foster a more transdisciplinary approach to therapy practice, while also

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\(^1\) Within this report, the term ‘therapist’ is used generically to refer to therapists, psychologists and family service co-ordinators
seeking to continue working according to the principles of family centred practice in accordance with the Victorian Government’s practice recommendations. Broadly, family-centered practice is a way of working with families, both formally and informally, to enhance their capacity to care for their children. Family-centered practice recognizes the strengths of family relationships and builds on these strengths to achieve optimal benefits for the family and the child. The transdisciplinary approach constitutes professionals undertaking interventions outside their own discipline, with a focus on collaboration with families and between therapists.

To create a transdisciplinary culture of collaboration and knowledge sharing, a number of strategies were adopted at the Southern ECI Service. These included:

- Case presentations by therapists to their colleagues;
- The development and use of a resource manual in 2007 (One Day at a Time) by the co-ordinator and personnel at Scope Southern Region that provides a number of resources to aid therapists and families. These resources include items such as local government and community resource contact information, diagnostic specific information, developmental stage checklists, development activity information, songs, and transitional information.

Further to these developments, a number of existing work practices were adapted to skill therapists to engage in transdisciplinary practice. These included:

- Professional Development Days conducted twice yearly for therapists to share information and hear from guest speakers;
- The use of joint visits (also referred to as dual visits) whereby therapists have a chance to work together and share knowledge and skills across disciplines in a supported manner;
- Group Programs which involved a number of children coming together to engage in shared activities, with a number of therapists present to direct interventions.
Data collection methods

Researchers collected data on a range of key domains at a number of time intervals commencing in November 2006 through to December 2009. Overall, eight main methods of data collection were used including;

- a yearly Parent Survey (with 68 parent respondents between 2006 and 2008),
- analysis of Family Service and Support Plans (FSSPs) (26 plans in total),
- an Outcomes and Process document attached to the Family Service and Support Plan (3 in total),
- a yearly Therapist Survey (with 24 therapist responses in total between 2006 and 2008),
- a record of manual usage (26 responses in total between 2007 and 2008),
- individual therapist interviews (6) and focus groups (3) in 2007 and 2008, and
- parent interviews (7 participants in total between 2007 and 2008).

Key findings

Outcomes

For the purpose of the study, outcomes were assessed according to outcomes for children and outcomes for families. The literature on outcomes examined for this study articulates the inter-relatedness of child and family outcomes in that positive outcomes for one will have positive outcomes for the other. The literature also offers little consistency in terms of identifying outcome areas or methods of measurement.

Outcomes for children were assessed in terms of the type of goals identified (or outcomes aspired to) within Family Service and Support Plans and the level of achievement of these. Outcomes or goals were classified in relation to the categories of function/activity, participation and environment (as defined by
the *International Classification of Functioning Classification and Health*, WHO, 2001) as well as in relation to nine broad life areas (Wilson, 2006). This is broadly consistent with the Early Childhood Intervention Association (ECIA) (Victoria Chapter) Outcome Statements that propose outcomes of service delivery for children and families (as well as communities) in the areas of functioning (understood as both knowledge and skills), and participation (which includes involvement with others, attitudes, support and coping) (Moore and Sargood, 2005).

In terms of findings, a clear majority of outcome goals for children (an average of 78% across 2007 and 2008) related to function/activity (e.g. ‘to sit independently and safely’). The remainder of goals were focused on achievements relating to participation and environment. This emphasis on function was also reflected in the analysis relating to life areas (Wilson, 2006), which evidenced the prevalence of goals relating to personal life (an average of 72%). The focus on function may suggest the application of a medical model of intervention rather than a social model. This is not surprising given the age of the children (birth-4 years), as parents are likely to be concerned about maximising the motor and cognitive skills of their child in the early stages of human development. While not explicit, arguably there is an implied element of participation in that the development of motor and cognitive skills may assist in greater life participation.

In terms of levels of achievement of outcomes for children, across 2007 and 2008 just over 50% of goals were judged by therapists and parents as either ‘achieved’ or ‘ongoing - progressing well’. Approximately a third were rated as ‘ongoing - continuing’. However, the level of success in achieving goals is not easily interpreted from this data. This quantitative analysis of achievement would suggest a mixture of significant success and an uncertain level of achievement given the ongoing need to work at certain goals. Given most of the goals were related to cognitive or motor development, this suggests many of these goals will require a long term focus and continuous intervention as progress is made. By contrast, some goals are framed as short term and therefore are more likely to be achieved. Also, no information is available with regard to the degree of disability and the anticipated timeframe for success. Such issues suggest that caution must be exercised in determining the success or not of a service based on statistical criteria. By contrast, the use of interview data evidences the overwhelmingly positive view of parents and therapists in regard to outcomes achievement for children.
Outcomes for families were assessed in terms of the impact of service on parenting capacity and on nine broad life areas. In addition, parents also provided ratings of satisfaction with the service, willingness to recommend the service to others, and an assessment of the extent to which their needs were met by the service. As with the results for children, outcomes for families were positive in relation to the measuring of nine life domains and the twelve items relating to parenting capacity. On average across 2007 and 2008, approximately two-thirds of parents reported very positive to positive impacts across life areas particularly in the areas of personal and family wellbeing, social life, educational life, and recreational and leisure life. Approximately one third also rated that the service had no impact on life areas, possibly because goals on FSSPs largely focused on function and parents may not have considered service impact beyond functional intervention. With regard to parenting capacity, only 13% in 2007 and 9% in 2008 saw the service as having no impact in this area with an overwhelming majority regarding the service as having a very positive or positive impact on parenting capacity.

Similarly, an average of 82% of parents in 2007 and 2008 rated the service as meeting most or all of their needs, and an average of 96% of parents in both years were ‘mostly’ or ‘very’ satisfied with the service. Consistent with this, an average of 89% of parents would ‘definitely’ or ‘probably’ recommend the service to others. Despite these positive results, the study reports concerns in the literature in regard to the use of satisfaction measures as proxy indicators for outcomes achievement.

It can therefore be concluded that, generally, the service has provided positive outcomes for children and families. Despite this, parents also identified areas for improvement in service delivery by identifying both enablers and barriers to positive outcomes.

In interviews, parent surveys, and in reviews of Family Service and Support Plans in 2007 and 2008, therapists and parents were asked to identify the enablers and barriers to outcomes. The enablers and barriers to positive outcomes identified by families are broadly consistent with those identified by therapists. The major enabler to achieving positive outcomes appears to be adequate resources - this includes the provision of competent and committed therapists to work empathetically with children and families with ongoing, regular therapeutic intervention and family support. Families also highlighted the need for access to equipment to support the child, and the provision of guidance, instruction and associated activities. All of this requires time, which families recognised as a barrier to outcomes, as they
attempted to juggle the various demands in their lives, while therapists were also restricted by time due to the various demands of their workloads. Other barriers identified were insufficient therapy provision and lack of money and resources.

It should be emphasised that overwhelmingly families praised the skill, empathy and dedication of the therapists. Many of them expressed the way in which they felt therapists had gone out of their way to support families and had demonstrated their commitment to working and collaborating alongside family members. Where families had concerns, they felt that service budgetary limitations hampered the extent of the work that could be done and that this was not a fault of the service or individual therapists but was systemic throughout the public sector. Funding issues impact all of the enablers and barriers mentioned above. More adequate funding targeting these key areas could work towards increasing services and better outcomes.

It should be noted that fundamentally outcomes are difficult to define and measure. What needs to be given weight is not so much a focus on quantifiable analysis which can only ever provide a partial and incomplete understanding. In considering what has happened for children and families, and been achieved by and for them, weight has to be given to a more complete story that emerges through talking with families and therapists, while considering the rich and complex circumstances of the intervention and the context in which it takes place.

**Family Centred Practice**

A number of indicators of family centred practice were used in the study including: an annual Parent Survey including 31 items adapted from the Measure of Processes of Care instrument (King, Rosenbaum & King, 1995); parent rating of their level of involvement in the development of Family Service and Support Plans (FSSPs); therapist rating of their familiarity of FSSPs in their case load; and interviews with parents and therapists.

The study results clearly evidence that family centred practice is a strength of the Southern Region Early Childhood Intervention Service. On surveys, parents reported very positive responses in all five domains
of family centred practice. Overall, the highest ranked domain of family centred practice was that of ‘respectful and supportive care’. This was echoed in interviews with parents, where respondents provided affirmations of this type of practice in Scope, and frequent examples of staff delivering highly personalised and timely support to their child and wider family.

The area judged to be the lowest rating of the domains of family centred practice was that of information provision, relating to both general and specific information. While a substantial majority of parents still rated these areas highly, overall they lag behind the results of the other domains. This is consistent with findings in other studies (Scope, 2004; King et al, 1998 cited in Moore and Larkin, 2005).

Another indicator of family centred practice is the level of family involvement in the development of Family Service and Support Plans, and the extent of therapist familiarity with and use of these as part of their ongoing practice. Study results evidence a very high rate of involvement of families in the development of FSSPs. However, results averaged across 2006-2008 also showed mixed levels of therapist familiarity with client FSSPs with some showing a high level of ‘indepth’ knowledge (13%), but most showing ‘good knowledge’ (59%). Of some concern is the finding that an average of 25% of therapists in 2006-2008 had only a ‘limited knowledge’ of the FSSPs of clients in their case load. However, in family interviews therapists were characterised as having significant knowledge about children, their families and life contexts, and were highly valued by parents for this. Some therapists commented on the limitations of the FSSP document, given the fluid and complex contexts in which they worked, and the lack of time available to engage with and update the document. Such comments suggest that therapists are working in family centred ways with a deep understanding of the families with which they work, but that the FSSP document is always going to offer a limited and sometimes limiting capture of, and guide to, this work.

**Transdisciplinary Practice**

Transdisciplinary practice was explored largely through annual therapist surveys, focus groups, and interviews, including discussion about definitions and understandings of the practice.
Therapists indicated that they saw transdisciplinary practice as involving a broader knowledge base that went beyond the therapists’ own discipline, with an understanding of elements of how other therapists worked, and the way this related to the child and family in a more holistic manner. However, therapists also expressed a large degree of discomfort with specific elements of transdisciplinary practice. This was reflected in their preference for the terms ‘collaborative practice’ or ‘knowledge sharing’ to describe their practice approach. Both are elements of transdisciplinary practice but are somewhat more flexible concepts that are more suggestive of team work.

In many instances, therapists expressed some uncertainty as to what exactly was expected of them within this model of practice. Therapists also expressed concern that clients should receive appropriate and quality services from qualified practitioners in each discipline, and that transdisciplinary practice would disadvantage clients if therapists were expected to provide an intervention outside of their discipline in lieu of a trained and qualified professional.

While therapists expressed a range of concerns about transdisciplinary practice, overall, ‘role release’ appears to be the element of this practice that therapists were most reluctant to embrace. This discomfort with role release relates to a range of barriers to the implementation of transdisciplinary practice in the Southern ECIS context. To begin with, therapists felt inadequately trained in other disciplines, with limited skills and supervision, to perform interventions outside of their discipline. This is supported by data that shows that the amount of formal meeting time to share knowledge has declined over the period 2006-2008 (with an average of 71% of therapists spending less than 1 hour per month in this way), despite therapists valuing this time as useful. This decline in formal time is countered by the rise in informal time, which is also deemed to be of great use. Overall, this data suggests that therapists gain a great deal from being able to share knowledge with one another, but time limitations are reducing the formal time, with therapists having to rely on informal methods (face to face, telephone, email).

Joint visits, where therapists from different disciplines visit the client together, can be considered another aspect of transdisciplinary practice that fosters interprofessional collaborative practice and skills exchange (towards role release). Joint visits are widely viewed by Scope therapists as a valuable learning opportunity to share information, learn skills and find solutions to problems while ensuring
everyone is working towards common goals. However, despite an overall positive summation of joint visits, these opportunities have declined over the period. Generally, the availability of therapists to one another has declined over the course of the study, and in interviews therapists have voiced the need for more support and the need to have greater access to one another in order to foster both collaborative, as well as family centred practice.

The Southern ECI Service has provided a number of resources to support transdisciplinary practice. In general, these resources appeared to offer limited support to the role release aspects of transdisciplinary practice. The manual, One Day at a Time, appears to be used by therapists for its regional service contact information rather than for information specific to other disciplines. In this manner, the manual is a useful tool to encourage general knowledge sharing rather than supporting role release skills. Likewise, video and case presentations were regarded as limited in value, however this may be due to their infrequency.

In summary, therapists identify the lack of available time and insufficient resources to undertake transdisciplinary practice to a level that could successfully lead to role release. Therapists also expressed concerns as to the level of skill required in disciplines other than one’s own, and whether role release is achievable. These barriers may account for therapists’ significant lack of confidence in acquiring transdisciplinary skills with seventy five percent feeling only ‘somewhat confident’ to acquire skills in a discipline not their own.

Overall, it appears though that therapists work in a collaborative and knowledge sharing manner that reflects many of the key elements of transdisciplinary practice. Where they do not work in a transdisciplinary manner is in the area of role release which requires a willingness to implement skills of another discipline. The literature argues that in a transdisciplinary model, a service needs to ensure there is adequate time for training and supervision. This is difficult given the demands placed on a service to adequately address growing numbers of clients. The time required to train and support therapists, appears to be significantly higher than what the Southern ECI Service is able to provide.

A culture of support for transdisciplinary practice in all of its elements requires time and a commitment from therapists, service providers and governments to ensure that transdisciplinary practice effectively meets the needs of families and children. Constant change and the need to update the knowledge and
skills of one’s own discipline means that it is difficult to confidently acquire and maintain a level of skill in another discipline. This raises the question that if to be transdisciplinary requires role release, then it is necessary for governments and service providers to consider whether such a practice is viable and achievable.

**Other findings – the story behind the results**

The measurement of key aspects of the Scope Southern Early Childhood Intervention Service tells only part of the story. There is a bigger story to be told, revealed in interviews with both families and therapists that shows a service operating in a context in which three factors are in tension. First, the complex environment of the families receiving services. In some situations, families present with a range of problems in their lives including housing and income support needs, physical and mental health problems, and parenting issues, among others, in addition to the complex needs related to raising a child with a disability. In some cases, families are experiencing extreme crisis, such as parents contemplating suicide. In this context, therapists require a wider skill set not just within the discipline of the ECI field but also related to counselling, social work and other fields, as well as substantial knowledge of other services and referral networks.

Against this is set the second major tension of service constraints related to funding limitations and policy and program parameters. These include high case loads of therapists, significant time spent in travel across a large region, and a limited allocation of therapist time per client. The service uses a workload model of ‘billable hours’ that requires eighty percent of a therapist’s work hours to be directly related to service delivery to clients. This model has significant negative consequences including forcing therapists to restrict necessary elements of their interventions to clients, and to forfeit professional development and support time for themselves. Lastly, there is a range of ingredients necessary to the delivery of a quality ECI service. These include: service planning (involving a range of therapists and family members); sufficient time spent in face to face service delivery with the client; engagement in follow up activities and sourcing further information; liaison and capacity building with other agencies such as local governments, day care providers and early childhood education services; co-ordination of all the services delivered to the family; involvement in professional development; and time spent in
transdisciplinary practice related issues. All this is undertaken in the knowledge that there is an immediate window of time where the child requires intensive support to achieve maximum developmental benefit. For families and therapists, there is often an experience of ongoing struggle to stay afloat with both parties feeling that resources and supports are inadequate. As one therapist stated; ‘You always feel like you’re treading water’ (Therapist 07).

Conclusion

Overall, the results evidence that the Southern Region ECI service is achieving well in relation to outcomes and family centred practice, while transdisciplinary practice remains a complex field requiring further consideration. In short, the research has evidenced the effectiveness of the service as well as highlighting some areas for improvement and the targeting of future resources. What was most significant to the researchers throughout this study was the admirable way in which therapists worked with families demonstrating their skill and commitment, often under very challenging circumstances.

The issues reported in this study in regard to service improvement, largely relate to a system outside of the specific service. The factors affecting families and their young children with disabilities are complex ones, as is the service and funding environment which is set up to support them. This study suggests that to best aid families, and to best resource therapists in this work, attention needs to be refocused on broader societal and systems change, and the resourcing of practitioners in this field to engage in this work. The following considerations summarise key areas for future action.

Considerations for service delivery

1. Meeting the complex needs of families: The study makes clear that the needs of families are complex and frequently crisis-driven, and that early childhood intervention staff needs skills and knowledge well beyond therapeutic disciplines to address these. To adequately meet these needs, services require specific resources to support early childhood intervention staff such as identified social work, counselling, and/or community work personnel with expertise in the area
of working with vulnerable families. While it could be argued that such resources are or should be located elsewhere in the broader service system, this study shows that therapists are unable to access these resources sufficiently, and that barriers of time and knowledge that function to hamper this access. Co-location of such resources within ECI services would assist in overcoming these barriers.

2. **Transdisciplinary practice:** While transdisciplinary practice is a stated element of early childhood intervention endorsed by the Victorian State Government (Early Years Service, DHS, 2005), this study has identified a range of difficulties with its implementation. As a result, services and governments need to review the expectations around the implementation of transdisciplinary practice, identifying what is realistic and appropriate, given the resources available to support its effective implementation. The study suggests multiple concerns with transdisciplinary practice, especially in the area of role release, and a clear preference of early childhood practitioners, in this service at least, for a focus on collaborative practice and knowledge sharing rather than role release.

3. **Managing workload, funding and quality service:** The staffing model used in the Southern ECI Service requires staff to be able to ‘bill’ eighty percent of their time as delivery of services to funded clients. This notion of ‘billable hours’ means that not only direct service delivery to clients is included, but all activity related to direct service such as travel time, time spent in developing resources or strategies, time spent in upskilling, and information searches related to the client, is also ‘billed’ against the client’s funded total hours of service delivery. Respondents in this study raised many concerns with this approach, not least the impact on clients and the impacts on the overall quality of service. Given that therapists are restricted in how much time they can spend on any aspect of an intervention, they therefore have to ration their time, selecting some aspects of an intervention and sacrificing others (such as spending time developing a customised resource, or researching the latest evidence in relation to a proposed technique). Overall, this approach to the management of service delivery runs counter to achieving the best quality service possible, and results in a rationed and ‘pared down’ service.
Similarly, this workload allocation model also undermines interprofessional and collaborative work, as well as ongoing professional development. This study repeatedly identified examples of these activities being restricted or denied due to the requirement to spend almost all paid work hours in the delivery services, without adequate allocation of time to the professional needs of staff as part of this service delivery role.

4. **Recognising and affirming work to achieve outcomes for families and children that go beyond ‘functioning’:** While this study found that goals documented as part of Family Service and Support Plans were predominantly focused on areas of ‘functioning’ of the child, therapists and families both frequently discussed the undocumented areas of work related to achieving outcomes in the area of family life, wellbeing, mental health, finances, and social participation, among others. In many instances, these areas were considered to be of immediate importance and therefore took precedence over other stated goals. In most cases, these were not documented or evaluated though ECI staff spent much of their intervention time on these necessary tasks. While there is an argument to suggest that such priorities and goal areas are too personal and sensitive to be formally documented, and that to do so would breach trust and privacy of families, greater valuing, recognition, and resourcing of this work is required within services.

In conclusion, this study shows that the Southern Region Early Childhood Intervention Service is effective in meeting the needs of children with disabilities and their families. As with all human service delivery, there is room for improvement in some areas. However, comments from families and therapists suggest that improvements are unlikely to occur without additional funding and resources. Without these, it is unlikely that the good results achieved here can be sustainable in the long term, given they rely on practitioners/therapists and families going above and beyond their personal and professional resources.
Section 1:
Introduction and Methods
Chapter 1: Introduction – background and context

This research project is an exploration of the early childhood intervention service (ECIS) provided by Scope Southern Region. The research seeks to examine the benefits and outcomes for families and children. In doing so, the project’s emphasis is on key practices such as family centred practice and transdisciplinary practice, while examining the enablers and barriers to providing positive benefits to families and children.

Why is there a need to conduct research into early childhood intervention (ECI)? Most simply there is a need to consider what early intervention services are trying to achieve and why. As Gallagher notes:

‘One ugly question we might ask ourselves is: Have we been intervening before we knew precisely what it was that we were trying to change? (Gallagher, 2002: 43-44).

This is a significant question that needs to be considered by all parties involved in ECI. Of equal significance is whether the identified aims of the families, services and government are being achieved. Without rigorous research that investigates specific aspects of early childhood intervention, the risk is that services continue to operate without questioning both the processes involved and the actual benefits experienced by children and families.

Defining early childhood intervention

There is no fixed agreed definition of early childhood intervention though most definitions offered by researchers in the field cover the same common characteristics to enable a broadly shared understanding. A general definition offered by Gallagher is that intervention represents an attempt to ‘make things better for children and families’ (Gallagher, 2002: 43). Shonkoff and Meisels in their definition of ECI note the need for multidisciplinary services to children from birth to five years of age to ‘promote child health and well being, enhance emerging competencies, minimize developmental delays, remEDIATE existing or emerging disabilities, prevent functional deterioration’ while supporting parents
and enhancing overall family functioning (Shonkoff & Meisels, 2000: XV11- XV111). Dunst defines early childhood intervention as the provision of support and resources to families of young children from members of informal and formal social networks that, both directly and indirectly, influence the child and family functioning (Dunst, 2007: 7).

The key components of early childhood intervention identified through these definitions include providing direct support to the child to enhance medical and social outcomes, while also providing support directly to the family to enhance their skills and competencies in supporting their child. This is done in the context of the community, with valuable support networks to be identified and encouraged in aid of the family.

**Scope Southern Region Early Childhood Intervention Service**

Scope is one of the largest providers of services to people with a disability in Victoria. The organisation provides disability services throughout Victoria to thousands of children and adults with physical and multiple disabilities. Scope’s mission is to support people with a disability to achieve their potential in welcoming and inclusive communities. Starting in 1948 as the Spastic Children's Society of Victoria, today Scope's services include areas such as therapy and psychology, home and respite, day and lifestyles, and employment services (Scope, 2011).

Scope Southern Region provides early childhood intervention to families and their children with a disability or developmental delay from birth until school entry. This intervention provides additional services and supports not usually available through universal (i.e. non-specialist) services. These additional services include: special education; therapy; counselling; service planning and coordination; as well as assistance and support to access services such as kindergarten and childcare. The Southern ECI Service aims to work in partnership with parents and families to provide them with the knowledge, skills and support to meet the needs of the child, and to optimise the child’s development and ability to participate in family and community life. Southern ECI Service’s head office is located in the Melbourne suburb of Mordialloc, with another centre located in the South-Eastern suburb of Pakenham. The service covers a wide region that incorporates Mornington Peninsula, Frankston, Kingston, Stonnington,
Glen Eira, Port Phillip, Bayside, Casey, Cardinia, and Greater Dandenong. To give some example of the area covered on some occasions, a Southern practitioner may see a family in Rosebud (Mornington Peninsula) before driving to visit another family in St Kilda (Glen Eira), a distance of 90 kilometres.

In order to provide an intervention service for their clients, Scope Southern ECI Service is staffed by therapists\(^2\) in a range of professional disciplines including physiotherapy, occupational and speech therapy, and psychology as well as early childhood education. These ECIS staff have substantial experience, averaging 14 years of prior professional practice (across therapists surveyed in 2007 and 2008). The service employed approximately 16 staff members at any one time. In 2007 for example, there were 7 occupational therapists, 6 physiotherapists, 2 speech therapists and 1 psychologist. Work days varied, with 5 therapists employed full-time and the remainder working various part-time arrangements. Overall, in 2007, therapists surveyed in this research, worked an average of 48.5 hours per fortnight, with a monthly client load of 12 children/families.

The following outline illustrates the services and supports provided by the Southern ECI Service:

- **Identification of Needs** – Children and family needs are identified in consultation with families and carers.

- **Family Service Coordination** - Families are offered a 'Family and Services Support Plan' to ensure that the services best meet the needs of the child and their family. These plans are reviewed yearly to determine the progress made on defined goals and to provide opportunity to consider changing goals based on family requirements.

- **Individual Sessions** – These involve consultation, therapy and advice from the ECI Service team about how to promote the development of the child, and to assist the family in supporting their child. The variety of specialists includes physiotherapists, occupational therapists, speech therapists and psychologists. They may work with the family and child either individually or jointly depending on family and child requirements. The intervention may be home based or community based such as at a kindergarten.

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\(^2\) Within this report, the term 'therapist' is used generically to refer to therapists, psychologists and family service co-ordinators.
• **Group Programs** - Children with similar needs can join together on a regular basis for group programs. These may include - but are not limited to - communication, sensory-motor, swimming/hydrotherapy, and gym groups. Group programs also provide an opportunity for parents and carers to meet and provide support to each other. The availability of group programs varies between regions. The Pakenham service runs group sessions every two weeks.

• **Equipment Advice and Assistance** – The service provides equipment-related assessment, advice and loans, plus assistance with funding applications for a range of equipment such as communication devices, mobility equipment and home modifications.

• **Promoting Community Inclusion** - ECI Service staff work at times with staff in local playgroups, childcare centres and kindergartens to facilitate the inclusion of children into community programs.

• **Referral** - staff can make referrals on behalf of families (with their permission), within or across agencies, to meet any new and identified needs.

• **Transition** - Assistance is provided to plan for successful transition into other programs; for example, moving across early intervention programs, to childcare or kindergarten, or moving on to school (Scope, 2011).

At the commencement of the intervention, therapists and families prepare a Family Service and Support Plan with both parties working collaboratively to produce a number of goals to guide the intervention. This plan is reviewed on a yearly basis and provides an opportunity for both parties to consider the level of achievement, and to record any information deemed relevant to the intervention. There is also provision to record progress of goals.

These ECI services and supports are funded in Victoria by the Victorian Department of Education and Early Childhood Development (DEECD), who fund Specialist Children’s Services (SCS) teams or Community Service Organisations (CSO) including not-for-profit organisations such as Scope. The number of government funded hours allocated to each family is dependent on the needs of the child, based on the initial intake assessment. Funding therefore provides a specified number of hours of
service delivery to each client, dependent on the amount of funding allocated by government. Scope staff must ensure that 80% of staff time (called ‘billable hours’) is allocated against clients’ funded hours, which includes work done on behalf of the client outside of the therapeutic intervention. This includes travel time, phone calls made to the client and/or on behalf of the client, completing forms associated with the client, sourcing information related to the client, and any other tasks undertaken in relation to the client.

In 2006, the Southern ECI Service underwent a period of significant change. The service had recently acquired funding ($60,000) for additional early childhood intervention places across the region. This led to an increase in the number of clients serviced - throughout the period of the research (2006 - 2009) client numbers were based on approximately 110 clients. At the same time, the service moved to foster a more transdisciplinary approach to therapy practice, while also continuing to work according to the principles of family centred practice in accordance with the Victorian Government’s practice recommendations. Broadly, family-centered practice is a way of working with families, both formally and informally, to enhance their capacity to care for their children. It focuses on the needs and welfare of children within the context of their families and communities. Family-centered practice recognizes the strengths of family relationships and builds on these strengths to achieve optimal benefits for the family and the child. All Southern therapists are required and supported to work in a family-centred manner – this commences from the moment of the families’ first contact with the Southern ECI Service where they are supported in making choices according to their requirements, continuing through to the formal planning process where families are supported in determining goals to work on. Throughout the intervention, therapists seek to empower families in a variety of ways that respects the expertise of the family and their child (for more on family centred practice see Section 3).

The transdisciplinary approach constitutes professionals undertaking interventions outside their own discipline with a focus on collaboration with families and between therapists. All parties foster the sharing of information to ensure that families and all therapists work together towards common goals. Rather than individuals working in isolation, the Southern ECI Service sought to create team environments across therapeutic disciplines in working with families, sharing both knowledge and discipline specific skills. To create a transdisciplinary culture of collaboration and knowledge sharing, a number of strategies were adopted at the Southern ECI Service. These included:
• Case presentations presented by therapists to their colleagues (some of which were video presentations showing the therapist working with the child and family). These were not conducted on a frequent basis due to time and funding issues but were sporadic;

• The development of a resource manual in 2007 (One Day at a Time) by the co-ordinator and personnel at the Southern ECI Service, which provides a number of resources to aid therapists and families. These resources include items such as local government and community resource contact information, diagnostic specific information, developmental stage checklists, development activity information, songs, and transitional information. The nature and extent of use of this manual was monitored throughout 2007 (reflecting seven fortights of use throughout the year) and once in 2008 (reflecting one fortnight of use) as part of this research.

Further to these developments, a number of existing work practices were adapted to skill therapists to engage in transdisciplinary practice. These included:

• Professional Development Days conducted twice yearly for therapists to share information and hear from guest speakers;

• The use of joint visits (also referred to as dual visits) whereby therapists have a chance to work together and share knowledge and skills across disciplines in a supported manner;

• Group Programs which involved a number of children coming together to engage in shared activities, with a number of therapists present to direct interventions.

The project

With such significant changes occurring in the Southern ECI Service, the service co-ordinator identifies the need to evaluate the service, with particular emphasis on outcomes for families and children. In addressing these significant aspects of service provision, the research seeks to provide important
information to assess the quality of service delivery, as well as to plan ways to improve and support necessary changes with the Southern ECI Service.

The research seeks to address a number of key aims. These are to:

- Contribute to evidence about outcomes for families and children, and key practices of service delivery, in the field of Early Childhood Intervention for children with disability;
- Provide families and therapists an opportunity to participate in service evaluation and improvement;
- Develop and trial useful methods of data collection about outcomes measurement that may have wider application within the early childhood sector.

Specifically, the study sought to explore three key research questions covering the areas of outcomes, family centred practice, and transdisciplinary practice. The questions are listed below and in more detail in chapter 2.

1. What are the outcomes experienced by families and children resulting from ECI services provided by Scope Southern Region?
2. What is the extent of family centred practice in use within ECI services provided by Scope Southern Region?
3. What are the elements and practices of supporting transdisciplinary practice in the region?

Researchers collected data on a range of key domains at a number of time intervals commencing in November 2006 through to December 2009.

These aims and research questions reflect the developments in early intervention in Victoria as well as addressing international trends – particularly with the focus on outcomes and the emphasis on family centred practice. At the same time, the growing interest in transdisciplinary practice requires greater
scrutiny of this mode of practice and model, with a need for more empirical evidence. This research aims to provide important information to assess the quality of the Southern ECI service delivery, as well as to suggest ways to improve and support Scope’s service delivery. It is also hoped that the findings will have a broader application amongst a variety of stakeholders – these include families who use or are considering using the service, governments, other ECI service providers and researchers in associated fields.

The historical development of early childhood intervention

Early intervention as a specialist support service to young children with disabilities is a relatively recent phenomenon. Social change in Western countries in the 1960’s and 1970’s prompted a shift in educational emphasis to the area of early intervention. The developmental psychologist, Urie Bronfenbrenner, identified principles for effective early intervention founded on an ecological approach which focuses on the complex layers of environment - from the family to the more broad social, economic, and political structures - as shaping a child’s development (Bronfenbrenner, 1979). Bronfenbrenner co-founded the early Head Start programs (1965) in the United States of America which sought to provide education, health and social services to children of low-income families. Central to the approach was an emphasis on parental involvement. The subsequent development of family centred intervention in Western countries grew out of family support programs of the 1960’s and 1970’s which were commonly community based and user directed.

In recent decades, early childhood intervention has evolved significantly, shifting from a professionally directed service based on medical treatment, to a family centred practice that seeks to respond to family priorities while aiming to empower families through a holistic (ecological) approach (Harbin, et al, 2000: 397). This shift has also been driven by the change from a medical model to a social model of disability. The medical model views disability as the result of physiological impairment with intervention focused on the cure or prevention of disability, while a social model focuses on ‘the social and environmental factors that affect families of disabled children, social attitudes towards impairment, and inadequacies in support’ (Sloper, 1999: 86).
The social model of disability is a reaction to the dominant medical model of disability which privileges the expertise of professional interventionists, particularly those in the medical field. The social model values the expertise of the person with the disability and those supporting them based on their lived experience. A social model of disability focuses on society as the main contributory factor in disabling people, identifying systemic barriers, negative attitudes, and exclusion by society (purposely or inadvertently) as factors that create disability. While physical, sensory, intellectual, or psychological variations may cause individual functional limitations or impairments, these do not have to lead to disability unless society fails to take account of these variations and limitations, thereby excluding people based on their individual differences. The origins of the social model of disability can be traced to the 1960s, while the specific term emerged from the United Kingdom in the 1980s (Oliver & Sapey, 2006).

In this context, the social model of disability provides a critique of medical approaches arguing that these are potentially fraught with structural and attitudinal impediments that act to ‘disable’ people. Despite these shifts in understanding and approaches towards disability, many families continue to privilege the medical intervention that will improve their child’s capacity to function in society (Seligman & Darling, 2007: 5-6).

This social model forms the theoretical basis for the Victorian Government’s ECI strategy.

**The Victorian early childhood intervention context: the Victorian Government policy and directional statements**

In Victoria, early childhood intervention aims to provide services and supports to children with disabilities or developmental delays from birth up until school entry. This intervention is provided and/or funded by the Department of Education and Early Childhood Development (DEECD) - the state government department which is responsible for the overview of early childhood intervention in Victoria. There are nine DEECD managed Specialist Children Services (SCS) Teams and over sixty Community Service Organisation (CSO) ECIS providers in Victoria.
The Department of Education and Early Childhood Development states that the aim of early intervention as provided by services:

... is to provide families with the knowledge, skills and support to meet the needs of their children and to optimise children’s development and their ability to participate in family and community life. All services are provided using a family-centred approach, recognising the importance of working in partnership with the family (DEECD, 2009a: 43).

This definition provides the essential vision of the Victorian Government for early childhood intervention services in Victoria. This vision is underpinned by the social model of disability with a focus on providing support to families ‘in raising their child within the family and community and enabling them [the child] to achieve their developmental, social and emotional potential’ (DHS, 2003: 2).

Children with disabilities accessing early childhood intervention in Victoria have a variety of disability types or developmental delays (as defined in the Victorian Disability Act 2006), and may have a range of physical, sensory and/or intellectual impairments which may restrict their full involvement in society and that of their carers. According to data provided in the KPMG report, Department of Education and Early Childhood Development: Reform of early childhood intervention (2008), most ECIS clients in Victoria have either a developmental delay or autism. Other disability types represented include:

- speech,
- physical,
- hearing/visual/sensory,
- intellectual,
- neurological,
- acquired brain injury,
In Victoria, early childhood services are dependent on an integrated system between *universal*, *targeted* and *intensive* services. Universal services include school, kindergarten, long day care, occasional care, family day care, outside school hours care, and maternal and child health services. Targeted services include early childhood intervention services, the Enhanced Maternal and Child Health Service, and kindergarten inclusion support services. Intensive services seek to resolve complex and sometimes ongoing challenges and conditions for specific child and family needs (DEECD, 2009b: 12). ECIS provide special education, therapy, counselling, service planning and coordination, along with assistance and support to children and their families to access services such as kindergarten and child care. These services aim to meet the individual needs of the child, with an emphasis on supporting the child in their natural environment while they participate in everyday experiences and activities. These services also seek to promote the competence and confidence of parents and other caregivers in providing the child with development-enhancing opportunities (KPMG, 2008).

There are a number of documents that outline the Government’s vision, strategies and framework for early intervention, all of which broadly outline the move to the combining of services and supports for children and families based upon the promotion of social inclusion.

Recent policy and directional statements regarding early childhood development and early childhood intervention released by the Victorian Government include the:

i) **Blueprint for Education and Early Childhood Development** (DEECD, 2008);

ii) **Victorian Early Years Learning and Development Framework: For all children from Birth to Eight Years** (DEECD, 2009a);

iii) **Growing, Learning and Thriving: Building on Victoria’s achievements in early childhood** (DEECD, 2009b);

iv) **Statement of principles for children and young people with a disability and their families** (Disability Services Division, DHS, 2009).

Together these documents outline the Victorian Government’s development framework, principles and vision for early childhood development.
Consistent with the Victorian Government’s early childhood framework, principles, and vision, the Victorian Government has specifically outlined its approach to supporting children with disability through its ‘Statement of principles for children and young people with a disability and their families’ (Disability Services Division, DHS, 2009). The statement is intended to guide the supports for children and young people with a disability and their families that are funded or provided by the Disability Services Division. Overall, the principles emphasise health and development outcomes for children, along with social inclusion and the rights of children with a disability to participate as fully as possible in the community. The central importance of families is recognised in assisting young people with a disability to realise their potential, as well as the providing of support to families to foster their ability to care for their child. The key focus is on ensuring that families are active decision-makers about how they are supported, and that supports are tailored to individual needs of children and their families at different stages of development (Disability Services Division, DHS, 2009).

Overall, these four Victorian Government policy statements emphasise child outcomes and the fostering of relationships between children, families and community. General themes emphasize the importance of governments and services in working in partnership with families while supporting them in achieving positive health and developmental outcomes for their children. Social inclusion for children and their families, and the right for all to participate fully in the community, are key goals of the Government based on the recognition of human rights.

**Victorian Government practice recommendations**

In Victoria, the ECI sector is guided by The Early Childhood Intervention Services (ECIS) Program Framework (Early Years Services Branch, DHS, 2005) which provides services with a framework of guidelines and recommendations to direct consistent practice in the delivery of ECIS throughout Victoria. This framework complements the Victorian Government vision and policy for early childhood intervention in Victoria.

According to the Early Years Services Branch, Department of Human Services (2005), key elements of ‘best practice’ were identified through a variety of international and national research which underlines
the Victorian Government’s practices and principles of service delivery. These key elements are deemed by the Victorian Government to be useful in understanding and informing service delivery across the variety of service models and forms of service interventions. These key elements as outlined in the *Early Childhood Intervention (ECIS) Program Framework* (2005) are:

- **Family Centred Practice**

  Family Centred Practice supports a collaborative relationship between professionals and families establishing outcomes for the child within the context of the family. It provides the opportunity for each family to make informed decisions relating to designing and implementing strategies for intervention that promote the well-being and optimal development of their child ... [and] results in the realisation of positive outcomes for the family and child (Early Years Services Branch, DHS, 2005: 4).

- **Natural Environments**

  The child and family’s everyday routines, activities and places of daily life are settings that provide the best opportunity to promote early childhood learning and development as well as strengthening the family’s capacity to support their child’s growth ... They [natural environments] foster opportunities for natural systems of support within inclusive community settings and the development of peer relationships with children without disabilities (Early Years Services Branch, DHS, 2005: 5).

- **Transdisciplinary Approach**

  In the transdisciplinary model, all team members (including the family) teach, learn and work together to accomplish a mutually agreed upon set of intervention outcomes. Individuals’ roles are defined by the child and family needs rather than by the function of a specific discipline ... (Early Years Services Branch, DHS, 2005: 6).

These models are representative of a form of practice and principles of the social model of disability which encompasses family centred practice and the use of natural environments, along with the recognition of the need to engage with the community and broader social institutions. The Southern ECI
Service seeks to operate in accordance with these principles of service delivery through implementing these service practices.

Government recommendations provide challenges for all ECI services which need to consider their processes of practice and the means to ensure positive outcomes for the recipients of their service.

**Conclusion**

In line with Victorian Government strategies, Scope’s Southern ECI Service adopts the philosophy and practice of the social model of disability within early childhood intervention. The service focuses on working to empower families and building their social inclusion capacity, while also providing therapeutic intervention to assist the child. This research seeks to examine the extent to which the service meets the requirements of children and their families in providing an intervention that leads to positive outcomes. Specifically, the research focuses on family centred practice and transdisciplinary practice, while acknowledging the service’s move towards working in natural environments. In doing so, the research seeks to provide information about early childhood intervention services both within a specific context and to contribute to the broader dialogue around early childhood intervention, outcomes and the issues associated with key methods of practice. This is significant given the need for evidence to determine the ways in which ECI can best make a positive difference for children and families.
Chapter 2: The research project

**ECIS effectiveness - the need for empirical research**

In recognising the need for research in the field of ECI, it is important to consider the type of research that needs to be conducted. Guralnick (1997) states that research conducted prior to 1986 was primarily based on comparisons between children and families receiving newly developed early intervention services and supports, and children and families receiving essentially no services or supports whatsoever, to determine whether ECI had a positive impact for children and families. Guralnick argues that research conducted prior to 1986 can be referred to as ‘first generation research’, and that it has established beyond doubt that ECI is effective overall in producing a positive impact on the wellbeing of both children and families. The need now is for more focused research that can assist in guiding specific program directions and be of value to all early childhood interventionists and families in their daily activities (Guralnick, 1997, 11-12). Guralnick refers to this as the question of *specificity* – identifying and evaluating the specific program features associated with optimal outcomes for children and families.

It is this issue of specificity that ultimately informs practice, improves the cost-effectiveness of services, minimizes false expectations, provides a research framework for evaluating innovative approaches, and may even be of value in helping us understand the mechanisms through which interventions operate (Guralnick, 1997: 13).

Likewise, Shonkoff and Phillips (2000: 379) argue for the need to move beyond the simple question of whether early childhood intervention works, and to consider what type of interventions work and what kind of impacts these interventions have on children and families.

