EVALUATING PARENT-PROFESSIONAL PARTNERSHIP: PARTNERSHIP AS PERCEIVED BY PARENTS OF AN EARLY INTERVENTION SERVICE FOR CHILDREN WITH A DIAGNOSIS OF AUTISM SPECTRUM DISORDER WITHIN A CITY HEALTH BOARD AREA OF THE REPUBLIC OF IRELAND

Rachel Mallia Borg, B.Sc. (Hons.), M. Ed.

Abstract
The importance of parents and professionals working in partnership has been discussed in academia for many years. However, professionals and parents today face several challenges when working together in the area of services for children with disabilities. A qualitative study was conducted, using a case study approach, to explore the perceptions of parents in an early intervention service for children with a diagnosis of Autism Spectrum Disorder. This service fell within a city health board area in the Republic of Ireland. Postal questionnaires were completed by thirty parents and semi-structured interviews were held with six mothers whose child had previously availed of the service, in order to explore parents’ views of the parent-professional partnership relationship. Participants identified the following six themes when discussing the topic of parent-professional partnership:

Communication, Equality, Mutual Trust and Respect, Personal Qualities, Commitment and Service Provision. Analysis revealed that parents appreciated professionals who communicated effectively, demonstrated commitment and understanding, promoted equality and valued the family. Service provision had an impact on the way parents and professionals worked together; suggesting that aspects such as the quantity of service also affected the partnership.

Introduction
‘Parent-Professional Partnership’ has been defined as a method of working involving both parents and professionals (Dempsey and Dunst, 2004). It implies working together on a particular assignment, to reach a particular objective by sharing decisions, collaborating and having a good relationship (Dale, 1996). This type of relationship has been increasingly mentioned as a recommended practice in successful service delivery for children with disabilities (White, 2002). Yet parents and professionals working together in partnership may not often be evident in practice (Keen, 2007). Whilst research has tended to focus on the satisfaction or dissatisfaction of parents working in partnership with professionals (Pinkus, 2005), few studies have concentrated on the perceptions of parents of children with Autism Spectrum Disorder (ASD) working with various early intervention professionals. In light of this relatively new way of looking at parent-professional partnership, the main aim of this case-study was to ascertain the experiences and opinions of parents of children with a diagnosis of ASD, who had previously worked with various professionals in an early intervention service.

Method
It was maintained that the use of both postal ‘questionnaires’ and ‘semi-structured interviews’ were best suited for this study.

Sampling Technique
‘Purposive’ and ‘criterion based’ sampling were chosen as the most appropriate sampling strategy. This method involves the purposeful selection of participants that meet some criterion to provide significant information that cannot be obtained from other alternatives (Guba and Lincoln, 1985). In this research the stipulated criteria were parents (mother/father) or guardians whose child was aged between two to five years at the time of service; had a previous diagnosis of ASD from a clinical practitioner; had previously attended the early intervention service; attended for at least three months; attended between September, 2007 and December, 2008.

Participants
Parents or guardians who met the above criteria were considered for this study. The catchment area for these participants covered three counties in the Republic of Ireland. For the first
phase of the study, all participants who met the above criteria received a questionnaire. In total forty-five participants met the above criteria, with thirty of the participants returning the questionnaire. In terms of parents, four were fathers and the rest mothers. Members of the above group, who had never worked with the researcher, were then considered for participation in the second phase of the study: the semi-structured interview. Those participants who demonstrated an interest in participating were then categorised according to the location of their address. Two participants were selected randomly from each county to ensure a dispersed sample. Selecting more than one participant from any given neighbourhood was avoided. Six participants were chosen in total, all of which were mothers.

Procedure

Phase One: The Questionnaire
The identified participants received a letter of introduction from the early services team, an information sheet from the researcher and a questionnaire form in an envelope. Participants were asked to fill in and return the questionnaire if they wished to be involved in the study.

The questionnaire consisted of statements categorised into themes. The statements in each of these sections were presented using five-point Likert items. An open-ended statement, “Feel free to comment”, was used to end each section. Each section asked respondents to indicate the degree to which they agreed with the statements. Participants were allowed to choose “no opinion” if they felt that this reflected their views. The statements related to the working relationship between parents and professionals. Space was provided at the end of the questionnaire for respondents to add any additional information. Completion was likely to take forty-five minutes.

Phase Two: The Semi-Structured Interview
Six weeks after the questionnaire was sent out, a subset of the initial participants received a further introductory letter from the early services team, an information sheet from the researcher and an ‘Expression of Interest’ form. The introductory letter introduced the second part of the study. If participants were interested in participating in the study, they were asked to return the ‘Expression of Interest Form’ to the researcher. From the pool of participants who returned this form, the appropriate candidates were then selected. Those participants, who had not been selected, based on the sampling criteria, received a letter from the researcher informing them of this and thanking them for their interest.