This second generation research into the specificity of early childhood intervention services can thus improve practice knowledge, while there is also the need to consider the specific context and circumstances of ECI services. As Forster observes:
An absence of locally based evaluation and research has left services trying to extrapolate evidence from overseas studies undertaken in significantly different circumstances. The lack of local information has made it difficult to disseminate local practice wisdom and establish common understandings (Forster, 2005: iii).

Such locally based research in Victoria is extremely limited, with no large-scale longitudinal studies that specifically focus on ECI and outcomes for children with disabilities and their families. Local studies may assist in providing a better understanding of Victorian ECI and informing service improvements that optimise outcomes for children and families.

**International and Australian empirical studies**

While few in number, there have been various longitudinal studies that focus on children with disabilities and their families and which aim to address the question of specificity. A literature review conducted by the researchers considered both international and Australian literature on the effectiveness of early childhood intervention for children with disabilities. Published studies incorporate research on a range of intervention types, including those focused on child interventions and those focused on parent interventions, or combinations of the two. Within the international literature, a number of large-scale international studies have been evaluated, including the following.

In the USA:

- Early Intervention for Infants and Toddlers with Disabilities and their Families: Participants, Services and Outcomes: National Early Intervention Longitudinal Study (NEILS), (Hebbeler, Spiker, Bailey, Scarborough, Mallik, Simeonsson, Singer, Nelson, 2007);

- Thirty Six Month Outcomes for Families of Children who have Disabilities and Participated in Early Intervention, (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005);

- Indiana’s First Steps Early Intervention System, (Conn-Powers & Dixon, 2005);
Indiana’s First Steps Early Intervention System, (Conn-Powers, Piper, & Traub, 2008).

In the UK:

Early Support: An Evaluation of Phase 3 of Early Support, (Young, Temple, Davies, Parkinson, Bolton, Milborrow, Hutcheson, & Davis, 2006).

These studies are significant in that they attempt to broadly evaluate early childhood intervention services and address, to varying degrees, the question of outcomes. They provide varying forms of evidence, using a variety of methodologies and are complex in their diversity. While these studies have value in their contribution to early childhood intervention and the efficacy of services in providing positive outcomes, the focus and range of the studies are varied and therefore the researchers conclude that direct comparisons with this study of the Southern ECI Service cannot be made.

The Australian literature examined appears to place a more direct emphasis on parent and family outcomes rather than a specific focus on outcomes for the child. The programs evaluated include:

A randomized, controlled trial of a home-based intervention program for children with autism and developmental delay, (Rickards, Walsteb, Wright-Rossi, Simpson & Reddihough, 2007);

One-year follow-up of the outcome of a randomised controlled trial of a home-based intervention programme for children with autism and developmental delay and their families, (Rickards, Walsteb, Wright-Rossi, Simpson & Reddihough, 2009);

Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomised controlled trial, (Tonge, Brereton, Kiomall, MacKinnon, King & Rinehart, 2006);

Evaluation of an intervention system for parents of children with intellectual disability and challenging behaviour, (Hudson, Matthews, Gavidia-Payne, Cameron, Meldon, Radler & Nankervis, 2003);
• Impact of music therapy to promote positive parenting and child development, (Nicholson, Berthelsen, Abad, Williams & Bradley, 2008).

The main focus of these programs was on developing parents’ ability to interact with their child successfully, whilst promoting effective coping strategies. There is some rationale for this in the international literature which suggests that increasing the capacity of the family will result in positive outcomes for the child (Young, Temple et al, 2006). According to Dunst, the purpose of family-centred practice is that through strengthening the abilities of parents and families, services aim to promote the child’s learning and development without the need for ongoing professional intervention and guidance (Dunst, 2007).

Overall though, Australian research appears to have paid minimal systematic attention to evaluating the effectiveness of early childhood intervention services for children with a disability and their families. The examples mentioned above highlight the limited empirical research available and the need for further research into child outcomes. Without rigorous investigation of services provided to children with disabilities and their families, there is the risk that services, despite good intentions, may not be as effective as possible in providing the best quality service and achieving optimal outcomes for children and their families.

**Research questions**

In response to both the existing evidence about the efficacy of early childhood intervention (discussed above), and the specific context of the Southern Region program (discussed in chapter 1), three main research topics were identified: outcomes for children and families; family centred practice; and transdisciplinary practice. These topics each deal with a substantial aspect of current practice in early childhood intervention, as well as explicitly addressing Victorian government policy in relation to key practice approaches and expected outcomes. In doing so, the research aims to address outcomes, and elements of practice that may contribute to positive outcomes, while considering some of the contextual factors that may contribute to service effectiveness.
Given the breadth of each topic, specific research questions were formulated for each, along with a set of sub questions or topic areas. These are listed below:

1. **What are the outcomes experienced by children and families resulting from ECI services provided by Scope Southern Region?**

   The research sought to identify and analyse:
   
   - the sorts of outcomes for children aspired to by families,
   - the level of achievement and types of outcomes achieved for children,
   - the level of achievement and types of outcomes achieved for families,
   - the extent to which service providers and families feel that needs have been met,
   - the level of satisfaction parents have with services received, and
   - the enablers and barriers to outcomes.

2. **What is the extent of family centred practice in use within ECI services provided by Scope Southern Region?**

   The research sought to identify and analyse:
   
   - how therapists understand family centred practice,
   - how parents rate the extent of family centred practice,
   - the level of parent involvement in Family Service and Support Plan development,
   - the extent of therapists’ familiarity with Family Service and Support Plans.
3. What are the elements and practices of supporting transdisciplinary practice in the region?

The research sought to identify and analyse:

- how therapists understand transdisciplinary practice,
- the degree and type of transdisciplinary work undertaken by the therapist,
- the resourcing and support of transdisciplinary work,
- the confidence, experiences and preferences of therapists working in transdisciplinary practice.

**Timeframe of research**

The research project commenced in 2006 with data collection focused on the delivery of ECI service in the years 2006, 2007 and 2008. Some data collection extended in 2009 with follow up surveying of parents and therapists who were involved in the service in 2008. Data analysis occurred throughout, with periodic reporting of results to the service and other stakeholders. Final analysis and report writing was concluded in 2011.

**Methodology**

Broadly this research is situated within an interpretive methodology. The Interpretive tradition is founded on the theoretical position that ‘there is no meaning in social realities apart from those ascribed to them by the individuals who experience them’ (Carr & Kemmis, 1986: 86). This position necessitates that researchers work with research subjects to build an understanding of what meaning the subjects construct of their experience. In this project, the viewpoints of parents and therapists are considered to be of prime importance and a range of methods of data collection and analysis are used to explore these. Each research topic (or question) can be understood as a largely independent investigation, utilizing its own methods. Given this, a detailed discussion of methods in relation to each
topic area, including relationship to methods developed by other researchers, is provided within each section of this report. A short summary of the methods of data collection and analysis is provided below.

The research design and all methods were subject to ethical review by the Scope Research Ethics Committee.

**Data collection methods**

Each topic of research is introduced by a scan of the relevant literature. This exploration provides a broad, but not exhaustive, picture of existing knowledge and approaches in each area. This literature is reported in each section of the report, and an effort has been made to identify where the literature has informed research methods and where it relates to findings.

Overall, eight main methods of data collection were used. Some of these were designed to collect data relevant to more than one research area, as identified in the table below.

**Table 1: Relationship of data collection methods to research topics**

<table>
<thead>
<tr>
<th>Method of data collection</th>
<th>Outcomes for children and families</th>
<th>Family Centred Practice</th>
<th>Transdisciplinary Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Survey</td>
<td>*</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Family Service and Support Plan</td>
<td>*</td>
<td></td>
<td></td>
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<tr>
<td>FSSP Outcomes and Process document</td>
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<tr>
<td>Therapist Survey</td>
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<tr>
<td>Record Sheet - manual usage</td>
<td>*</td>
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<td>*</td>
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<tr>
<td>Therapist interviews</td>
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<tr>
<td>Therapist focus groups</td>
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<tr>
<td>Parent interviews</td>
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<td>*</td>
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</tbody>
</table>
Each of these methods is briefly described below. Detailed information pertaining to the development and use of each method is included in each of the topic sections of this report. A discussion of the efficacy of research methods is provided in section five.

**Parent Survey (59 items)**

Given the methodological interest in the viewpoint of parents, a major method of data collection was an annual Parent Survey conducted at the end of 2006, 2007 and 2008. The survey (see appendix i) included fifty nine items covering the research topic areas of outcomes and family centred practice. Items were drawn both from existing research (see King, Rosenbaum & King, 1995) and were also researcher generated. Items included:

- Measure of Processes of Care (MPOC) re family centred practice – 31 items
- Outcomes and impacts of service - 9 items
- Parenting capacity - 12 items
- Enablers and barriers to achievement of goals – 2 items
- Level of involvement in goal setting and FSSP – 1 item
- Satisfaction with service – 3 items
- General feedback – 1 item

The 2006 Parent Survey included only the MPOC items and the General feedback item (32 items).

In general, all families who had received an ECI service in the year of data collection were sent a survey and provided with the opportunity to participate. Sample sizes are presented in each section, and summarized in table 2 below.
Family Service and Support Plan (FSSP)

As discussed in section three of this report, Family Service and Support Plans are a major practice strategy in ECI and provide an existing method of data documentation within ECI services, particularly relating to the outcomes expected of service provision. The FSSP process ideally involves both family members and the ECI practitioner/s. FSSPs usually document information about:

- Goals
- Tasks
- Personnel
- Review of outcomes.

Researchers in this project further developed the FSSP format to include a greater emphasis on capturing outcomes, by adding a numeric rating scale to the area for qualitative description of outcomes on FSSPs (see appendix ii). The review of outcomes was not always undertaken within FSSP documents accessed for this project.

All families receiving services in 2007 and 2008 were offered the opportunity to provide consent for researchers to view and analyse information provided on the family/child’s FSSP documents over the timeframe of the research.

FSSP Outcomes & Process Document (3 items)

As part of seeking to capture more detailed information in relation to outcomes relevant to FSSPs, researchers also developed a short data collection tool to be appended to FSSPs (see appendix iii). This one page document included:

- Enablers to success - 1 item
- Barriers to success - 1 item
Further changes/actions needed to ensure positive outcomes - 1 item.

Therapists were asked to add this one page document to FSSPs and complete it during review of FSSPs in 2007 and 2008. It was intended that this approach would become an embedded practice element of FSSP review. However, this did not occur to any great extent.

**Therapist Survey (18 items)**

Again, given the methodological interest in identifying practitioners’ views, an annual Therapist Survey was developed to collect data in relation to all three research topic areas (see appendix iv). The survey included:

- Workload and work history - 3 items
- Supervision received - 1 item
- Availability of therapist peers - 1 item
- Amount of hours spent in knowledge sharing activities - 4 items
- Rating of quality of time in knowledge sharing activities - 4 items
- Level of acquaintance with client FSSPs - 1 item
- Confidence in transdisciplinary work - 3 items
- General comment - 1 item

The survey was administered once in each year in 2006, 2007 and 2008. Items in the survey draw on concepts from the transdisciplinary literature in particular, but are otherwise researcher generated.
**Record Sheet - Manual Usage**

One major initiative of the Southern ECI Service to support transdisciplinary practice was the development of a new resource manual, discussed in section 1. Given this, it was felt that data about the usage of the manual was relevant to the topic of transdisciplinary practice in particular. A record sheet was developed by researchers (see appendix v). The thirteen resource categories of the ‘One day at a time’ manual were rated in terms of:

- Times used for therapist own use;
- Times used for/given to families;
- Source of retrieval of resource.

It was intended that record sheets would be completely fortnightly for a period of six months in 2007 (immediately after the introduction of the manual), and again in 2008 for a period of three months, with therapists instructed to indicate use in relation to the past fortnight. However, data in relation to only seven fortnights in 2007 and one fortnight in 2008 was collected due to workload constraints on therapists.

**Therapist interviews**

Interviews with therapists were considered a major source of data in relation to all research topics. All therapists in both 2007 and 2008 were offered the opportunity to participate in interviews. Interviews were conducted in a semi structured manner around the following questions:

1. What type of therapy do you provide and what is your length of service?

2. How do you determine what is a positive outcome for a client?

3. What do you see as the enablers to success in working with clients to achieve positive outcomes?

4. What do you see as the barriers to success in working with clients to achieve a positive outcome?
5. What change/action needs to occur to enable both you as a therapist, and Scope overall, to achieve positive outcomes for clients?

**Therapist focus groups**

Focus groups with therapists were targeted particularly at the beginning of the research project in order to provide an opportunity for general group discussion about the nature of the work and the work context. All therapists were invited to participate in each focus group, and interviews offered as alternatives or supplements to this participation. Focus groups were semi structured and provided data in relation to all three research topics, though were largely focused on the topics of family centred and transdisciplinary practice.

1. How do you understand family centred practice?
   a. do you continually refer to the Family Service and Support Plan to guide your practice?
   b. to what extent are you aware, in an ongoing manner, of the role of other therapists in working towards achieving the goals and positive outcomes identified by the family?

2. To what extent have you used therapeutic knowledge outside of your discipline in working with children and their families? Can you provide examples?

3. How comfortable are you in working in a knowledge sharing and practising capacity? Do you have reservations?

4. How do you rate the effectiveness of the following in aiding therapeutic practice?
   a. clinical presentation videos,
   b. joint (dual) visits,
   c. the manual,
d. other knowledge sharing strategies.

5. How supported do you feel in working in knowledge sharing ways?

6. What are the factors that affect the level/quality of knowledge sharing?

7. What would assist you in working in a knowledge sharing capacity?

Parent interviews

Interviews with parents were also considered a major source of data in relation to all research topics. A majority of parents in both 2007 and 2008 were offered the opportunity to participate in interviews. Parent interviews were largely unstructured but utilised the following prompts:

1. What have been the good things about the service you have received from Scope?

2. What have been the not so good things, or areas to improve about the service you have received from Scope?

3. What changes have occurred for your child and family as a result of the service from Scope?

Participation rates

As discussed above, the opportunity to participate in research data collection was offered to all therapists and a majority of parents involved in the Southern ECI Service in the year of data collection. In the case of parents, this represented between 80 and 96 families who were offered participation opportunities in each year of 2006 - 2008. In relation to therapists, each year an average of 16 therapists, representing all ECI therapists on staff, were offered participation opportunities.
However, actual participation rates varied (see table 2). Only around one quarter of parents participated in annual surveys, and a far smaller number volunteered for interview. While most therapists participated in focus groups, fewer participated in other opportunities such as surveys and interviews.

While there is no concrete data to evidence the reasons for this level of participation, therapist workload and parenting demands (discussed by those who did participate) appear to be factors in the limited take-up of participation opportunities (this is discussed further in section five).

Table 2: Number of respondents for each data collection method: 2006-2008

<table>
<thead>
<tr>
<th>Data collection method</th>
<th>Actual response size n =</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006</td>
</tr>
<tr>
<td>Parent Survey</td>
<td>23</td>
</tr>
<tr>
<td>Family Service and Support Plans (FSSPs)</td>
<td></td>
</tr>
<tr>
<td>FSSP Outcomes &amp; Process Document</td>
<td>2</td>
</tr>
<tr>
<td>Record Sheet - manual usage</td>
<td></td>
</tr>
<tr>
<td>Therapist Survey</td>
<td>11</td>
</tr>
<tr>
<td>Therapist interviews</td>
<td>2</td>
</tr>
<tr>
<td>Therapist focus groups</td>
<td>2</td>
</tr>
<tr>
<td>Parent interviews</td>
<td>3</td>
</tr>
</tbody>
</table>

**Data analysis methods**

This range of data collection methods required both quantitative and qualitative methods of data analysis. Again, these are discussed in detail within each topic section of the report.

In the main, survey, record sheet and FSSP related data was analysed to determine frequency of response in various categories. In many cases, frequencies were compared across years, and to other reported results in the literature where relevant. In most cases, percentages have been rounded to the
nearest whole number, so totals may not always add to one hundred percent.

By contrast, interview and focus group data was largely analysed thematically. In many cases, themes were generated deductively by drawing on ideas and concepts evident in the literature and previous research. In some areas, themes arising from an inductive grounded analysis of the data were also reported. Interview quotes are included throughout the report, with the type of respondent (therapist focus group, therapist, or parent), and the year to which the quote pertains, identified in brackets after each quote.

Structure of the report

As discussed above, each of the research topic areas is provided with a section in this report. The focus of the next section (section two) of the report is on outcomes of service delivery, reporting on the topic of outcomes for children and families. Sections three and four deal with the processes of service delivery that aim to contribute to outcomes, namely family centred practice (section three) and transdisciplinary practice (section four).

Each section contains an identification of the relevant research questions and sub topics. Methods of data collection and analysis for each sub topic are also presented in further detail. This discussion includes identification of the sources of each method, and the areas developed by researchers. Sample sizes are also identified. This discussion of methods provides a context in which the results for each research question, presented in each section, can be interpreted.

A final discussion of overall themes and conclusions is provided in section five. This section also provides a reflection on the efficacy and limitations of research methods. Finally, the section concludes with a short set of considerations for service delivery.
Section 2:

Outcomes of Service Delivery
Chapter 3: Identifying outcomes

Outcome measurement of service provision is increasingly recognised as a means by which services can be evaluated. Such an approach to service evaluation focuses attention on whether services are making a positive difference in the lives of their clients. One of the major elements of this research project is the exploration of the type and level of outcomes achieved as a result of ECI service provision in Scope’s Southern Region.

Defining outcomes

The concept of ‘outcomes’ from services is used widely in discussing social service provision of all types. Despite this level of attention, there is little consistency in what the term ‘outcome’ refers to.

The Early Childhood Outcomes Center in the United States of America, defines ‘outcome’ as:

a benefit experienced as a result of services and supports received. Thus, an outcome is neither the receipt of services nor satisfaction with services, but rather what happens as a result of services provided to children and families (Early Childhood Outcomes Center, 2005).

Moore and Sargood (2005) argue that there is a critical need for shared understanding among families and service providers about what outcomes they are trying to achieve. They refer to outcomes in terms of ‘results’, ‘impacts’, ‘changes’ and ‘differences’ for recipients of services, raising important questions that highlight the need for focusing on specific outcomes:

Why do we do what we do? What are the critical results that should be achieved at the end of early childhood intervention services? What impact or changes are desired? What differences should services have made for children with additional needs and their families? (Moore & Sargood, 2005: 2).
In summary, a consistent aspect of these definitions is that an outcome is understood to be an end result or consequence, hopefully a benefit, experienced as a result of services and supports that are received. It is regarded as a means by which services can be evaluated as to their overall effectiveness.

Defining an outcome broadly as an impact or a result then necessitates definition of the specific types of outcomes in focus, along with the consideration of who defines what outcomes are important. Shifts in emphasis from the medical to the social model of disability, have been reflected in changes within the ECI field in relation to philosophy, practice, and the outcomes valued (Moore, 1996; Shonkoff and Meisels, 2000). The variety of stakeholders involved in ECIS, various visions of early intervention, multiple focuses of interventions, and varied models of service delivery, all mean that outcome definition continues to be varied and inconstant.

In recent years in the ECI field, there have been attempts to establish broad outcome frameworks, both internationally and in Australia. These frameworks allow a degree of comparison across services as to the extent to which outcomes are being met, while allowing scope for families to establish their own specific goals within these broader areas. Early Childhood Intervention Australia (ECIA) (Victoria Chapter) has undertaken consultation with parents and ECI practitioners to identify outcomes of Australian ECI services. From these consultations, an outcomes statement has been produced which aims to list the impacts and changes that are expected as a result of accessing a service (Moore and Sargood, 2005:3). Further, the authors suggest that being outcome driven (rather than process driven) is based on the general principle of ‘starting with the end in mind’ (Moore and Sargood, 2005:2). The aim is to overcome fragmentation in order to achieve a unified sense of purpose and direction amongst all stakeholders to provide better experiences for families and children (Moore and Sargood, 2005).

The ECIA (Victoria Chapter) Outcome Statements propose outcomes of service delivery at three levels: for children, for families, and for communities (Moore and Sargood, 2005). At each level, outcomes are identified in the areas of functioning (understood as both knowledge and skills), and participation (which includes involvement with others, attitudes, support and coping) (Moore and Sargood, 2005:5). The concepts of function and participation are drawn from the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) (2001). Reflecting the social model of disability, the ICF acknowledges that disability is constructed by the social context and is the result of the
relationship between the individual’s impairment, personal factors and the social context in which these exist.

**Outcomes for children**

As part of the development of the ECIA (Victoria Chapter) outcome statements, Moore and Sargood (2005) discuss the literature relating to outcomes for children resulting from the provision of early childhood intervention services. They suggest that outcomes for children have been traditionally understood in relation to child development, i.e. the building of skills, as well as the prevention or amelioration of secondary concerns (Moore and Sargood, 2005:9). Guralnick also notes this historical focus on outcomes in relation to developmental domains such as early motor development, and cognitive and language development (Guralnick, 1997: 14-15). In addition, Guralnick (1997) argues for the need to include broader outcomes domains, considered more ‘integrative’, such as the development of children’s social competence or improving children’s health status.

The ECIA Outcome Statements for children includes both developmental and ‘integrative’ outcomes. Outcomes for children are named as follows:

**Outcomes re functioning:**

- Children will gain functional, developmental and coping skills that are appropriate to their ability and circumstances;

- Children will show confidence and enjoyment in their everyday life.

**Outcomes re participation:**

- Children will participate meaningfully in home and local community activities to the extent of their ability;

- Children will experience and enjoy family life and community activities that are preferred by the family (Moore and Sargood, 2005: 6).
These outcome statements are necessarily broad as they are intended to encompass a wide diversity of early childhood services and the children they support. Nonetheless, they serve as a useful, broad framing of the sorts of outcomes expected of early childhood services.

Outcomes for families

Outcomes for families are also of importance both in their own right and as mediating factors in the child’s development (Guralnick, 1997: 14-15). The Early Childhood Outcomes Center (USA) identifies that outcomes for children and families are interdependent, as positive outcomes for one will have a positive impact for the other (Early Childhood Outcomes Center, 2005). Dunst and Trivette (2009) state that ‘the goal of early childhood intervention is to support and strengthen caregivers’ (practitioners, parents, or both) confidence and competence to promote and enhance young children’s interactive competencies, optimizing their learning and development’ (2009: 40). The ultimate purpose of intervention is to improve child outcomes, either directly or less directly, by improving the capacity of others - particularly families. The literature about outcomes for families resulting from ECI services is summarised by Moore and Sargood (2005). They suggest that outcomes for families have been previously understood in terms of both impacts of services (including: fostering their child’s skills, partnerships with services, advocating for themselves, building a strong support system, feeling more optimistic about the future and experiencing a better quality of life) and family satisfaction with services (Bailey & Wolery, 2002 cited by Moore and Sargood, 2005:9). More recently, emerging work has focused on the measurement of satisfaction with parents’ mastery of various parenting roles and activities (i.e. the Life Participation for Parents scale, Fingerhut: 2009), within an early childhood intervention and disability context.

The ECIA Outcome Statement proposes the following outcomes for families:

Outcomes re functioning:

- Families will be able to nurture and support their child according to their values and preferences;
• Families will be able to identify and address the needs of their child(ren) and family;

• Families will be able to advocate for themselves and their family, to the degree they choose.

Outcomes re participation:

• Families will participate in social and community activities to the degree they choose;

• Families will feel supported by personal networks and local communities (Moore and Sargood, 2005: 7).

Again, these outcome statements are necessarily broad in encompassing the wide diversity of early childhood services and the families they support.

Methods for measuring outcomes

As well as needing to consider what an outcome is, it is also important to identify effective ways to identify the extent to which outcomes are being achieved. Harbin, Rous and McLean (2005) note that there is an urgent need to identify and measure outcomes for children and families, while Hogan and Murphey (2002) argue that focusing on outcomes has the potential to achieve significant progress in addressing issues that concern children, families and communities. They argue that what gets measured gets done and this in turn can create a critical mass of progress leading to positive change (Hogan & Murphey, 2002). However, despite significant discussion about the benefits of early childhood intervention, there is no agreed set of methods to measure outcomes.

Meisels and Shonkoff argue that the early childhood intervention field has struggled to document its effectiveness, in part due to ‘the methodological and logistical constraints of inadequate outcome measures’ (2000: 4). The implication is that ‘we should develop and use reliable ways of measuring whether we have achieved the outcomes we [are] aiming at’ (Moore, 2006: 6).
To date, outcomes have been defined and measured using a variety of methods and with a variety of focuses. Despite this diversity, what is common amongst researchers interested in family centred early childhood practice is recognition of the importance of gaining the views of families. As a result, many research methods draw on this approach.

**Implications for this research**

This brief overview of existing approaches to outcomes measurement in relation to ECI services presents some key themes that were used to underpin this study. First, this study takes the definition of outcome as a broad impact or effect of service provision. This requires outcomes measurement to focus beyond the level of ‘output’ and to seek to capture what happened as a result of service intervention. Secondly, multiple researchers and the ECIA (Victoria Chapter) outcomes framework identify the importance of exploring outcomes for children, families and communities. This study focuses on outcomes for children and families, though it remains beyond the scope of the study to assess the outcomes for community. Thirdly, the ECIA outcomes framework offers a useful starting point for outcomes identification. Finally, given the lack of established measurement methods, this study developed a range of methods that aimed to capture a broad range of outcome areas consistent with, but not confined to, the ECIA outcome framework.
Chapter 4: Outcomes for children from Scope Southern ECIS

Introduction

As discussed in Chapter 3, consistent with the ECIA Outcomes framework (Moore and Sargood, 2005), this research chose to focus attention on outcomes for children and outcomes for families, recognizing that these are not mutually exclusive. This chapter discusses the methods and results of researching outcomes for children receiving services from Scope Southern ECI Service during 2007 - 2008. Outcomes for families are dealt with in Chapter 5.

The key research question in this area was: What are the outcomes experienced by families and children resulting from ECI services provided by Scope Southern Region? In particular, this chapter presents methods and results relating to the following sub elements of the broader research question:

- the sorts of outcomes for children aspired to by families,
- the level of achievement and types of outcomes achieved for children.

What outcomes are examined?

Based on the ICF (WHO, 2001), the ECIA (Victoria Chapter) Outcomes framework identifies outcomes in two broad categories: function and participation (Moore and Sargood, 2005). These categories were used in this study in order to investigate outcomes for both families and children, along with the third ICF category of environment. In addition, the category of participation was further detailed in this study, by identifying nine life domains which could be understood as life areas in which participation might occur. These domains were drawn from other research conducted by Scope and Deakin University, and included the following life areas: personal life; social life; recreational and leisure life; educational life; economic life; cultural life; spiritual life; political life; and the environment (Wilson, 2006). This focus on
participation, with an emphasis on specific life areas, is consistent with the ICF and ECIA recognition of the importance of participation as a key outcome for families and children.

Using these categories enabled researchers to gain information about the extent to which outcomes (and intended outcomes) for children relate to function, broader environmental change, or various areas of life participation. Further outcome areas were identified in relation to families which are discussed in chapter 5.

**Research methods to collect data about outcomes for children**

Chapter 3 identifies that there are no commonly utilised research methods for collecting data in relation to outcomes for children related to ECI service provision. This meant that researchers in this study were required to develop and trial new methods of data collection.

For the purposes of this research, outcomes for children were identified and evaluated using two main data collection methods:

- Family Service and Support Plans (FSSPs);

Each of these data collection methods is discussed below. In addition, both families and therapists were interviewed by researchers, and data from these interviews is used where relevant to help explore the nature and extent of outcomes for children.

**Family Service and Support Plans**

Family Service and Support Plans (FSSPs) are used as a standard part of early childhood intervention service delivery. FSSPs document the goals for service delivery for the child and family, and actions to be undertaken towards these. James & Chard (2010, drawing on Garrgiulo and Kilgo, 2000), describe individual service plans (or FSSPs) as
a process of collaboration between families and team members ... [resulting] in a document for each child and family that provides a written record of agreed decisions that focus on child and family strengths, needs, prioritised goals, and plans to address those goals (2010: 278).

McWilliam, Ferguson, Harbin, Porter, Munn and Vandiviere (1998) further identify the sorts of features of a Family Service and Support Plan, if it is to be considered family-centred:

A family-centered document is positive, written with understandable language, and has the right balance of precision and scope. A document that reflects what the family wants should have no more equivocation than the family feels. Neither the ambiguity of professional jargon nor the double talk of bureaucratic evasion should appear. A document with recommended practices should emphasize developmentally appropriate activities, individualized interventions, and integrated services and should de-emphasize therapy-oriented activities, indeterminate interventions, and segregated services. Finally, a functional document should be written in a way that enables it to be used as both a service plan and an intervention curriculum. Plans with distant outcomes (i.e., not to be accomplished for 1 year or more), unintelligible interventions, and meaningless tasks are not very likely to be used (1998: 69 quoted in Moore and Larkin, 2005:38).

Family Service and Support Plans in Scope largely adhere to these descriptions. In the Scope Southern ECI Service, FSSPs are reviewed at least once annually, and sometimes on a six monthly basis, in order for families and therapists to evaluate progress and further target interventions. This means that all children receiving services should have at least one FSSP per year, and in many cases two are completed.

In this way, FSSPs represent a base for key information about the intent of ECI service provision for each child and their family. In particular, FSSPs offer details about the goals of service delivery as identified by families and therapists. Documented goals offer ways of identifying the outcomes to be achieved for children. Given this, researchers in this study proposed that FSSPs are important sources of data, and targeted them as data collection tools. To do this, researchers sought permission from parents of children to access FSSPs for children receiving ECIS in 2007 and 2008. In 2007, nine (9) families provided
consent for researchers to access their child’s FSSPs (totalling 17 FSSPs in this period), and eight (8) families did so in 2008 (totalling 9 FSSPs in this period).

Formats for FSSPs vary. While FSSPs offer a good source of data about the intentions or goals of service delivery for children (and, in some cases, families), they do not necessarily offer documentation about the level and type of achievement against these goals. The format of FSSPs in use in the Scope Southern ECIS in 2006 (at the commencement of the study) offered significant detail about family context, weekly activities of children, goals of service, and aids and equipment needs. In addition, the format offered space for a descriptive review of outcomes achieved. However, the completion of FSSPs through to the stage of outcome review was not universal, with many FSSPs in 2006 providing detailed information about family contexts and goals, but not detailing outcomes achieved. Where outcomes were described, information was varied and often succinct (e.g. ‘not yet’).

Given that a major purpose of this study was to determine not only the type of outcomes desired but the level to which they were achieved, researchers worked with service providers to make modifications to the FSSP format in use. A numeric coding scale was added to record the level of outcome achieved, alongside the description of outcomes in the FSSP. The coding scale was to be completed as part of the normal review process conducted by therapists with family members at 6 or 12 monthly intervals. The scale asked therapists and parents to rate each goal as:

1. Goal achieved;
2.i) Goal ongoing – progressing well;
2.ii) Goal ongoing – moderate progression;
2.iii) Goal ongoing – continuing; or
3. Goal changed (and a reason provided).

The adapted format for FSSPs was to be used throughout 2007 and 2008.

Not all FSSPs developed in 2007 and 2008 underwent formal review, and not all reviews chose to utilise the numeric scale in the outcomes section. As a result, numeric outcomes data was provided for 7
children/families in 2007 (totalling 8 FSSPs reviewed) and 8 children/families in 2008 (totalling 3 FSSPs reviewed).

**Family Service and Support Plan Outcomes and Process Document**

In addition to adding a numeric scale to the FSSP format in order to capture the extent to which outcomes were deemed to be achieved, researchers also designed a one page addendum to the FSSP. This data collection tool was to be used in conjunction with FSSPs, when they were reviewed either 6 or 12 monthly during 2007 and 2008. The appended ‘FSSP Outcomes and Process’ document sought to collect therapist and parent views in three areas:

- Enablers to success (including people, activities, equipment, resources, finances, environment, policies and time etc), and which of these was the biggest help;

- Barriers to success (including people, activities, equipment, resources, finances, environment, policies and time etc), and which of these was the biggest barrier; and

- Further changes/actions needed to ensure positive outcomes.

Space was provided on the document for qualitative comment in all three areas. In developing this document, researchers drew on previous work by Scope, and in particular the Measurement of Outcomes of Services and Supports (MOSS) tool (Quilliam & Wilson, 2010; Quilliam, Wilson, Hagiliassis, Nicola-Richmond, 2010), and the Most Significant Change Tool (Davies & Dart, 2005). This work provided a rationale and a method for documenting data about the factors contributing to outcomes, such as enabling and inhibiting factors. This was considered to be important data for service evaluation as it provides services with information to target changes and improvements by fostering enablers and minimising barriers to outcomes.

As stated above, not all FSSPs underwent formal review, and not all reviews included completing the appended FSSP Outcomes and Process document. In total, the FSSP Outcomes and Process document was made available to researchers in only 3 instances (in relation to 2 reviews in 2007 and 1 in 2008).
Research methods to analyse data about outcomes for children

The above discussion identifies that data was collected about both the type of goals or outcomes aspired to for children (i.e. the intended focus of services), as well as the extent to which outcomes were achieved. In addition, data was collected about the barriers and enablers to outcomes which will be discussed in chapters 7 and 8.

Analysis for types or focus of goals (intended outcomes)

More data was available in relation to the intended outcomes or goals of services (17 FSSPs relating to 9 children in 2007, and 9 FSSPs relating to 8 children in 2008), than was available in relation to the extent of goals achieved (8 FSSPs of 7 children/families in 2007, and 3 FSSPs of 8 children/families in 2008). Given this, it was decided to undertake a detailed analysis of the types or focus of goals identified in the provided FSSPs.

In order to analyse the focus of goals (or intended outcomes), each goal was categorized in terms of whether its focus was to do with function/activity, participation or environment. While broadly consistent with the ECIA outcomes framework (Moore and Sargood, 2005), this approach was more strongly aligned with the ICF (WHO, 2001). The ICF describes a detailed set of:

- ‘body functions’;
- ‘activities’ - relating to the specific activity restriction as a result of the disability;
- ‘participation’ - relating to the specific participation restrictions associated with the disability; and
- ‘environment’ - enumerating the range of environmental factors mediating the experience of disability.

Whilst the ICF classification provides a useful framework, the literature highlights some critiques of this model, specifically in relation to the distinction between these main concepts. One particular critique is that the concepts may overlap in use and are often hard to distinguish from one another (Noonan et al
2009: 1896). Given this complexity, it was decided for this research to link the concepts of ‘function’ and ‘activity’ together as a single category. This is also consistent with the analytical approach used in other Scope research related to outcomes of therapy services to adults with disabilities (Quilliam, Wilson, Hagiliassis & Nicola-Richmond, 2010), and therefore allows for some comparisons across data sets should this be useful.

Results from this analysis show the number of goals with an intended outcome in the area of function/activity, participation, and environment. Where goals evidenced an explicit, rather than implicit, statement related to more than one category, each category was recorded.

However, in addition, it was felt that these outcome categories were not nuanced enough to capture the areas of a child’s life to which outcomes related. For this reason, a second analysis was conducted to categorise the goals identified by families for their children in relation to nine life areas. This analysis drew on a life domains outcome framework developed by Scope and Deakin University (Wilson, 2006). As discussed earlier, this analysis presents results providing more detailed information about the types of participation that the goals relate to.

**Analysis for extent of achievement of goals**

The main method for analysing the extent of achievement of goals was a quantitative analysis of the numeric data provided in relation to outcomes reviewed on the FSSPs. This analysis presents the proportion of goals at each achievement level.

In addition, in both cases, interview data from therapists and parents has been integrated to add further detail to the results.
Results

The sorts of outcomes for children aspired to by families: focus of goals (intended outcomes)

As discussed above, goals documented on FSSPs provided in 2007 and 2008 were analysed to determine the outcomes aspired to for children (or intended outcomes). Overall, 117 goals were analysed in 2007, and 69 in 2008.

As discussed above, the first analysis of goals was in relation to the categories of the ICF (WHO, 2001): function/activity, participation, and environment. Overwhelmingly, the focus of goals in both years was predominantly on the area of function/activity, with 74% of goals focused in this way in 2007, and 82% in 2008 (see table 3). The categories of participation and environment evidenced a relatively even spread of focus from the remaining goals (9-14% across both years).

Table 3: Focus of family goals based on ICF categories

<table>
<thead>
<tr>
<th>Year</th>
<th>Function/Activity</th>
<th>Participation</th>
<th>Environment</th>
</tr>
</thead>
</table>
| 2007 | - 117 goals (some goals have multiple domain focuses)  
- 9 children/families  
- 17 FFSPs | 74% | 12% | 14% |
| 2008 | - 69 goals (some goals have multiple domain focuses)  
- 8 children/families  
- 9 FFSPs | 82% | 9% | 9% |

Given the age of the children (birth-4 years), this focus is not surprising as parents and therapists were concerned with overall development, and the day to day acquisition and use of key motor and cognitive functions and skills. Many comments in FSSPs and in interviews reflected this focus, as the following examples of goals transcribed from FSSPs show:

Goal: To sit independently and safely.
Goal: To help develop [child’s] understanding of ‘Do this and then do/get that’.

Goal: Begin to increase toileting awareness.

Goal: Increase fine motor skills.

Parents frequently identified outcomes in these functional areas during interviews. For example, one parent described her child’s outcomes as follows:

In that six months he just started talking, but then in the last 6 months he really has come a long way (Parent 07).

However, as stated above, some goals also focused on the child’s participation, with goals focusing on the development of particular skills for social participation, or in commencing new activities in the community (such as Kindergarten). FSSP goals such as those below are examples of this:

Goal: To participate in community activities.

Goal: To be able to play with other kids.

Goal: To join in to activities in the play group and kindergarten settings.

Goal: To have an appropriate greeting.

Goals focused on the ‘environment’ (14% in 2007, and 9% in 2008), tended to be related to accessing aids and equipment, and building capacity of others in the child and family’s environment to support the child. The following FSSP goals evidence this focus:

Goal: To trial walkers.

Goal: Kelly chair - source top up funding.

Goal: For us to be able to continue to get to kinder/school etc. attend appointments, and other family activities, through having reliable transport.
The second method of analysis of the focus of goals sought to explore the nature of life participation in more detail by analysing goals against the nine life areas: personal life; social life; political life; cultural life; recreational and leisure life; economic life; educational life; spiritual life; and the environment (Wilson, 2006).

Table 4: Focus of family goals: based on life domains

<table>
<thead>
<tr>
<th>Outcome domains</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>117 goals (some goals have multiple domain focuses)</td>
<td>69 goals (some goals have multiple domain focuses)</td>
</tr>
<tr>
<td></td>
<td>9 children/families</td>
<td>8 children/families</td>
</tr>
<tr>
<td></td>
<td>17 FSSPs</td>
<td>9 FSSPs</td>
</tr>
<tr>
<td>Personal Life</td>
<td>66%</td>
<td>77%</td>
</tr>
<tr>
<td>Environment</td>
<td>11%</td>
<td>8%</td>
</tr>
<tr>
<td>Social life</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Recreational life</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Educational life</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Economic life</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Cultural life</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Spiritual life</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Political life</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other (not classified above)</td>
<td>1%</td>
<td>0</td>
</tr>
</tbody>
</table>

Perhaps predictably, the greatest level of goal focus was in the area of Personal Life, which was the focus of 66% of goals in 2007 and 77% in 2008 (see table 4). In this analysis, goals relating to personal development, health, function and wellbeing are included in the Personal Life category, hence it is not surprising that most goals fall within this category. Other categories of life participation that evidenced a minor focus were those of Social Life (7% of goals in 2007; 5% in 2008); Educational Life (7% of goals in 2007; 4% in 2008), and Recreational Life (7% in 2007; 5% in 2008).
2008). Consistent with the ICF analysis discussed above, a further 11% of goals in 2007 and 8% of goals in 2008 focused on the broader environment in which the child and the family lives. In this way, some families can be seen to identify a variety of goal aspirations for their children across a range of life areas.

Overall, the goals analysed evidence that parent aspirations for their children are broadly consistent with the ECIA (Victoria Chapter) outcomes framework (Moore and Sargood, 2005), with a weighting toward functional, more than participation, outcomes though a range of participation goals are also named and valued by parents. Finally, a proportion of goals also revolve around the need for changes to the broader environment of the child in order for the child to achieve life aspirations. This last focus is not well captured in the ECIA outcomes framework (at level of child, family or community) and highlights the need for service provision to encourage and support environmental change.

However, despite using both the ICF (WHO, 2001) and a more detailed life areas framework, it is likely that such approaches to outcomes measurement still miss elements of outcomes and intentions behind service delivery. While goals are often written to focus on function (as discussed above), therapists clearly also held broader views about the purpose of their work and the outcomes they expected, as is evident in interviews with therapists:

[I] see a positive outcome as important to motivate children - [the] child needs to take on responsibility of change and undertaking the tasks set (Therapist 08).

It can vary from family to family. For example – for one family experiencing a whole range of problems, just letting me in the door every fortnight is a positive outcome (Therapist 08).

These comments are indicative of reflections on outcomes whereby less tangible outcomes that are difficult to measure and evaluate - such as ‘motivating children’ or ‘taking on responsibility’ - are often valued by therapists.

Additionally, not all outcomes identified by families and therapists appear to be recorded on FSSPs, despite the clear value of documenting positive and achievable outcomes. As stated by one therapist:
A positive outcome is one that is based on something that is measurable. And so, where possible, I try and write and set goals so a positive outcome would be an achievement of that goal. But more often than not goals are unfortunately kept in one’s head as a general understanding and they are not written down specifically somewhere. That’s a limitation (Therapist 08).

Such comments highlight some of the complexity of naming outcomes and raise questions about the specific indicators that might be considered to evaluate less concrete outcomes.

**The level of achievement of goals**

As discussed above, analysis of the achievement of goals was largely reliant on use of the numeric scales provided within the FSSPs. Overall, results were varied across both years. In both years, the majority of goals in FSSPs were rated as either ‘Achieved’ (22% in 2007; 46% in 2008), or ‘Ongoing - Progressing Well’ (35% in 2007; 7% in 2008). The remaining goals, a little less than half, were assessed as having moderate or continuing progress.

**Table 5: Level of achievement of goals in FSSPs**

<table>
<thead>
<tr>
<th>Result of goal</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achieved</td>
<td>22%</td>
<td>46%</td>
</tr>
<tr>
<td>Ongoing - Progressing well</td>
<td>35%</td>
<td>7%</td>
</tr>
<tr>
<td>Ongoing - Moderate progression</td>
<td>11%</td>
<td>18%</td>
</tr>
<tr>
<td>Ongoing - Continuing</td>
<td>30%</td>
<td>29%</td>
</tr>
<tr>
<td>Goal changed</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>
This suggests that outcomes were achieved or well progressed for around half of the stated goals of children. Descriptive data provided as part of FSSPs, along with interview data from families, reinforces these positive statistics, as exemplified by these comments from parents during interviews:

He has come on in leaps and bounds (Parent 07).

Yes. He is improving all the time and Scope therapists notice it – probably because they don’t see him all the time. It’s definitely helping – definitely improving him (Parent 08).

[Therapist] has done a great job – she has got [child] talking. She’s coming along very well (Parent 08).

Therapists also reported positive outcomes during interviews. One therapist described a range of outcomes evidenced by comments from others in the child’s context:

A positive outcome in early intervention would be the feedback that I get from parents and the rapport that I establish from parents. It’s a generalized thing – going more on instinct and gut feeling: ‘Okay, this is working well because I have a good rapport with the family. They seem to have taken onboard suggestions’. When I do the next visit they might say: ‘Yeah, we tried that and that worked okay – that’s going well. I think he or she is doing really well’. We would judge positive outcomes by the verbal feedback (Therapist 08).

Despite clear evidence (both quantitative and qualitative) of positive achievement of goals/outcomes, around one third of goals are identified as ‘Ongoing – Continuing’, which suggests a less than moderate progression in many cases. It is difficult to account for this with any surety, but while it may reflect the quality of the service, this was not indicated in interviews. It is more likely that the goal is inherently long term and ongoing.

As stated above, in most cases goals identified were related to cognitive or motor development of the child. Comments in FSSPs tend to suggest that such goals could be seen to require a long term focus as the child experienced ongoing growth, development and change in these areas. As such, most goals
were not likely to be fully achieved or completed within a one year (or six month) period. For example, in one case the goal was articulated as:

To encourage more chewing. Currently, [child] is good with all textures, but he doesn’t move the food from side to side. He uses his tongue rather than his teeth to reduce food size.

Progress was rated as ‘Ongoing - Continuing’ and the following description provided:

Becoming more aware as his understanding is developing and can try activities suggested.

Most goals and evaluative comments reflected this type of normal continuous evolution of the child (and family’s) capabilities. Descriptive comments in the outcomes section of FSSPs suggest that such goals are hard to evaluate as they are unlikely to be fully achieved, and development progresses at varying rates.

Moore and Larkin (2005:41) discuss previous research in the USA that suggests that Family Service and Support Plan goals may not always be appropriate and achievable. They note that studies by Goodman (1992) and Goodman and Lloyds (1993) of support plans from fifteen early childhood intervention programs found:

a clear tendency for goals to be pitched beyond children's developmental levels. As a result, the same goals tended to be repeated from year to year. This appeared to be more the result of inappropriate expectations than of the children needing to practice the relevant skills extensively in order to learn them (quoted in Moore and Larkin, 2005:41).

Certainly, a proportion of goals in Southern FSSPs were repeated in plans across years of service, however it is not clear if this is a reasonable and relevant practice or the result of ‘inappropriate expectations’ as proposed by Moore and Larkin (2005).

This discussion suggests that while long term goals should be recorded when developing plans, it is important that smaller goals, that form part of the long term strategy, are identified. This provides the
possibility of working on achievable goals in the short term and having success while working towards bigger goals. This does raise challenging questions about the value of measuring outcomes. Does a low success rate mean the service has ‘failed’ or is it more indicative that long term goals were set and therefore most goals will be viewed as ongoing? Likewise a high achievement of outcomes may also say more about the type of goals set and their chance of being achievable in the short term, than it does about the competency of the service or the result of ‘inappropriate expectations’. These are difficult issues to reach definitive conclusions on and worth bearing in mind when assessing plans and level of achievement of outcomes. Overall, though, this tension does not undermine the need to consider the need to work towards positive outcomes and to be able to assess them in some constructive way.

Overall, therapists appeared to take a pragmatic approach to goal identification and outcomes measurement. As one therapist in a focus group described:

It’s also about how you do the plans and record the goals and whether there’s allowance for all the outcomes you might achieve. That’s why I like recording where they [i.e. the child/ren] are at that moment, so that when you do the review you can reassess and get a sense of what you’ve achieved. So you may not achieve the goal but the family can see that there has been a change because it’s written there. So maybe now they’re saying five words while before they were just looking at us (Therapist Focus Group 08).

This suggests that of most importance is the attention given to concrete and observable changes over time, and affirming this progress with families.

Conclusion

The above discussion recognizes the complexity of evaluating outcomes and suggests caution must be exercised in making definitive claims. With this in mind, this study found that there was an overwhelming focus on goals relating to function/activity for children which is not surprising given the age of the children (from birth to four years of age) and the desire to maximise the child’s development at a crucial time. This focus on function/activity was reflected in the data around life domains with the
greatest level of impact rated in the area of ‘personal life’ (which incorporates health). Therapists, in interviews, recognised a broader array of outcomes that are often not captured in Family Service and Support Plans. With regard to the level of achievement of goals, approximately half of the goals assessed on FSSP’s were achieved or well progressed. This level of success was reflected in interviews with families. Approximately a third of goals for children were ongoing reflecting the nature of functional goals that are part of a child’s progressive development.
Chapter 5: Outcomes for families from Scope Southern ECIS

Introduction

While the discussion in chapter 4 identifies positive evidence of outcomes being achieved for children, these outcomes are inextricably linked to outcomes for parents and the broader family. As one therapist commented:

    The whole therapist thing’s tricky because I could go to a family and be an OT. I could say ‘right let’s have a look at his toileting now or are we going to make a splint for his hand or whatever.’ But that’s not the main issue. These may be little side issues to much bigger issues. There may be a whole lot of extended family issues and you’re sitting there and they are looking at you … and so you ask ‘what’s going on?’ and out comes all these major problems and issues (Therapist 08).

As discussed in chapter 3, the literature articulates the inter-relatedness of child and family outcomes in early childhood intervention. Consistent with the literature and with the ECIA outcomes framework, this research focuses attention on both child and family outcomes. This chapter discusses the methods and results of researching outcomes for families whose children were receiving services from Scope Southern ECI Service during 2007-2008.

The key research question in this area was: What are the outcomes experienced by families and children resulting from ECI services provided by the Scope Southern Region? In particular, this chapter presents methods and results relating to the following sub elements of the broader research question:

- the level of achievement and types of outcomes achieved for families,
- the extent to which service providers and families feel that needs have been met.
What outcomes are examined?

As discussed in chapter 3, outcomes for families have been defined in a wide range of ways. Broadly, outcomes in this area have focused on increasing parent and family competence and confidence in a wide range of areas including parenting capacity, self advocacy, understanding the social service system, as well as improving quality of life. The ECIA outcomes framework identified family outcomes in the areas of functioning (largely parenting capacity) and participation. Consistent with this, this study focused attention on outcomes to do with participation in a range of life areas (as was explored in relation to outcomes for children), as well as parent capacity.

Research methods to collect data about outcomes for families

Chapter 3 identifies that there are no commonly utilised research methods for collecting data in relation to outcomes for families related to ECI service provision. This meant that researchers in this study were required to develop and trial new methods of data collection.

For the purposes of this research, outcomes for families were identified and evaluated using one main data collection method, that of an annual Parent Survey. This method is discussed below. In addition, both parents\(^3\) and therapists were interviewed by researchers, and data from these interviews is used where relevant to help explore the nature and extent of outcomes for families.

Parent Survey

Researchers wished to offer the opportunity to participate in the research to a majority of parents receiving ECIS. A survey instrument was considered to be the best mode to achieve this maximum level of reach. (In addition, parents were offered the opportunity to be interviewed).

\(^3\) By coincidence, all interviews were with mothers.
A fifty-nine (59) item survey (see appendix i) was developed to be used at the end of each year, to enable parents to evaluate and comment on the services they had received. The survey aimed to collect data in relation to multiple research questions of this study and included:

- 31 items asking parents to evaluate the level of family centred practice as part of their ECI service (based on the Measure of Processes of Care [MPOC] instrument, King, Rosenbaum & King, 1995). These results will be discussed in Chapter 10 which focuses on family centred practice;

- 9 items rating the impact/outcome of services across nine life areas (Wilson, 2006; Wilson, Hagiliassis & McGrellis, 2008);

- 12 items rating the impact of services on parenting capacity (Wilson, Hagiliassis & McGrellis, 2008);

- 2 items identifying enablers and barriers to outcomes;

- 1 item identifying the parental level of involvement in goal setting and FSSP development;

- 2 items rating satisfaction with the service received;

- 1 item rating to the extent the service met needs;

- 1 item of general feedback.

Of particular relevance to the research question on outcomes measurement, the survey included three sets of items relating to outcomes for families and parents. Parents were asked to report: 1) the impact of services on the lives of their family and children across nine life areas; 2) the impact of services on their capacity as a parent; and 3) the extent to which services had met their needs. It should be noted that, with the exception of the consideration of parent capacity, all areas of inquiry here potentially encompass outcomes for both parents and children as family members.

The first set of items, known as the ‘Outcomes and Impacts Scale’ was drawn from work previously undertaken by Scope researchers in the context of evaluating flexible funding packages in the ECI sector.
in Victoria (Eastern region) (Wilson, Hagiliass & McGrellis, 2008). These items asked parents to ‘rate the extent to which the Scope ECIS program has had an impact on your child and family...’ in the following nine life domains:

- personal and family wellbeing;
- social life;
- political life;
- cultural life;
- recreational and leisure life;
- economic life;
- educational life;
- spiritual life;
- your environment.

Parents rated the impact of the ECIS on each life area using a five point rating scale ranging from a very positive impact, through no impact, to a very negative impact. As with the measurement of outcomes for children, it was felt that generating information in relation to impact on life areas provided more detail about the types of participation outcomes experienced by families (consistent with the ECIA outcomes framework).

The second set of items, known as the ‘Parenting Capacity Scale’, was drawn from the same source (Wilson, Hagiliass & McGrellis, 2008) and asked parents to rate the impact of the Scope ECI program on their own capacities as parents. A second set of questions on the survey asked parents to ‘rate the extent to which the Scope ECIS program has had an impact on you as a parent...’ in terms of twelve items relating to parents’ capacity to parent their child, support their development, and access appropriate community resources and services.
Again, a five point rating scale of impact of very positive to very negative impact was used. Wilson, Hagiliassis & McGrellis (2008) explain that items within the scale were drawn from both the Family Empowerment Scale (Koren, DeChillo & Friesen, 1992) as well as researcher-developed items. Again, it was felt that these items added detail to the broad family outcome areas identified under the area of functioning in the ECIA outcomes framework (for example, ability to nurture and support child, address their needs, and be competent family advocates), as well as exploring other areas discussed more broadly in the literature.

The third set of items were researcher generated and related to satisfaction with services, with one item rating the extent to which the program met parent/family needs. On this item parents were asked to identify whether no needs were met, only a few met, most met or all needs were met.

The Parent Survey was sent out to the majority of service recipients in both 2007 (94 families) and 2008 (96 families). Of these, twenty six (26) parents returned completed surveys in 2007 and nineteen (19) in 2008. A shortened Parent Survey was sent to families at the end of 2006 (80 families), comprising only the first set of items about family centred practice. This shorter survey aimed to benchmark results only for this aspect of the research and will be discussed in chapter 10 which focuses on family centred practice.

**Research methods to analyse data about outcomes for families**

All data generated from Parent Surveys in relation to outcomes achieved for families, and the extent to which their needs were met, was analysed quantitatively to identify the proportion of families experiencing the range of achievement levels across a range of outcome types.

Interview data was used to supplement these findings and is also presented below.
Results

Outcomes for families related to impact on life areas (participation)

Overall, families in both 2007 and 2008 reported positive impacts across all life areas resulting from ECI service provision (see table 6).

Life areas in which families and children experienced the greatest positive impact from ECI services were:

- **Personal and family wellbeing.** This life area was described on the survey as including: health, happiness, mobility, communication, doing things more independently. In 2007, 88% of parents reported an overall positive impact in this area as a result of services, and 100% reported this in 2008. This domain also showed the highest average score of all domains in both 2007 and 2008 (as shown in appendix vi), evidencing this as the domain with the highest level of positive impact;

- **Social life,** described on the survey as including friendship and relationships, getting along with others and community involvement. In 2007, 68% of parents reported an overall positive impact in this area, and 79% did so in 2008. This area showed the second highest average score, evidencing that families rated a high level of positive impact in this domain;

- **Educational life,** described on the survey as including ‘learning and problem solving, being part of educational programs for your child or family (e.g. kindergarten or parent education)’. Eighty percent (80%) of parents in 2007 reported an overall positive impact in this life area resulting from ECIS, though only 59% of families rated this as positively impacted in 2008;

- **Recreational and leisure life,** described on the survey as being involved in recreational or leisure activities at any level, possibly through attending activities, playing an active part or doing ‘what you enjoy’. In 2007 ECI services positively impacted on 80% of families in this area, though only 58% of families experienced a positive impact in this domain in 2008.
Table 6: Impacts of ECI service on life areas, 2007 and 2008

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal and family wellbeing</td>
<td>44%</td>
<td>63%</td>
<td>44%</td>
<td>37%</td>
<td>8%</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social life</td>
<td>28%</td>
<td>32%</td>
<td>40%</td>
<td>47%</td>
<td>28%</td>
<td>21%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Political life</td>
<td>28%</td>
<td>11%</td>
<td>20%</td>
<td>53%</td>
<td>52%</td>
<td>32%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Cultural life</td>
<td>28%</td>
<td>16%</td>
<td>16%</td>
<td>16%</td>
<td>56%</td>
<td>63%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Recreational and leisure life</td>
<td>36%</td>
<td>32%</td>
<td>44%</td>
<td>26%</td>
<td>16%</td>
<td>37%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Economic life</td>
<td>32%</td>
<td>26%</td>
<td>20%</td>
<td>37%</td>
<td>40%</td>
<td>32%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Educational life</td>
<td>36%</td>
<td>37%</td>
<td>44%</td>
<td>22%</td>
<td>16%</td>
<td>32%</td>
<td>4%</td>
<td>11%</td>
</tr>
<tr>
<td>Spiritual life</td>
<td>25%</td>
<td>5%</td>
<td>16%</td>
<td>75%</td>
<td>74%</td>
<td></td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Your environment</td>
<td>36%</td>
<td>42%</td>
<td>36%</td>
<td>16%</td>
<td>20%</td>
<td>37%</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>Average</td>
<td>32%</td>
<td>29%</td>
<td>29%</td>
<td>30%</td>
<td>34%</td>
<td>36%</td>
<td>3%</td>
<td>4%</td>
</tr>
</tbody>
</table>

The area of personal and family wellbeing encompasses a wide range of topics including health, happiness, choice etc. Due, however, to this breadth of topics, it is difficult to determine exactly what parents are indicating when they rate this life domain as highly impacted by the ECI service. One
possibility is provided by a therapist who commented on the sorts of services and supports families were provided with.

I’ve got a lot of families that have had to get food vouchers so they can put food on the table. And it really does make a difference. If you’re fighting to get food on the table that’s really different to ... that’s your main priority - not the fact that your child needs a $1000 standing frame (Therapist 07).

This kind of support is obviously essential to families, and therapists clearly understood it as part of their role to assist in such areas of need.

As well as these positive findings, there were on average approximately a third of families in both 2007 and 2008 who reported no impact on various life domains. However, in the Personal and Family Wellbeing life domain only 8% in 2007 and none in 2008 reported no impact. Also, an exceedingly small proportion of families identified negative impacts resulting from the provision of ECI services. The domains of Economic life, Recreational and Leisure life, and Your environment each showed negative impacts in both years (2007 and 2008), though only a small number of families identified impacts as negative (5-9%). As the survey provided no descriptive commentary from parents in this area, it is unclear what this negative impact entails or results from.

**Outcomes relating to parent capacity**

Overall, parents reported positive outcomes across all parenting capacity items as a result of the ECI service delivered (see table 7). There is very little delineating between the impacts on different areas of parent capacity rated in this scale. Areas which showed the greatest impacts (combining ‘very positive’ and ‘positive’ impact) were:

- Knowing how to help your child grow and develop - 96% of parents in 2007, and 94% in 2008 identified that the program achieved a positive impact in this area;
Having ideas and strategies to support your child - 96% of parents in 2007, and 89% in 2008 identified that the program achieved a positive impact in this area. This item also showed one of the highest average scores of all items in both 2007 and 2008, evidencing this as one of two items with the highest level of positive impact (see appendix vii). In interview, one parent described this as follows:

If they hadn’t been helping me with [child] I wouldn’t have had a clue ... And because they helped me with [child], I know more activities and what not to do with [child] (Parent 08).

Knowing how to play and have fun with your child - 89% of parents in both 2007 and 2008 identified that the program achieved a positive impact in this area. This item also showed one of the highest average score of all items in both 2007 and 2008, evidencing this as one of two items with the highest level of positive impact (see appendix vii);

Feeling effective and confident as a parent - 88% of parents in 2007, and 94% in 2008 identified that the program achieved a positive impact in this area. One parent discussed their increased confidence in an interview as follows:

And I’ll tell them [therapist] about something that he [child] has done ... And they will say ‘that’s really good’. And I guess they are giving you a pat on the back saying ‘you’re doing the right thing - whatever you’re doing is working’ (Parent 07).

Feeling confident that you are an expert on your child - 88% of parents in both 2007 and 2008 identified that the program achieved a positive impact in this area;

Knowing what services your child needs - 88% of parents in 2007, and 84% in 2008 identified that the program achieved a positive impact in this area.
Table 7: Impact of ECI service on parenting capacity, 2007 and 2008

<table>
<thead>
<tr>
<th>In each of the following areas, rate the extent to which the Scope ECIS program has had an impact on you as a parent</th>
<th>Very positive impact</th>
<th>Positive impact</th>
<th>No impact</th>
<th>Negative impact</th>
<th>Very negative impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing how to help your child grow and develop</td>
<td>42%</td>
<td>47%</td>
<td>54%</td>
<td>47%</td>
<td>4%</td>
</tr>
<tr>
<td>Working with others to solve problems with your child when they happen</td>
<td>36%</td>
<td>35%</td>
<td>48%</td>
<td>53%</td>
<td>12%</td>
</tr>
<tr>
<td>Getting information to help you better understand your child</td>
<td>38%</td>
<td>28%</td>
<td>31%</td>
<td>67%</td>
<td>31%</td>
</tr>
<tr>
<td>Working with agencies and professionals</td>
<td>38%</td>
<td>42%</td>
<td>50%</td>
<td>37%</td>
<td>8%</td>
</tr>
<tr>
<td>Knowing what services your child needs</td>
<td>40%</td>
<td>37%</td>
<td>48%</td>
<td>47%</td>
<td>12%</td>
</tr>
<tr>
<td>Understandings the service system your child is involved in</td>
<td>42%</td>
<td>37%</td>
<td>38%</td>
<td>53%</td>
<td>15%</td>
</tr>
<tr>
<td>Feeling effective and competent as a parent</td>
<td>46%</td>
<td>47%</td>
<td>42%</td>
<td>47%</td>
<td>12%</td>
</tr>
<tr>
<td>Knowing how to play and have fun with your child</td>
<td>54%</td>
<td>63%</td>
<td>35%</td>
<td>26%</td>
<td>12%</td>
</tr>
<tr>
<td>Feeling confident in parenting your child</td>
<td>46%</td>
<td>42%</td>
<td>38%</td>
<td>47%</td>
<td>12%</td>
</tr>
<tr>
<td>Feeling confident that you are an expert on your child</td>
<td>42%</td>
<td>47%</td>
<td>46%</td>
<td>41%</td>
<td>12%</td>
</tr>
<tr>
<td>Using resources in your community</td>
<td>28%</td>
<td>26%</td>
<td>44%</td>
<td>58%</td>
<td>24%</td>
</tr>
<tr>
<td>Having ideas and strategies to support your child</td>
<td>46%</td>
<td>63%</td>
<td>50%</td>
<td>26%</td>
<td>4%</td>
</tr>
<tr>
<td>Average</td>
<td>42%</td>
<td>43%</td>
<td>44%</td>
<td>46%</td>
<td>13%</td>
</tr>
</tbody>
</table>
In interviews, parents reported their increased confidence which becomes especially reinforced when clear changes occur for their child:

We feel we are on the road to betterment. He has gone from a child with very little communication skills, to someone that is possibly close to his peers if not in some cases a bit more chatty than some of his fellow two years old ... And we definitely have noticed and everyone has noticed a big difference in him. And I guess we feel more in control and that we are heading in the right direction ... that we have someone to help us so we’re not on our own (Parent 07).

A very small number of parents also identified negative impacts against a small range of items as a result of the service. The item of ‘Understanding the service system your child is involved in’ was identified as one where 4-5% of parents (representing one respondent) identified negative impacts in each year (2007 and 2008). Overall, negative impacts of services were identified by only three of the twenty six parents who completed surveys in 2007 and two of the nineteen parents completing surveys in 2008.

**Outcomes relating to extent of needs met**

Finally, parents were asked to evaluate the extent to which the ECI service met their needs on a four point scale ranging from ‘all met’ to ‘none met’ (see table 8). Whilst this measure does not identify the type of outcomes generated by the program, it does enable parents to evaluate the effectiveness of the program in relation to the personalised needs and aspirations of each family.

**Table 8: Extent to which ECI program met family needs, 2007 and 2008**

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>All met</td>
<td>36%</td>
<td>32%</td>
</tr>
<tr>
<td>Most met</td>
<td>48%</td>
<td>47%</td>
</tr>
<tr>
<td>Only a few met</td>
<td>16%</td>
<td>16%</td>
</tr>
<tr>
<td>None met</td>
<td></td>
<td>5%</td>
</tr>
</tbody>
</table>
Overall, a large majority of families identified that the ECIS program had met most or all of their needs (84% in 2007 and 79% in 2008). Responses in 2008 showed a slight reduction in the level of needs being met, including one respondent who felt no needs had been met by the program.

This data does not provide information in regard to why needs failed to be fully met. During interviews, therapists discussed the difficulty in meeting needs, recognising that no service can be perfect and meet all the needs of every family the service supports. One therapist suggested that it is important to recognise the limitations of what can be achieved for any family while acknowledging outcomes may be outside those expressly stated:

I’m very aware that it doesn’t matter what families have as their priority and what their needs are, we are never actually going to be able to do everything. And that’s just the reality. And I’m very comfortable with that reality now … I’m very comfortable with ‘I can only do what I can do’. And I’m quite careful about explaining that to parents too. So I can get to the end of the year and go, ‘Ok, well probably would have liked to have got the [therapist] here and extra time of [another therapist]. And I probably would have liked to focus a bit more on that, but that just hasn’t happened, but we’ve achieved all these other things. As long as the family is happy with what we have achieved and I feel we have achieved something then I’m comfortable with that (Therapist 08).

Overall, the general comments from families expressed on surveys broadly supported this view. Parents valued the outcomes achieved whilst recognising the complex task of allocating limited resources to meet them.

**Conclusion**

A range of parent and family outcomes were examined in this study, covering the areas of family functioning (parenting capacity) and family participation (across nine life areas). There is strong evidence to suggest that Scope Southern ECI service provision makes a significant and positive difference in both areas. Generally, parents indicated increased confidence in their capacity as parents, while they also
identify that the service had a positive impact on the life areas of personal and family wellbeing, social life, educational life, and recreational and leisure life. Overall, the service largely met family needs.
Chapter 6: Satisfaction with Scope Southern ECIS

Introduction

The key research question ‘What are the outcomes experienced by families and children resulting from ECI services provided by the Scope Southern Region?’ is comprised of multiple sub elements. A final area of investigation of this study related to outcome measurement was that of the level of satisfaction parents have with services received.

The discussion provided in chapter 3 identifies that one of the common ways used to measure outcomes resulting from ECI service provision, is that of satisfaction with services. While there are a range of critiques of equating satisfaction measures with achievement of outcomes (some of which are discussed below), this study did collect data on this indicator. Satisfaction is discussed here in chapter 6 as one measure of service effectiveness and included, broadly, within the discussion of outcomes measurement.

Satisfaction as an outcome measure

Moore and Larkin (2005) report that parent satisfaction is commonly used as an evaluative measure for ECI services and that a high level of satisfaction is a recurring finding in the literature. They propose a range of factors potentially influencing this result including: the services were based on a high level of family centred practice (McNaughton, 1994); parents may have only limited experience with ECI services and are therefore unable to make comparative judgements; satisfaction may reflect high levels of parent gratitude for services received; and finally, satisfaction and dissatisfaction may not be mutually exclusive or oppositional concepts (Moore and Larkin, 2005:31). As discussed by Moore and Larkin when reviewing a range of published research about parent satisfaction with early childhood services:
it is possible for parents to report that they are very satisfied with services overall while identifying some quite unsatisfactory aspects of service ... How services are delivered appears to be more important to parents than what is delivered. Parents particularly value respectful and supportive care from practitioners, and being treated as equals. When they are dissatisfied with aspects of service, it is most often because practitioners do not respect or understand their views, or fully inform or involve them in decisions. Parents are also dissatisfied when services are intermittent, poorly coordinated or hard to access (Moore and Larkin, 2005: 33).

As Moore and Larkin (2005) state, a number of studies (for example King, Cathers, King & Rosenbaum, 2001; Donabedian, 1988) suggest that parent satisfaction may be more linked to elements of service structure and practice processes than with the outcomes of services. This suggests that though satisfaction is an important concept in service evaluation, it is a complex one and is not a clear proxy for outcome measurement.

Though the correlation with outcomes is problematic, discussion of parent satisfaction has been included in Section 2 on Outcomes of Service Delivery, as it is a common and important measure of services.

**Research methods to collect and analyse data about levels of satisfaction with services**

Data was collected as part of the Parent Survey undertaken in 2007 and 2008. Families were asked to report against two questions regarding their satisfaction with the ECI program. Firstly, they were asked to rate their level of satisfaction with the service they received. Secondly, parents were asked to identify the probability of recommending the Scope Southern ECI program to others. Twenty six (26) parents returned completed surveys in 2007 and nineteen (19) in 2008. In addition, interviews with parents and therapists yielded significant commentary in this area.
Data from surveys was analysed quantitatively to identify the proportion of responses in each category. Interview data was analysed thematically and integrated into results where relevant.

Results

Satisfaction with ECI services

The majority of families in both years were very satisfied with the service, and a further third ‘mostly’ satisfied in both years (see table 9). Together, these responses show 96% of all respondents in 2007 and 95% of respondents in 2008 were satisfied with the program. One respondent (4-5%) in each year offered no opinion or was indifferent.

Table 9: Level of satisfaction with the ECI service received 2007 and 2008

<table>
<thead>
<tr>
<th>Level of satisfaction with service received</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>64%</td>
<td>58%</td>
</tr>
<tr>
<td>Mostly satisfied</td>
<td>32%</td>
<td>37%</td>
</tr>
<tr>
<td>Indifferent / No opinion</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Quite dissatisfied / not satisfied at all</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Probability of recommending the ECI service to others

Overall, 88-90% of respondents in both years would probably or definitely recommend the program to others (see table 10). Only two respondents (4-5%), i.e. one in each year, would probably or definitely not recommend the program.
Table 10: Probability of recommending the ECI program, 2007 and 2008

<table>
<thead>
<tr>
<th>Probability of recommending the program to others?</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitely</td>
<td>60%</td>
<td>79%</td>
</tr>
<tr>
<td>Yes, probably</td>
<td>28%</td>
<td>11%</td>
</tr>
<tr>
<td>Not sure</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>No, probably not</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>No, definitely not</td>
<td>4%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Comments from families during interviews echo these results with parents commenting:

Had we not received those services, we wouldn't have been able to get the equipment because they just knew who to talk to and what letters to write, how to get funding ... it’s mind-blowing about what they understand about how to get things (Parent 07).

Overall, the service has been great. I think it has really helped [child] a long way (Parent 08).

It’s been really good - God only knows where we would be if we didn’t have [therapist] and all the rest of them helping us out and getting him walking. When he came home he didn’t even know how to roll over - from his back to his front - he would just lie there. God only knows how long it would have taken to achieve that if [therapist] and other physios weren’t there helping him (Parent 08).

This high level of satisfaction is generally consistent with previous research that identifies high levels of parent satisfaction with services where these utilise family centred practices (King, King, Rosenbaum & Goffin, 1999; Law et al 2003, cited in Moore and Larkin, 2005).

While, in the survey, parents overwhelmingly expressed satisfaction with the service, interviews did yield statements of dissatisfaction with the service or parts of it. In particular, the lack of communication with regard to service frequency was expressed by one parent (who otherwise spoke positively about the service):
There has been no outline of services or plan – need for more of a formal contract outlining what services and their frequency … Daughter required intensive therapy yet this has not been received. Initially the therapist was coming every three weeks but this has gradually declined with no explanation and no contact (Parent 08).

and

[Therapist] has been sent emails but has not replied. [Therapist] was to work on therapy such as ‘going to the toilet’ and was to assist with storybooks but there has been a lack of progress and response on these issues (Parent 08).

The same parent expressed concern over the lack of transitional support:

My daughter will soon begin school yet there has been no support for her. No advising on any transition aids or initial support … Our experience over the last year is not that great – not to take away all the good work done but need for improvement (Parent 08).

Another parent was concerned that there wasn’t a more holistic approach and that therapists were restricted by the confines of a specific therapeutic discipline and a detachment from the broader needs of the child and family:

I think the thing that stands out is that the therapists seem very tunnel-visioned - if you like - in their area of therapy in the sense that they don’t see the child as a whole. They see them as they are labelled … It seems a lot of the time to be focused on the negative … which that’s what they are there for, but you also want to hear them say - you know - good things… A lot of them are just driven by the therapy rather than the emotional side of it. It’s hard to do it all, but it would be nice to have someone that could empathise a bit more. Or at least understand a little bit more that your whole life isn’t just revolving around this therapy (Parent 07).

While these comments are not indicative of general parent response, this range of comments reinforces the earlier discussion about the complexity of utilising satisfaction as an outcome measure.
Conclusion

Overall, most families were satisfied with the service provided by Scope Southern Region with approximately two-thirds ‘very satisfied’, and 88%-90% of families surveyed in 2007 and 2008 noted that they would recommend the program to others. Interviews were mainly praising of the service, however individual concerns were expressed suggesting areas in which the service needed to improve - including communication, transitional support (to school) and the need for a more holistic approach. The need for more therapy was also expressed.
Chapter 7: Enablers to outcomes

Introduction

The previous chapters discuss the types of outcomes and the extent to which they were achieved for both children and their families. In addition, this research included a focus on the enablers and barriers to outcomes as the last sub element of the overall research question related to outcomes: What are the outcomes experienced by families and children resulting from ECI services provided by the Scope Southern Region?

The literature discussed to date suggests that there remains a lack of clarity around the outcomes of ECI services as well as ways to measure them. In addition, there appears to be little attention paid to identifying the factors that contribute to or impede the achievement of outcomes. However, as disability practitioners (2001) argue:

    The point is not to collect information - it is to learn enough about how things are going so we can keep going or change direction with confidence. We want monitoring which leads to action to improve ... [practice], and to have a positive impact on people’s lives (Ritchie et al, 2001: 177).

This suggests that any outcomes measurement approach must not only identify outcomes, but also the factors that enhance or impede these.

Research methods to collect data about the enablers to outcomes4

As discussed in chapter 4, Scope had previously undertaken work on data collection methods to identify the enablers and barriers to outcomes in other service types (Quilliam & Wilson, 2010). This work drew

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4 Also applies to barriers to outcomes (see chapter 8).
on the Most Significant Change Technique developed by Davies and Dart (2005) and aimed to identify the factors, both positive and negative, associated with identified changes or outcomes.

The focus on identifying enablers and barriers to outcomes was implemented in three ways within this study:

1. the FSSP Outcomes and Process document (i.e. an addendum to the FSSP) was developed that enabled therapists and parents to outline their views on enablers and barriers to successful outcomes (see chapter 4 discussion of this method).

2. two items (one each related to enablers and barriers) were included in the Parent Survey. The survey item related to enablers asked families to identify: ‘What helped you / your child achieve the goals you identified this year?’ A further prompt suggested parents might consider ‘people, activities, equipment/aids/resources, money, environment, policies, time, etc’. Parents provided a range of written answers in the open-text box provided within the survey. It should be noted that people were not responding to set questions regarding specific enablers or barriers but were invited to reflect on what they identified themselves.

3. both parents and therapists were asked to identify enablers and barriers to outcomes during interviews.

In total, provision of data as part of the FSSP Outcomes and Process document was made available to researchers in only 3 instances (in relation to 2 FSSPs in 2007 and 1 in 2008).

A further twenty six (26) parents returned completed Parent Surveys in 2007 and nineteen (19) in 2008. However, only 23 of the 26 provided data about enablers and barriers in 2007, and 12 of 19 in 2008. In addition, 7 parent and 6 therapist interviews were conducted and 3 therapist focus groups.
Research methods to analyse data about the enablers to outcomes

The largest data set in relation to enablers was that of Parent Surveys. This data was collated thematically by identifying topic areas from the data. The proportion of respondents in each year identifying each theme or topic area was then calculated quantitatively. In addition, proportions of respondents in the two years were averaged as a way to identify a ranking of the most frequently nominated enabler topic. Given that a potentially different cohort of parents was completing the Parent Survey each year, it was decided not to analyse shifts in the frequency with which enablers were mentioned between the years, as it was felt that such shifts might only reflect parent differences rather than changes in service context.

Interview data from both parent and therapist interviews, was also collated by theme, using the topic areas established from the survey data as the categories of analysis. Given the small number of interviews, no quantitative analysis was undertaken to identify the frequency of response. Instead, excerpts from interviews are used to provide insight into the meanings of the themes identified in Parent Surveys.

Given the small number of responses from the FSSP data (3 in total), it was decided not to separately analyse this data.

Results

Across 2007 and 2008, twelve categories of enablers are identified by parents from the Parent Survey (see table 11). The three main enablers impacting on outcomes are:

- the provision of specialist services (identified by an average of 58% of parents);
- equipment and resources (identified by 50%);
- the provision of guidance, instruction and associated activities (identified by an average of 49% of parents).
Table 11: Enablers to outcomes: Percentage of parents identifying key enablers (from those completing this section of Parent Survey)

<table>
<thead>
<tr>
<th>Enablers</th>
<th>Ranking average % of respondents 2007-2008</th>
<th>2007 (n=23)</th>
<th>2008 (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope people/ therapist/ private therapist/ therapy</td>
<td>58%</td>
<td>57%</td>
<td>58%</td>
</tr>
<tr>
<td>Equipment / resources</td>
<td>50%</td>
<td>57%</td>
<td>42%</td>
</tr>
<tr>
<td>Activities / guidance/ instruction</td>
<td>49%</td>
<td>48%</td>
<td>50%</td>
</tr>
<tr>
<td>Time</td>
<td>30%</td>
<td>17%</td>
<td>42%</td>
</tr>
<tr>
<td>Money, affordability</td>
<td>24%</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>People (non specified)</td>
<td>20%</td>
<td>22%</td>
<td>17%</td>
</tr>
<tr>
<td>Outside agencies/ working with other services</td>
<td>15%</td>
<td>13%</td>
<td>17%</td>
</tr>
<tr>
<td>Home visit i.e. delivery of ECI service in the home</td>
<td>8%</td>
<td>9%</td>
<td>17%</td>
</tr>
<tr>
<td>Access to facilities</td>
<td>4%</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Continuity of practitioner / therapist</td>
<td>4%</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Practice approach</td>
<td>4%</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>A known diagnosis</td>
<td>2%</td>
<td></td>
<td>4%</td>
</tr>
</tbody>
</table>

This emphasis, on both the delivery of therapy and the guidance provided to parents, is consistent with findings from an earlier American study by Wehman and Gilkerson (1999). This study asked parents open-ended questions about the most helpful aspects of the services they received. The most commonly mentioned helpful aspects of service were identified as technical knowledge and skills of
practitioners (reported by 40% of parents); direct child-focussed therapy services (34%); and parent education (32%) (cited in Moore and Larkin, 2005: 26-27).

As discussed above, in interviews parents also discussed enablers to outcomes, as did therapists. These responses have been organised against the relevant enabler identified in parent survey data and presented below. These interview responses further illuminate some, but not all, of the themes emerging as key enablers.

**Scope therapists and staff; private therapists; provision of therapy**

As identified above, in both years the biggest enabler identified in Parent Surveys was access to specialist services such as Scope staff, Scope therapists, private therapists and therapy in general.

In every interview conducted with parents, Scope therapists were highly praised for their skills, knowledge, commitment to the family, and the willingness of therapists to take on tasks that supported the family beyond therapeutic intervention. The following comments from two parents reflect this theme:

[Therapist A] is an amazingly qualified woman and has fantastic ideas and knowledge - she’s a fabulous woman. And the same for [therapist B] as well - she’s a great resource as well - certainly very knowledgeable and creative as well. She provides lots of creative ideas and so forth. So definitely the quality of the staff is really high at Scope and so without a doubt that is the stand-out thing about the service (Parent 08).

They’ve never cancelled on me ... I’ve got all their mobile numbers - they are willing to hand those out which is good especially if you need them. With equipment and things as well - my physio is chasing up a standing frame at the moment so hopefully we might get one of those. They’ll always come back and report on what they were following up or supposed to be doing (Parent 08).
Families reported that outcomes were positive and they highly valued the therapeutic intervention provided, seeing this as the main contributor to outcomes, as shown in the comments from two parents below:

When he [son] was learning to walk the OT came more frequently. There was a month or a month and a half when she came every week because she really wanted to get him walking. I don’t know how she worked it out with all the finances and stuff but she was there every week. She was brilliant. And because she was there every week he walked so much quicker than if he was by himself without any help (Parent 08).

Now she’s [daughter] just about crawling, she’s starting to talk … and yes, we do other things with her, but ultimately the original therapy that she got started was all that rolling. And I just … she could very well still be lying on her back (Parent 07).

Equipment and resources

The next most commonly identified enabler was that of equipment and resources. Equipment and resources were identified by 57% of parents on surveys in 2007 and 42% in 2008.

In interviews, families aligned equipment with the work of therapists who were seen as instrumental in advocating for the families in their efforts to get these necessary resources. The willingness of therapists to support and assist families in this area was a strong feature of the service according to parents. The majority of families interviewed spoke of the various ways in which therapists took the time to contact other services on behalf of the families, advocate for them and assist them with funding applications for equipment.

My daughter’s now got a Heart Walker, she gets AFOs … we’re having to renovate our house and even though we now can’t get the services from Scope anymore, they’re still going to help us to get anything we need in our house. We need ramps – they helped us get other ramps, renovations on the bathroom to make that suitable. We’re getting other things
changed in the house and they’re still helping us with all that. So - I wouldn’t have known where to go, or who to apply to (Parent 07).

Yeah, definitely being able to access equipment and funding has been fantastic. They have been really helpful - filling out forms and getting that going and getting my son into 3 year old kinder this year. There’s been lots of support there (Parent 07).

Activities, guidance and instruction

Activities, guidance and instruction were identified as enablers by around half the parents completing surveys, and as such was the third most frequently reported enabler. One parent mentioned:

Because they supply not only advice and therapy, but even … you know … giving you websites or printouts, and set the age that will help learning aids or teaching aids. Even that spoon device that helps him have a better grip on his fork or spoon. So there are things that you probably don’t even know are useful until they say ‘have you tried this?’ (Parent 07).

Though these were the top three enablers mentioned by parents in surveys, other enablers mentioned on surveys received more discussion in interviews with parents. These are presented with a summary of this discussion below.