At the beginning of the interview meeting, the information contained in the information sheet was reviewed with the participant. Participants were then asked to sign a consent form. They were also informed about the duration of the interview, which was approximately one hour. The interview was conducted using a ‘semi-structured’ format.

The questions used to guide the interview had been developed based on the aim of the research, the literature, questionnaire results and discussion with other professionals working in the area of early intervention. The wording and order in which the questions were asked were changed depending on how the interview progressed (Corbetta, 2003).
The format allowed for further clarification, explanation and probing when new views and opinions emerged (Gray, 2009).

Data Analysis

Questionnaire Content

Statistical analysis of the questionnaire data was performed using the ‘Statistical Package for the Social Sciences’, version 11.0. Replies were entered into a computer and analysed on a frequency distribution basis of responses leading to a percentage calculation of responses for each statement. Twenty-two of the thirty participants made qualitative comments in the open-ended statement at the end of most sections in the questionnaire. These comments indicated possible issues for the researcher to probe during the interview stage of the research process. Common statements for many of the participants included:

1. Dissatisfaction with the amount of clinical input provided by the early services team; and
2. Satisfaction with the empathic skills demonstrated by the professionals.

The importance of working in partnership with parents, by listening to their opinions, was stressed by most participants in the final section of the questionnaire. The analysed data were used from the completed questionnaires as a guide to further refine information gathering during the interview process. Conversely, ‘data display’ consists of organising the information obtained to provide easy access for drawing conclusions and giving recommendations (Miles and Huberman, 2002). The themes and their associated sub-categories are illustrated below. An explanation of the findings, referred to as ‘Conclusion drawing’ (Miles and Huberman, 2002) is presented thereafter. Alternatively, ‘verification’ (Miles and Huberman, 2002) refers to the process of verifying the findings by constantly checking the data. Reliability was verified throughout the study by using a variety of strategies, including verbatim transcripts and member checks (Patton, 2002). Prior to analysis, verbatim transcripts were sent to the participants to check the authenticity of the work.

Findings of Analysis

Table 1 below provides an overview of the six themes that emerged from the data, including their definition, along with their respective sub-categories.
Table 1
Six Themes of Parent-Professional Partnership with Related Sub-categories

<table>
<thead>
<tr>
<th>Themes and Definitions</th>
<th>Sub-categories</th>
</tr>
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<tbody>
<tr>
<td>Communication:</td>
<td>• Frequent</td>
</tr>
<tr>
<td>Professionals</td>
<td>• Positive</td>
</tr>
<tr>
<td>communicated</td>
<td>• Honest</td>
</tr>
<tr>
<td>information to parents</td>
<td>• Understandable</td>
</tr>
<tr>
<td>in a way that was positive, understandable and respectful. Communication between parents and professionals was useful, honest and frequent.</td>
<td></td>
</tr>
<tr>
<td>Equality:</td>
<td>• Service</td>
</tr>
<tr>
<td>Parents</td>
<td>• Implementation</td>
</tr>
<tr>
<td>felt they had an equal say in service implementation and decision making. They felt they were working as equal partners. Professionals empowered parents to help their child.</td>
<td></td>
</tr>
<tr>
<td>Mutual Trust and Respect: Parents</td>
<td>• Took time to answer questions</td>
</tr>
<tr>
<td>felt they could trust and respect professionals and this was demonstrated through the professionals' conduct and relations.</td>
<td></td>
</tr>
<tr>
<td>Personal Qualities:</td>
<td>• Listened</td>
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<tr>
<td>Parents perceived that the professionals demonstrated particular qualities</td>
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which consecutively helped them to work effectively with the professionals.

Commitment: • Demonstrated Commitment
Parents felt that the professionals demonstrated dedication by being devoted to their child and family.

Service Provision: • Quantity
Parents discussed their satisfaction with service provision.

Communication
The first significant finding in the study was the importance of the way professionals communicated information to parents. Communication has been mentioned as an important element in the parent-professional partnership process (Bastiani, 1993). The findings of this study indicated that most parents felt that the professionals communicated information in an effective manner. It was felt that information was communicated frequently and appropriately, in various forms such as written notes. According to Davies and Hall (2005), providing parents with information empowers parents to make decisions about their child's needs. Some parents described how at times they felt overloaded with information and although useful, positive and honest, the information may have not been adequate at the time. Furthermore, questionnaire results revealed that a small percentage of parents (6.6 per cent) strongly disagreed or disagreed to some extent that the amount of
information communicated to them was well-organised and useful.