Working with other services and outside agencies

On Parent Surveys, parents identified that the Scope ECI service worked well with other agencies outside of Scope and that this was considered to be an enabler to outcomes. This enabler was identified by 13% of parents in 2007 and 17% in 2008, making this the seventh most frequently mentioned enabler on surveys. In addition, parents frequently discussed this enabler in interviews. The following transcripts from one parent interview provide examples of the complex ways in which therapists assist families:
The therapists have gone to all these different meetings - on top of therapy - and have helped us with the Council. They’ve set up proceedings to do standing-transfers and toileting, done training for the family day care people. That’s not their job, it’s the Council’s job to train them. But they’ve gone in to bat for us because they’ve known how important family day care was for us. So they’ve done training, they’ve gone into meetings with the Council...I think they have gone above and beyond what they have to do based on the number of hours allocated to help us. A lot of it has been in their own time. That’s when you know they enjoy what they do and that they really care and want to help you (Parent 07).

and

So they were kind enough to do the therapy in the family day care environment with other kids around. And we found that was more beneficial because they had other kids to model off, and the kids would do what they were doing and interact. They not only did the physio and so forth in the family day care but they also assisted family day care to receive the equipment that was required to feed her in and all those sort of things - and that came through Noah’s Ark (Parent 07).

While families expressed the need for the option to have one on one home visits (discussed below), they also valued intervention conducted in various community settings, as did therapists. This applied not only to Scope settings (for example centre-based intervention) but also for the need for Scope services to be linked with other services within the community. This has the aim of multiplying supports for the family and perhaps providing more variety of resources. These elements, both real and ideal, were seen as enablers to outcomes, as discussed by a therapist below:

There’s a lot of diversity here. You can’t just provide a service that covers everybody. So to be active in the community and to be appropriate within the context of the family it is good to have a local resource centre ... You have to be linked and localised ... Out here we are very involved in early intervention networks. So instead of going ‘we are great, we do this, we are the best’ and Yooralla are going ‘we’re great, we’re the best’, we all just pitch in and say ‘what are we going to do about this?’ And we’ll say ‘we’ll do this, you do that’. It’s very collaborative, that’s one of the good things out here. We are part of the community, part of
where people can drop in. So while [management] pushes for a service without any walls, the walls here are probably quite good to have [i.e. in terms of having a centre where people/groups can come together for a common purpose] (Therapist 08).

Therapists seek to support the family by providing support beyond therapeutic intervention by assisting families to resolve problems and address a wide array of needs. They seek to do this by linking in with other services. As Harrison notes; ‘Family support should concern itself with the creation and support of community’ (Harrison, 2007: 101).

Home visits

Though families and therapists valued service delivery in a range of community settings, some parents explicitly made reference to the value of ‘home visits’ by therapists. On Parent Surveys, 9% of parents in 2007 and 17% in 2008 identified home visits as an enabler to outcomes. This was also discussed by parents in interviews. One parent, below, explained that home visits were more convenient and less work for parents:

I guess them just coming out to you and showing us what we can do to help [the child] in the home as well. It’s just convenient and easy - don’t have to put him in a car and all that stuff (Parent 08).

Continuity of practitioner / therapist

Continuity of practitioner / therapist was identified as an enabler on Parent Surveys by 8% of families in 2008 (though none discussed this on surveys in 2007). This was briefly commented on in an interview with one family, as presented below:

We’ve been able to keep the same therapists from the word go which has just been fantastic (Parent 07).
Practice approach

Various elements of the practice approach used in Scope’s ECI service were identified as enablers on Parent Surveys by 8% of parent respondents in 2008 (though none reported this on surveys in 2007). While the practice approach may not have been frequently identified in Parent Surveys, during interviews parents and therapists identified various elements of practice that they recognised as important to achieving positive outcomes. In parent interviews, the Scope Southern Region service was praised for the service provided, not only in terms of the quality of individual therapists, but with regard to the service provision and the options provided to parents. To be able to choose between one on one intervention in the home or joining in with a bigger group was seen as a positive and enabling form of intervention.

So I don’t mind if I have to go somewhere, but I like the fact that my son gets one-on-one. Because in the group setting we were going to an early intervention program before we started with Scope, and we were there six months and I just didn’t feel we were getting anywhere (Parent 07).

Like parents, therapists also outlined the value of joint visits, communication and building rapport with families as significant enablers to outcomes. Most therapists regarded joint visits as an opportunity to best support families as they provided opportunities to gain shared understanding about a client as they worked towards common goals. Therapist comments about joint visits are presented in Section 4. The following discussion outlines therapist responses to the other areas of practice approach.

Along with families, therapists identified effective communication - that which enables shared understanding amongst families, therapists and service providers - as an important enabler to positive outcomes. Communication between therapists is an important element of the practice approach to ensure they are working towards common goals that are shared by families. Families are also empowered by effective communication which is a central part of relationship building. One therapist discussed this as follows:

I think … the way that you have a team - the families have a lot of people and therapists, and case managers. And I think the communication between those people and the way
these people all work together and all understand where the families are up to really helps as well. And, you know, if you have a case manager who you communicate really well with ... you just get things done so much quicker. You can help each other out, if you all know where you are up to ... that makes a big difference (Therapist 07).

Relationship building depends on communication and the personal qualities of the therapist. One therapist identified the important quality of empathy as part of the approach to practice. To win the confidence and trust of families requires that families feel that the therapist understands the family situation and is there as an ally to support the family. One therapist explained this enabling aspect of the practice approach as follows:

There’s an underlying assumption ... Are you from DHS? Are you going to attack me? So for us to be accepted into their homes and for them to open up is a huge philosophical shift. To go from ‘are you part of DHS? Are you going to take our kids away?’ to then going ‘oh, she’s really nice. I can share with you and you won’t judge me’. And that’s the thing - families verbalise that. They will say, ‘you come in and you don’t judge me.’ We go in as a family service co-ordinator not judging but saying ‘what can I do for you?’ ... Not everyone - as we’ve discovered - works the way we do. Some people don’t have the ability to empathise (Therapist 08).

Consistent with the principles of family centred practice, a core part of the practice approach is a commitment to empowering families, which, as the below comment from a therapist suggests, is reliant on positive relationships between families and therapists.

So it’s really about developing that whole relationship and being able to have the families understand - in whatever way they understand it - that they have to do something to help themselves. So I think it’s about empowering the families and for them to understand that we are not magic, and that they are the ones that are really going to make the changes (Therapist 07).
Finally, therapists also identified the elements in their work contexts that enabled them to practice well, and achieve positive results for families. The majority of therapists identified that regular team meetings and the opportunity for case discussion were important. The ability to have the time to share information with other therapists, both pertaining to their joint work with clients or specific discipline base, was regarded as central to effective practice and positive outcomes. To this end, meetings needed to not only deal with administrative issues but it was important that therapists be able to take ownership of some meeting time to meet their needs which aims to have the flow on effect of meeting the needs of the families they serve.

When I first started here last year, part of the team meeting was presentations and case discussions, and I found that really valuable. Most of it was outside my experience and outside a lot of my work, but I still found it really interesting to hear the discussions because it really helped me understand how the other therapists worked, and what they can offer, and what their skills are. But somewhere into last year that stopped and it just became very administrative - the whole meeting ... I think it's valuable for all of the therapists to meet even within their own discipline, even across ... maybe even across southern and eastern [service regions], like to actually have that professional support as well as the multidisciplinary support (Therapist 07).

**Conclusion**

The above discussion highlights that families and therapists broadly identified similar enablers to outcomes. In particular, families identified the skills and commitment of the therapists who supported them in accessing equipment and other resources while also providing them with activities, guidance and instruction. It was clear that families highly rated the importance of the therapist in the life of their family and child, but that the value of this role was hinged on a set of attributes including a wide knowledge base, considerable professional expertise, detailed knowledge of the child and family, personal empathy and relationship building skills. In addition, families valued the way therapists worked with outside agencies, fostering collaboration between services.
Therapists identified a number of enablers throughout the course of the interviews. In summary, these key enablers included a range of practice approaches as well as organisational supports. Practice approaches included joint visits, a focus on building relationships between therapists and families, and the personal qualities of the therapist – notably empathy, along with the effective communication between families, case managers and therapists. Organisational supports such as the provision of opportunities for therapists to meet and discuss professional issues, and to use meeting times effectively for this purpose, were also identified as enablers to outcomes.

These set of enablers, from the viewpoints of both parents and therapists, are clearly inter-dependent and, as such, represent a complex but essential set of factors necessary to the achievement of outcomes.
Chapter 8: Barriers to outcomes

Introduction

As discussed in chapter 7, this research included a focus on both the enablers and barriers to outcomes. Chapter 8 presents the results identifying the factors impeding outcomes.

Research methods to collect data about the barriers to outcomes

The focus on identifying enablers and barriers to outcomes was implemented via three data collection methods, (FSSP Outcomes and Process document, parent surveying, and interviewing), explained in chapter 7.

In total, provision of data as part of the FSSP Outcomes and Process document was made available to researchers in only 3 instances (in relation to 2 FSSPs in 2007 and 1 in 2008).

A further twenty six (26) parents returned completed Parent Surveys in 2007 and nineteen (19) in 2008. However, only 23 of the 26 provided data about enablers and barriers in 2007, and 12 of 19 in 2008. In addition, 7 parent and 6 therapist interviews were conducted, along with 3 therapist focus groups.

Research methods to analyse data about the barriers to outcomes

Data identifying barriers is analysed in the same way as that collected to identify enablers, (described in chapter 7). As identified in chapter 7, the largest data set in relation to barriers was that of Parent Surveys.
Results

Across the two years, families identified thirteen (13) categories of barriers inhibiting outcomes. By far, the most frequently identified barrier was that of ‘time’, largely relating to lack of time or time pressures on families (see table 12).

Table 12: Barriers to outcomes: Percentage of parents identifying key barriers (from those completing this section of Parent Survey)

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Ranking average % of respondents 2007-2008</th>
<th>2007 (n=23)</th>
<th>2008 (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>36%</td>
<td>39%</td>
<td>33%</td>
</tr>
<tr>
<td>Not enough therapy</td>
<td>23.5%</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>Money</td>
<td>17%</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Lack of service follow up / support</td>
<td>17%</td>
<td>26%</td>
<td>8%</td>
</tr>
<tr>
<td>Family capacity: family stress and energy levels; juggling work and family; personal / family characteristics</td>
<td>14.5%</td>
<td>4%</td>
<td>25%</td>
</tr>
<tr>
<td>Equipment</td>
<td>12.5%</td>
<td>17%</td>
<td>8%</td>
</tr>
<tr>
<td>Sickness / response of child</td>
<td>10.5%</td>
<td>13%</td>
<td>8%</td>
</tr>
<tr>
<td>None</td>
<td>8.5%</td>
<td></td>
<td>17%</td>
</tr>
<tr>
<td>Policies /waiting list</td>
<td>6%</td>
<td>4%</td>
<td>8%</td>
</tr>
<tr>
<td>Lack of/ inappropriate activities</td>
<td>4.5%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Change of staff</td>
<td>4.5%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Unforeseen circumstances</td>
<td>4%</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Transdisciplinary practice</td>
<td>2%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Level of therapist experience</td>
<td>1.5%</td>
<td>3%</td>
<td></td>
</tr>
</tbody>
</table>
The averaged frequency of responses across two years, shows the biggest barriers to outcomes identified as time (36%), not enough therapy (23.5%), money (17%), lack of service follow up and support (17%), and family capacity (family stress and energy levels; juggling work and family; childcare responsibilities) (14.5%). Overall, these are similar to findings from the American study by Wehman and Gilkerson (1999) who found that the biggest barriers to achieving family involvement in ECI services were: providing service at times that were incompatible with family commitments (for 40% of parents); poor parent-practitioner communication (30%); insufficient level of service provision (28%); and, difficulties in finding childcare for siblings (22%) (cited in Moore and Larkin, 2005: 26-27).

These key results are discussed further below in order of priority. Data is also added from interviews with families and therapists in 2007 and 2008 to help illuminate the nature of key barriers.

**Time**

Time was identified as the biggest barrier to outcomes on Parent Surveys with 39% of parents in 2007 and 33% in 2008 nominating this as a barrier. Unfortunately, comments on surveys did little to further unpack this issue of time from the parent perspective. While parents in interview did not choose to focus on this barrier, some further comment from parents were recorded as part of the FSSP review process. These include discussion of the difficulty in balancing the time required to attend to multiple children’s needs within a family setting, as well as the lack of everyday ‘happy time’ that is not related to parents doing therapy-related work with their child.

Therapists interviewed all discussed time as a significant issue. Therapists were able to elaborate on the effect of time constraints in the service they provided. Time was a significant issue in trying to arrange appointments with families, with members often not available at the same time so that more time was spent by the therapist having to see members of the same family at different times and locations. As one therapist discussed:

> Probably time is a big one. With a lot of families I see, one of the big ones is that the parents work full time. And so how do you get in touch with them when you’re delivering messages
to other people? And you can talk to them on the phone but it’s not the same as having a parent in the room, with where you are up to and all that sort of thing ... It’s the amount of time you actually get with the family ... Families who can’t get organized and struggle to fill out a form ... You know it doesn’t work quite so well with them. The amount of time is really tricky. And our timetables ... you’ve got kids that are in family day care, child care, they stay with their grandma ... And you have to get to these places and make sure everyone knows the same thing. All the people that care for those children have different agendas - like ‘it’s not my responsibility to do this. I’m not going to pass on that information’. So that sometimes is really hard (Therapist 07).

This description identifies the additional time required to ensure all those involved in the child’s care are informed to support therapy/service goals and activities. The care environment for the child is complex with many carers (formal and informal) involved. There needs to be time spent with each. To some extent, such comments resonate with findings from an American study of parent/practitioner partnerships in early intervention programs (Brotherson and Goldstein, 1992 cited in Moore and Larkin, 2005). In this study, parents reported that practitioners could make the best use of parents’ time by fitting therapy and education into their family’s daily routine and environment, and by listening to what parent’s know about their child and family. Factors that contributed to an inefficient use of parents’ time included lack of coordination between service providers and lack of services generally for families and children in the community (Moore and Larkin, 2005: 35).

Another aspect of time constraints discussed by therapists was that brought about by the competing time demands of ‘hands-on’ therapy and the many related tasks in general family support. For example, supporting families by assisting them with various applications often meant there was less therapeutic time with the child. Two therapists described this as follows:

I do two hour ones [sessions], like the EI kids I see now, I probably see a lot of them less often and do longer visits. I think too, it’s very dependent on the educational background and the socioeconomic status of the parents and that type of thing. I’m hardly doing therapy these days, and you need two hours just to sort through their issues. We did a housing application that took - I can’t tell you how long. We got it done. And that we have to write.
Like, I’ve got to write a report. I don’t know what to write because I haven’t done any therapy. Now I just go, and ... it’s going to wipe out two hours (Therapist Focus Group 07).

I’m now making my phone calls while I’m driving, and taking my phone calls while I’m driving. I don’t have enough time. I’m just really busy. But in theory all those phone calls ... like to be on the phone for half an hour with the family, and then you’re on the phone to the case manager, and then come back and google a lot of stuff for them on the net. Yeah, you do things constantly ... But also funding with regards to equipment and family needs is a nightmare. We spend so much time looking for funding when you could be doing something else with that child (Therapist Focus Group 07).

Time constraints are also tied in with funding limitations. Therapists identified tight budgetary requirements as placing greater demands on their time.

I think there is so much emphasis - and there always has been with Scope - on the dollar amount. Likes it’s down to - you have to have this many contact hours a day, and you have to do this, and this costs this much, and you can’t spend more than that time ... It all comes down to money, but it’s so hard to be running around ... and you just don’t get stuff done quickly enough. You don’t get time to come in to the office and sit down and do all your planning. Your planning is in the car when you’re driving. And just time that you’re all [i.e. fellow therapists] in the office together to catch up ... You just never get a chance to see other people [therapists]. And that’s partly because we have a lot of part-timers ... doesn’t help (Therapist 07).

Isn’t this a numbers game though? Because I’ve sat in meetings here when they’ve looked at numbers and you might have to say how many clients you see and kids you’re seeing or whatever, and the implication is you’re not seeing enough. You’ve got a few gaps here or whatever, and you say ‘oh God, I don’t seem to ...’ But the pressure - and that’s coming from way up at the top somewhere that says ‘this is your budget’, and it’s almost you can’t do what we would like to do in constraints of the budget (Therapist Focus Group 07).
They [i.e. service managers] have to make the numbers work - and I get that because that’s what their job is - to make the numbers work. And to make sure we get paid, and to make sure we have got the resources that we need. And I understand that. But we are the ones with the person in front with the tears, and saying to them ‘really you’ve gone over your hours and I don’t think we can talk about this now’. You know, that’s not family centred practice, so that part of it is tricky (Therapist 07).

Time and budgetary constraints mean that therapists are constantly having to make compromises as to how best serve the family and child given that there are a limited number of hours available to the family. Such compromises may have an impact on outcomes for the family as well as placing therapists under pressure in terms of the significant decisions they have to make.

**Not enough therapy**

Parent responses on Parent Surveys frequently identified not enough therapy as a barrier. Twenty two percent (22%) of parent respondents in 2007 and 25% in 2008 identified this item, leading to it being the second most frequently reported barrier by parents. Parent interviews echoed this concern and though parents were somewhat reticent to discuss barriers generally at interview, preferring to report on their positive experiences, lack of therapy was a repeated concern.

Families overwhelmingly wanted more therapy and saw it as important to their child’s development. They identified this not as a fault of Scope’s service, but as a financial issue with responsibility lying ultimately with governments. Two parents’ views are reported below:

I don’t know if things changed or whatever - but now it’s definitely three weekly to sometimes monthly which means we are probably getting a therapist every 2 weeks [i.e. once a month for each of two disciplines]. So, I suppose it’s not much different, but initially we were under the impression we would be getting - in a 3 week period - 2 visits ... But maybe in a month he will be lucky to get the 2 visits in the month - one from each [discipline e.g. Occupational therapy, Physiotherapy]. So it sounds like a criticism, but I know the
funding part ... But I’m not complaining, because you know ... obviously it’s a government funded service and I realize that the budget’s tight (Parent 07).

I’d like to see the therapists get more funding to be able to see the children on a more regular basis rather than pushing it out every three weeks. I mean it’s basically nearly once a month. I believe there should be more therapists to allow the children to be seen every week. I think my daughter - the more you do with her, the better she is. And I think the more that we can get therapists in there to do different things the more we are going to see out of our kids. I just think areas to improve would be to get more therapy - I know that there is a waiting list and it’s just becoming more and more predominant that there are kids with disabilities ... The government should give more funding (Parent 08).

Insufficient access to speech therapy was often singled out by families. This is an issue that Scope has had to deal with due to an overall shortage of speech therapists in the sector. One family reported a virtual absence of service delivery in this area, as follows:

But I do feel we have been left to our own devices for much of this year, particularly for speech. Because the problem is when a therapist is going to be working with you they need to actually be here and we have had an issue with getting enough of their services, particularly with speech. Once every three weeks for speech and OT. And once every three weeks has been happening with OT but I can’t say it has been happening with speech. It did happen in term 2 and term 3, but terms 1 and 4 have been a disaster. Speech is the key service required (Parent 08).

This lack of resources for speech therapy was also recognised by therapists who saw it as a budgetary constraint.

That [children not getting enough therapy] goes back to money, doesn’t it. With a budget ... it would fit into everything if we had some more money to employ other people. Our kids aren’t getting the language work that they should be because we just don’t have the resources. And we can’t expect the families to do it (Therapist Focus Group 07).
This concern over insufficient therapy for some clients was largely attributed by therapists to changes in funding arrangements to a more individualised approach. This resulted in less flexibility in terms of being able to provide more assistance to families whose circumstances might require it. One therapist explained the lack of responsiveness in the system and the resulting inadequate allocation of services to some clients as follows:

But just the flexibility too ... If a child really needs more hours, and you can see that it will help, it would be nice to take hours from somewhere and put them somewhere else. It’s a bit set on how much there should be (Therapist 07).

Lack of sufficient therapy hours was also seen by therapists to be contributed to by distances between clients. Travel time is charged against the family’s allocated funds and so means less time available for other forms of support. As one therapist explained:

When we go on a really long travel - we’ve got a kid with eye needs at Rye. So you know, each time we go down there we’re not going [for just the one hour], it’s always two to three hours. And he’s way over his [allocated] hours. But what can you do with oxygen tubing attached to him the whole time, not sitting up on his own ... (Therapist Focus Group 07).

**Lack of service follow up and support**

Lack of service follow up and support was the fourth most frequently identified barrier on Parent Surveys, with 26% of parent respondents identifying this in 2007, though only 8% mentioned it in 2008. While in interviews, the majority of family members praised the communication of therapists and their commitment to timetables, some parents did identify problems with lack of follow up across key periods (such as kinder to school transition), and poor communication about service delivery.

During interview, one family member expressed concern over a lack of communication during the holiday period.
The over Christmas period - we never knew when they were coming back on board. And no-one called me until mid February and said ‘Hi. Me again’. So for all of January there is nothing. Their last session was 15th December - so that’s six weeks / two month period. I suppose I would have preferred for someone to say ‘we start back on this date, someone will contact you’ … I guess I could of chased them up if I had of known when to expect them back rather than wait for 6-8 weeks … There is nothing on - there is no play group. It breaks up your week a lot. There is no play group, no child care, there’s nothing during that whole of January - everyone shuts up shop (Parent 07).

Another parent indicated they didn’t know who to contact in Scope beyond the specific therapist. Finally, one family member was concerned at what she experienced as a lack of support during the critical transition period at the end of early intervention and the commencement of primary school.

> Daughter will soon begin school yet there has been no support for my daughter. No advising on any transition aids or initial support (Parent 08).

**Lack of appropriate, or provision of inappropriate, activities**

Though only 9% of parent respondents on the Parent Survey in 2007 (and none in 2008) identified the lack of appropriate activities as a barrier to outcomes, this was mentioned by families in interviews in 2007. One family expressed a concern that families didn’t have the option for both one on one intervention as well as play group intervention but recognised this as a funding issue.

> But there may be a lot of mums that don’t go to play group … that the child would really get a lot out of the social interaction but they don’t want to lose the individual therapy. So obviously if budgeting was different – and I guess it’s a big point because it will always be tight - but if it was it would be great if they could offer a group and one-on-one therapy (Parent 07).
Change of staff and staff turnover

The lack of sufficient therapy appeared to be amplified by staff turnover. Again, though only 9% of parent respondents in 2007 identified this issue on Parent Surveys (and none in 2008), families interviewed in 2007 did comment on this. Parents in interviews highlighted that when staff remained consistent (as was the case with many families) then it was good for families and children to have consistency in building rapport and shared understanding. Alternatively staff turnover was an issue for some families - particularly for those requiring speech therapy. This is not surprising given the high importance attached to relationship building as a key practice approach by both staff and families. This is reflected in the following comments from parents:

They’ve been brilliant speechies and [child] has built up a beautiful rapport with them ... and then they leave. That’s the only bad thing I have to say. Other than that - even the new speechies try and work along the same lines, so they try and pick up where the last one left off which has been really good for him ... So it takes him a while to feel comfortable with a new staff member. And I think other kids are like that - they like consistency (Parent 08).

So I just find that there is a big turnover of staff all the time. In such a short period of time we’ve been with Scope - we’ve had quite a few people. People don’t seem to hang around very long - I don’t know what it is (Parent 08).

Barriers to therapist practice

In addition to discussing barriers to client outcomes, therapists also identified barriers to effective practice. It is assumed that factors that act as barriers to effective practice, also negatively affect outcomes for clients. Therapists identified a number of significant barriers to their practice including insufficient time and opportunity for support, exacerbated by the increasing mobility of staff. In addition, therapists discussed structural barriers relating to client funding. Of greatest consequence though is the complex environment in which therapists are required to work, often with families in crisis and with few or no resources to draw on to support these families. Each of these issues is discussed below.
Time constraints result in less opportunity for therapists to debrief and spend time with one another discussing clients and being able to draw on the expertise and support of one another. In focus groups therapists stated:

I really think we need more opportunity for debriefing. You can’t carry it, it’s too heavy a load. There’s the lack of time within the structure to talk and share ...

and

If we are expected to be transdisciplinary then we do need that time to talk and share. There needs to be time allocated ... The bottom line is that people will leave - they will burn out. Especially with young therapists ... (Therapist Focus Group 08).

With less centre-based therapy, therapists are more mobile and transitory resulting in less contact between therapists and less time for one another.

Yeah. And it’s really hard in our job to keep up even with each other. You don’t see each other ... I guess email helps but you’re not in the office everyday and you don’t have access to email every day. You can go for a week and forget to tell them [therapists] something (Therapist 07).

The fundamental problem with the kind of service that we are is that we are always moving - we are always in transit. It makes the formal time doubly important because you don’t see everyone at the lunch table like in a rehab centre or wherever. You don’t see someone at morning tea. It’s very important to have time together (Therapist Focus Group 08).

Therapists also identified funding constraints and workload models, such as that of ‘billable hours’, as significant barriers to effective practice. These have been discussed briefly in relation to the barrier of time, as such models significantly limit the amount of time therapists have available for interventions. The notion of ‘billable hours’ requires therapists to provide capped amounts of service to each client, with all tasks related to interventions (including travel, communication, follow up and development of resources) to be billed or tallied against the allocated total hours per client per annum. One therapist describes this system as follows:
I’m supposed to bill for anything that is directly attributed to that client. So if I’m reading some notes on autism to present to the client ... then that is billed to that client (Therapist 08).

However, therapists report that this acts as a considerable barrier to quality practice as it places limitations on the type and level of activity provided as part of any intervention.

You have to structure your day so that you’re seeing a certain number of people a day to meet your quota. So you might have to spend an extra twenty minutes speaking with someone but that’s something you can’t do because you have to go to your next appointment (Therapist Focus Group 08).

As it stands, everything that we do for a client has to be billed so you end up not doing it because you have to weigh up the outcome. Is it worth me spending an hour on the internet or an hour going through my resource folder to find something that would suit this child perfectly? Or, do I just give them a generic strategy that should work okay, that might work - or should work okay, because it’s going to save them ... or the parent x amount of dollars? (Therapist 08)

Thinking about the statistical side of things is a barrier. Focusing on statistics rather than the important aspects of practice - like worrying about not being able to come back again because we’ve already used up too much time there. Or, I can’t stop and talk to you because it affects the billable hours, or we can’t do it in a meaningful way (Therapist Focus Group 08).

One therapist suggested that the end result of these demands and pressures placed on therapists is a sense of being overwhelmed and struggling to feel in control of their situation.

I’ve been given this case load and I’ll be creative to make it work. But there’s also sometimes [when] I can’t do this and I can’t make it work and it’s all falling apart. And it can fall apart - and people don’t get seen. So there’s that fine line between being capable and
being given that work to do, and being creative and being energized by that. But at some point it can all collapse (Therapist Focus Group 08).

This same therapist felt that it was important that service management be aware of the issues therapists are raising. Advocacy from service managers for a more effective system was considered an important element:

You also need advocacy from the manager to advocate on behalf of the team to report to senior management so as to provide all that we need to do our job effectively. Often it’s brick walls all the way up the line (Therapist Focus Group 08).

These constraints on effective practice occur in a practice environment that is extremely complex and with few resources available to assist families or therapists. Therapists repeatedly describe the families they work with as being ‘at risk’ or in crisis, presenting with complex family, health, social and financial problems. One therapist described this during interview:

It’s at the level too where if we’re working with a family where there’s another organisation and they are saying ‘I’m really concerned about these children and I’m going to report it to government authorities’. We go ‘No, stop, stop, stop. Think about what you are doing. Let’s re-visit and think about what we’re doing. Let’s work out what we’re actually doing for this family - does this need to happen for this family? We can’t just start off a chain of events.’ So for that family it might mean sitting down with the mum and saying, ‘We’ve got concerns for you and your child and we need to figure out what to do. What should we do?’ (Therapist 08).

This kind of work is clearly at the coal face of crisis, with ‘people under severe stress’, and relies on strong relationships with the family along with significant levels of trust. Much of this work remains undocumented for the reasons described below:

We are dealing with an intense level of emotional support - people under severe stress, who talk about having the pills nearby and swallowing them all. And that you can’t write on a Family Service and Support Plan. You can’t even write it on a triplicate [form]. You can’t document this stuff because it is shared with us on a basis of trust. It comes from the
knowledge that we won’t run off to protective services. That if we have concerns then we will
discuss it with them [family] - that we are in there with them. It’s important that people know
that what they share with us will be treated with respect (Therapist 08).

In such contexts, therapists report that much of their time is spent on addressing these immediate
needs, as described by therapists in a focus group:

So for most of our families in terms of priorities, the therapy doesn’t rate, the other stuff far
outweighs the therapy. Often by the time you deal with and face all these personal and social
issues, there is no time left to help the kid work with say, their speech (Therapist Focus Group
08).

Therapists are often alone in providing these supports, given there are few other resources in the
community available to assist. Added to their workload is the burden of finding and negotiating any
supports available for families:

... that places even more pressure on us when we might have a family on a waiting list for
case management and who can’t access it within the community. And so the only people
involved are us, and yet we are supplying all their therapy needs as well as all the social issues
and financial issues that we are somehow supposed to - if not deal with directly - link them
into services and all that takes a lot of time and energy (Therapist Focus Group 08).

Within their own workplace at Southern ECIS, therapists lack supports for this work, which results in
added stress and the worry that they have not covered all bases in seeking appropriate supports for
families in crisis. As described in one therapist focus group:

We used to have discipline specific meetings, but that’s all gone. Sometimes it’s a bit urgent
that you tell someone something. Committing suicide ... If you’re on the phone and someone
is telling you that and you’re going, ‘I’m in the office and I don’t know what to do’. So I’ve
called her again and it’s all okay sort of. And I did things, but yes, you actually need to debrief
so you don’t blow. But sometimes you need to tell someone something so that you can at
least go ... Like suicide - I don’t know what to do. And not just that - I don’t want someone –
what happens to them - on my head. And you just need to know that you’ve done something or told someone, so even if you can’t stop something happening, at least someone else knows. And if they think you missed something or should have done something, well, someone can tell you (Therapist Focus Group 07).

This need for further support and resourcing was expressed as a major need by therapists. Therapists repeatedly discussed a sense of their own inadequate knowledge and skills in this area of supporting the broad needs of families in crisis:

The complexity of the service is getting worse. If you are the only person or team assisting them [i.e. families in crisis], you are expected to know how to assist them with things like funding or a source of information about such and such - ‘do you know anything about it? I really need it - how do I get some help?’ (Therapist Focus Group 08).

And someone who does all the family co-ordination deals with all the ... crisis stuff. I do stuff that I don’t know anything about that takes me ten hours to do because I don’t know anything. But someone [i.e. a relevant professional] could have done it in five minutes (Therapist Focus Group 07).

Therapists repeatedly called for further specialist resources in this area, to overcome these barriers in regard to inadequate skills and resources to support families in crisis. In particular, therapists noted the lack of, and need for, sufficient psychology and social work services.

I think there’s the problem of when it comes down to duty of care where we’re getting situations that families are in such crisis and you are the only one there to do something - and those situations are difficult. You can’t just walk away without some sort of follow-up. If you’re going to walk out the door you need to call a service that can act quickly like a social service, not a speech therapist or OT (Therapist Focus Group 08).

We are trying to fill those roles and we don’t have the skills for them. And often they are fairly major and ongoing needs for families. So often it’s not just a quick answer - it requires the skills of a social worker or a psychologist (Therapist Focus Group 08).
Can I please tell our bosses to please employ a social worker? (Therapist Focus Group 07).

Now there are no social workers and minimal psychologists that I can ring to ask ‘what can I do about this?’ I’m desperate, desperate, desperate (Therapist 08).

This sense of desperation was a prevailing one among therapists. Working in this environment where families presented with complex situations and issues, with little support available to either families or therapists, is an ongoing struggle:

But I don’t think people actually understand what you do in a day ... You just wouldn’t believe it. And stuff happens during the day that is totally out of your control, and it all just goes pear shaped and you can’t actually describe that. But pear shaped happens a lot (Therapist Focus Group 07).

It just is how it is. Everyone is running around trying to do the best - survival mode (Therapist Focus Group 07).

**Conclusion**

Parents and therapists describe extremely complex environments in which support is provided. Within these environments there are many barriers that affect outcomes for children and families. Many families describe significant lack of time, money and energy, along with insufficient services and supports to meet their varied needs. ECI service providers are required to work with multiple family members and carers, as well as other paid service providers such as kindergartens and childcare providers. Throughout the interviews, as well as the less descriptive survey data, there is a sense of many families in crisis, and therapists being stretched to support them adequately, often operating without the back up of other services and professional peers. For families and therapists, there is often an experience of ongoing struggle to stay afloat with both parties feeling that resources and supports are inadequate and barely enough to prevent people from drowning. As one therapist stated; ‘You always feel like you’re treading water’ (Therapist 07). This is not an atomised set of barriers, but a set of
inter-related elements that are overlaid to form the complex environment in which services are delivered.
Section 3:
The Process of Service Delivery: Family Centred Practice
Chapter 9: Defining Family Centred Practice

This research has a major focus on the type and level of family centred practice within the Scope Southern ECI Service. This focus is based on two rationales. First, a common understanding of the evaluation of social services requires a focus on both the ‘effort’ put into service delivery, as well as the ‘effect’ of service delivery (Friedman, 2000). The area of ‘effect’ is that of establishing the outcomes or impacts of service delivery, as has been done in Section 2 of this report. The area of ‘effort’ is commonly understood to include a focus on both the outputs of service (i.e. how much was done) as well as the processes and practices of service delivery (i.e. how well service was provided) (Friedman, 2000). Within this approach, a focus on the process of service delivery is considered an important aspect of service evaluation. This rationale is reinforced in an ECI environment where there has been a strong focus on the processes or practices of early intervention as critical to effective service delivery. Within the ECI sector, family centred practice has been identified as a key process, and has also been linked with the achievement of outcomes. Family centred practice is also identified by the Victorian government as a key element of ECI service provision (Early Years Branchm DHS, 2005). These rationales highlight the importance of exploring the nature and extent of family centred practice in this study.

Exploring the literature

Defining Family Centred Practice

As discussed above, family centred practice is a key concept in early childhood intervention. There are many definitions of family centred approaches and family centred services. This set of practices is relevant across a range of service areas including early childhood care and education settings, services for families with children with special needs, child protection, family policy, health and hospital settings. A good discussion of the literature on family centred practice is available in Moore and Larkin (2005) “More than my child’s disability...”: A comprehensive literature review about family centred practice and family experiences of early childhood intervention services.
Two definitions serve to capture the thrust of ideas found in discussions of family centred practice. Viscardis (1998) defined a family-centred approach as one that:

... begins with the child’s and family’s strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers (p. 44).

In relation particularly to children with disabilities or special needs, Law, Rosenbaum, King, et al (2003) defined family centred practice as:

... made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognises that each family is unique: that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered (quoted in Moore and Larkin, 2005:2).

On the basis of significant research by a range of researchers, the US Council for Exceptional Children (Division of Early Childhood) has synthesised the best practice principles of family centred practice. These are re-published in Moore and Larkin, 2005 (pp. 11-12), and provided below:
Recommended Family-Based Practices
(US Council for Exceptional Children: Division of Early Childhood)

Families and professionals share responsibility and work collaboratively
> Family members and professionals jointly develop appropriate family identified outcomes.
> Family members and professionals work together and share information routinely and collaboratively to achieve family-identified outcomes.
> Professionals fully and appropriately provide relevant information so parents can make informed choices and decisions.
> Professionals use helping styles that promote shared family/professional responsibility in achieving family-identified outcomes.
> Family/professionals’ relationship-building is accomplished in ways that are responsive to cultural, language, and other family characteristics.

Practices strengthen family functioning
> Practices, supports, and resources provide families with participatory experiences and opportunities promoting choice and decision making.
> Practices, supports, and resources support family participation in obtaining desired resources and supports to strengthen parenting competence and confidence.
> Intra-family, informal, community, and formal supports and resources (e.g., respite care) are used to achieve desired outcomes.
> Supports and resources provide families with information, competency enhancing experiences, and participatory opportunities to strengthen family functioning and promote parenting knowledge and skills.
> Supports and resources are mobilized in ways that are supportive and do not disrupt family and community life.

Practices are individualized and flexible
> Resources and supports are provided in ways that are flexible, individualized, and tailored to the child’s and family’s preferences and styles, and promote well-being.
> Resources and supports match each family member’s identified priorities and preferences (e.g., mothers and fathers may be different).
> Practices, supports and resources are responsive to the cultural, ethnic, racial, language, and socio-economic characteristics and preferences of families and their communities.
> Practices, supports, and resources incorporate family beliefs and values into decisions, intervention plans, and resources and support mobilization.
**Practices are strengths and assets-based**

- Family and child strengths and assets are used as a basis for engaging families in participatory experiences supporting parenting competence and confidence.
- Practices, supports and resources build on existing parenting competence and confidence.
- Practices, supports and resources promote the family's and professionals’ acquisition of new knowledge and skills to strengthen competence and confidence.

A significant element of family centred practice, that is discussed in the literature, is a plan of intervention based on a collaborative process between family members and service providers. This plan is known by various names, for example ‘individualised family service plan’ or, as in this study, ‘family service and support plan’. Moore and Larkin argue that these plans:

> ... are one of the key features of family-centred practice. They are used to formalise agreements reached between service providers and parents about identified needs and expectations, the actions to be taken, and who is responsible for each action (Moore and Larkin, 2005: 38).

It is a key expectation in the literature that parents are involved in the development of the plan and the identification of goals and actions for service delivery (Moore and Larkin, 2005:39). The role of the plan within family centred practice, parent involvement in its development, and its use by ECI practitioners is further discussed in chapter 11.

**Family Centred Practice as ‘best practice’ linked to outcomes**

It is argued by many researchers and practitioners (e.g. James, 2010; Dunn, 2000 - both cited in Moore and Larkin, 2005), that family centred practice is considered ‘best practice’ in services concerned with child development. In a review of key research findings, Moore and Larkin (2005) find that family centred practice is generally beneficial. Clear benefits have been found for parents and families, with indirect benefits for children (2005:20). There is increasing evidence that family centred practice contributes to outcomes for both parents (and wider family members), as well as the child. Drawing on a
number of studies, Moore and Larkin (2005:17-19) note the range of outcomes for families and parents identified as resulting from services using family centred practice as including: increased parent satisfaction with services; reduced family stress levels; satisfaction with parenting; parent empowerment; family wellbeing; family functioning and cohesion; and parent control.

Though it is difficult to establish a clear relationship between the mode of practice (i.e. family centred practice) and outcomes for children, some studies have attempted to show a relationship. For example, Moore and Larkin (2005) note that a series of studies by Law, Darrah, Pollock, et al (1998) were designed to develop and evaluate a family centred approach to the provision of therapy services for young children with cerebral palsy. This included using family centred approaches to develop goals of service. Children in these services showed measurable improvements in functional performance, however, it is not clear the extent to which this was attributable to family centred practice. Similarly, a review of research in this field by McBride (1999, cited in Moore and Larkin, 2005) identified positive outcomes for children, including increased involvement in activities, when attributes of family centred relationships between parents and practitioners were present. In this way, there appears to be emerging research evidence that family centred practice contributes to outcomes for both parents and children.

**Methods for measuring family centred practice**

Given the linking of family centred practice with outcomes for both children and families, attention has turned to finding methods to assess the extent of family centred practice delivered to families in early childhood services. In its review of literature in this area, a range of existing methods and data collection instruments are documented by Scope (Appendix 1 of Scope, 2004). These are broadly divided into three areas of focus: 1) measuring the presence of key indicators of agency or service provider procedures as rated by the service provider; 2) measurement of key indicators of practitioner behaviour and approach, as measured by parents; 3) measurement of key indicators present in the development of individual family support plans (Scope, 2004). Of these, previous Scope research in ECI (Scope, 2004) has utilised the CanChild developed Measure of Processes of Care (MPOC) (King, Rosenbaum & King, 1995) which focuses attention on the second of these areas.
A key aspect of the MPOC aproach to measurement of family centred practice is the identification of five core domains within a family centred approach of ECI practitioners:

1. Enabling and partnership
2. Providing general information
3. Providing specific information
4. Co-ordinated and comprehensive care
5. Respectful and supportive care (King, Rosenbaum & King, 1995).

Each domain includes a number of question items that together provide a comprehensive exploration of the extent of practice in each domain. These items are collated into a survey format primarily targetted at parents. This survey tool has several different published forms including a 56 item as well as a 20 item survey. The MPOC instrument has been used widely in the evaluation of ECI services in a number of countries.

**Implications for this research**

This research focuses attention in a number of areas. Consistent with the discussion in the literature of the definition of family centred practice, this study has sought to explore the understandings of therapists in regard to this practice. It was felt that a comparison of ‘local’ understandings with the broader literature would provide a useful starting place for this research. In addition, this study focuses attention on parent rating of practitioner behaviour (i.e. levels and type of family centred practice). As discussed above, this is one of three trends in research in this area. To do this, this study follows the method of earlier Scope research (2004) and utilises the MPOC tool. Finally, this study also explores a second trend in research in family centred practice (identified above), relating to elements of the Family Service and Support Plan. The literature repeatedly reinforces the importance of parent involvement in the development of FSSPs, as well as the necessity of practitioner awareness of and engagement with
the FSSP. Both of these elements are explored in this research. In this way, this research adds to existing knowledge in key areas in relation to family centred practice and utilises an established method of data collection about it.
Chapter 10: The nature and extent of Family Centred Practice in Scope Southern ECIS

Introduction

As discussed in chapter 9, family centred practice is central to effective ECI service provision. This study identified the key research question in this area as: What is the extent of family centred practice in use within ECI services provided by Scope Southern Region? This question was comprised of the following sub elements:

- how therapists understand family centred practice,
- how parents rate the extent of family centred practice,
- the level of parent involvement in Family Service and Support Plan development,
- the extent of therapists’ familiarity with Family Service and Support Plans.

In particular, this chapter presents methods and results relating to the first two of these sub elements, exploring therapist understandings of family centred practice, and parent perceptions of the nature and the extent of this practice. The remaining two sub elements are discussed in chapter 11.

Research methods for collecting data about the understandings of and extent of family centred practice

This chapter describes the data collection methods in regards to two sub elements of the research question about family centred practice, i.e.:

- how therapists understand family centred practice,
• how parents rate the extent of family centred practice.

Therapist understandings of family centred practice were elicited through focus groups and interviews with therapists. In total, three focus groups comprising therapists were held (two in 2007 and one in 2008), as well as six individual interviews with therapists in 2007 and 2008. Interview data also provided information about the extent of family centred practice.

Parent rating of the extent of family centred practice was determined, in the main, via the Parent Survey. Chapter 5 describes the Parent Survey, which was developed as the major method of collecting data from parents between 2006 and 2008.

A fifty-nine (59) item survey was developed to be used at the end of each year, and aimed to collect data in relation to multiple research questions of this study. In relation to family centred practice, the survey included thirty-one (31) items asking parents to evaluate the level of family centred practice as part of their ECI service (based on the Measure of Processes of Care [MPOC] instrument, King, Rosenbaum & King, 1995).

As discussed in chapter 9, the MPOC was developed by CanChild to enable parents to rate the extent of family centred practice in ECI services (King, Rosenbaum & King, 1995). This tool had been used in earlier Scope research that evaluated the levels of family centred practice across Scope ECI services throughout six regions of Victoria (Scope, 2004). This research included a review of measurement methods for family centred practice, and endorsed the MPOC as relevant for use in Scope for a range of reasons. Given this review, and the existence of earlier data through the use of the MPOC in Scope, the current study also used the MPOC as a means of collecting data from parents receiving ECI services from Scope Southern Region between 2006 and 2008.

For this project, researchers developed a specially adapted version of the MPOC tool in order to reduce the number of items included in the survey, as a means of reducing burden on parent respondents. The adapted version was developed by:

1) identifying items from the MPOC-56 that were highly valued as a service element by respondents in the Scope (2004) research;
2) identifying items that received a low performance rating by respondents in the Scope (2004) research;

3) identifying items in each of the five domains of family centred practice identified by King et al (1995) that appeared to best reflect the quality elements aspired to by the Scope Southern Region ECI Service;

4) matching all of the above to determine priority items;

5) deleting items that appeared to echo or duplicate other items.

Researchers initially looked at the shortened MPOC-20 version to see if it matched well the items generated from above. It was felt that it omitted key areas that were needed to evaluate the Scope Southern Region service. As a result, researchers have developed a shortened version of MPOC-56, being a 31 item survey instrument containing items across all five domains of family centred practice. Item wording has been retained with the exception of small contextual changes to make the wording relevant to an Australian context of service delivery.

It is anticipated that this approach maintains confidence in the construct validity of items (as these have been rigorously tested elsewhere), as well as enabling comparisons with a wide set of existing data using these items (including the Scope, 2004 research).

As part of the Parent Survey, the MPOC 31 was sent to the majority of families who received services in each of the years of 2006, 2007 and 2008. Of these, twenty three (23) parents returned completed surveys in 2006, twenty six (26) in 2007, and nineteen (19) in 2008.

In addition, parents were offered the opportunity to be interviewed and to discuss elements of the service they received.

One other method of data collection, a Record Sheet - Manual Use, was utilised to supply further data relevant to two of the domains of family centred practice related to information provision. Therapists completed periodic Record Sheets detailing the resources used within the ‘One Day at a Time’ Manual, a
newly developed collection of resources. This data collection method is further detailed in Section 4 as it has greatest relevance to research about transdisciplinary practice.

Research methods for analysing data about the understandings of and extent of family centred practice

Data in relation to therapist understandings of family centred practice was collected via individual interviews and focus groups. Responses to the question on this topic were collated and analysis undertaken to identify key themes. Results are presented below.

Data in relation to parent perception of the extent of family centred practice was collected by survey and interviews with parents. Survey data was analysed by organizing survey items into the five domains of family centred practice. For each item, the frequency of parent rating was identified, as well as an average rating of items within each domain of practice. Highest and lowest ranking items were identified as a means of understanding those areas of practice where performance excelled and where improvement should be targeted. Results across years 2006 – 2008 were compared to establish whether trends were evident in relation to improvements in practice. Finally, data was compared with data available from previous Scope research (Scope, 2004). The Scope research in 2004 analysed results from fifty (50) parents accessing Scope ECI services (across Victoria) as at 1st January 2003. This comparison aimed to identify whether trends in regard to Southern ECIS were consistent with those of ECI services across all regions of Scope in 2003.

In addition, parent interview data was thematically analysed and where relevant, included in these results to further illuminate parent perceptions of family centred practice. Therapists too, as part of their interviews and focus groups, provided comments about the extent of family centred practice. These were thematically analysed and included where relevant.
Results

Therapists’ understandings of family centred practice

During interviews and focus groups, Scope therapists provided their own definitions of family centred practice. These are strongly consistent with those provided in the research literature. Therapists readily named the expertise of families as central to their understandings of family centred practice, and the importance of fostering the family’s capacity:

[The] family [is] constant in [the] child’s life - [they] want the best for them, know the child better than we do. They have strengths, and [we work to] to enable those strengths and help them know this can make a difference in their child’s life - to empower so they can question and decide when dealing with medical staff (Therapist 08).

In general, therapists repeatedly identified the importance of focusing on both the child’s needs and those of the family as a whole, as discussed in the family centred practice literature:

I would define it [i.e. family centred practice] as addressing the needs of the family as a whole and not just the child. And being driven by what they see as important at the time whilst at the same time offering information and support and advice when it’s sought (Therapist 08).

I think working with families to achieve the goals that are most important for them ... Sometimes that’s not even specifically about the child that’s the focus of our attention, but sometimes about other family issues. So it’s a matter of them setting the priorities and you working with them (Therapist 07).

This focus on responding to the priorities as set by the family is a key tenet of family centred practice discussed in the literature. Also consistent with literature on family centred practice, therapists identified the importance of building family capacity - not just through direct therapy to the child but also the provision of information and through supporting a wide range of family needs. One therapist addressed this in some detail:
I just see it as ... meeting the goals as a family whatever they want or whatever they may be ... that you’re achieving them and not your own agenda about your own specific wants and needs ... It’s what the family thinks is important. But in saying all that, I think you need to educate the family so they have enough information to be able to know what they want in the end. If you’ve got a child with disability you wouldn’t even know where to begin. You don’t know what to expect ... or what you’re allowed to ask for, or what you’re allowed to want. It’s a bit new to all of them. So I think as much as it’s about what the family wants and the family needs, and it is about meeting those goals and not your own - I think it’s also that you have to give them the information and education to be able to do that. Also it means it’s more about the child in the family as a whole - it’s not just about goals and about doing things just for that child. It might be about doing, like helping the sibling, or helping the mum and dad to something - whether it be the family needs a break and organizing respite. So it’s not just about that child and what that child will be able to do. It’s about the whole family operating (Therapist 07).

Overall, Scope therapists offered interpretations of family centred practice that were consistent with multiple elements discussed in the broader literature in this field, and evidenced strong commitment to the principles of this approach.

**Extent of family centred practice**

As part of the Parent Survey, parents in 2006, 2007 and 2008 rated the extent of family centred practice evident in the service they had received. Results are presented below (see also appendix viii). Each domain of family centred practice is discussed separately, then results compared across domains and years.

1) **Enabling and partnership**

Survey questions in this domain focused on the extent:
• parents felt like partners in their child’s care (along with the service providers);
• of opportunities to make decisions about services;
• of positive feedback and encouragement given to parents;
• of opportunities to identify important treatment goals;
• of details given about the services to be provided (such as reasons for them, type of therapies, length of time etc);
• of consultation about options for treatment and services;
• parents felt trusted by the service as the ‘expert’ on their child.

Overall, parents rated the process of service provision in this domain highly over all three years, with a steady improvement in most areas between 2006 and 2008 (see table 13).

Table 13: Extent to which service provider staff demonstrate identified work practices in the Enabling and Partnership domain of family centred practice (Percentage of parent ratings)

<table>
<thead>
<tr>
<th></th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=23)</td>
<td>78%</td>
<td>21%</td>
<td>1%</td>
</tr>
<tr>
<td>2007 (n=26)</td>
<td>92%</td>
<td>8%</td>
<td>1%</td>
</tr>
<tr>
<td>2008 (n=19)</td>
<td>94%</td>
<td>4%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Note: Percent = Average % of response, collating all seven survey items for this domain for each year of service delivery.

The survey item with the highest score in this domain was that of ‘makes you feel like a partner in your child’s care’. This item rated the highest for both 2007 and 2008, receiving an average rating across respondents of 6.6 in 2008 and 6.5 in 2007 out of a possible top score of 7. The items with the lowest rating were that of ‘provide opportunities to make decisions about services (average rating of 5.6 in 2008 and 6.0 in 2007) and ‘tell you about options for treatment or services for your child (e.g.
equipment, school, therapy)’ (average rating of 5.7 in 2008 and 5.9 in 2007). Both of these items showed a marginally lower level of parent satisfaction in 2008 than in 2007. While results are positive, these findings also suggest a need to ensure the service provider informs families about the service options available and empowers families in making decisions about services. This is important given the complexity of service provision and the myriad of decisions families have to make.

These scores are largely consistent with the results from Scope research (Scope, 2004) which found that parents similarly rated the item ‘makes you feel like a partner in your child’s care’ most highly in this domain (with an average rating of 6.2). Overall, in the 2004 study, 85% of parents rated the items in this category as being present ‘often’ or ‘to a great extent’, which is slightly lower than the level of parents in 2007 and 2008 in Southern ECIS.

During interviews, many parents commented on the strong relationships formed between therapists and families.

The interaction between the therapists and us has been really good - we've formed friendships I think. My child has been really able to respond to them. They do an amazing job - they really do (Parent 08).

Families commented on therapists being approachable and open to ongoing consultation with parents:

They have given their mobile phone number - so that means they are very approachable ... I guess it shows that they are happy to be contacted. And I’ve never really had to call them, but it's good to know you could (Parent 07).

Such comments resonate with the elements of the ‘enabling and partnership’ domain of family centred practice.

Therapists too provided additional explanation about family centred practice during interviews. As shown in the definitions of family centred practice provided by therapists, and discussed above, therapists demonstrated strong commitment to a partnership and enabling approach in their practice. One therapist observed:
I think that in our jobs there is the two [components]: the whole real discipline specific, knowledge, skills stuff, but there is this whole other area - like how you develop the relationship with the family, and how you support them. Like really vague stuff … and I think it’s hard to teach and hard stuff to figure out exactly what it is. But it’s that interesting type stuff that makes it interesting to think about the way you work (Therapist Focus Group 07).

However, not all comments by therapists positively evaluated Scope’s performance in this domain. Several therapists felt that the focus on providing services within the family home or natural environment of the child, had meant less options for families in regard to treatment and services. Such opportunity to make decisions about services is a key element of enabling and partnership. As one therapist describes:

If we’re truly talking about family-centred practice, there is no longer an opportunity for families to come and see us if they don’t want us to see them in their home or if they don’t want to pay travel … It’s also an invasion of their privacy. People have a right to their privacy if that’s important … We’ve had a number of families this year who would much prefer to have their therapy in a clinical situation (Therapist Focus Group 08).

This therapist suggests that home visits are not always preferred by families, but there is no longer opportunity to properly be directed by families and consult with them on such treatment options.

Philosophically DHS [Department of Human Services] is shifting more and more to the kind of program that we have here - which is the therapist going out to the family’s home. But this takes away the family’s right to choose. There is an assumption I think that home-based is what people want (Therapist Focus Group 08).

Another therapist reinforces this idea, recognising that a more family centred approach would offer a greater range of service choice, including group and centre-based activities.

I get so many families asking me about groups: that I want my child to go to a group and I want to meet other parents. And then half of my job is finding out what groups are available. And I don’t do it very well at all because I never know. We have a couple of groups
but they don’t suit everyone in terms of where they are located. I’ve been to one - out in Frankston. Talking really broadly as an ideal, I question our service delivery sometimes. I wonder if we need to have more of a focus on centre-based for those who want centre-based because not everyone wants you to come in to their house and have to clean up before the therapists get there (Therapist 08).

While it is not clear from the parent data, these comments may provide some explanation in regard to the lower rating of items in this domain relating to opportunities to decide about service options. According to the therapists above, service options are limited. These comments highlight the complexity of family centred practice around family-directed service options, and what this might mean in terms of resourcing a wider range of disability-specific and community based services.

2) Providing general information

Parent Survey questions in this domain focused on the extent to which parents felt:

- they received adequate information about the types of services offered by Scope or in the community;

- information was available in various forms, such as a booklet, kit, video, etc;

- the entire family were provided with opportunities to obtain information;

- they received adequate information about their child’s disability (e.g., its causes, how it progresses, future outlook).
Table 14: Extent to which the service provider staff demonstrate identified work practices in the Providing General Information domain of family centred practice (Percentage of parent ratings)

<table>
<thead>
<tr>
<th></th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=23)</td>
<td>38%</td>
<td>59%</td>
<td>3%</td>
</tr>
<tr>
<td>2007 (n=26)</td>
<td>63%</td>
<td>36%</td>
<td>2%</td>
</tr>
<tr>
<td>2008 (n=19)</td>
<td>74%</td>
<td>20%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Note: Percent = Average % of response, collating all four survey items for this domain for each year of service delivery.

Overall, there appears to be consistent improvement of service delivery in this domain between 2006 and 2008, with 74% of respondents in 2008 reporting that staff frequently worked to provide general information to them (see table 14). These scores are mostly higher than those reported by parents in the Scope research in 2004. In that study, 54% of parents rated these elements of family centred practice as being present ‘often’ or ‘to a great extent’, which is higher than the level of parents in the Southern Region in 2006, but significantly lower than those in 2007 and 2008. Overall, Scope Southern Region ECI service has performed better in this domain than the combined ECI services of Scope in the 2004 study.

In this current study, the item that respondents scored most highly was that of providing information about the types of services offered by Scope or in the community (receiving an average rating of 6.2 out of 7 in 2008 and 5.2 in 2007). This was commented on by one parent during interview:

"Every six months they do a family service review so [the therapist] will come out and discuss where we need to go and what to do next in my opinion and possibly in their opinion as well, which is really helpful. They send out newsletters which is good. They are quite good at letting us know what is around. And they have their website too which is good (Parent 08)."

This was also rated the highest item by parents in the 2004 study, with an average rating of 4.9 out of 7, a somewhat lower rating overall than Southern Region 2006 - 2008.
In the current study, the item that rated the lowest in this domain was that of providing information about the child’s disability (e.g., its causes, how it progresses, future outlook). This item rated poorly with an average score of 4.6 out of 7 in 2008 and 4.4 in 2007. This item was also rated the lowest in the Scope 2004 study (with an average rating of 3.8 out of 7).

Analysis of data in relation to therapists’ use of the resource manual, *One Day at a Time*, provides additional insight into service delivery in this domain of family centred practice. Of the thirteen topics within the resource manual, twelve (92%) relate to general information provision such as information about developmental stages, local government and community services, and activity sheets. Of these, the most frequently used item by therapists is the developmental activity sheets (often handed to parents) accounting for 43% of manual use, along with information about local government and community resources (21% of manual use). In addition, no therapist recorded use of diagnostic specific information during the period of data collection around manual use. Such usage results appear broadly consistent with the highest and lowest rated items by parents. For example, manual use suggests no use of diagnostic information, and parents rate poorly therapist provision of information about the child’s disability. Beyond this, it is not clear the extent to which the introduction of the manual in 2007 accounted for the improvement in parent ratings in this domain between 2006 and 2008, though a causal link may be possible. The resource manual is discussed further in Section 4 in relation to transdisciplinary practice.

Research literature in ECIS highlights the importance of the provision of general information to families. Two research studies conducted in 1990 (Able-Boone et al 1990; & Summers et al 1990 cited in Moore and Larkin, 2005:27) identified that parents with children in ECI services highly prioritised the importance of receiving information as part of the service, particularly information about their child’s needs and available community resources. A third study conducted in 1997, confirmed these findings, adding that parents also wanted information about the complex interrelationships of programs and service organisations (Wesley et al 1997 cited in Moore and Larkin, 2005: 35). Additionally, Summers et al (1990 cited in Moore and Larkin, 2005) found that parents wanted information to be made available in different formats and offered at different times, given that families’ ability to absorb information is variable depending on their personal contexts. Moore and Larkin (2005) comment:
The literature shows that families want accurate information that is shared in a complete and unbiased manner but leaves them with some sense of hope for the future ... If service providers are to improve their practices in relation to providing general information to families, strong links and partnerships with key specialist and universal child and family services need to be in place (2005:56).

While the findings from Parent Surveys suggests that improvements could be made in relation to this domain of family centred practice, this is not to undermine the positive achievements noted by parents in this domain. As one parent summed up in interview:

... she’s the one they call the family service and support provider. She’s brilliant. Anything she doesn’t know is not worth knowing. If there’s anything we need to know she will find out and tell us - she’s really good that way (Parent 08).

3) Providing specific information

Survey questions in this domain focused on the extent to which parents felt the service:

- provided them with written information about their child’s progress;
- told them about the results from assessments;
- notified them about the reasons for upcoming case conferences, meetings, etc., about their child.
Table 15: Extent to which the service provider staff demonstrate identified work practices in the Providing Specific Information domain of family centred practice (Percentage of parent ratings)

<table>
<thead>
<tr>
<th>Year</th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006  (n=23)</td>
<td>60%</td>
<td>28%</td>
<td>12%</td>
</tr>
<tr>
<td>2007  (n=26)</td>
<td>78%</td>
<td>14%</td>
<td>8%</td>
</tr>
<tr>
<td>2008  (n=19)</td>
<td>82%</td>
<td>11%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Note: Percent = Average % of response, collating all three survey items for this domain for each year of service delivery.

As with the other domains, this domain showed consistently improving responses from parents between 2006 and 2008 with 82% of parents reporting the service frequently provided specific information to them about their child’s progress (see table 15). This represents an improvement of 22% since 2006. This result for 2008 is slightly higher than that achieved in the Scope 2004 research, where 81% of parents felt these elements were present often or to a great extent. However, notably, both 2006 and 2007 scores fall below the Scope 2004 study result. Despite this comparison, the Southern data shows a significant improvement of service delivery in this area over the period of the study.

The item rating the highest in this domain was that of providing parents with written information about their child’s progress (receiving an average rating of 5.9 out of 7 in 2008 and 6.1 in 2007). The lowest rating item was that of notifying parents about the reasons for upcoming case conferences, meetings, etc., about their child (with an average rating of 5.7 in 2008 and 4.6 in 2007). This was also rated the lowest of these items in the Scope 2004 study (with a rating of 5.1).

During interviews, parents provided several examples of the provision of specific information. One parent explained how this was particularly important as a mechanism to ensure both parents benefitted from the skills and information delivered as part of ECI services:

I’ve found each week that they [i.e. therapists] write a report based on the week’s sessions, and maybe points to look at for next time which I find really good because obviously my husband and I are trying to help our son jointly and he [husband] is never
here for the session. So it’s always good for him at the end of the day - I leave it out for him in a folder so at the end of the day he can read the points that were spoken about and then talk to me about them ... so that’s really good (Parent 07).

Another parent emphasized the importance of written guidance for parents who commenced with little prior experience of parenting or children with disabilities:

Each time they [the therapists] had therapy with them [the children], they wrote down what they did and what we were supposed to do at home. That was fantastic! First child, first time for everything and we had no idea. We had never been into the disability side of things (Parent 07).

Finally, the data from the reporting of manual use adds some further insight to practices in this domain. This data identifies that though only one category of the resource manual pertains to the provision of specific information about service delivery to the family and child, this is an area well used by therapists. Use of resources about the Family Service and Support Plan accounts for 14% of all reported manual use in 2007 and 2008.

4) **Coordinated and comprehensive care for the family and child**

This domain represents the largest set of items in the MPOC 31 with fourteen questions relating to service provision with the following characteristics of family centred practice:

- looking at the needs of the ‘whole’ child (e.g. mental, emotional, and social needs) instead of just physical needs;

- making sure that the child’s skills are known to all persons working with the child, so the skills are carried across services and service providers;

- giving parents information about their child that is consistent from person to person;

- planning together so staff are all working in the same direction;
• recognizing the demands of caring for a child with special needs;

• developing both short-term and long-term goals for the child;

• taking the time to establish rapport with parents/family or the child when changes occur in services;

• showing sensitivity to the family’s feelings about having a child with special needs (e.g. their worries about their child’s health or function);

• making sure that at least one team member is someone who works with parents and the family over a long period of time;

• making themselves available to parents as a resource (e.g. emotional support, advocacy, information);

• suggesting therapy plans that fit with the family’s needs and lifestyle;

• providing ideas to help parents/families work with the health care ‘system’;

• following up at the next appointment on any concerns parents discussed at the previous one;

• seeming aware of the child’s changing needs as he/she grows.

Table 16: Extent to which the service provider staff demonstrate identified work practices in the Coordinated and Comprehensive Care for Family and Child domain of family centred practice (Percentage of parent ratings)

<table>
<thead>
<tr>
<th></th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006  (n= 23)</td>
<td>78%</td>
<td>20%</td>
<td>2%</td>
</tr>
<tr>
<td>2007  (n=26)</td>
<td>89%</td>
<td>10%</td>
<td>1%</td>
</tr>
<tr>
<td>2008  (n=19)</td>
<td>95%</td>
<td>4%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Note: Percent = Average % of response, collating all fourteen survey items for this domain for each year of service delivery.
As with the other domains, this domain of family centred practice also shows consistent improvement in parent ratings (almost 20% improvement) between 2006 and 2008. Parents in 2008 rated this element of family centred practice extremely highly, with 95% identifying it as a feature of practice that occurred often or to a great extent. This is a significantly higher rating than that provided by parents in the Scope 2004 study, where 84% rated these elements as occurring often or to a great extent in the service.

Particularly high rating items in both 2007 and 2008 were:

- making sure that at least one team member is someone who works with you and your family over a long period of time (average rating of 6.5 in 2007 and 6.6 of 7 in 2008);

- following up at the next appointment on any concerns you discussed at the previous one, with an average rating of 6.4 in 2007 and 6.6 of 7 in 2008. This item was ranked the highest in the Scope 2004 study also with a rating of 6.0;

- seeming aware of your child’s changing needs as he/she grows (average rating of 6.3 in 2007 and 6.6 of 7 in 2008); and

- recognizing the demands of caring for a child with special needs (average rating of 6.2 in 2007 and 6.6 of 7 in 2008).

During interviews, parents also commented on other elements of co-ordinated and comprehensive care. One parent praised the therapist’s focus on the ‘whole child’, not just the child’s physical needs:

the OT will even look at others things - not just physical things - a whole gamut of things
(Parent 07).

The same parent also commented on the commitment to goal focused practice and found this to be very useful. The parent noted that the therapy work also was sensitive to the needs of other siblings and able to involve them in activities:

They [the therapists] also seem to write a goal - like each 6 months or whatever they’ll say ‘this is where we want to get’. So that keeps you on track on what areas you need to work.
So, not many criticisms ... Yeah, they are really good and they are patient too with my other daughter because she wants to be involved (Parent 07).

Overall, parents repeatedly commented on therapists’ commitment to providing quality practice to best meet the needs of the child, often going beyond what was perceived to be the basic requirements of service:

The therapy itself is great - they don’t seem to be in a hurry. I think it’s approximately an hour that we are suppose to have, but you know sometimes they will be here an hour and a half ... two hours (Parent 07).

Despite this significant overall improvement on items between 2006 and 2008, a significant decrease in parent ranking is evident on the item rating the extent to which staff make sure that the child’s skills are known to all persons working with the child, so the skills are carried across services and service providers. This item received an average rating of 6.3 out of a possible 7 in 2007, but only an average rating of 4.8 in 2008, making this the lowest ranked item in this year. It is not clear from the data whether parents were critical of the level of co-ordination and information sharing between Scope therapists, or between Scope and other agencies working with the child. Notwithstanding this result, one parent in a 2007 interview provided positive comments on the level of co-ordinated care between Scope therapists:

They really seem that they are team working rather than individual therapy. We have been really pleased ... and his all round improvement has been out of this world (Parent 07).

The second lowest rated item was that of staff providing ideas to help parents work with the health care system. This item received an average rating of 5.8 in 2008 and 5.6 in 2007. This was the lowest ranked item in the Scope 2004 study with an average rating of 5.3 out of 7.

Despite these items on which lower parent ratings were given, this domain of family centred practice was rated very highly overall.
5) Respectful and supportive care

Survey questions in this domain focused on the extent to which parents felt the service:

- treated them as an individual rather than as a ‘typical’ parent of a child with a disability;
- provided a caring atmosphere rather than just giving information;
- remembered personal details about their child or family when speaking with parents.

Table 17: Extent to which the service provider staff demonstrate identified work practices in the Respectful and Supportive Care domain of family centred practice (Percentage of parent ratings)

<table>
<thead>
<tr>
<th></th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=23)</td>
<td>91%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>2007 (n=26)</td>
<td>88%</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>2008 (n=19)</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Note: Percent = Average % of response, collating all three survey items for this domain for each year of service delivery.

As with the other domains, this domain shows overall improvement in parent ratings between 2006 and 2008, though with the lowest ratings occurring in 2007 (see table 17). All parents (100%) responding to surveys in 2008 (i.e. 19) rated the service as often or to a great extent delivering on elements of respectful and supportive care. This is higher than the 90% of parents who rated these elements as occurring often or to a great extent in the Scope 2004 study.

All three items in this domain received high average ratings of between 6.2 and 6.7 of a possible rating of 7 in both 2007 and 2008. This is broadly consistent with the Scope 2004 study that also found that all three items received high average ratings between 6.1 and 6.3. The highest ranking item in 2008 was that which related to treating parents as an individual rather than as a ‘typical’ parent of a child with a disability (with an average rating of 6.7).
In interviews, parents commented on each of these elements of family centred practice. In relation to providing a caring atmosphere, three parents explained that this approach encompassed both care for the child as well as the family:

We found the people [therapists] have all been very caring people … but not only just for the child but even for my welfare, which, I was of course, more interested in the child. You certainly don’t feel like you’re on your own. They obviously are getting paid, but you do feel like they care (Parent 07).

They [therapists] were great in support and so forth … Just the added assistance to support the family network … to me they’ve gone above and beyond. Like I rang them of a night-time on a mobile phone that ended up being a personal mobile and they spoke to me for ages just trying to calm me down and sort myself out. It’s support through and through. It’s not just supporting the child - it’s supporting the network - and the family as well to support the child (Parent 07).

This level of support extended into broader family support for parents, as one parent comments below. This type of support was particularly helpful because of the therapist’s relationship with the child and their ability to effectively communicate with and support the child as well as the parent:

Again with [therapist] - she is really good to talk to. She’s one of those people that knows how to just stand there and listen. And she doesn’t make a judgement one way or the other. She’s good for when I need to blow off steam (laughs). She’s always there to offer advice or someone else to talk to if she feels it’s warranted. They’ve all been very supportive. Just for example, when [child’s] dad and I split up, [therapist] was like ‘Well if you need to talk to someone there is someone you can talk to, and there’s someone that can come and talk to [child] who [child] can understand. And if you need money to move out, there’s this and this available, and there is respite if you need it, and home help if you need it … Whatever you need, we can do it’. So they are very supportive - I was really surprised at how much support there is out there for kids with disabilities (Parent 08).
Comparing sub domains of family centred practice

As discussed in the section describing methods of data analysis, results were compared to identify averaged ratings for each domain in each year. This was done as a means of identifying the domains in which performance is rated lower as it was felt these could then be targeted in future service improvement strategies in order to improve practice.

For the purpose of this analysis, attention is focused on the most recent year of data collection, 2008.

In 2008, parents reported a high level of service delivery across all five domains of family centred practice (see table 18). The domain receiving the greatest number of parent positive responses was that of ‘Respectful and supportive care’ (100% of parents), followed by the domain of ‘Co-ordinated and comprehensive care’. The lowest ranked domains were the two information provision domains, with that of ‘Providing general information’ falling more than 25% below that of the top performing domain and receiving only 74% of parents reporting positive service delivery in this area.

Table 18: 2008 Percentage of parent ratings comparing performance across domains, organised by ranking

<table>
<thead>
<tr>
<th>Family centred practice domains</th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respectful and supportive care</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Co-ordinated and comprehensive care</td>
<td>95%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Enabling and partnership</td>
<td>94%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Providing specific information</td>
<td>82%</td>
<td>11%</td>
<td>7%</td>
</tr>
<tr>
<td>Providing general information</td>
<td>74%</td>
<td>20%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Lower results in the two information provision domains are consistent with evaluations of other services discussed in the literature. A 1998 study of 436 parents receiving ECI services for children with disabilities in one region of Canada found that, across services, the lowest rated domains of family centred practice were the two information provision domains (King et al, 1998 cited in Moore and Larkin, 2005:4). This was also the result for the Scope 2004 study. This suggests that these domains remain important areas to focus practice improvement on for all ECI services.
Some of these trends were also present in 2007 (see table 19) and 2006 (see table 20), particularly in relation to the lowest performing domains relating to the provision of information, in particular general information. It should be noted though, that performance improved between 2007 and 2008 in all five domains, and that the lowest ranked domains improved markedly between 2006 and 2008 (with an increase of around 20% of parents rating service delivery in these areas more positively between 2006 and 2008).

Table 19: 2007 Percentage of parent ratings comparing performance across domains, organised by ranking

<table>
<thead>
<tr>
<th>Family centred practice domains</th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling and partnership</td>
<td>92%</td>
<td>8%</td>
<td>1%</td>
</tr>
<tr>
<td>Co-ordinated and comprehensive care</td>
<td>89%</td>
<td>10%</td>
<td>1%</td>
</tr>
<tr>
<td>Respectful and supportive care</td>
<td>88%</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>Providing specific information</td>
<td>78%</td>
<td>14%</td>
<td>8%</td>
</tr>
<tr>
<td>Providing general information</td>
<td>63%</td>
<td>36%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Table 20: 2006 Percentage of parent ratings comparing performance across domains, organised by ranking

<table>
<thead>
<tr>
<th>Family centred practice domains</th>
<th>Often/great extent</th>
<th>Sometimes-never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respectful and supportive care</td>
<td>91%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Enabling and partnership</td>
<td>78%</td>
<td>21%</td>
<td>1%</td>
</tr>
<tr>
<td>Co-ordinated and comprehensive care</td>
<td>78%</td>
<td>20%</td>
<td>2%</td>
</tr>
<tr>
<td>Providing specific information</td>
<td>60%</td>
<td>28%</td>
<td>12%</td>
</tr>
<tr>
<td>Providing general information</td>
<td>38%</td>
<td>59%</td>
<td>3%</td>
</tr>
</tbody>
</table>

It is interesting to note the dominance of the domain ‘respectful and supportive care’ across two of the three years as the highest rated domain of family centred practice in the Southern ECIS. This was also rated as the top ranked domain in the Scope 2004 study. Previous research has identified a link between
this domain and parent satisfaction with ECI services. As discussed in Moore and Larkin (2005), a study of 645 parents of children with special needs by King, Cathers, King and Rosenbaum (2001) explored the major features of care associated with satisfaction and dissatisfaction with services, and found the domain of respectful and supportive care (i.e., feeling listened to and having a sense of rapport with service providers) the most commonly discussed by parents, whether satisfied or dissatisfied.

**Conclusion**

This chapter has explored therapist understandings of family centred practice and the extent to which parents feel it is delivered as part of the Southern ECI service. Therapist understandings of family centred practice align strongly with those expressed in the literature, and therapists evidence strong commitment to these principles of practice. Overall, parents perceive a high level of family centred practice delivered as part of the service. Areas of family centred practice that could be most targeted for improved service delivery are those relating to specific and general information provision to families.
Chapter 11: The use of Family Service and Support Plans

Introduction

Chapter 10 dealt with the first two sub elements of the overall research question: What is the extent of family centred practice in use within ECI services provided by Scope Southern Region? This chapter deals with the last two sub elements of this question, namely:

- the level of parent involvement in Family Service and Support Plan development,
- the extent of therapists’ familiarity with Family Service and Support Plans.

The focus of inquiry for this chapter is on the use of Family Service and Support Plans as these are identified in literature as central elements of a family centred approach. As discussed in chapter 4, Family Service and Support Plans are an integral part of the ECI service provided by Scope and are completed by therapists and families together in consultation, with an emphasis on the empowerment of the family to establish goals both for the child and the family. The plan is a central tool in documenting and guiding the intervention process, with the family members and service personnel working as a team to plan and implement the service tailored to the family’s concerns and needs. In this way, both the process of development and the plan itself reflect key tenets of family centred practice.

Family involvement in the development of service plans, goal setting and service direction is a key element of family centred practice, though it is also recognised that families should be able to choose their level and type of involvement (McGonigal et al, 1994). In this context, this research sought to explore the extent to which families felt they were involved in the development of FSSPs.

Additionally, family centred practice principles identify that it is important that FSSPs are known to all therapists and those involved in the treatment of the child. Harrison (2007a) notes that while intentions may be good, often plans are never consulted or reviewed after being completed and filed away. The risk is that plans are completed as required by governments but that the task does not appear as relevant to the service provision for the family. However, when plans are regarded as an opportunity to
have the family drive the process rather than being viewed as red tape, they can be a tool that assists family empowerment and the achievement of goals. As Harrison states: ‘The creation of a living, working Individual Family Service Plan provides the mechanism to further family centred practice, review progress with families and collect valuable data on outcomes as assessed by the families’ (Harrison, 2007a: 76). For these reasons, therapists need to be familiar with FSSPs as well as actively use them in their practice. In this context, this study also sought to identify the use of and familiarity with FSSPs by therapists at Scope. These results are reported later in this chapter.

**Research methods for collecting data about engagement with Family Service and Support Plans as an element of family centred practice**

This chapter describes the data collection methods in regards to the above two sub elements of the research question.

The level of parent involvement in the development of FSSPs was determined through the annual Parent Survey. As discussed previously, surveys in 2007 and 2008 included a range of items addressing different research questions, including one item identifying the level of parental involvement in goal setting and FSSP development. Parents were asked: ‘To what extent did you feel you directed the selecting and setting of goals in the Family Service and Support Plan?’ They were offered a three choice response: to a great extent; to some extent; not at all. A majority of parents receiving services in 2007 and 2008 were sent Parent Surveys at the end of each year with twenty six (26) in 2007, and nineteen (19) in 2008 returning completed surveys\(^5\).

Therapist use of and familiarity with the FSSPs of families in their case load was assessed via the Therapist Survey. This survey is discussed in detail in Section 4, given it largely pertains to the collection of data about transdisciplinary practice. The survey comprised eighteen items, including one item regarding therapists’ level of acquaintance with client FSSPs. Therapists were asked to identify ‘To what extent are you acquainted with the FSSP of the clients in your client case load?’ and offered a choice of

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\(^5\) As discussed previously, Parent Surveys in 2006 only included MPOC items and did not include additional items exploring other research questions.
four responses: have no knowledge of most FSSPs; have limited knowledge of most FSSPs; have good knowledge of most FSSPs; have indepth knowledge of most FSSPs. The survey was administered once annually in 2006, 2007 and 2008 to all therapists. It was completed by eleven (11) therapists in 2006, nine (9) in 2007, and four (4) therapists in 2008.

In addition, parents and therapists participated in interviews and focus groups in 2007 and 2008. Data from these events that relates to this topic is included below.

**Research methods for analysing data about engagement with Family Service and Support Plans as an element of family centred practice**

Data in relation to both questions collected through parent and therapist surveys was collated for each year group, and frequency of each response type calculated. Comparisons are made across each year cohort to identify trends and changes, if any.

This quantitative data is supplemented by interview excerpts that relate to these two sub elements of the research question. In thematising interviews from parents and therapists, relevant extracts were identified and included in the results below.

**Results**

**Parent involvement in FSSPs**

As discussed above, as part of Parent Surveys, parents in 2007 and 2008 were asked to rate the extent to which they were involved in the goal setting process within the Family Service and Support Plans.

In 2008, 93% reported they were involved to a ‘great extent’, with a further 7% identifying they were involved to ‘some extent’. This represents an increased involvement from 2007, where 78% of families reported they were involved to a ‘great extent’ and 22% reported they were involved to ‘some extent’.
Interviews with therapists indicated that the constructing of a FSSP and the setting of goals was more or less a joint process negotiated between therapists and families.

So sometimes I make suggestions as to how I think that I could help and give them [parents] the option of choosing. Some parents are more assertive than others. Some might say ‘that’s not going to work for me, but could you do something else?’ - then it’s a negotiation process. So I guess it is guided by my suggestions, but it’s very much a negotiated thing (Therapist 07).

It really varies. Some parents will say, ‘I don’t know - you just tell me. I don’t know what I need to do’. Or there are a few scenarios: there’s one where they’ll say: ‘I don’t know – you just tell me’. Or there’s another one where they’ll say: ‘You’re the physio and I want physio, and you’re the speech and I want speech, and you’re OT so I want OT’. They don’t know, have an idea what that meant - they just want those three therapies. Another scenario is that they get a bit more specific - but really specific to the therapy. They’ll go: ‘well you’re the speech therapist so I want her to be able to eat solid food’. I find very few families talk about the family. It’s all just about the child … [for example] ‘I want him/her to go to kinder and child care centre’ (Therapist 07).

One therapist suggested that the process of developing a FSSP was easier for some families than it was for others, and that education levels and socio-economic status may account for why some families are more comfortable with the process than others.

And so that’s all about getting a good relationship with them, and understanding who they are, and how they operate … what sort of family they are. And even what kind of understanding they have and their level of … without being a bit discriminating … their level of education. I’ve got families who their mum’s barely finished year 9 or year 10. They come from really dysfunctional families. There has been drugs and all kinds of bad stuff involved, and that’s really different to very highly educated parents with really good jobs, and disposable income and all that sort of thing. So it’s really getting to understand … and that’s the relationship and that sort of stuff … that families understand what I need, because
they’re the ones that make the difference, at the end of the day. You just guide them into making the right decision or making choices that they want (Therapist 07).

While families may desire differing kinds of involvement in FSSP development, overall the vast majority of parents felt they were involved to a high degree.

**Therapist familiarity with FSSPs of clients in case load**

During the annual Therapist Survey between 2006 and 2008, therapists were asked to rate the extent of their acquaintance with the Family Service and Support Plans of the clients in their case loads. On average across this period, 13% reported an ‘indepth knowledge’ and a further 59% reported a ‘good knowledge’ of FSSPs (see table 21). This suggests that almost three quarters of therapists had a strong knowledge of the FSSPs of their clients. By contrast, an average of 25% reported a ‘limited knowledge’, and 3% reported ‘no knowledge’ of their clients’ FSSPs.

Familiarity with FSSPs decreased in 2008 with no therapists identifying as having an ‘indepth knowledge’ (compared with 22% in 2007).

**Table 21: Extent of therapists’ acquaintance with FSSPs of clients in case load**

<table>
<thead>
<tr>
<th></th>
<th>Indepth knowledge</th>
<th>Good knowledge</th>
<th>Limited knowledge</th>
<th>No knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2006 (n=11)</strong></td>
<td>18%</td>
<td>45%</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td><strong>2007 (n=9)</strong></td>
<td>22%</td>
<td>56%</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td><strong>2008 (n=4)</strong></td>
<td>22%</td>
<td>75%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td>13%</td>
<td>59%</td>
<td>25%</td>
<td>3%</td>
</tr>
</tbody>
</table>

This set of data suggests that around one quarter of therapists have only a limited knowledge of their clients’ FSSPs, and that levels of indepth knowledge appear to be decreasing. On the surface, this
appears to be a concerning result. Yet lack of knowledge with the specific detail of a FSSP does not necessarily indicate a lack of knowledge about the family and child.

Therapist interviews offer further comment on therapist engagement with FSSPs. The following comments not only reflect therapist familiarity with FSSPs but also offer therapist reflection on the use of and value of FSSPs. Overall, there is a sense that the plans are a useful tool to guide intervention for therapists and as a reminder for families about what it is they wish to achieve. However, therapists also recognise a range of limitations - that the complexity of an intervention cannot be captured in a document and that there are a whole range of ever-changing contingencies which effectively reduces a FSSP to an ideal or a guide. The ambiguity therapists expressed over FSSPs is reflected in the following extracts from a therapist focus group:

I think they [FSSPs] are valid and valuable but impossibly can’t record everything. They miss out on the rich detail and there are issues of confidentiality. And a lot of it’s contextual and that can’t be captured. It might be knowing how the mother works and copes as a parent and this guides my thinking in how I approach her. And that’s not something you can write on paper, nor would I want her to see it. Nor is it the sort of information you would want to pass on to someone else (Therapist Focus Group 08).

The thing for me about the Family Service and Support Plan is when we do one and I read it later, I think ‘oh yeah, that’s good and that’s good’, but there’s something about it not being the thing that drives what we’re doing. We do the plan because we have to and not because it really actually works ... You set the goals but in the day to day reality you find that you are dealing with things that are in the moment and not necessarily related to the goals and so you might rarely get a chance to go back to the Family Service and Support Plans ... I should do a plan for every one of my clients - but I haven’t - and I won’t (Therapist Focus Group 08).

It’s also a question of whether it’s a family tool or therapist tool. I think it’s a family tool that can be used to draw them back on track and remind them of what it is they want to achieve - to remind them of what was important to them. And sometimes families will do that of their own accord - so they will go back to it and discuss the things they wanted to achieve like their child to walk or talk ... I try to bring back into conversation the goals that we
originally set and remind them that this is what you said you wanted to achieve. So the goal might be to feel pleasure around other children and I will remind the parent that this was an important thing they wanted to work towards - so having it written down I just bring it up in conversation. So it is a matter of how you write it and use it as a tool - otherwise, it could just sit in his file until time to review (Therapist Focus Group 08).

While this last comment from a therapist outlined the FSSP as a valuable resource for families, the therapist also noted there could also be family rejection of plans and goal setting:

I worked with a mother last week and she thinks setting goals is a load of nonsense. She’s a nurse and thinks it’s [goal setting and plans] all overkill (Therapist Focus Group 08).

A number of therapists indicated that their use of plans was limited. They cited a range of reasons for this including: the complexity of plans (not being user-friendly); that they were more paper-work for families; or the lack of therapists’ time to look at them. Three therapist’s comments are reported below:

We probably don’t sit down and formally review them as often as would be a good idea, but that’s just something that I haven’t done before. I’m new to this sector and getting into that … when you are into the swing of all the things that are happening and funding for kinder - it’s a huge year. And one of the things that I find is there is a lot of paper work for families and sometimes you sort of think, ‘I’ll just note these things down as goals and at some point we will put them together as a formal plan’. And - yeah - it would be better if it happened sooner rather than later. I think it would be great if it was little bit more user-friendly … I know it’s being updated all the time … Maybe it’s just not user-friendly for me yet because it’s a new thing for me. But I do think it’s useful and I do refer to that with families all the time (Therapist 07).

A lot of the therapists will photocopy and put it in the other therapists’ pigeon-holes. But even the time of getting that is not really great. Sometimes emails, sometimes you run into each other, or sometimes you will call and you try really hard. I’ve got to the point where … if it’s stuff where I’m like ‘it won’t make a difference in what they are doing’, I just don’t bother too much (Therapist 07).
You set all these goals but I’m personally bad at following up on them - physically taking the plan out and looking at them and going ‘Okay, we were talking about doing that and I should be working on that’. But I think that’s just me ... I don’t know - maybe it’s not. I think it’s a weakness of mine ... I tend to keep the goals or rough objectives in my head so I don’t refer to the plans as I should (Therapist 08).

In a focus group, therapists noted the dynamic and changing nature of child and family needs, and how this aspect of service was not captured in the FSSP and hence reduced use of the document:

‘Things change so much and you have to deal with things happening for the family and child at that moment, so you aren’t always going back to the plan (Therapist Focus Group 08).

Significantly one therapist noted that much of the work provided by therapists was of a personal nature in their interaction with families and that sensitivity towards certain material meant that it couldn’t be recorded. This was also an issue when it came to evaluating outcomes from plans - that much of what the therapist did and achieved for the family sat outside the measurement of a plan.

Last week I had a mum come here standing at the front door crying, comatose and in tears, had nearly taken all her pills the night before, not knowing where to go. ‘I don’t know where to go’. So for that family for her to know to come here and know that we’d be here and it’s ok, to be able to talk and know where to go from here - that’s successful. But that’s not written on her Family Service and Support Plan. But that’s a positive outcome for she’s now linked into appropriate support and counselling. She’s feeling better about things. You can’t measure that. And it’s not written on the Family Service Plan ... Some of those things you can’t write down. You can’t write on their plan ‘attempted to commit suicide - things are great now’. The quality of our work in terms of being a part of the inner circle of support that they can draw on is really powerful. Really powerful (Therapist 08).

Overall, survey data shows that most therapists evidence a good working knowledge of the FSSPs in the case load. In addition, their comments reveal a knowledge of the family and child well beyond the document itself, and a nuanced understanding of the value and limitations of FSSPs in their practice.
Conclusion

This chapter sought to report on the level of parent involvement in Family Service and Support Plan development, and the extent of therapists’ familiarity with Family Service and Support Plans. In terms of evaluating the extent of family centred practice in an ECI service, it assumed that high levels of family involvement in and therapist knowledge of FSSPs is consistent with the principles of family centred practice. Overall, the data provided evidence of a high level of parent involvement in FSSP development and of therapist familiarity with them.

However, the data set also reveals how complex it is to use indicators such as familiarity with and use of Family Service and Support Plans as measurements of family centred practice. Therapist comments tell a more complex story than does survey data in this instance. Even when discussing the limitations of plans, or their limited use of them, therapists reveal a detailed and thorough knowledge of families and their needs. They consistently report a deep connection with families and a sensitivity to very complex family circumstances. These comments all evidence key elements of family centred practice. Finally, therapists report on the tension between documentation (such as FSSPs) and the private needs and achievements of families. This tension is unlikely to be resolved but is perhaps a constant element of sensitive and competent family centred practice. This suggests that it is the kind of knowledge practitioners hold about families and their children, rather than familiarity with a planning document, that is the more meaningful indicator of family centred practice in this instance.
Section 4:  
The Process of Service Delivery:  
Transdisciplinary Practice
Chapter 12: Transdisciplinary practice - exploring the literature

This research has a major focus on the emerging approach of transdisciplinary practice within early childhood intervention and the Scope Southern ECI Service. As discussed in chapter 1, the Scope Southern ECI service was moving to foster a more transdisciplinary approach to therapy practice. This is broadly in accordance with the Victorian Government guidelines (cited in chapter 1), The Early Childhood Intervention Services (ECIS) Program Framework (Early Years Services Branch, DHS, 2005). As part of this, Scope was implementing a range of strategies to support this development. Hence, the necessity of and interest in exploring elements of transdisciplinary practice.

An initial task in this aspect of the research study, is to more clearly define the practice. The following is a summary of a number of texts relevant to the defining and understanding of transdisciplinary practice. It is not exhaustive but rather a means of establishing a context for evaluating practice within the Scope Southern ECI Service. Exploring the complex variety of factors that make up transdisciplinary practice - factors upon which there is no definitive agreement - suggests that transdisciplinary practice is an *ideal* model and that a range of factors will impact the implementation and practice of this model. This suggests caution in measuring a service against a fixed model that does not take into account the context in which it is being implemented.

**Defining transdisciplinary practice**

What constitutes transdisciplinary practice is somewhat contested, though the general consensus is that transdisciplinary practice is governed by professionals undertaking therapy tasks outside of their own discipline. The transdisciplinary approach was originally conceived as a framework for professionals to share important information and skills with primary caregivers – in this sense it has affinities with family centred practice with its emphasis on collaboration and empowerment. The origins of this practice can be located to the 1970s when the United Cerebral Palsy Association in America developed a model that sought to better address the needs of families who had children with complex high needs. It was also
regarded as a model that was deemed to provide understaffed and underfunded services with a way of sharing knowledge and skills to provide a better and more ‘cost effective’ service, enabling more children to be assisted (Davies, 2007, McGonigel et al, 1994).

McGonigel et al state that the transdisciplinary approach is a recommended practice for offering family-centred, coordinated, and comprehensive service to infants and their families (1994: 95). Carpenter claims that a transdisciplinary model of intervention is ‘more ‘in tune’ with the family life pattern; more naturalistic and responsive to the child’s context’ (2005: 180). According to Davies, an Australian ECIS manager, what she terms ‘transdisciplinary team practice’ provides an integrated and coordinated service for the child and their family (2007: 43). Davies emphasises that this approach requires team members to ‘teach, learn and work together across disciplinary boundaries’ (Davies, 2007: 42). Similarly, Bruber defines transdisciplinary practice as a model for professionals working as a team that addresses both the developmental needs of the child and their family through the integration of the team members and their expertise (Bruber, 2010: 343). Rather than having team members solely addressing specific aspects of the child’s intervention related to specific disciplines, children’s and families’ needs are addressed by therapists across a range of disciplines. Transdisciplinary practice seeks to integrate a child's developmental needs across the major developmental domains.

For Davies, the three main features of a transdisciplinary team approach involve:

i) shared meaning in which team members understand and appreciate the terminology and basic principles of other disciplines, and how the family and each discipline contributes to the child’s and family’s development,

ii) multiskilling in which team members become skilled across a range of disciplines,

iii) role release whereby team members share their expertise then ‘let go’ of their specific role when appropriate so that other team members and the family can utilise their acquired techniques in a supported manner from other team members (Davies, 2007: 49-50).

Based on an extensive review of transdisciplinary literature, King et al (2009) propose three essential and unique operational features of transdisciplinary practice in line with the work of Foley (1990). Essentially these can be summarised as:
i) Team assessment including the family: the initial assessment involves professionals from multiple disciplines assessing the child simultaneously using both standardized and informal methods. Parent involvement includes the providing of information and administering structured tasks. Following the assessment, information and impressions are shared, followed by reflections of all those involved.

ii) Ongoing collaborative interprofessional teamwork: ongoing teamwork amongst professionals is an intensive interaction among the team members ‘enabling them to pool and exchange information, knowledge and skills, and work together cooperatively’ (King et al, 2009: 213).

iii) Role release: to be transdisciplinary in practice, professional members of the team share knowledge and expertise in an ongoing process whereby team members learn skills outside of their own discipline. They are then supported in learning to apply them at appropriate times. The shared understanding amongst teams members through ongoing collaboration and role release aims to develop a mutual vision to ‘meet the holisitic needs of the child within the family context’ (King et al, 2009: 213).

The practice of role release is also emphasised by McGonigel et al (1994), along with Davies (2007) and King et al (2009). McGonigel et al (1994) define role release as the most challenging aspect of transdisciplinary team development. Through role release, team members give up to one another intervention strategies from their own disciplines: ‘In this phase of the process [role release], a team member puts newly acquired techniques into practice under the supervision of team members from the discipline that has accountability for those practices’ (McGonigel et al, 1994: 108). Carpenter regards transdisciplinary practice as an effective way of delivering a service that meets both the child’s and the family’s needs through therapist’s willingness to engage in role release, working jointly with families around shared perspectives (Carpenter, 2005: 180-181).

These authors outline an understanding of transdisciplinary practice that emphasises teamwork amongst practitioners to build a shared understanding in collaboration with families. This collaborative approach involves the sharing of knowledge and skills, while supporting one another in applying these skills to assist children and their families.
The collaborative process is evident in Garland et al (quoted in McGonigel et al, 1994: 100) who identify key components of a transdisciplinary team which include:

- **Philosophy of Team Interaction** - team members commit to teach, learn, and work across disciplinary boundaries to plan and provide integrated services.
- **Family Role** - families are always members of the team and determine their own role.
- **Lines of Communication** - the team meets regularly to share information and to teach and learn across disciplines (for consultation, team building, etc.).
- **Staff Development** - staff development across disciplines is critical to team development and role transition.
- **Assessment Process** - the team participates in an arena assessment, observing and recording across disciplines.
- **Individual Family Service Plan Development** - staff and family develop plan together based on family concerns, priorities, and resources.
- **Individual Family Service Plan Implementation** - team members share responsibility and are accountable for how the plan is implemented by one person, with the family.

The collaborative relationship between transdisciplinary practice and families is emphasised by advocates of transdisciplinary practice (McGonigel, 1994, Davies, 2007 and King et al, 2009). McGonigel et al (1994) note the importance of the collaborative process between families and staff, with the family supported in their autonomy and their own unique skills and knowledge of their child. The authors also argue that the collaborative nature of the transdisciplinary model provides continuing examination and refinement of the service delivery program to ensure services make the most of their time and resources to support children and their families (1994: 128):
From the outset of its involvement with a transdisciplinary intervention team, the family is a respected team member. Families see that their knowledge of their children and their priorities for services are both important and respected (McGonigel et al, 1994: 125).

In this way, transdisciplinary practice seems to offer a strong alignment with family centred practice.

The challenges of transdisciplinary practice

To work in a transdisciplinary manner is a challenge, both for practitioners and service providers, as transdisciplinary practice confronts established ways of thinking and engaging in early childhood intervention. King et al (2009) argue that to practice in a transdisciplinary manner, service providers must ‘grasp the concepts of role release and collaborative interprofessional teamwork and display the skills required to deal with the practicalities each entails’ (2009: 215). Ongoing interaction among team members is crucial in providing support for one another. This is a likely challenge for managers to ensure there are opportunities for frequent interaction so that practitioners have the opportunity to be supported in taking on knowledge and learning new skills from across disciplines. ‘An appreciable amount of time is required for teams to plan, practice, and critique their work together, and to be able to deliver efficient and cost-effective services’ (King et al, 2009: 216). This is echoed by McGonigel et al who argue:

It [the transdisciplinary model] requires a great deal of planning, time, and - initially - expense. Program administrators must provide the necessary inservice time and training for the development of a transdisciplinary team and the necessary indirect service time for the team to implement transdisciplinary practice (1994: 111).

McGonigel et al (1994) note the problem of inadequate meeting time, with the need for regular clinical conferences to ensure that therapists are sharing their advice and support and are working towards the goals outlined in the support plan:

Although administrators may be tempted to limit team meeting time in order to serve more children and families, such a step is shortsighted and ultimately fatal to the transdisciplinary
process. The quality of services provided by the transdisciplinary team cannot be assured without the necessary meeting time to reflect on what is being offered (McGonigel et al, 1994: 122).

The authors also argue that therapists must be committed to the transdisciplinary model, to follow steps working towards role release, and to recognize the implications it has for their behaviour and their team. Importantly, they must commit to help and support one another. Such an approach also requires a strong leader who can foster an environment of ‘mutual trust and support’ while being able to ‘motivate, challenge, manage and coordinate’ on behalf of the team (McGonigel, 1994: 123-124).

As well as considerable resources to support team learning and collaboration, transdisciplinary practice also requires a specific knowledge set alongside a particular set of personal attributes of practitioners. Pretis (2006) argues that part of the uniqueness of early childhood professionals is that while they require extensive and precise technical expertise, they are ultimately more ‘generalists’ than specialists. He argues that there is a need for common ground knowledge for practitioners which should include ‘extensive knowledge of human development (biological, psychological, and social), details of various disabilities and their developmental patterns, knowledge of the contributions of other disciplines, current tools, current developmental theories, and corresponding clinical practices’ (Pretis, 2006: 45). This does not mean that different professional fields lose their importance or identity, but that they should be complemented by a common philosophy and common ethics in ECI so that the sharing of knowledge and skills is underpinned by shared understanding and goals. As Pretis argues:

Specific common ground for competencies related to working together includes knowing about the concepts of cross-discipline practices, being able to work with different disciplines, and knowing how to plan an intervention in a team (2006: 46).

For practitioners, the challenge is to not only be open to redefining their professional identity and being willing to undertake new skills outside of their discipline, but also to engage their personal qualities in a manner that enhances their professional skills. As Carpenter notes:

Skilled professionals will no longer be concerned solely with their own disciplinary boundaries, but with their capabilities as empathetic human beings and the sensitive
application of their disciplinary skill base in order to enhance the lives of the families that they support (Carpenter, 2005: 181).

To this end, service providers must be mindful of the qualities of the professionals they employ. Hiring practices become crucial in the development and maintenance of a transdisciplinary team: ‘Individuals who do well within the team are open-minded, comfortable working outside the ‘expert’ model, good listeners, and receptive to feedback’ (King et al, 2009: 220).

**The need for evidence**

These challenges for service providers and practitioners make essential the need for evidence as to the effectiveness of supports for practitioners as they undertake transdisciplinary practice.

Evidence assists in determining the most effective ways for service providers and practitioners to develop a transdisciplinary way of undertaking early childhood intervention. While there has been much written theoretically about transdisciplinary practice, there is - according to King et al (2009) - little evidence resulting from practice about how to deliver transdisciplinary services.

Little is known about the roles of practitioners; the types of services that can be offered within this approach (e.g. home visits, parent training); and how managers can provide structures, supports and opportunities to create and sustain smoothly functioning and effective transdisciplinary teams (King et al, 2009: 212).

It is also worth noting that while various authors have argued for the benefits of a transdisciplinary approach (Carpenter, 2000; Kilgo et al, 2003; McGonigel et al, 1994; Smith, 1998), there remains little empirical research in the ECI sector to support the theoretical and assumed advantages of this mode of working. King et al note that many of the presumed benefits of transdisciplinary practice have not been evaluated (King et al, 2009: 221). A recent study (Bell et al, 2009) claims that a U.K. collaborative transdisciplinary intervention led to positive outcomes regarding waiting times, therapy session attendance and caseload numbers, following a service restructure. However, the authors acknowledge
that further research is required for a greater understanding of the precise factors responsible for the results.

**Implications for this research**

The existing literature on transdisciplinary practice highlights a common set of ideas about the nature of the practice, while also offering what might be considered a continuum of practice elements that practitioners and services might attain as part of transdisciplinary practice. The notion of ‘role release’ appears to be at one end of this continuum, but equally, authors discuss a range of other collaborative practices. The current research study draws on these understandings of transdisciplinary practice and investigates the presence of some of these elements. In addition, the literature highlights the importance of seeking to understand ‘local’ definitions of transdisciplinary practice, both ideal and actual.

The literature also identifies a number of resourcing and support issues related to effective transdisciplinary practice. However, it also identifies a lack of research evidence about the benefits of and key service supports for transdisciplinary practice. Such an extensive evaluation is beyond the scope of this research. However, the lack of research in this field points to the value of focusing inquiry on practitioners’ experience. This involves an understanding of, and concerns with, transdisciplinary practice, along with an appraisal of the service support for the transdisciplinary model of intervention. Such an evaluation provides the opportunity for insight into the issues concerning the practical application of transdisciplinary practice.

Finally, of critical importance are the views of practitioners – those who are faced with the task of working in a transdisciplinary manner. Their experiences, particularly in determining what the enablers and barriers are in order to be effective in this form of service delivery, are critical in pursuing effective methods of service delivery that maximise outcomes for children and families, while also considering the needs of those providing the intervention. Also, it is important to ascertain the views of practitioners as to how comfortable they feel with transdisciplinary practice and what they consider are the significant issues for therapists in implementing this model of intervention. Key issues here include the experiences
of practitioners, including their satisfaction and confidence in working in the different modes, and the processes of sharing knowledge through transdisciplinary practice.
Chapter 13: The degree and type of transdisciplinary practice and the effectiveness of resources and supports for it

Introduction

As McGonigel et al (1994) claim in their work on the transdisciplinary team, ongoing examination and refinement is vital to any high quality program. Services and staff must confront the compelling question: ‘Are we making the most of our time and resources to support the children and families we serve’ (1994: 128). This question is pertinent to transdisciplinary practice and the need to examine key issues around practice, particularly from the experience of therapists. The following questions draw on the literature examined in chapter 12 to reflect some of the key issues pertaining to the therapists’ experience of transdisciplinary practice.

This study identified the key research question in this area as: What are the elements and practices of supporting transdisciplinary practice in the region? This question was comprised of the following sub elements:

- how therapists understand transdisciplinary practice,
- the degree and type of transdisciplinary work undertaken by therapists,
- the resourcing and support of transdisciplinary work,
- the confidence, experiences and preferences of therapists working in transdisciplinary practice.

In particular, this chapter presents methods and results relating to the first three of these sub elements. The remaining sub element is discussed in chapter 14.
Research methods to collect data about the degree and type of transdisciplinary practice and the effectiveness of resources and supports for it

This chapter describes the data collection methods in regards to three sub elements of the research question about transdisciplinary practice, i.e:

- how therapists understand transdisciplinary practice,
- the degree and type of transdisciplinary work undertaken by therapists,
- the resourcing and support of transdisciplinary work.

Therapist understandings of transdisciplinary practice

Therapist understandings of transdisciplinary practice were elicited through focus groups and interviews. In total, three focus groups comprising therapists were held (two in 2007 and one in 2008), as well as six individual interviews with therapists. Two individual interviews were conducted in 2007 and four in 2008.

The degree and type of transdisciplinary practice undertaken by therapists

The sub element relating to the degree and type of transdisciplinary work involves a broad set of concepts and elements. To confine this to a manageable task in terms of data collection, a small sub set of key elements of transdisplinary practice, broadly derived from literature, was identified and the extent to which they occurred measured. These were identified to be:

- the availability of therapists to each other (for professional support, exchange, peer learning and collaboration),
- time spent by therapists in meeting or discussing together (both informally and formally) matters relating to clients, or service delivery and clients, in their case load,
• time spent by therapists in coordinating activity between therapists and clients (i.e. coordinating across therapeutic disciplines around one client),

• time spent in joint visits of therapists (from different disciplines) to clients.

These elements received various discussions in the transdisciplinary literature and have been identified as important elements of the practice.

Given there are no clear benchmarks about how much time is ‘enough’ or ideal in relation to each of these elements, it was felt important to investigate the perceived quality of this time. This aimed to give a sense of whether time engaged in these elements was worthwhile from the perspective of therapists.

These elements were explored via a Therapist Survey conducted once annually in 2006, 2007 and 2008. The Therapist Survey was comprised of eighteen (18) items including nine (9) relating to the above. Items covered the following topics:

• Workload and work history - 3 items;

• Supervision received - 1 item;

• Availability of therapist peers - 1 item;

• Amount of hours spent in knowledge sharing activities - 4 items;

• Rating of quality of time in knowledge sharing activities - 4 items;

• Level of acquaintance with client FSSPs - 1 item;

• Confidence in transdisciplinary work - 3 items;

• General comment - 1 item.

Though all therapists were offered the opportunity, not all therapists completed surveys, or all questions on the surveys, and sample sizes are therefore small. In 2006, eleven (11) therapists completed surveys, nine (9) therapists in 2007; and four (4) in 2008. None of the years achieved a 100% response rate from
therapists. This suggests that the data provided from surveys may not accurately reflect the experiences and views of the therapist group as a whole, and should therefore be treated cautiously.

For each question relating to the extent of transdisciplinary practice and perceived quality of time spent in it, therapists responded to a five point rating scale. The wording varied to suit the topic of each item.

The resourcing and support of transdisciplinary work

As discussed in chapter 1, a number of supports and resources were introduced, with some existing practices adapted, to support and foster transdisciplinary practice in the Scope Southern ECI service. Existing practices included professional development days, dual or joint visits by therapists (from different disciplines) to clients, and the delivery of group programs to clients. Strategies specifically introduced with the move to transdisciplinary practice included; case studies (involving disciplinary case presentations including video presentations of therapist work with clients) and the development and introduction of a resource manual (‘One Day at a Time’). Therapists were invited to comment on the effectiveness of these activities and other resources and supports during interviews and focus groups.

In particular, one of these activities - the resource manual - represented a substantial new resource developed with the intention of providing information to therapists and families. This manual was seen as a key support to transdisciplinary practice. As a result, one element of data collection was focused around the use of this resource. To this end, a ‘Record Sheet - Manual Usage’ was developed. This Record Sheet identified the thirteen resource categories of the ‘One day at a time’ manual and provided a way of recording the usage over the past fortnight for: i) the number of times used for therapists’ own use and; ii) the number of times used for or given to families. Record sheets were issued at fortnightly staff meetings to enable therapists to record which aspects of the manual they were using over the previous fortnight and the number of times they were using it. Individuals were not identified on the record sheets. Administration staff collected the record sheets at each fortnightly meeting and returned them to researchers. It was intended that record sheets would be completed each fortnight for six months in 2007, and three months in 2008. However, due to the workload associated with staff meetings, record sheets were offered for completion in only seven fortnights in 2007, and in one
fortnight in 2008. In total, twenty five (25) were returned in 2007 (with between 1-6 therapists reporting in any fortnight), and one (1) in 2008. As record sheets are anonymous, it is not clear how many individual therapists were involved in completing record sheets.

**Research methods to analyse data about the degree and type of transdisciplinary practice and the effectiveness of resources and supports for it**

In order to determine therapist understandings of transdisciplinary practice, interview and focus group data was transcribed, with quotes identified that addressed this element of the research question.

The degree and type of transdisciplinary practice was determined through an analysis of Therapist Survey data. This data was analysed quantitatively to determine frequency of responses in regard to:

- amount and quality of formal meeting time,
- amount and quality of informal meeting time,
- amount and quality of time in joint visits,
- availability of therapists to each other.

Findings for each year (2006, 2007 and 2008) were compared to identify trends and changes. Due to a lack of benchmark data in relation to the ideal amount of time to be spent in each activity analysed, it was not possible to do an analysis against such data to determine the adequacy or otherwise of the level of time spent in each activity. For this purpose, the measure of the perceived quality of time was used to provide some judgement of the value of each element of transdisciplinary practice assessed. Given many factors affect the quality of this time, the results are indicative of areas that may require further investigation in regard to ways to improve the value of such activities.

To explore the experience relating to the use of resources and supports for transdisciplinary practice, researchers analysed the two data sets of interview/focus group data and the ‘Record Sheet - Manual Usage’. The interview and focus group data was analysed by organising data in relation to key supports
provided for transdisciplinary practice, namely joint or dual visits; group programs; the manual; and professional development activities. Extracts from interviews and focus groups have been used to illuminate therapists’ experience of these supports. In addition, interview and focus group data was analysed to identify themes in relation to transdisciplinary resources and supports. This analysis generated an additional topic area, that of time as a resource to support this practice, as well as some more general comments. Finally, ‘Record Sheet - Manual Usage’ data was analysed quantitatively to determine the frequency of use for each category of the manual. As there was a low rate of response in 2008, data from 2007 and 2008 was combined and no analysis of changes in use between 2007 and 2008 undertaken. This data further illuminated therapist comments about the value of the manual as a transdisciplinary resource.

**Results**

**Therapists’ definition of transdisciplinary practice**

To first determine how Scope Southern Region therapists understood transdisciplinary practice and what was expected of them, therapists were asked during interviews and focus groups about their definition and understanding of transdisciplinary practice. Overall, the comments focused on some of the key elements discussed in the literature including knowledge sharing, learning new skills, and applying the knowledge and skills in practice. Therapists defined transdisciplinary practice as follows:

I think having a bit more of a knowledge about what everyone else does, so that I can assist with what everyone is trying to achieve ... (Therapist Focus Group 07).

I think it means really having a bit more of a broader knowledge so you can give families some information, and skills and things, that aren’t just necessarily historically relevant to your discipline (Therapist Focus Group 07).

I think it’s awareness of seeing the child in a much more holistic way than just thinking speech therapy. [For example, in] speech therapy; I only care about their talking and their
eating. That’s part of it, but it’s also - I think it’s about knowing how far you can actually go with your skills (Therapist Focus Group 07).

However, there was also uncertainty about what transdisciplinary practice was really all about:

Okay, here’s a confession. I don’t really get it. I mean I understand the vague concept. I just find it so hard to get a grasp of it all that I just keep ignoring it (Therapist Focus Group 07).

A therapist focus group conducted in September 2006 identified a number of components of how therapists saw transdisciplinary practice. They regarded working together in sharing discipline knowledge as important, with an emphasis on practical, contextualised sharing of experience. While therapists displayed a conceptual understanding of the practice, there was a reluctance to fully embrace and take ownership of transdisciplinary practice. Researchers identified that for therapists to ‘sign up’ fully to the practice left open the possibility of being negatively measured against a set of transdisciplinary criteria. In the focus groups and individual interviews, therapists often indicated confusion as to the specific levels, or degree, of transdisciplinary practice required of them.

The concern seemed to be that when discipline specific boundaries become less strictly defined, uncertainty arises over expectations. Therapists were much more comfortable with the idea of collaborative practice and knowledge sharing - more benign concepts that captured much of transdisciplinary practice without the seemingly fixed and inflexible criteria. ‘Collaboration’ and ‘knowledge sharing’ were seen as general and broad terms that captured the more fluid way in which therapists worked together in accordance with the circumstances of each unique family situation, without taking on the task of delivering a therapeutic intervention outside their own discipline.

This indicates that while therapists performed many of the tasks associated with transdisciplinary practice in line with the literature, they did not regard themselves at the stage of role release whereby

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6 It should be noted that there is a body of literature that deals with the concept of collaboration within health services. For an overview of the literature see D’Amour et al (2005), ‘The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks’, in Journal of Interprofessional Care (May 2005) Supplement 1: 116-131. This literature is not further discussed here and the terms ‘collaborative practice’ and ‘collaboration’ are used to reflect only therapist views, not in reference to other concepts and practices discussed in this literature set.
they would be undertaking interventions outside of their discipline. Indeed, therapists were largely opposed to adopting a role release approach for a range of reasons, well expressed in the following interview excerpts from two therapists:

I think it’s great in theory as long as you’re not there because there is a lack of the other therapists. I think that if everyone can have an understanding of each other’s roles and to employ the same strategies, then that’s an ideal. I think that when we are all involved, and we do joint visits, then we do that … But I don’t agree that it’s the role of an OT to do the job that a speech pathologist would be doing if they were there. So TD [transdisciplinary] is great as long as it’s not short-changing the client (Therapist 08).

Remember there’s four years of study to learn one discipline and to reach a level to achieve that. Like a GP - a good GP knows his limits and when to refer on. And we need to know our limits and when to refer on to another specialist (Therapist 08).

This suggests that Scope Southern Region therapists greatly value co-ordinated and collaborative practice based on knowledge sharing across disciplines and between therapists and families. However, a fully transdisciplinary model, including role release, is not embraced by therapists.

**The degree and type of transdisciplinary practice undertaken by therapists**

For the purposes of this study, understanding of the degree and type of transdisciplinary practice focused on identifying the amount of time spent in a range of activities related to this practice. Additionally, findings were generated about the perceived quality of time spent in these activities.
The amount and quality of formal meeting time for ECIS therapists to share knowledge relevant to clients

Therapists were asked to rate the amount and quality of time spent in formal meetings with fellow Scope staff to discuss clients or service delivery. Overall, the amount of hours spent in formal meetings for this purpose appeared to decrease between 2006 and 2008 (see table 22).

Table 22: Total amount of hours in formal meetings in the last four weeks with other therapists and family coordinators discussing clients

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 hour</th>
<th>1-3 hours</th>
<th>4-6 hours</th>
<th>More than 6 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td>55%</td>
<td>27%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td>44%</td>
<td>11%</td>
<td>22%</td>
<td>11%</td>
<td>11%</td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td>50%</td>
<td>25%</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>50%</td>
<td>21%</td>
<td>22%</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>

An average of fifty percent (50%) of therapists reported that during 2006-2008 they spent no time in formal meetings, ‘over the past four weeks’, discussing clients together. A further, 21% reported spending less than 1 hour over the four week period in formal meetings, and 22% spent between 1 and 3 hours over the four week period in such meetings.

Therapists also rated the quality of this time in relation to sharing knowledge relevant to work with their clients (including knowledge of other disciplinary approaches) with the responses ranging from ‘minimal use’ to ‘of great use’ (see table 23).

Table 23: Quality of time spent in formal meetings in sharing knowledge relevant to work with client

<table>
<thead>
<tr>
<th></th>
<th>Not of any use</th>
<th>Of minimal use</th>
<th>Useful</th>
<th>Very useful</th>
<th>Of great use</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=9)</td>
<td></td>
<td>22%</td>
<td>44%</td>
<td>33%</td>
<td></td>
</tr>
<tr>
<td>2007 (n=8)</td>
<td></td>
<td>13%</td>
<td>25%</td>
<td>25%</td>
<td>38%</td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td></td>
<td>25%</td>
<td>25%</td>
<td></td>
<td>50%</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td>20%</td>
<td>31%</td>
<td>19%</td>
<td>29%</td>
</tr>
</tbody>
</table>
On average across the three years 2006-2008, only 20% of therapists rated formal meetings as of minimal use to sharing knowledge, whereas 31% found them useful, 19% found them very useful, and 29% found them to be of great use. The trend evidenced between 2006 -2008 suggests that less time was being spent in formal meetings, while staff continued to find formal meetings to be useful. Overall, an average of 79% found formal meetings to be useful to of great use.

The amount and quality of informal meeting time / discussion between ECIS staff to share knowledge relevant to clients

Therapists reported that they spent far more time in informal meetings and discussion with their peers, than they did in formal meetings (see table 24).

Table 24: Total amount of hours in informal meetings in the last four weeks with other therapists and family co-ordinators discussing clients

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 hour</th>
<th>1-3 hours</th>
<th>4-6 hours</th>
<th>More than 6 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td></td>
<td>36%</td>
<td>18%</td>
<td>36%</td>
<td>9%</td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td></td>
<td>11%</td>
<td>56%</td>
<td>11%</td>
<td>22%</td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td></td>
<td></td>
<td>50%</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>16%</td>
<td>41%</td>
<td>32%</td>
<td>10%</td>
<td></td>
</tr>
</tbody>
</table>

On average between 2006 and 2008, most therapists (41%) spent between 1-3 hours over the past four weeks in informal meetings, while a further 32% spent between 4-6 hours during this period, and 10% spent more than 6 hours over this period.

Therapists highly valued the quality of the time spent in informal knowledge sharing with other professional staff (see table 25). Across the three years, an average of 64% of therapists surveyed rated this time to be of great use to them, with a further 11% finding it very useful.
Table 25: Quality of time spent in informal meetings/discussions in sharing knowledge relevant to work with client

<table>
<thead>
<tr>
<th>Year</th>
<th>Not of any use</th>
<th>Of minimal use</th>
<th>Useful</th>
<th>Very useful</th>
<th>Of great use</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=10)</td>
<td></td>
<td></td>
<td>50%</td>
<td></td>
<td>50%</td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td></td>
<td></td>
<td></td>
<td>33%</td>
<td>67%</td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td></td>
<td></td>
<td>25%</td>
<td></td>
<td>75%</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td></td>
<td>25%</td>
<td>11%</td>
<td>64%</td>
</tr>
</tbody>
</table>

Between 2006 and 2008, there was an increase in therapists reporting this time to be of great use to their knowledge sharing around clients. Further, no therapists reported this time to be of no or minimal use. In comments on surveys, therapists reported informal time to be of great value with one therapist stating that ‘informal meetings and discussions have definitely improved with the use of email. This is a time to knowledge share as well as to debrief’. This suggests that therapists were able to engage in ‘virtual’ discussions and support.

The amount and quality of time spent in joint visits of ECIS staff to clients

One feature of transdisciplinary practice discussed in the literature is that of joint visits and joint assessment where therapists jointly attend meetings or therapeutic activities delivered to clients. In terms of developing transdisciplinary practice, such sessions can enable therapists to ‘teach and learn from one another’ (King et al 2009: 218). Overall, therapists identified a decline in time spent in joint visits over the period 2006-2008 despite the majority of therapists finding them of great use.

Surveys completed by therapists in 2006 – 2008, identify the amount of time spent in these joint visits to clients over a four week period (see table 26). Over the three years, an average of 48% of therapists reported they undertook no joint visits within a four week period. A further 13% spent less than 1 hour in this activity over the period. Slightly more than a quarter of therapists (28%) spent 1-3 hours in this activity within the four weeks, and an average of 10% spent 4-6 hours in joint visits. In 2008, the number of therapists undertaking no joint visits increased dramatically evidencing that, in 2008, 75% of therapists
participated in no joint visits within the four week survey period. This suggests a trend away from time spent in joint visits in 2008.

Table 26: Total amount of hours spent in joint therapist visits to clients in the last four weeks

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 hour</th>
<th>1-3 hours</th>
<th>4-6 hours</th>
<th>More than 6 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td>36%</td>
<td>27%</td>
<td>27%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td>33%</td>
<td>11%</td>
<td>33%</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td>75%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>48%</td>
<td>13%</td>
<td>28%</td>
<td>10%</td>
<td></td>
</tr>
</tbody>
</table>

Overall, most therapists found joint visits to be of great use (an average of 56% between 2006-2008) though there was a marked decline in 2008. An average of a further 11% found them to be very useful, and 26% found them to be useful. Only 7% of therapists, on average, found them to be of minimal use (see table 27).

Table 27: Quality of time spent in joint visits of therapists to clients

<table>
<thead>
<tr>
<th></th>
<th>Not of any use</th>
<th>Of minimal use</th>
<th>Useful</th>
<th>Very useful</th>
<th>Of great use</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=10)</td>
<td></td>
<td>11%</td>
<td>33%</td>
<td></td>
<td>56%</td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td></td>
<td>11%</td>
<td>11%</td>
<td></td>
<td>78%</td>
</tr>
<tr>
<td>2008 (n=3)</td>
<td></td>
<td></td>
<td>33%</td>
<td>33%</td>
<td>33%</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td>7%</td>
<td>26%</td>
<td>11%</td>
<td>56%</td>
</tr>
</tbody>
</table>

The following comment from a therapist interview reflects the value of joint visits:

I think they [joint visits] are absolutely fantastic. I think you can sit around and talk about ‘why don’t you try this?’ and ‘why don’t you try that?’, but when you actually see the other therapist with their hands on the child, it’s so much more - I don’t know ... having that visual thing in your head is so much more useful (Therapist 07).
By 2008, fewer therapists valued the time spent in joint visits as highly, with only 33% finding them to be of great use (this may also reflect the fact that there was less opportunity for therapists to conduct joint visits in 2008).

King et al argue that, for therapists, both ongoing formal and informal time spent sharing information and knowledge, and supporting one another can ‘help to create an atmosphere of learning and trust and break down barriers between expert and novice’ (2009: 220).

Availability of therapists to each other

Finally, therapists reported on the extent to which their peers (fellow therapists and family coordinators) were available to them in order to ask questions and share knowledge generally (see table 28). Overall, these results suggest a moderate degree of availability of peers to each other for the purposes of knowledge sharing and support.

**Table 28: Availability of therapists to each other in the last four weeks**

<table>
<thead>
<tr>
<th></th>
<th>Never available</th>
<th>Rarely available</th>
<th>Sometimes available</th>
<th>Frequently available</th>
<th>Always available</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=9)</td>
<td></td>
<td>11%</td>
<td>78%</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td></td>
<td>20%</td>
<td>70%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td></td>
<td></td>
<td>75%</td>
<td></td>
<td>25%</td>
</tr>
<tr>
<td>Average</td>
<td>10%</td>
<td>74%</td>
<td>7%</td>
<td>8%</td>
<td></td>
</tr>
</tbody>
</table>

On average, across 2006-2008, 74% identified their peers to be ‘sometimes available’, a further 7% found them to be ‘frequently available’, and 8% found their peers to be ‘always available’. Ten percent (10%) of therapists found their peers to be ‘rarely available’. As discussed in interviews, this reflects the mobile nature of the work given that most therapists are working out in the community and performing interventions in the home. Further constraints on therapist time were also reported as impacting on availability to one another.
**Resources and supports for transdisciplinary practice**

A key part of transdisciplinary practice is the supports that are provided to therapists and the culture of sharing knowledge and skills across disciplines. As Davies (2007) notes, traditional undergraduate courses do not specifically focus on transdisciplinary approaches. With each discipline taught in isolation, there is little understanding across disciplines for students. Also, each discipline has its own discourse which makes communication often difficult when working in a transdisciplinary team (Davies, 2007: 56). Services must be willing to provide training, programming, and evaluation for all therapists, as well as ongoing support and upgrading of skills. ‘This commitment is demonstrated by giving staff the time and energy necessary to teach, learn, and work across traditional disciplinary boundaries’ (Davies, 2007: 58).

As mentioned previously (see Section 1), the Southern ECI Service has sought to develop a number of methods of skilling workers in transdisciplinary practice. The following draws on therapist interviews discussing these various supports, as well as quantitative data relating to use of the manual. In addition, interview and focus group data identifies a further theme of time as a resource which is discussed below. This data discusses the value of these resources as mechanisms to support transdisciplinary practice.

**The Resource Manual - One Day at a Time**

In interviews therapists indicated that overall they found the manual a useful resource. According to the data, in relation to the therapists’ use of the resource manual, the category eliciting most use (43%) related to developmental activity sheets that were designed as a tool to assist therapists in activities outside of their discipline (see table 29).
Table 29: Therapists’ use of the Resource Manual: ‘One Day at a Time’

<table>
<thead>
<tr>
<th>Categories of the manual</th>
<th>No. of times of use (across 7 fortnights 2007 and 1 fortnight 2008)</th>
<th>% of use</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL</td>
<td>228</td>
<td></td>
</tr>
<tr>
<td>Developmental activity sheets</td>
<td>98</td>
<td>43%</td>
</tr>
<tr>
<td>Local govt and community resources</td>
<td>47</td>
<td>21%</td>
</tr>
<tr>
<td>Family Service and Support Plan</td>
<td>32</td>
<td>14%</td>
</tr>
<tr>
<td>Songs/toys</td>
<td>16</td>
<td>7%</td>
</tr>
<tr>
<td>Home made items</td>
<td>13</td>
<td>6%</td>
</tr>
<tr>
<td>Camera</td>
<td>9</td>
<td>4%</td>
</tr>
<tr>
<td>Developmental stage information</td>
<td>8</td>
<td>4%</td>
</tr>
<tr>
<td>Family empowerment</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>Family centred practice</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Useful signs</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Diagnostic specific information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grieving</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

However, there is insufficient data to determine whether these sheets were used as a trandisciplinary tool or used as a tool by therapists within their own discipline. Interviews with therapists, with regard to their use of the manual, suggest that the manual’s value lay more with the information and contact details for various external resources and agencies that could assist families, rather than the more specific discipline based material that would aid both therapists and families in a transdisciplinary manner. The following quotes are representative of therapists’ use of the manual and their thoughts with regard to its value.

When I’ve had time … there are some really good parts to it and I have used it in terms of looking for certain things I can give to families, and then looking for local information. There was a lot of time that I was actually referring to it for who’s here and what’s the phone
number, where’s this service located ... that sort of thing was really useful. I haven’t used it a lot in terms of giving stuff to the families. But I don’t think that’s because it’s not useful. I think it’s because it’s broader than what my role is. Because my case role was basically just autism, autism, autism. I wasn’t using the broader range of things (Therapist 07).

I haven’t really used it I have to confess ... I find it quite broad. I’m reluctant to hand out anything that’s not my discipline which I guess is what they would be useful for. But I’m reluctant to because I don’t know where and...what I should be directing a parent to. In terms of the more broad general information, that part is good. I look up contact details and broad information. But in terms of actual therapy or activity type stuff, I don’t really use it (Therapist 07).

I have used it - I’ve borrowed bits from it. The thing I’ve referred to the most is the information on various council areas - stuff about play groups and kindergartens in the area. Because again that’s part of our role as family service coordinators - to be able to provide families with information about where they can access respite or which playgroup they can go to ... I found it better for the general information because that’s the stuff I don’t know anything about (Therapist 08).

One therapist found it an extremely useful tool and indicated a willingness to engage across the entire spectrum of information and resources that were available:

I find it extremely helpful - songs, exercise sheets - professional way to present a program to parents. The service information is great and good to share. It’s very meaningful and helpful to parents. The assessment tools are very good. I use it all year - I’d be lost without it. It’s also invaluable for young therapists just beginning their journey (Therapist 08).

Overall, it appears that therapists found the manual extremely useful in terms of general information with the value of having a large array of information on hand, particularly in relation to other local supports and services. It appears that therapists were reluctant to use information specific to a discipline that was not their own. This suggests that the manual is currently of limited value as a resource that supports
practitioners to acquire or practice skills and knowledge outside of their discipline, and as such, it is questionable whether it is supporting this aspect of transdisciplinary practice.

**Professional development activities - video and case presentations**

The literature identifies professional development as a critical resource necessary for transdisciplinary practice, particularly as traditional therapist training does not encompass the skills required of collaborative work across disciplines. In interviews, therapists repeatedly commented on the inadequate level of training in this regard:

> What continually comes up at different forums is the amount of knowledge we’re meant to have. We are dealing with everything from newborn babies to teenagers wanting to drive. So we’re struggling with that. So it’s a challenge also having to take on other roles, and often you don’t feel confident because you haven’t been properly trained (Therapist Focus Group 08).

> But there is kind of an expectation that we will be [transdisciplinary] without doing the training. And we are all adaptable, flexible people going with the flow - trying to do it or do our best. So it becomes: ‘Well you’re doing a good job so keep doing it’ (Therapist 08).

In partial recognition of this need, Scope Southern Region introduced specific professional development opportunities designed to support transdisciplinary practice. These were largely designed as periodic activities of differing levels of formality. One element of this was that of video and case presentations. In discussing these, therapists were somewhat ambivalent as to their value. Overall, they found them somewhat useful in acquiring new knowledge but felt that the knowledge would not necessarily be translated into useable skills that they could use in their own unique situations. Three therapists described video and case presentations in the following ways:

> They’re good [videos] and they’re really helpful and a good learning tool, but in terms of your day to day questions, it doesn’t necessarily solve that problem. The problem that the
kids you saw yesterday and you are seeing tomorrow - it doesn’t necessarily solve that (Therapist Focus Group 07).

At the time [during case presentations/videos], if you see someone doing something from another discipline, it makes a lot of sense, and you go ‘isn’t that great’. But then you go off by yourself and you’ve forgotten something that is really ... you think ‘it’s not working for me’ (Therapist Focus Group 07).

More often than not I found them [case presentations] interesting. And sometimes you would pick up things ... but I don’t think I learned huge amounts of things that I’m going to take away and use (Therapist 07).

It appears that therapists acknowledge there is some value to these learning tools but that the value is somewhat limited. Their comments may reflect the sporadic nature of video and case presentations which require significant time to do well. Given they did not occur regularly, it may be that therapists did not have the opportunity to constantly have new learnings reinforced. However, these comments suggest that such activities hold some value but further work needs to occur in order to make these effective resources to support transdisciplinary practice.

**Joint (dual) visits**

As discussed above, therapists spent a proportion of their time conducting joint or dual visits to clients and valued this time highly. The transdisciplinary literature identifies the opportunity for practitioners from different disciplines to share assessment / diagnostic and intervention tasks as an important aspect of transdisciplinary practice (King et al, 2009; McGonigel et al, 1994). Similarly, during interviews, Scope therapists identified the value of joint visits in terms of knowledge sharing and skill development.

I think it’s good when we can do lots of joint visits. It gives us a chance to work with someone else and see what they are doing. You kind of get the chance to share information. I think if there were more shared visits it would be good. There needs to be more allocation of funds for that (Therapist 08).
Things that work really well are when we have an opportunity as therapists to do joint visits because you are sharing ideas and often working towards similar goals. The flip side to that is that we don’t often have the opportunity to do that - and that’s due to timetables. It’s almost impossible to arrange it (Therapist 08).

We found you pick up so much more in joint visits than you do by yourself. You come away from each visit with so much more information. You have more time to talk and observe ... We try to do dual visits when we can. It’s good for our skills and to help brainstorm for families - to be able to look at it differently and share and find solutions (Therapist 08).

One therapist claimed that while dual visits can be beneficial for therapists, ultimately the determinant of their value lay with whether dual visits were beneficial in achieving positive outcomes for the family:

I think they can be really good. I think it really depends on the family ... and how ... just the way you all work together ... the two therapists and the family. Sometimes it’s too much for a family to have two people. And sometimes just if the therapists work differently - that’s not really a great idea because you have one who works in some way and one may be really laid back. And if you’re going with someone who is one way different to you, it can be a disaster ... Sometimes it’s really effective - like you both need to be there to solve a problem. And it’s useful for transferring information, but in terms of the child’s time and that, I think it really depends on what you’re doing there. Like, if you’re just ... it’s great to learn from each other, but if that’s all your doing - learning from each other - and it’s not really helping you get those child’s goals achieved, then that’s a bit of an issue (Therapist 07).

**Group programs**

As discussed in chapter 1, group programs involved a number of children coming together to engage in shared activities with a number of therapists present to observe and intervene. Therapists affirmed the value of these sessions as a transdisciplinary resource:
The other thing where I pick up skills is in the group. And I picked up a lot of skills last year in groups. And I think [other therapist] probably did too because we are coming from very different points of view. Yeah. And I walked into the group and thought, ‘OK. Yeah - need to make some changes’. Working together in that close proximity - once a fortnight, running a group, dealing with families and siblings, and then actual therapy goals for children - that was very useful as well. I think most of the [Pakenham] therapists are involved in groups - that’s where you do learn your transdisciplinary skills a lot (Therapist 07).

We all learn from each other when those groups are running on a regular basis. It gives you the most amazing amount of knowledge naturally (Therapist Focus Group 07).

While group programs occurred largely in only one geographic area of the ECI service, they appear to have significant value as a transdisciplinary resource to those staff who participated in them.

**Time as a resource**

In addition to the programmed resources and supports for transdisciplinary practice discussed to date, a further resource was identified by therapists in focus groups and interviews. Therapists provided a rich commentary on time as a critical resource for transdisciplinary practice.

The notion of time as a resource for transdisciplinary practice is also evident in the literature. King et al note that ‘an appreciable amount of time is required for teams to plan, practice and critique their work together, and to be able to deliver efficient and cost-effective services’ (King et al, 2009: 216). Therapists echoed this need and regularly expressed that they lacked enough time to effectively deal with the day to day demands of the job, let alone find the time to undertake opportunities to effectively learn new knowledge and skills to a competent level. The following quotes typify how therapists feel limited in the time it takes to undertake skills outside of their own disciplines and competencies.

You need a lot more time to do transdisciplinary - you have to think, whereas the stuff that you know that’s very familiar you can do. It’s just something else you have to think about, or
ask questions about it or go and research or something, and that’s a lot of time (Therapist Focus Group 07).

I don’t think it’s efficient (transdisciplinary practice) ... And if someone else for whom it was their actual background and knowledge - they could have done it in half an hour. And it just took me three hours and I haven’t really done it very well. Like that’s my big drama with it ... the time that it takes to get all that information across and deliver it well (Therapist 07).

It’s all like if you’ve only got this much time, I’m going to jump in and do what I know really well to help you with those things. And the other things that I don’t know so well ... well someone else can do it. You’ve only got so much time and it’s like I’d better do the best stuff well (Therapist Focus Group 07).

The concern, then, is that lack of time means that there are limited opportunities to learn and that the supports become minimal due to financial and time restrictions.

There need to be extra supports put in. I think there is just an assumption that you can do it, basically (Therapist Focus Group 07).

**General comments on resources and supports**

Finally, during interviews and focus groups, therapists discussed the issue of resources and supports for transdisciplinary practice more generally. For transdisciplinary practice to work, therapists need to know that if they seek support it will be available. Support may be sought from fellow therapists (who need to have the time and willingness to provide support), but perhaps more importantly there has to be a service culture of support. One therapist contrasted the positive and specific local supports made available through Scope Southern Region, with the prevailing lack of support at a wider organisational and structural level.

I think there’s more emphasis in the Southern team in supporting each other and in knowledge sharing. Even though it’s not billable time it certainly seems very important. We
are allowed to have our TD [transdisciplinary] meetings and that sort of thing. But that’s just at our manager level. I don’t feel the organization as a whole supports that because they give us that very unrealistic figure of 80 percent billable hours. When it comes down to it … I know we are meant to be more business minded and everyone can be, but there is a compromise between the quality of service (Therapist 08).

This comment echoed discussion in focus groups about the restrictions placed on practice by structural mechanisms such as the requirement to spend identified minimum proportions of paid time in service delivery (e.g. 80%) that is directly ‘billable’ against a client’s funding allocation. In this way, broader organisational policies directly undermined the provision of local supports and resources for transdisciplinary practice.

In the final analysis, while therapists generally spoke positively of the resources and supports provided, they also identified fundamental failure of support provision when needed:

> I think the feelings [about working in a transdisciplinary manner] are for me positive and negative. I think there are some really great positives. But I think that it can be difficult. And it really does depend on what supports there are … when you hit that negative part where you go ‘what do I do now?’ If those supports are there, it’s great and you move on. And if the supports are not there, that’s when you feel like a fraud (Therapist Focus Group 07).

**Conclusion**

This chapter has explored therapist understandings of transdisciplinary practice, the extent to which elements of it occur, and the value of resources and supports designed to foster it. In the main, therapists largely define transdisciplinary practice that reflect key elements of the literature and, as a result, are uncomfortable with aspiring to this type of practice in its ideal or fully realised form. Therapists strongly support a practice which is knowledge sharing and collaborative, but not one of role
release. However, therapists report that they regularly undertake a number of elements of transdisciplinary practice, also consistent with a knowledge sharing and a limited role release approach.

In particular, therapists spend most time in informal meetings and discussions with their peers to support this practice – which they value highly. Other elements of transdisciplinary practice, such as formal meetings, joint visits and case co-ordination are less frequently practised. While therapists find the transdisciplinary resources available to them (such as joint visits, professional development activities and the manual) to be generally useful, their value appears to be limited by the inadequate time available to maximise benefits. These resources have increased shared knowledge but have not equipped therapists to practice confidently outside of their own discipline. It should be noted that this may not have been their intention. Finally, time and wider organisational support are identified as critical resources to support transdisciplinary practice as they underpin and enable meaningful opportunities for learning, collaborative work and the use of resources.

These findings provide an important context for examination of the final element of the research question about transdisciplinary practice related to the confidence of therapists to practice in a transdisciplinary way. This is presented in the following chapter.
Chapter 14: Confidence, experiences and preferences of therapists in transdisciplinary practice

Introduction

Chapter 13 dealt with the first three sub elements of the overall research question: What are the elements and practices of supporting transdisciplinary practice in the region? This chapter presents methods and results relating to the remaining sub element of the research question:

- the confidence, experiences and preferences of therapists working in transdisciplinary practice.

This research topic focuses attention beyond the mechanics of transdisciplinary practice such as the level of supports and resources provided for it, and addresses what the literature identifies as an important component of the practice – practitioner confidence. The issue of confidence covers not only the area of confidence in exercising current skills, but in taking on new ones and seeking support to do so. An element of this is the confidence to identify and name one’s limitations (as a first step to addressing these limitations). The literature discusses these affective elements of practice: confidence in, comfort with and preference for this work mode.

King et al identify that the process of acquiring new skills necessary for transdisciplinary practice requires both training and supervision, often from peers, and this can be intimidating for therapists, particularly for novice team members, as skills are scrutinised (2009: 220). Davies notes that trust and confidence are required in both the other team members and also one’s own skills (2007: 57). When skills are required, therapists need a level of personal confidence and comfort in performing interventions from other disciplines (King et al, 2009: 221). While knowledge, skills and resources are critical to transdisciplinary practice, this discussion speaks to the importance of the more affective elements of confidence, experience and preferences of therapists.
Research methods to collect data about the confidence, experiences and preferences of therapists in transdisciplinary practice

This chapter describes the data collection methods in regards to the last sub element of the research question about transdisciplinary practice, in relation to ascertaining the confidence, experience and preferences of therapists in working in this mode.

Two main methods of data collection were utilised in relation to this topic: Therapist Survey and interviews/focus groups with therapists.

The Therapist Survey included three items relating to therapist confidence across a variety of aspects of transdisciplinary practice. These included:

- confidence to identify own limitations in regard to work in a transdisciplinary way;
- confidence to seek support to work in a transdisciplinary way;
- confidence to acquire skills in other disciplines.

Therapists rated their own confidence levels in relation to each item on a four point scale, with a choice of: not confident; somewhat confident; confident; and very confident. As discussed in chapter 13, the Therapist Survey was conducted once in each year with eleven (11) therapists completing surveys in 2006, nine (9) therapists in 2007; and four (4) in 2008.

Therapists also participated in interviews and focus groups where they discussed this topic. In particular, therapists were asked to discuss their degree of comfort in this mode of work, and reservations they had about it. In total, three focus groups comprising therapists were held (two in 2007 and one in 2008), as well as six separate interviews with therapists.
Research methods to analyse data about the confidence, experiences and preferences of therapists in transdisciplinary practice

In order to determine therapist level of confidence in relation to each of the three areas targetted (acquisition of skills, identification of own limitations, and seeking support), Therapist Survey data was analysed to determine frequency of responses in each year. Results for each year were compared to identify trends and changes.

Interview and focus group data was used to provide further insight into therapist views and experiences about these topics. Data was matched to each topic area and relevant quotes selected.

Results

Overall, therapists reported high levels of confidence in their ability to identify their own limitations with transdisciplinary work (see table 30). Across 2006-2008, an average of approximately one quarter (28%) of therapists reported feeling ‘very confident’, with a further 60% feeling ‘confident’ in this regard.

Table 30: The confidence to identify own limitations in regard to work in a transdisciplinary team

<table>
<thead>
<tr>
<th>Year</th>
<th>Not confident</th>
<th>Somewhat confident</th>
<th>Confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td>9%</td>
<td>64%</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td></td>
<td>67%</td>
<td>33%</td>
<td></td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td>25%</td>
<td>50%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>11%</td>
<td>60%</td>
<td>28%</td>
<td></td>
</tr>
</tbody>
</table>

However, consistent with the trend evident in other related data below, therapist confidence to identify their limitations in relation to transdisciplinary practice decreased in 2008.
Overall, therapist interviews reflected these findings. Where doubtful about their own knowledge or skills set, therapists expressed confidence in recognising these limits, and in finding out what needed to be done. This was particularly so where the child had complex or high needs.

Like most stuff I can do a bit, but I just think ... I don’t think I’m giving a great service if I’m the one that is saying ‘here you go, this is what you should do’. I find it easier to go back and say ‘okay I’ll find out’. And I’ll happily go ask, but I’ll ask that specific question and then go back with it. I don’t just off the top of my head just do it (Therapist 07).

Yeah, the fewer needs they have the easier it is. A completely disabled child - all of us are much more hesitant about ‘are we doing the right thing?’ (Therapist Focus Group 07).

[You] get to that point where you say, ‘okay, this skill I can’t really take. I can’t manage this by myself - I don’t have enough knowledge, I don’t have enough skills’ (Therapist Focus Group 07).

Therapists identified recognition of their transdisciplinary limitations but also acknowledged a degree of uncertainty as to whether this was acceptable – this was compounded by the confusion over the level of skill and knowledge required in order to be transdisciplinary:

This is where I don’t get the whole thing. I don’t think I understand it enough, because I feel like I’m supposed to know more than I should now. So maybe that’s my problem. Not more than I should, but more than I do. So I don’t know where it stops. I don’t know how much I should know. And if I should have known that or if I did need to go away - I have no idea where the boundaries are about that. And so maybe that’s me, maybe that’s just what I’ve got to sort out (Therapist Focus Group 07).

I just feel like there’s just too much and I just can’t ... that’s just me. I’m not speaking for anyone else, but I don’t know what I’m supposed to know. And I can’t get a grasp ... and it’s too much, and I’m just never going to get there (Therapist Focus Group 07).

As Davies notes, often there is a lack of clear differentiation of responsibilities among team members. The challenge is to continually work at clarifying roles within the team and to encourage open
communication among team members (Davies, 2007: 57). Such open communication may provide the opportunity for therapists to clarify and understand what is expected of them and to provide greater understanding of the boundaries around their level of intervention outside of their own discipline.

As part of the Therapist Survey, therapists were asked to rate their confidence to seek support to work in a transdisciplinary way (see table 31). Most therapists reported a reasonable level of confidence in this area, with 64% identifying as ‘very confident’ or ‘confident’ on average across the three years of the survey.

Table 31: The confidence to seek support to work in a transdisciplinary way

<table>
<thead>
<tr>
<th>Year</th>
<th>Not confident</th>
<th>Somewhat confident</th>
<th>Confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td>9%</td>
<td>27%</td>
<td>55%</td>
<td>9%</td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td>22%</td>
<td>44%</td>
<td>33%</td>
<td></td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td>50%</td>
<td>50%</td>
<td>14%</td>
<td></td>
</tr>
</tbody>
</table>

An average of one third (33%) of therapists across the three years 2006-2008 reported as only ‘somewhat confident’. In addition, 9% felt ‘not confident’ at all in 2006, though in 2007 and 2008 no therapists reported feeling ‘not confident’. Therapists appeared to experience less confidence in seeking support for a transdisciplinary approach in 2008 than in other years.

Survey data did not provide information about the reasons for this assessment of confidence. Interview data, discussed in this and the previous chapter, helps illuminate some of the possible reasons for this. It is possible that confidence to seek support is linked to the availability or lack of supports when needed.

Finally, therapists were asked to rate their confidence to acquire skills in other disciplines (i.e. professional domains in which they were not qualified). In this area, therapists reported lower levels of confidence (see table 32). An average of three quarters (75%) of therapists surveyed between 2006-2008 felt only ‘somewhat confident’ to acquire skills in disciplines not their own. Confidence in this area decreased dramatically between 2006 and 2008, and no therapists indicated that they were ‘confident’
or ‘very confident’ in 2008. In 2008, one quarter (25%) of therapists had no confidence in their ability to acquire skills in other disciplines.

Table 32: The confidence to acquire skills in other disciplines

<table>
<thead>
<tr>
<th></th>
<th>Not confident</th>
<th>Somewhat confident</th>
<th>Confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006 (n=11)</td>
<td>73%</td>
<td>18%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>2007 (n=9)</td>
<td>78%</td>
<td>11%</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>2008 (n=4)</td>
<td>25%</td>
<td>75%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>8%</td>
<td>75%</td>
<td>10%</td>
<td>7%</td>
</tr>
</tbody>
</table>

In this way, not only did therapists feel less confident in their ability to acquire skills from other disciplines - they also felt less confident to identify their own limitations in 2008 (see table 30). Taken together, this set of data seems to suggest that confidence with transdisciplinary approaches decreased in 2008.

In interviews a common theme from therapists was concern that while they could acquire competency in their own discipline as a result of years of professional study and supervised practice, to take on the responsibility of skills outside of one’s own professional discipline led to concerns of competency.

It’s all right if someone is showing you exactly and you get it exactly right that time, but I’d get really worried about - in some situations there are some things, not everything, but doing it slightly wrong (Therapist Focus Group 07).

I’ve heard people in our team say, to take it to an extreme, ‘I feel like a fraud’ ... And in that situation it’s been - I mean that’s a very emotional response, and it’s been an emotional response because it’s been in a situation where resources that were needed weren’t there, and supports for that person that were needed weren’t there. So it’s [transdisciplinary practice] got problems in that respect (Therapist Focus Group 07).

Further to this was the recognition that the amount of knowledge therapists required was continually increasing and covering broader areas of practice.
The population of our clients - the disability type things - all those things have changed where I feel so generic now. I have no idea what I know, I have no idea who I can handle, whereas it used to be very much ... it was so much easier to keep control of what you knew, to figure out what you needed to know, even from other disciplines. Whereas now, it feels like I need to know everything about everything from every discipline. And we can’t possibly (Therapist Focus Group 07).

Therapists also suggested that the ability to acquire skills in other disciplines is likely to be increased for experienced therapists. As one therapist noted, less experienced therapists may struggle to acquire skills outside their own discipline especially given the often solitary nature of the practice model in the Southern ECIS.

I think if you’re a younger therapist who has only a small amount of experience and you come into this environment where you’re on your own virtually all the time, I’m not really sure how those people would be actually gaining any idea of how the other disciplines would work (Therapist Focus Group 07).

The literature too identifies that the ability and confidence to acquire transdisciplinary skills is linked to length of prior practice experience. Ericson (1993), cited in King et al (2009), suggests that transdisciplinary practitioners require at least ten years prior professional experience in order to feel comfortable with the transdisciplinary approach. According to Davies, for new graduates, adapting to this new model is challenging as it is easier for them to practice within the ‘expert model’ and focus on skills of their own discipline (2007: 58). King et al share a similar concern, noting that novice team members often feel most comfortable developing their expertise within traditional disciplinary boundaries (2009: 220).

However, while lack of experience may account for lower levels of confidence to acquire transdisciplinary skills in less experienced team members, Therapist Survey data also reveals that the majority of therapist respondents were highly experienced practitioners. In 2007, the average number of years that therapists had been practising as a therapist was 17 (with more than half having more than twenty years of experience), and in 2008 the average was 11 years. This suggests that lack of confidence to acquire new skills was related to factors other than the experience levels of the therapists.
Conclusion

The three chapters of section 4 address the key research question: What are the elements and practices of supporting transdisciplinary practice in the region? Section 4 explores definitions of transdisciplinary practice, how it is viewed in the Southern ECI service, the time spent by therapists in various elements of this practice and their valuing of these elements. In addition, it discusses therapist views of a range of resources and supports to foster this practice. As discussed below, chapter 14 concludes with an examination of therapist confidence, experiences and preferences of therapists working in transdisciplinary practice.

Therapists indicated a high level of confidence to identify their transdisciplinary skill limitations and were largely confident in seeking support. However, the confidence to acquire these skills was low, with confidence decreasing dramatically between 2006 and 2008. This may in part be due to the lack of supports when needed, while there is also uncertainty over the level and skill required to be transdisciplinary. Interview data identified that time constraints also limit therapist ability to acquire the necessary knowledge and skills.
Section 5:
Discussion and Conclusions
Chapter 15: The bigger picture

Introduction

This research project has sought to contribute to the evidence base in the field of early childhood intervention for children with disabilities. Broadly, the research aimed to provide a range of information exploring the outcomes and practices of the Scope Southern Region Early Childhood Intervention Service. In order to do this, the project also needed to engage with methods of collecting and analyzing information about these outcomes and practices. In particular, an aim of the research was to provide an opportunity for families and therapists involved in the service to participate in this project. This chapter concludes this research study by discussing the key findings and conclusions in regard to the three main research questions of the study. It commences with a discussion of the research methods, their value and limitations.

Reflection on research methods

One of the aims of this study was to develop and trial useful methods of data collection about outcome measurement that may have wider application. As presented in each section of the report, there is considerable discussion in the literature about the complexity and difficulty of undertaking research in this area. Existing methods of data collection and analysis relevant to each research topic of this project were not readily available. This meant that project researchers were required to adapt or develop new methods of data collection for use in this project. Researchers drew on a range of methods, including surveys, recording sheets, planning documents, interviews, and focus groups. These methods aimed to collect the views and experiences of parents and therapists, and capture outcomes for both children and families. Four main methods of data collection will be discussed here, as these have either existing use within the ECI sector, or have the potential for use in other similar research. These methods include:
• The Parent Survey (designed by project researchers but incorporating some items drawn from other published research [King, Rosenbaum & King, 1995]);

• The Family Service and Support Plan (an instrument used widely in ECI services but with the addition of a numeric outcomes scale for review purposes, added by project researchers);

• The FSSP Outcomes and Process document (appended to the FSSP above and developed by project researchers);

• The Therapist Survey (developed by project researchers).

While there is a range of criteria that could be used to guide a discussion of the merits and limitations of research tools (see for example Andresen, 2000 or Horsch, 2005), the below discussion will largely focus on: the effective capture of key concepts (i.e. defining and measuring ‘outcomes’ and ‘transdisciplinary practice’); respondent burden; administration issues to do with data collection and analysis; and, the comparability of findings.

Capturing key concepts: did the research methods capture what we wanted to know?

Defining and measuring outcomes

As discussed earlier, there is no consistent articulation of outcomes in early childhood intervention, nor are there agreed and well documented methods for outcomes measurement. Other researchers have documented some of the problems associated with trying to generate consistency in both regards (Meisels & Shonkoff, 2000). Some of these problems associated with defining and measuring outcomes were also reflected in comments by therapists interviewed as part of this study.
In this study, therapists discussed the nature of outcomes achieved for families, and struggled to define these uniformly. In particular, therapist comments identify the difficulty of generalizing outcomes across diverse family experiences.

It’s going to vary for each family, and what you might focus on to measure as a positive outcome. The fact that they let you into their lives fortnight after fortnight is in itself a positive outcome. This might be seen as tiny but, for that family, it might be incredibly significant (Therapist 08).

Such comments recognise the small, nuanced yet significant changes in family life and coping that are difficult to capture and categorise in outcomes measurement tools. Therapists readily discussed this difficulty:

[Outcomes are] very difficult to define and measure. A lot of our Family Service and Support Plans may not be deemed successful if you just look at them as a piece of paper. But it may be successful in that we can look at the family and say it is successful for what we’ve done ... If we were to look at each individual family we would be able to say ... we’ve now moved to here with the child and the family engaging (Therapist 08).

The complexity and the context driven nature of early childhood intervention means that any attempt to neatly define and evaluate outcomes can never be an exact science. This remains a significant limitation of this study.

Anticipating some of these issues, the approach taken in the study was to opt for the broadest possible definition of outcomes wherever possible, and allow a focus on outcomes for children, parents or families. In this way, it was hoped that outcomes captured would reflect the diversity of definition and experience in the cohort. To this end, the Parent Survey defined outcomes variously: as ‘impacts’ across nine broad life domains; in terms of elements of parent capacity discussed in the literature; in terms of ‘needs met’ by the service; and in terms of parent satisfaction with the service. The Family Service and Support Plan similarly allowed a focus on parent, family or child outcomes which were expressed as ‘goals’ of intervention, and allowed these to be self defined or negotiated between parents and therapists. This led to a breadth of outcome or goal areas which were analysed by using the categories
of the ICF (WHO, 2001) and the life domains framework used in the Parent Survey (Wilson, 2006). These two frameworks of analysis provided information of different types, and raise useful questions about the focus of the service and the outcomes aspired to within it.

While these approaches produced useful data on the subject of outcomes, many issues remain. As therapists discussed above, researchers struggled to categorise goals on FSSPs. Some goals implied multiple categories of expectation, and some didn’t fit easily into any category. More difficult still was the assessment of goal achievement. This was made harder by the small number of completed FSSPs that provided a follow up review or evaluation of goal attainment. It was apparent, from reading goals, that many goals would be relevant throughout a child’s development across many years, and were iterative and developmental in nature. In this sense, quantifying goal achievement was always going to be a near impossible task. Whilst this could be overcome by asking therapists to support families to identify more concrete, atomized goals with clear outcome stages, this feels like an unnecessary imposition and a diminution of the overall meaningfulness of the goal for the family. The measuring of achievement in a quantifiable way is likely to always be flawed: it is based on a possibly false assumption that all goals need to be achieved or completed; that achievement levels are able to be defined and measured; and that achievements are ultimately comparable across goals, individuals, contexts and interventions. In the end, there is evidence that the family and therapist know what is intended and what is achieved, and describe this best when asked to narrate their experience, within a very specific context. In terms of service accountability, this is arguably the primary element of evaluation. Linked to this, is the need to affirm and respect small changes and achievements, and to recognize that measuring outcomes is, at times, overly intrusive in the lives of people.

Of greatest use in the exploration of outcomes, was the identification of enablers and barriers to outcomes that occurred within the Parent Survey, the FSSP Outcomes and Process document, and in interviews with parents and therapists. In all cases, parents provided clear statements of both barriers and enablers, and these were frequently repeated across the respondent group. This data gives clear direction for service improvement and the targeting of strategies and resources to maximise enablers and minimise barriers. The main issue with the written forms of data collection here was that of lack of depth and, sometimes, clarity. For example, parents would frequently identify ‘time’ as a barrier but fail
to expand on this concept within written documents. Interviews assisted in overcoming this issue and providing an interpretive context to such shorthand responses.

**Defining and measuring transdisciplinary practice**

Section four provides a discussion of the various understandings and definitions of transdisciplinary practice. Chief among these, is a focus on ‘collaborative interprofessional teamwork’ (King et al, 2009: 213) as well as multiskilling and ‘role release’ (King et al, 2009:213; Davies, 2997:50) across disciplines other than a therapist’s own. In the absence of other data collection tools, the Therapist Survey was designed by project researchers to explore aspects of these two elements of transdisciplinary practice. Items on the Therapist Survey sought to identify the amount and quality of time spent in collaborative work, and levels of confidence regarding multiskilling and other aspects of transdisciplinary practice. In addition, the Therapist Survey aimed to capture information relating to the service context and the resources and supports available to foster transdisciplinary practice, given these have also been discussed in the literature (McGonigel et al, 1994; King et al, 2009). In particular, items focused on time spent in formal and informal meetings between staff; joint therapy sessions (across disciplines) with clients; and co-ordination of services across therapy staff. While all of these items provided useful information regarding transdisciplinary practice, of particular value was the focus on therapist self assessed levels of confidence in transdisciplinary skills, and the perceived quality of time spent in different interprofessional activities. Whereas data about the amount of time spent in various transdisciplinary practice related activities was interesting, given there are no established benchmarks within the literature for the necessary or optimum level of time required, such data was difficult to interpret in a meaningful way.

Of most value to the study were focus groups and interviews with therapists that enabled researchers to explore therapists’ own understandings and definitions of transdisciplinary practice, and the key factors influencing its effectiveness. A problem with the Therapist Survey was that it was related to concepts within the transdisciplinary practice literature that were not necessarily embraced by the therapists in the service. By contrast, interviews enabled researchers to understand the definitions of transdisciplinary practice accepted by therapists, and the aspects of this practice they rejected. This
approach very quickly introduced a critique to the concept of transdisciplinary practice that would have been missing had the survey, with its reliance on the concepts of the literature, been the only method of data collection in use.

Overall, as discussed elsewhere in this report, this reflection on research methods in relation to exploring key concepts emphasises that concepts involving human interaction and experience will always be difficult to define and measure. Any research method will yield partial and flawed results that rely on critical interpretation by all stakeholders to bring a balanced and nuanced meaning to the object of inquiry.

**Respondent burden and administration issues**

One of the features of several of the data collection methods used in this study was the relatively poor response or usage rate of various instruments. A factor to consider here is that of respondent burden, along with administration issues, discussed below.

The Parent Survey received a response rate of between one fifth to one quarter of the parent group (who accessed services in any of the years 2006 - 2008). In general, parents who completed surveys did so with thoughtfulness, providing written comments at the end of surveys, and with 92% of respondents answering all question items. This suggests two groups of parents; those who chose to participate and, having done so, participated fully, and those who chose not to participate at all. It is not clear what occurred for this latter group and researchers can only surmise that the survey was too onerous, language or cultural elements were not adequately catered for in survey design, or that other life activities (as a parent of a child with a disability) took priority over spending time on survey completion.

Similarly, response rates for the Therapist Survey were not high and decreased each year, being 69% in 2006, 56% in 2007, and 25% in 2008. This may have been related to the mode of administration (i.e. handed to staff in staff meetings for completion in their own time), or to respondent burden (given that therapists uniformly discussed workload and time pressures in interviews).
Finally, completion of the review of Family Service and Support Plans, including the FSSP Outcomes and Process document, was also limited. Each ECIS client had a Family Service and Support Plan drawn up on at least an annual basis, with some clients having several plans in a year. As discussed earlier in the report, researchers amended the FSSP format by adding both a numeric outcomes measurement scale to rate achievement against goals during a review period, as well as the FSSP Outcomes and Process document which listed enablers and barriers to outcomes. These documents were distributed separately to service staff. It was hoped that improving data capture within existing service documentation would prove an effective means of data collection. However, there was an ad hoc and limited use of review documentation. The reasons for this are not clear but could include: ineffective communication to therapists in regards to new FSSP and review documentation; lack of therapist or parent time to complete a formally documented review process; or lack of confidence in, or agreement with, the way outcomes were being measured within these documents. Given the reliance on Family Service and Support Plans as a key feature of service delivery in the ECI sector, it is important to reflect on the extent to which such documents might also effectively capture research and service evaluation data. Further work is needed to address barriers to the effectiveness of this method.

Overall, this study utilized a range of methods of data collection, including some designed to be an integrated part of service delivery (such as the review of FSSPs). Limited response rates and usage patterns for these methods suggest a need to focus on ways to increase respondent participation (both for service staff and clients). Interview data emphasises the time-pressured context of both staff and families, and it is likely that this is a major factor affecting response rates.

**Comparability of data**

A common criteria for designing and evaluating research methods is the extent to which they generate data that can offer meaningful insights by comparisons with existing relevant data (for example, results from other services or other population groups). The literature made clear that there is little such comparable or benchmark data available. This meant that though data was collected, for example in the areas of transdisciplinary practice and outcomes of service, it was difficult to interpret these results in terms of their relationship to other services and the broader field. As a result, this study could not
evaluate whether the service was doing better or worse than other comparable services in relation to the focal areas of the study.

The exception to this was the area of family centred practice, where the use of the MPOC in a range of published studies allows some comparison. Of particular use in this study, was the ability to benchmark the Southern Region results to earlier results (2004) within broader ECI services of Scope. This attests to the value of selecting data collection methods and repeating these within services across years. This kind of comparability, with both prior service data and data from the wider literature, offers the sector key information about family centred practice.

However, given the diversity of services, clients and valued outcomes in this sector, comparability of data may not be an achievable or meaningful element of research methods in this field. For this reason, a focus on comparing results within services across time spans, in order to evaluate the extent of increased achievement and service improvement, may be the most relevant approach.

**Discussion of key findings**

Each section of this report presents the results in relation to each of the three main focuses of this study: outcomes; family centred practice; and transdisciplinary practice. The following section summarises these results and presents discussion in relation to some of the broader issues that have arisen from this study.

**Outcomes**

The study sought to identify and evaluate the outcomes experienced by children and families resulting from ECI services provided by Scope Southern Region. More specifically the research sought to identify and analyse:

- The sorts of outcomes for children ascribed to by families,
• The level of achievement and types of outcomes achieved for children,
• The level of achievement and types of outcomes achieved for families,
• The extent to which service providers and families feel that needs have been met,
• The level of satisfaction parents have with services received, and
• The enablers and barriers to outcomes.

For the purpose of the study, outcomes were assessed according to outcomes for children and outcomes for families. The literature on outcomes examined for this study (see chapter 3) articulates the inter-relatedness of child and family outcomes in that positive outcomes for one will have positive outcomes for the other. Both the types and level of achievement were analysed, with both presenting difficulties in terms of definitions and measurement (as discussed above). In terms of findings, a clear majority of outcome goals for children (an average of 78% across 2007 and 2008) related to function/activity as defined by the ICF (WHO, 2001). The remainder of goals were focused on achievements relating to participation and environment. This emphasis on function was also reflected in the analysis using the life domains framework (Wilson, 2006).

The focus on function may suggest the application of a medical model of intervention rather than a social model. In addition, this focus is not surprising given the age of the children (birth-4 years), as parents are likely to be concerned about maximising the motor and cognitive skills of their child in the early stages of human development. While not explicit, arguably, there is an implied element of participation in that the development of motor and cognitive skills may assist in greater life participation. Perhaps more consideration could be given by therapists and families in making more explicit the links between functional/activity goals and achievements relating to broader participation and environmental change.

In term of levels of achievement of outcomes for children, across 2007 and 2008 just over 50% of goals were either ‘achieved’ or ‘ongoing - progressing well’. Approximately a third were ‘ongoing - continuing’. However, the level of success in achieving goals is not easily interpreted from this data. This quantitative analysis of achievement would suggest a mixture of significant success and an uncertain level of
achievement given the ongoing need to work at certain goals. Given most of the goals were related to cognitive or motor development, this suggests many of these goals will require a long term focus and continuous intervention as progress is made. By contrast, some goals are framed as short term and therefore are more likely to be achieved. Also, no information is available with regard to the degree of disability and the anticipated timeframe for success. Such issues suggest that caution must be exercised in determining the success or not of a service based on statistical criteria, where outcomes may be difficult to quantify and timeframes for anticipated success variable. This highlights the importance of other sorts of data, such as interview data. Such data evidences the overwhelmingly positive view of parents and therapists in regard to outcomes achievement for children.

Similarly, outcomes for families were positive in relation to the measuring of nine life areas and the twelve items relating to parenting capacity. On average across 2007 and 2008, approximately two-thirds of parents reported very positive to positive impacts across life areas particularly in the areas of personal and family wellbeing, social life, educational life and recreational and leisure life. Approximately one third also rated that the service had no impact across various life areas, possibly because goals on FSSPs largely focused on function and parents may not have considered service impact beyond functional intervention. With regard to parenting capacity, only 13% in 2007 and 9% in 2008 saw the service as having no impact in this area with an overwhelming majority regarding the service as having a very positive or positive impact on parenting capacity.

It can therefore be concluded that, generally, the service has provided positive outcomes for children and families. This was supported by high levels of parent satisfaction with the service, as well as overall high support for recommending the service to other families. Despite this, parents also identified areas for improvement in service delivery by identifying both enablers and barriers to positive outcomes.

The enablers and barriers identified by families are broadly consistent with those identified by therapists (see chapters 7 and 8). The major enabler to achieving positive outcomes appears to be adequate resources - this includes the provision of competent and committed therapists to work empathetically with children and families with ongoing, regular therapeutic intervention and family support. Families also highlighted the need for access to equipment to support the child, and the provision of guidance, instruction and associated activities. This relates to issues of empowerment and parenting capacity. For
therapists to provide this service there needs to be adequate opportunities for therapists to engage in joint visits, case discussions and knowledge sharing in relation to both specific clients and ECI more broadly. This also involves working, where necessary, with outside agencies and collaborating effectively with families, case managers and other therapists.

All of this requires time which families recognised as a limitation as they attempted to juggle the various demands in their lives, while therapists were also restricted by time due to the various demands of their workloads. Therapists noted that co-ordination of people and tasks, (such as completing funding applications for families to obtain equipment), meant less time for other therapeutic intervention with the child. Therapists also stressed in interviews that there was often no time for debriefing with colleagues, leaving some therapists feeling overwhelmed. Time pressures are also mentioned in a study by Iacono and Cameron (2009), where Australian speech therapists in early childhood intervention noted time limitations affecting the quality of interventions, significant amounts of unpaid overtime, and the risk of staff burnout. In the current study, this lack of time, and heavy workloads of therapists, may have contributed in some instances to families feeling there was a lack of communication between them and the service.

It should be emphasised that overwhelmingly families praised the skill, empathy and dedication of the therapists. Many of them expressed the way in which they felt therapists had gone out of their way to support families and had demonstrated their commitment to working and collaborating alongside them. Where families had concerns, they felt that service budgetary limitations hampered the extent of the work that could be done and that this was not a fault of the service or individual therapists but was systemic throughout the public sector. Funding issues impact all of the enablers and barriers mentioned above. More adequate funding targeting these key areas could work towards increasing services and better outcomes.

In concluding this discussion on outcomes, it should be noted that fundamentally outcomes are difficult to define and measure. Less weight should be given to quantifiable analysis which can only ever provide a partial and incomplete understanding. In considering what has been achieved by and for children and families, weight has to be given to a more complete story that can only begin to be captured through talking with families and therapists, while considering the rich and complex circumstances of the
intervention and the context in which it takes place. Much of the therapists’ work and achievement was not only related to the FSSP and recorded goals but often involved the unrecorded supports and interventions done for and alongside families. Value needs to be assigned not only to statistical data which offers some guide to the success of intervention, but also a stronger value placed on the narrated experience of families and the critical reflection of practitioners. This is not a scientific paradigm to establish fixed truths but a more sociological one whereby understanding is more nuanced, and based on perspective and context. Together, the statistical measurement and the views and understandings of those involved can provide an insight into ECI, while still recognising that any conclusions are context specific, incomplete and open to interpretation. Like any claim to truth in the human sciences, all such claims can only be partial.

**Family Centred Practice**

The second key research question of this study focused on investigating the extent of family centred practice in use within ECI services provided by Scope Southern Region. In particular, the research sought to identify and analyse:

- How therapists understand family centred practice,
- How parents rate the extent of family centred practice,
- The level of parent involvement in Family Service and Support Plan development,
- The extent of therapists’ familiarity with Family Service and Support Plans.

The study results clearly evidence that family centred practice is a strength of the Southern Region’s Early Childhood Intervention Service. On surveys, parents reported very positive responses in all five domains of family centred practice, and showed an even higher rating than the earlier Scope-wide data collected in 2004. Overall, the highest ranked domain of family centred practice was that of ‘respectful and supportive care’. This was echoed in interviews with parents, where respondents provided affirmations of this type of practice in Scope, and frequent examples of staff delivering highly
personalised and timely support to their child and wider family.

The area judged to be the lowest rating of the domains of family centred practice was that of information provision, relating to both general and specific information. While a substantial majority of parents still rated these areas highly, overall they lag behind the results of the other domains. This is consistent with both the earlier Scope research (2004) and other published literature, discussed in chapter 10. This suggests that ECI services generally still have more work to do in order to better meet the needs and preferences of parents in the area of appropriate, timely and effective information provision. As therapists in this study and authors in the wider literature comment, improved information provision is likely to be a tricky balance between providing to parents a sense of hope for the future, balanced with clear, accurate information about what can be expected in terms of outcomes of intervention and the availability of ongoing supports.

Another indicator of family centred practice is the level of family involvement in the development of Family Service and Support Plans, and the extent of therapist familiarity with and use of these as part of their ongoing practice. Study results evidence a very high rate of involvement of families in the development of FSSPs. However, results also showed mixed levels of therapist familiarity with client FSSPs with some showing a high level of ‘indepth’ knowledge, but most showing ‘good knowledge’. Of particular note here was the 25% or more of therapists in both 2007 and 2008 who had only a limited knowledge (or less) of the FSSPs of their clients. This result sits somewhat at odds with parent and therapist discussions in interviews. In these, therapists were characterised as having significant knowledge about children, their families and life contexts, and were highly valued by parents for this. Some therapists commented on the limitations of the FSSP document, given the fluid and complex contexts in which they worked, and the lack of time available to engage with and update the document. Such comments suggest that therapists are working in family centred ways with a deep understanding of the families with which they work, but that the FSSP document is always going to offer a limited and sometimes limiting capture of, and guide to, this work.
Transdisciplinary Practice

The research sought to examine the elements and practices of supporting transdisciplinary practice in Scope’s Southern Region, mainly through the understandings and experiences of therapists. Specifically, the research sought to identify and analyse:

- How therapists define transdisciplinary practice,
- The degree and type of transdisciplinary work undertaken by therapists,
- The resourcing and support of transdisciplinary work,
- The confidence, experiences and preferences of therapists working in transdisciplinary practice.

To begin with, it is important to consider how therapists define and understand what transdisciplinary practice entails. Therapists indicated in focus groups that their definitions of transdisciplinary practice reflected elements of the literature. They saw the practice as involving a broader knowledge base that went beyond the therapists’ own discipline with an understanding of elements of how other therapists worked, and the way this related to the child and family in a more holistic manner. This also involved skilling families, with families and therapists all sharing knowledge towards common goals. Many elements of transdisciplinary practice - especially in terms of working with families in a family centred manner and sharing knowledge (more informally than formally) - are evident in the Southern ECI Service.

However, therapists also expressed a large degree of discomfort with specific elements of transdisciplinary practice. This was reflected in their preference for the terms ‘collaborative practice’ or ‘knowledge sharing’ to describe their practice approach. Both are elements of transdisciplinary practice but are somewhat more flexible concepts that are more suggestive of team work.

Therapists felt significant unease with the notion of transdisciplinary practice. In many instances, therapists expressed some uncertainty as to what exactly was expected of them within this model of practice. Therapists also expressed concern that clients should receive appropriate and quality services from qualified practitioners in each discipline, and that transdisciplinary practice would disadvantage
clients if therapists were expected to provide an intervention outside of their discipline in lieu of a trained and qualified professional.

While therapists expressed a range of concerns about transdisciplinary practice, overall, ‘role release’ appears to be the element of this practice that therapists were most reluctant to embrace. This discomfort with role release relates to a range of barriers to the implementation of transdisciplinary practice in the Southern ECIS context, discussed below.

Firstly, therapists felt inadequately trained in other disciplines, with limited skills and supervision, to perform interventions outside of their discipline. This is supported by data that shows that the amount of formal meeting time to share knowledge has declined over the period 2006-2008, despite therapists valuing this time as useful. This decline in formal time is countered by the rise in informal time which has increased over the period and is deemed to be of great use. Overall, this data suggests that therapists gain a great deal from being able to share knowledge with one another, but time limitations are reducing the formal time, with therapists having to rely on informal methods (face to face, telephone, email). Therapists rated informal time more highly than formal time, suggesting that being able to share time related to their specific needs may be deemed more valuable than formal time where the agenda is set by others. It may be fair to surmise that the informal time spent in knowledge sharing is focused on how best to support the child and family overall, rather than the development of skills for role release.

As stated during a therapist focus group:

Just like when you do have the time ... how that’s used [is important]. So I think that if occasionally we were able to say at the start of the meeting; ‘list down some clients you want to have a chat about’. And even if you only just have two minute chats, that would be so valuable. So therefore it’s great to do the case studies and have the videos, but in a way it feels like extra to what you’re already doing. I’ve got 20 questions I’ve got to ask of the people that are in the room and you’ve got to get them before they run out the door (Therapist Focus Group 07).

Overall, lack of time is a significant gap in the resourcing of skills acquisition and exchange for role release - particularly when therapists are also finding it difficult to establish the time to speak with one another about their clients. This echoes the literature that highlights the requisite elements of time,
planning, expense and commitment (McGonigel et al, 1994) in order to effectively implement a transdisciplinary model of practice.

Joint visits, where therapists from different disciplines visit the client together, can be considered another aspect of transdisciplinary practice that fosters interprofessional collaborative practice and skills exchange (towards role release). Joint visits are widely viewed by Scope therapists as a valuable learning opportunity to share information, learn skills and find solutions to problems, while ensuring everyone is working towards common goals. Similarly, group therapy activities, where several therapists provide interventions to a group of children with similar needs, were considered valuable opportunities for practical and supported application of knowledge and skills. Despite this, a cautionary tone was struck by one therapist who noted that it can be overwhelming for families to have to deal with more than one therapist at a time, while there is also a need to ensure when therapists do work together that they are suitably matched for a successful working arrangement. However, despite an overall positive summation of joint visits, these opportunities have declined over the period. Generally, the availability of therapists to one another has declined over the course of the study, and in interviews therapists have voiced the need for more support and the need to have greater access to one another in order to foster both collaborative, as well as family centred practice.

The Southern ECI Service has provided a number of resources to support transdisciplinary practice, though budgetary limitations have restricted the amount of support developed and implemented to foster transdisciplinary practice to date. In general, these resources appeared to offer limited support to the role release aspects of transdisciplinary practice. The manual, One Day at a Time, appears to be used by therapists for its regional service contact information rather than for information specific to other disciplines. In this manner, the manual is a useful tool to encourage general knowledge sharing rather than supporting role release skills. Likewise, video and case presentations were regarded as limited in value though, given they were done sporadically, this may affect evaluation of their effectiveness. More regular presentations may serve to develop knowledge and skills over time that would continually be reinforced.

In summary, therapists identify the lack of available time and insufficient resources to undertake transdisciplinary practice to a level that could successfully lead to role release. Therapists also expressed
concerns as to the level of skill required in disciplines other than one’s own, and whether role release is a realistic expectation given the complexity of their interventions and the contexts in which they occur. These barriers may account for therapists’ significant lack of confidence in acquiring transdisciplinary skills with seventy five percent, on average, feeling only ‘somewhat confident’ to acquire skills in a discipline not their own.

In conclusion, it appears that therapists work in a collaborative and knowledge sharing manner that reflects many of the key elements of transdisciplinary practice. Where they do not work in a transdisciplinary manner is in the area of role release – or to put it in more simple terms – a willingness to implement skills of another discipline. In a transdisciplinary model, a service needs to ensure there is adequate time for training and supervision which is difficult given the demands placed on a service to adequately address growing numbers of clients. These demands are evident in Scope’s Southern ECI Service where workloads, the burden of travel across a large region, time limitations, and the complexity of servicing clients, often with difficult personal issues to be addressed, means that the service as a whole - and therapists individually - do not have the time required to fully implement transdisciplinary practice. In short, the time required to train and support therapists, appears to be significantly higher than what the Southern ECI Service is able to provide.

To strive towards achieving transdisciplinary practice requires support from the government and the service system, and the need to consider the workloads of therapists and the challenges they face in working in a transdisciplinary way. A culture of support for transdisciplinary practice in all of its elements requires time and a commitment from therapists, service providers and governments to ensure that transdisciplinary practice effectively meets the needs of families and children. It also means considering the extent to which knowledge sharing can translate into role release and whether this is a desirable and achievable goal. Given the limitations relating to service resources, particularly time constraints, therapists appear to find it challenging to implement the skills of their own discipline let alone that of another. Constant change and the need to update the knowledge and skills of one’s own discipline means that it is difficult to confidently acquire and maintain a level of skill in another discipline. This raises the question that if to be transdisciplinary requires role release, then it is necessary for governments and service providers to consider whether such a practice is viable and achievable.
In this manner, transdisciplinary practice is an *ideal* model of practice, and only one model among many in the ECI field. As McGonigel et al (1994) outline, there are three service delivery models that structure interaction among team members: multidisciplinary, interdisciplinary and transdisciplinary. There are similarities and differences amongst the models and to equivocally state that a team works solely according to one model at all times is problematic. The complex and fluid arrangements between a service, therapists, families and the social environment in which they operate, mean that operating and measuring according to a fixed set of criteria will remain contentious. At best, the ideal remains a goal towards which all parties can strive though may never fully achieve. Models can only provide a guide that can never be a fixed blueprint. Unlike engineering blueprints, models that involve the complexity of human relationships and complex, changing social environments, must be fluid enough to allow those involved to work together in a manner that fits the requirements of all in order to achieve the best outcomes possible.

**Other findings – the story behind the results**

The measurement of key aspects of the Scope Southern Region Early Childhood Intervention Service tells only part of the story. The research has sought to identify and focus on critical areas of ECIS including outcomes, family centred practice and transdisiplinary practice. But there is a bigger story to be told. This story is revealed in interviews with both families and therapists who identify the complexity of their circumstances, revealing an ongoing struggle. While overall, the service provided by Southern has resulted in positive outcomes, a bigger picture frames the Southern story and this broader context needs to be recognised.

The service operates in a context in which three factors are in tension. First, the complex environment of the families receiving services. Practitioners/therapists work with a range of care givers within the family environment including: parents (often where only one is directly present during service delivery); extended family members; siblings; paid and unpaid carers such as family day care providers and respite staff etc. Additionally, families present with complex problems in their lives including housing and income support needs, physical and mental health problems, and parenting issues, among others, in
addition to the complex needs related to raising a child with a disability. In some cases, families are experiencing extreme crisis, such as parents contemplating suicide. As Harrison notes,

Families with a child who has a disability or developmental delay invariably come into early childhood intervention services with diverse and complex needs beyond the need for paediatric therapy. These often include, but are not limited to, grief counselling, respite, financial assistance, education about existing services and assistance to access those services, assistance to managing challenging behaviour, advocacy, companionate or relationship support (Harrison, 2007: 96).

In this context, therapists require a wider skill set not just within the discipline of the ECI field but also related to counselling, social work and other fields, as well as substantial knowledge of other services and referral networks.

Against this is set the second major tension of service constraints related to funding limitations and policy and program parameters. These include high case loads of therapists, significant time spent in travel across a large region, and limited hours per client. Lastly, there a range of ingredients necessary to the delivery of a quality ECI service. These include: service planning (involving a range of therapists and family members); sufficient time spent in face to face service delivery with the client; engagement in follow up activities and sourcing further information; liaison and capacity building with other agencies such as local governments, day care providers and early childhood education services; co-ordination of all the services delivering to the family; involvement in professional development; and time spent in transdisciplinary practice related issues. All this is undertaken within the pressure of the perception that there is a small but important window of time where the child requires intensive support to achieve maximum developmental benefit.

None of these sets of issues is atomised or isolated, but each is interrelated. One set of complexities is overlaid onto another, forming this complex environment in which services are delivered. This environment has been noted in other recent Australian studies (Dodd et al, 2009; Iacomo & Cameron, 2009), including discussion of unpaid overtime undertaken by therapists, the complex and difficult circumstances of families, insufficient funded hours of intervention, and lack of resources to properly focus support on the immediate presenting needs of families (acknowledging that these may not relate
to therapy provision). Not surprisingly, there is often a pervasive sense of impending crisis, for both families and therapists. This raises important issues for the sustainability of service delivery, particularly the need to affirm and recognise the complex and difficult context in which services are delivered, and the toll on both families and staff.

Conclusion

This research sought to explore the effectiveness of an early childhood intervention service. In doing so, it focused on evaluating the service within the accepted practice modes of the early childhood intervention sector, particularly in relation to family centred practice, transdisciplinary practice and the outcomes these contribute to. The results evidence that the Scope Southern Region ECI Service is achieving well in relation to outcomes and family centred practice, while transdisciplinary practice remains a complex field requiring further consideration. In short, the research has evidenced the effectiveness of the service as well as highlighting some areas for improvement and the targeting of future resources. Staff of the service, along with the families they work in partnership with, deserve commendation on these successes. What was most significant to the researchers throughout this study was the admirable way in which therapists worked with families demonstrating their skill and commitment, often under very challenging circumstances.

The issues reported in this study in regard to service improvement, largely relate to a system outside of the specific service. The factors affecting families and their young children with disabilities are complex ones, as is the service and funding environment which is set up to support them. Early childhood intervention occurs in this multifaceted environment. This observation is not new and has been developed previously by Bronfenbrenner (1979) who notes the nested systems or contexts that influence child and family development. However, in pursuing a focus on improvement in the ECI sector, it is possible that this broader ecological analysis has been lost in the focus on specific ECI practices such as family centred and transdisciplinary practice. The broader conclusions of this study suggest that to best aid families, and to best resource therapists in ECI, further attention needs to be refocused on broader societal and systems change.
The following considerations summarise key areas for future action.

**Considerations for service delivery**

1. **Meeting the complex needs of families:** The study makes clear that the needs of families are complex and frequently crisis-driven, and that early childhood intervention staff needs skills and knowledge well beyond therapeutic disciplines to address these. To adequately meet these needs, services require specific resources to support early childhood intervention staff such as identified social work, counselling, and/or community work personnel with expertise in the area of working with vulnerable families. While it could be argued that such resources are or should be located elsewhere in the broader service system, this study shows that therapists are unable to access these resources sufficiently, and that barriers of time and knowledge function to hamper this access. Co-location of such resources within ECI services would assist in overcoming these barriers.

2. **Transdisciplinary practice:** While transdisciplinary practice is a stated element of early childhood intervention endorsed by the Victorian State Government (Early Years Service, DHS, 2005), this study has identified a range of difficulties with its implementation. As a result, services and governments need to review the expectations around the implementation of transdisciplinary practice, identifying what is realistic and appropriate, given the resources available to support its effective implementation. The study suggests multiple concerns with transdisciplinary practice, especially in the area of role release, and a clear preference of early childhood practitioners, in this service at least, for a focus on collaborative practice and knowledge sharing rather than role release.

3. **Managing workload, funding and quality service:** The staffing model used in the Southern ECI Service requires staff to be able to ‘bill’ eighty percent of their time as delivery of services to funded clients. This notion of ‘billable hours’ means that not only direct service delivery to clients is included, but all activity related to direct service such as travel time, time spent in developing resources or strategies, time spent in upskilling, and information searches related to
the client, is also ‘billed’ against the client’s funded total hours of service delivery. Respondents in this study raised many concerns with this approach, not least the impact on clients and the impacts on the overall quality of service. Given that therapists are restricted in how much time they can spend on any aspect of an intervention, they therefore have to ration their time, selecting some aspects of an intervention and sacrificing others (such as spending time developing a customised resource, or researching the latest evidence in relation to a proposed technique). Overall, this approach to the management of service delivery runs counter to achieving the best quality service possible, and results in a rationed and ‘pared down’ service.

Similarly, this workload allocation model also undermines interprofessional and collaborative work, as well as ongoing professional development. This study repeatedly identified examples of these activities being restricted or denied due to the requirement to spend almost all paid work hours in the delivery services, without adequate allocation of time to the professional needs of staff as part of this service delivery role.

4. **Recognising and affirming work to achieve outcomes for families and children that go beyond ‘functioning’**: While this study found that goals documented as part of Family Service and Support Plans were predominantly focused on areas of ‘functioning’ of the child, therapists and families both frequently discussed the undocumented areas of work related to achieving outcomes in the area of family life, wellbeing, mental health, finances, and social participation, among others. In many instances, these areas were considered to be of immediate importance and therefore took precedence over other stated goals. In most cases, these were not documented or evaluated though ECI staff spent much of their intervention time on these necessary tasks. While there is an argument to suggest that such priorities and goal areas are too personal and sensitive to be formally documented, and that to do so would breach trust and privacy of families, greater valuing, recognition, and resourcing of this work is required within services.

In conclusion, this study shows that the Southern Region Early Childhood Intervention Service is effective in meeting the needs of children with disabilities and their families. As with all human service
delivery, there is room for improvement in some areas. However, comments from families and therapists suggest that improvements are unlikely to occur without additional funding and resources. Without these, it is unlikely that the good results achieved here can be sustainable in the long term, given they rely on practitioners/therapists and families going above and beyond their personal and professional resources.


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Scope, (2011),


Wilson, E. (2006), Defining and measuring the outcomes of inclusive community for people with disability, their families and the communities with whom they engage, in C Bigby, C Fyffe & J Mansell (Eds), From Ideology to reality: current issues in implementation of intellectual disability policy, Proceedings of the Roundtable on Intellectual Disability Policy, La Trobe University, Bundoora.


Appendices
Appendix i

Parent Survey (2007 and 2008 version) – Scope Southern Region ECIS Research
PARENT / CARER SURVEY – SCOPE SOUTHERN REGION ECIS RESEARCH

INSTRUCTIONS

This survey asks a range of questions about:

- The quality of the service you have received from Scope
- The outcomes and impact of the service you have received from Scope
- Your overall satisfaction with the service from Scope.

Section 1: Quality of service

We would like to know about your perceptions of the care you have been receiving from your child’s Scope Early Childhood Intervention (ECI) service.

The questions in this section are based on what parents, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn’t happen) to you at your Scope ECI service. You are asked to answer each question on a scale from 7 (To a Great Extent) to 1 (Never).

The care that you and your child receive from the Scope Early Childhood Intervention Service may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. **PEOPLE:** refers to those individuals who work directly with you or your child.
   
   These may include physiotherapists, occupational therapists, speech pathologists and psychologists, family service coordinators etc

2. **SERVICE:** refers to all staff from the Scope ECI service, whether involved directly with your child or not.
   
   In addition to therapists they may include support staff such as office staff, administrative personnel, etc.

We would like you to think of the service you have received overall, across all the staff involved. However, if you feel that it is more sensible to divide your comments and report on different staff separately, please contact Robert Campain on 8311 4013 to obtain further survey forms.
INSTRUCTIONS CONTINUED

The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

Indicate how much each event or situation happens to you.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES ...</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>... provide you with clear instructions on how to complete them?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

If you circled #7 (To a Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If your circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.
**Section 1: Please answer the following questions**

We would like you to think about your experiences with Scope ECI services during 2006. We are interested in your personal thoughts. We would like you to answer this questionnaire without discussing it with any Scope staff members.

For each question, please indicate how much the event or situation happens to you by circling one number (from 1 to 7) that you feel best fits your experience.

**PEOPLE** refers to those individuals who work directly with you or your child. These may include physiotherapists, occupational therapists, speech pathologists and psychologists, family service coordinators etc.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD ...</th>
<th>Indicate how much this event or situation happens to you at Scope</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>To a Great Extent</td>
</tr>
<tr>
<td>1. ... suggest therapy plans that fit with your family’s needs and lifestyle?</td>
<td>7</td>
</tr>
<tr>
<td>2. ... offer you positive feedback or encouragement (e.g., in carrying out a home program)?</td>
<td>7</td>
</tr>
<tr>
<td>3. ... take the time to establish rapport with you or your child when changes occur in your services?</td>
<td>7</td>
</tr>
<tr>
<td>4. ... make sure that your child’s skills are known to all persons working with your child, so the skills are carried across services and service providers?</td>
<td>7</td>
</tr>
<tr>
<td>5. ... tell you about options for treatment or services for your child (e.g., equipment, school, therapy)?</td>
<td>7</td>
</tr>
<tr>
<td>6. ... provide ideas to help you work with the health care “system”?</td>
<td>7</td>
</tr>
<tr>
<td>7. ... recognize the demands of caring for a child with special needs?</td>
<td>7</td>
</tr>
<tr>
<td>8. ... trust you as the “expert” on your child?</td>
<td>7</td>
</tr>
</tbody>
</table>
### Indicate how much this event or situation happens to you at To a Great Extent

<table>
<thead>
<tr>
<th>Event</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. ... look at the needs of the “whole” child (e.g., at mental, emotional, and social needs) instead of just at physical needs?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>10. ... show sensitivity to your family’s feelings about having a child with special needs (e.g. your worries about your child’s health or function?)</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>11. ... remember personal details about your child or family when speaking with you?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>12. ... follow up at the next appointment on any concerns you discussed at the previous one?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>13. ... make sure that at least one team member is someone who works with you and your family over a long period of time?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>14. ... provide opportunities for you to make decisions about services?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>15. ... tell you about the results from assessments?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>16. ... provide a caring atmosphere rather than just give you information?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>17. ... tell you details about your child’s services, such as the reasons for them, the type of therapies and the length of time?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>18. ... treat you as an individual rather than as a “typical” parent of a child with a disability?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...</td>
<td>Indicate how much this event or situation happens to you at</td>
<td>Scope</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
<td>-------</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To a Great Extent</td>
<td>Sometimes</td>
<td>Never</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>19. ... develop both short-term and long-term goals for your child?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>20. ... plan together so they are all working in the same direction?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>21. ... make sure you have opportunities to explain what you think are important treatment goals?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>22. ... make you feel like a partner in your child’s care?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>23. ... provide you with written information about your child’s progress?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>24. ... seem aware of your child’s changing needs as he/she grows?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>25. ... make themselves available to you as a resource (eg. emotional support, advocacy, information)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>26. ... give you information about your child that is consistent from person to person?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

Please continue to the next page...
**SERVICE** refers to all staff from Scope ECI Service, whether involved directly with your child or not. In addition to therapists, these people may include support staff such as office staff, administrative personnel, etc.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT DOES THE SERVICE:</th>
<th>Indicate how much this event or situation happens to you at Scope</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>To a Great Extent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. ... make information available to you in various forms, such as a booklet, kit, video, etc.?</td>
<td>7  6  5  4  3  2  1  0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. ... give you information about the types of services offered by Scope or in your community?</td>
<td>7  6  5  4  3  2  1  0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. ... notify you about the reasons for upcoming case conferences, meetings, etc., about your child?</td>
<td>7  6  5  4  3  2  1  0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. ... have information available about your child’s disability (e.g., its causes, how it progresses, future outlook)?</td>
<td>7  6  5  4  3  2  1  0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. ... provide opportunities for the entire family to obtain information?</td>
<td>7  6  5  4  3  2  1  0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 2: Outcomes and impacts of service

The following questions ask about some areas in which the Scope ECIS program may have had an impact, either positive or negative, on your child and family.

You are asked to answer each question on a scale from 5 (Very Positive Impact) to 1 (Very Negative Impact).

<table>
<thead>
<tr>
<th>In each of the following life areas, rate the extent to which the Scope ECIS program has had an impact on your child and family …</th>
<th>Very positive Impact</th>
<th>Positive impact</th>
<th>No impact</th>
<th>Negative impact</th>
<th>Very negative impact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal and family wellbeing</strong> That is, in the area of health, happiness, mobility, communication, doing things more independently.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Social life</strong> That is, in the area of friendship and relationships, getting along with others and community involvement.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Political life</strong> That is, in the area of having a say about things that affect you (eg in a local service or community group, about your area, school, funding etc).</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Cultural life.</strong> That is, being involved in cultural activities (eg. arts, music, theatre, dance at any level). This might be through attending activities or playing an active part. Or being part of your own cultural group.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Recreational and leisure life</strong> That is, being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Economic life</strong> That is in terms of your family’s finances, employment or business.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Educational life</strong> That is, learning and problem solving, being part of educational programs for your child or family (eg kinda or parent education).</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Spiritual life</strong> That is, any aspect of your family’s religious or spiritual activities.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Your environment</strong> That is, your family’s access to and enjoyment of public spaces (eg parks, pools, theatres, shopping centres, public transport etc) or your own private space (eg. your home). Making environments you use more accessible and appropriate (eg playgroups, kindergartens, library, etc).</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
We are also interested in whether the support and/or service you received through the Scope ECIS program has had an impact, either positive or negative, on your skills and confidence in the parenting of your child.

Again, you are asked to answer each question on a scale from 1 (Very Negative Impact) to 5 (Very Positive Impact).

<table>
<thead>
<tr>
<th>In each of the following areas, rate the extent to which the Scope ECIS program has had an impact on you as a parent….</th>
<th>Very positive impact</th>
<th>Positive impact</th>
<th>No impact</th>
<th>Negative impact</th>
<th>Very negative impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing how to help your child grow and develop</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Working with others to solve problems with your child when they happen</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Getting information to help you better understand your child</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Working with agencies and professionals</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Knowing what services your child needs</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Understanding the service system your child is involved in</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Feeling effective and competent as a parent</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Knowing how to play and have fun with your child</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Feeling confident in parenting your child</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Feeling confident that you are an expert on your child</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Using resources in your community</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Having ideas and strategies to support your child</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
You may remember that earlier in the year, you worked with a Scope staff member (a key worker or therapist) to develop a Family Service and Support Plan (FSSP) that identified goals and actions.

To what extent did you feel you directed the selecting and setting of goals in the Family Service and Support Plan? (please circle)

To a great extent                      To some extent                      Not at all

We are interested in finding out about the things that affected the level of outcomes or achievement of the goals you identified for your child and family for this year.

What helped you / your child achieve the goals you identified this year? (please write a comment)

(For example: people, activities, equipment/aids/resources, money, environment, policies, time, etc.
Which of these was the biggest help?)

What has stopped you / your child achieve the goals you identified this year? What made achieving the goals more difficult?

(For example: people, activities, equipment/aids/resources, money, environment, policies, time, etc.
Which of these was the biggest problem or barrier?)
Section 3: Satisfaction

Finally, the following question asks about your overall satisfaction with the Scope ECIS program.

In an overall sense, are you satisfied with the service you received?
- Very satisfied
- Mostly satisfied
- Indifferent / No opinion
- Quite dissatisfied / not satisfied at all

Would you recommend the program to others?
- No, definitely not
- No, probably not
- Not sure
- Yes, probably
- Yes, definitely

To what extent has the program met your needs?
- None met
- Only a few met
- Most met
- All met

Would you like to tell us anything else, or do you have any other comments?

Thank You For Your Time
## EARLY CHILDHOOD INTERVENTION SERVICES

### FAMILY SERVICE AND SUPPORT PLAN – SCOPE SOUTHERN REGION

<table>
<thead>
<tr>
<th>NAME:</th>
<th>DATE OF PLAN:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB:</td>
<td>DATE OF REVIEW:</td>
</tr>
</tbody>
</table>

### Participants:

### CURRENT SITUATION

<table>
<thead>
<tr>
<th>Weekly activities</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other regular activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

250
<table>
<thead>
<tr>
<th>What we would like</th>
<th>How it will happen</th>
<th>Who will be involved</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Codes for outcome of goals:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Goal Achieved</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Goal Ongoing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>i) Progressing well</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>ii) Moderate progression</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>iii) Continuing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3. Goal Changed (reason)</td>
</tr>
</tbody>
</table>

Prepared by: signature (name)

Parent signature (name in brackets)

Parent signature (name in brackets)
<table>
<thead>
<tr>
<th>Item</th>
<th>Existing &amp; Ordered equipment (note if on order and order date)</th>
<th>Additional info (location/setting it will be used, funding/ownership)</th>
<th>Further/New Needs</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroller/wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seating (e.g. dining, lounge…)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bath/showering</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change Facilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifting equipment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car seating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toilet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix iii

Review of FSSP Outcomes and Process document (as attached to FSSP)

To be completed by the therapist and family following completion of the FSSP. Please attach to the plan and return to administration.

Client Name______________________  Therapist Model______________________

<table>
<thead>
<tr>
<th>What is working – enablers to success</th>
<th>What’s not working – barriers to success</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prompts:</td>
<td>Prompts:</td>
</tr>
<tr>
<td>- People, activities, equipment/aids/resources, finances, environment, policies, time etc. What else?</td>
<td>- People, activities, equipment/aids/resources, finances, environment, policies, time etc. What else?</td>
</tr>
<tr>
<td>- Which of these was the biggest help?</td>
<td>- Which of these was the biggest problem/barrier?</td>
</tr>
</tbody>
</table>

What further change/action needs to occur to ensure a positive outcome?

Further Comments
Appendix iv

Therapist Survey

Southern Region ECI Service

Therapist Survey – Knowledge Sharing

1. How long have you been practicing as a therapist? (Equivalent number of years – i.e. exclude any breaks from practice).

_________

2. On average, how many hours a fortnight are you employed by Scope Southern Region?

_________

3. How many hours of formal supervision from your line supervisor or discipline supervisor have you received in the last 3 months?
   
   None less than 1 hour 1-3 hours more than 3 hours

4. How would you rate the availability of other therapists to you (to ask questions, share knowledge) in the last 4 weeks?
   
   Always Frequent Sometimes Rarely Never
   Available available available available available

5. In the last 4 weeks, how many ECIS clients have you had in your case load?

_________

6. In the last 4 weeks, what is the total amount of hours you have spent meeting with another Scope Southern Region therapist or family service co-ordinator to discuss clients or service delivery to the clients in your case load?

   - time spent in formal meetings
     
     none less than 1 hr 1-3 hrs 4-6 hrs more than 6+

   - time spent in informal meetings/discussion (including emails etc)
     
     none less than 1 hr 1-3 hrs 4-6 hrs more than 6+

   - time spent co-ordinating the activity between therapists to clients
     
     none less than 1 hr 1-3 hrs 4-6 hrs more than 6+

   - time spent in joint visits to clients
     
     none less than 1 hr 1-3 hrs 4-6 hrs more than 6+
7. How do you rate the quality of this time to sharing knowledge relevant to work with the client (including knowledge of other disciplinary approaches)?

- Quality of time spent in formal meetings
  Not of any use  Of some use  Useful  Somewhat useful  Very useful

- Quality of time spent in informal meetings/discussion (including emails etc)
  Not of any use  Of some use  Useful  Somewhat useful  Very useful

- Quality of time spent co-ordinating the activity between therapists to clients
  Not of any use  Of some use  Useful  Somewhat useful  Very useful

- Quality of time spent in joint visits to clients
  Not of any use  Of some use  Useful  Somewhat useful  Very useful

8. To what extent are you acquainted with the FSSP of the clients in your client case load?

<table>
<thead>
<tr>
<th>Have no knowledge of most FSSP’s</th>
<th>Have limited knowledge of most FSSP’s</th>
<th>Have good knowledge of most FSSP’s</th>
<th>Have indepth knowledge of most FSSP’s</th>
</tr>
</thead>
</table>

9. To what extent do you feel confident about your ability to:

- identify your limitations (within working in a transdisciplinary team)
  Not confident  Somewhat confident  Confident  Very Confident

- seek support (to work in a transdisciplinary way)
  Not confident  Somewhat confident  Confident  Very Confident

- acquire skills in discipline areas not your own (within ECI Services)?
  Not confident  Somewhat confident  Confident  Very Confident

Are there any further comments you wish to make?

Thank You

For further information please contact either Robert Campain or Erin Wilson on 8311 4013.
Appendix v

Record Sheet - Manual Usage

One Day at a Time

Table: Record Sheet – Southern ECI Service

<table>
<thead>
<tr>
<th>Categories of the manual</th>
<th>Times used in last fortnight</th>
<th>source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For own use</td>
<td></td>
</tr>
<tr>
<td>Local Govt &amp; community resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family-Centred Practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Service &amp; Support Plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Empowerment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic Specific Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dev Stage Checklists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dev Activity Sheets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Songs/Toys</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home-made Items</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful Signs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition Info</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grieving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Camera</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: ‘For Own Use’ refers to checking information primarily used for the therapist’s knowledge to aid in supporting the family/child. ‘Given to Families’ refers to information sheets provided to the family.
Appendix vi

Parent rated impact of ECI service on life areas (from annual Parent Survey)

Average rating on each life area i.e. the average of the scores of all family responses in each life area.

Note: average ratings reflect scores where 1 = highest positive impact and 5 = lowest negative impact

<table>
<thead>
<tr>
<th>Life domains</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average score</td>
<td>Lowest rating</td>
</tr>
<tr>
<td>Personal and family wellbeing</td>
<td>1.7</td>
<td>4</td>
</tr>
<tr>
<td>Social life</td>
<td>2.1</td>
<td>4</td>
</tr>
<tr>
<td>Political life</td>
<td>2.2</td>
<td>3</td>
</tr>
<tr>
<td>Cultural life</td>
<td>2.3</td>
<td>3</td>
</tr>
<tr>
<td>Recreational and leisure life</td>
<td>1.9</td>
<td>4</td>
</tr>
<tr>
<td>Economic life</td>
<td>2.3</td>
<td>5</td>
</tr>
<tr>
<td>Educational life</td>
<td>1.9</td>
<td>4</td>
</tr>
<tr>
<td>Spiritual life</td>
<td>2.5</td>
<td>3</td>
</tr>
<tr>
<td>Your environment</td>
<td>2.0</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix vii

Parent rated impact of ECI service on parenting capacity (from annual Parent Survey)

Average rating on each item for parenting capacity (i.e. the average of the scores of all family responses in each item).

Note: average ratings reflect scores where 1 = highest positive impact and 5 = lowest negative impact.

<table>
<thead>
<tr>
<th>Item</th>
<th>2007</th>
<th></th>
<th></th>
<th>2008</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average</td>
<td>Lowest</td>
<td>Highest</td>
<td>Average</td>
<td>Lowest</td>
<td>Highest</td>
</tr>
<tr>
<td></td>
<td>score</td>
<td>rating</td>
<td>rating</td>
<td>score</td>
<td>rating</td>
<td>rating</td>
</tr>
<tr>
<td>Knowing how to help your child grow and develop</td>
<td>1.6</td>
<td>3</td>
<td>1</td>
<td>1.7</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Working with others to solve problems with your child when they happen</td>
<td>1.7</td>
<td>3</td>
<td>1</td>
<td>1.9</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Getting information to help you better understand your child</td>
<td>1.9</td>
<td>3</td>
<td>1</td>
<td>1.8</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Working with agencies and professionals</td>
<td>1.8</td>
<td>4</td>
<td>1</td>
<td>1.8</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Knowing what services your child needs</td>
<td>1.7</td>
<td>3</td>
<td>1</td>
<td>1.8</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Understandings the service system your child is involved in</td>
<td>1.8</td>
<td>4</td>
<td>1</td>
<td>1.8</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Feeling effective and competent as a parent</td>
<td>1.7</td>
<td>3</td>
<td>1</td>
<td>1.6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Knowing how to play and have fun with your child</td>
<td>1.6</td>
<td>3</td>
<td>1</td>
<td>1.5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Feeling confident in parenting your child</td>
<td>1.7</td>
<td>4</td>
<td>1</td>
<td>1.7</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Feeling confident that you are an expert on your child</td>
<td>1.7</td>
<td>3</td>
<td>1</td>
<td>1.6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Using resources in your community</td>
<td>2.0</td>
<td>4</td>
<td>1</td>
<td>1.9</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Having ideas and strategies to support your child</td>
<td>1.6</td>
<td>3</td>
<td>1</td>
<td>1.5</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
### Percentage of parent response on each item organised by domains of family centred practice

#### Enabling and Partnership

<table>
<thead>
<tr>
<th>Question number on survey</th>
<th>Question item</th>
<th>Year</th>
<th>To a great extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>... make you feel like a partner in your child's care?</td>
<td>2008</td>
<td>63.2</td>
<td>36.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>69.2</td>
<td>19.2</td>
<td>7.7</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>30.4</td>
<td>30.4</td>
<td>21.7</td>
<td>13.0</td>
</tr>
<tr>
<td></td>
<td>... provide opportunities for you to make decisions about services?</td>
<td>2008</td>
<td>47.4</td>
<td>21.1</td>
<td>21.1</td>
<td>10.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>44.0</td>
<td>32.0</td>
<td>20.0</td>
<td>4.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>26.1</td>
<td>39.1</td>
<td>4.3</td>
<td>17.4</td>
</tr>
<tr>
<td></td>
<td>... offer you positive feedback or encouragement (e.g., in carrying out a home program)?</td>
<td>2008</td>
<td>52.6</td>
<td>42.1</td>
<td>5.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>65.4</td>
<td>15.4</td>
<td>11.5</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>34.8</td>
<td>39.1</td>
<td>17.4</td>
<td>8.7</td>
</tr>
<tr>
<td></td>
<td>... make sure you have opportunities to explain what you think are important treatment goals?</td>
<td>2008</td>
<td>50.0</td>
<td>27.8</td>
<td>11.1</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>57.7</td>
<td>23.1</td>
<td>7.7</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>26.1</td>
<td>34.8</td>
<td>13.0</td>
<td>13.0</td>
</tr>
<tr>
<td></td>
<td>... tell you details about your child’s services, such as the reasons for them, the type of therapies and the length of time?</td>
<td>2008</td>
<td>47.4</td>
<td>31.6</td>
<td>10.5</td>
<td>10.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>42.3</td>
<td>23.1</td>
<td>23.1</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>30.4</td>
<td>21.7</td>
<td>13.0</td>
<td>13.0</td>
</tr>
<tr>
<td></td>
<td>... tell you about options for treatment or services for your child (e.g., equipment, school, therapy)?</td>
<td>2008</td>
<td>36.8</td>
<td>26.3</td>
<td>26.3</td>
<td>10.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>42.3</td>
<td>30.8</td>
<td>15.4</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>30.4</td>
<td>26.1</td>
<td>13.0</td>
<td>8.7</td>
</tr>
<tr>
<td>Question number on survey</td>
<td>Question item</td>
<td>Year</td>
<td>To a great extent</td>
<td>Sometimes</td>
<td>Never</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>------</td>
<td>-------------------</td>
<td>-----------</td>
<td>-------</td>
<td>----------------</td>
</tr>
<tr>
<td>28</td>
<td>... give you information about the types of services offered by Scope or in your community?</td>
<td>2008</td>
<td>55.6</td>
<td>16.7</td>
<td>16.7</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2007</td>
<td>30.8</td>
<td>19.2</td>
<td>19.2</td>
<td>15.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td>26.1</td>
<td>13.0</td>
<td>17.4</td>
<td>13.0</td>
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<td>... make information available to you in various forms, such as a booklet, kit, video, etc.?</td>
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<td>... provide opportunities for the entire family to obtain information?</td>
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<td>... have information available about your child’s disability (e.g., its causes, how it progresses, future outlook)?</td>
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Providing specific information

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<td>... look at the needs of the “whole” child (e.g., at mental, emotional, and social needs) instead of just at physical needs?</td>
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<td>... make sure that your child’s skills are known to all persons working with your child, so the skills are carried across services and service providers?</td>
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<td>... recognize the demands of caring for a child with special needs?</td>
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<td>... develop both short-term and long-term goals for your child?</td>
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<td>... take the time to establish rapport with you or your child when changes occur in your services?</td>
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<td>... show sensitivity to your family’s feelings about having a child with special needs (eg. your worries about your child’s health or function?)</td>
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<td>... make sure that at least one team member is someone who works with you and your family over a long period of time?</td>
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<td>... suggest therapy plans that fit with your family’s needs and lifestyle?</td>
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<td>... provide a caring atmosphere rather than just give you information?</td>
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<td>... remember personal details about your child or family when speaking with you?</td>
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