In addition, most parents felt that the professionals used language that was uncomplicated. Pena (2000) supports this argument and suggests that using complex language may discourage effective partnership.

**Equality**

An equal say in decisions made about the way services were to be delivered to the child and his/her family was identified repeatedly as a key component in the partnership process. The idea of professionals and parents sharing ideas on the way services are to be delivered to the child have been well documented in literature and are essential to partnership working (White, 2002). Although a high percentage (>50 per cent) of responses from the questionnaire data indicated that parents had an equal say in how services were to be delivered, interview data revealed that empowerment to access and control resources was not demonstrated. Parents spoke of how their children were given fortnightly therapy sessions without being given the opportunity to decide how services were going to be implemented. Although resources may have influenced the way services were delivered, Dunst, Trivette, Davis and Cornwell (1988) suggest that in order for parents to be supported professionals need to encourage empowerment. This means that professionals are required to involve parents in “every aspect of the setting’s work” (Wall, 2003, p.55). Despite this, parents reported that they were given an equitable opportunity to make decisions about their child’s strengths and needs and also to provide input. Research suggests that these decision-making opportunities promote empowerment (Carlson, 1991) which in turn can have a positive effect on parents’ attitudes towards partnership working (White, 2002). Surprisingly, some parents felt that at times it was appropriate for professionals to take the lead in this decision-making process, as long as the professionals consulted with them beforehand. White (2002) suggests that such instances signify that parents trust professionals enough for them to take the lead because they are aware that the professionals will notify them of the decisions they have taken and the reason for doing so.

**Mutual Trust and Respect**

Data analysis revealed that the professionals acknowledged parents’ opinions and contributions, signifying that respect was demonstrated (Barr, 2003). Additionally, professionals’ perception that parents knew the most about their child was also reported by the participants Wall (2003) emphasises that such information is beneficial to an effective partnership because ultimately the professionals’ work is improved, and consequently the child progresses. Findings from this study also revealed that professionals took time to answer any questions the parents had. Indeed, 96.7 per cent of participants in the questionnaire strongly agreed or agreed to some extent with this statement.

**Personal Qualities**

In order to ensure that partnership work is being carried out, it is suggested that the professional listens, enquires and remains open at times that are needed by parents (Dale, 1996). All parents reported that the professionals understood what they were going through, were friendly and listened to their concerns and
opinions. Questionnaire results revealed that 93.3 per cent of participants agreed/agreed to some extent that the professionals were sympathetic in their manner towards them. However, interview data revealed that at times the professionals did not often negotiate on their position or behaviour when working in partnership. Some participants reported that the professionals did not always meet their expectations. Although professionals were reported to listen to their concerns, on some occasions they did not help them to resolve the difficulties they had in relation to their child. The “negotiator model” of working in partnership with parents, proposed by Dale (1996), suggests that professionals should alter the way they deliver services in order to develop effective parent-professional partnership. In order to do so, professionals are encouraged to not only listen to what parents have to say but also help them to problem solve (White, 2002). As mentioned previously, successful parent-professional partnerships often depend on the professional’s interpersonal skills such as communicating effectively. Hence, the professionals may have lacked the skills necessary to help parents with their difficulties at the time. It is suggested that professionals obtain further training to fully develop these skills (Ebbeck and Waniganayake, 2003).

Commitment
When asked whether parents felt that the professionals demonstrated commitment, all participants responded positively to this statement. Parents responded well to professionals who gave the extra measure of service to their family by carrying out home visits, outside of the therapy sessions, and also by giving a lot of their time. Parents also reported that the professionals’ genuine intent was to do the best for their child. Indeed, questionnaire data revealed that 93.4 per cent of participants strongly agreed/agreed to some extent that the professionals demonstrated commitment towards their child. Whilst parents reported that the professionals demonstrated commitment by being available should they have wished to discuss any issues or concerns, some parents suggested that professionals should demonstrate more commitment and support by initiating more regular contact with parents. This may explain why 76.7 per cent of parents in the questionnaire agreed/agreed to some extent that the professionals were not always available. Hurst (1997) suggests that professionals should not ignore parents’ needs, in this case the regular contact, yet they must be flexible in the manner in which they meet these needs.

Service Provision
Another main finding, also reported in current literature (Turnbull and Turnbull, 1997) relates to the social support that is required for families to adjust and cope with their child’s diagnosis. Whilst parents reported that professionals communicated information frequently, the idea of providing formal support to families was still raised by some parents. Parents would have appreciated the help from a professional such as a social worker to support them and make them feel less isolated, thus signifying that these services were not accessible. Professionals may argue that supporting parents can be problematic especially in a service with no support staff. However, it is important to recognise that such
issues may have an effect on the intensity of parental involvement which may subsequently prevent effective parent participation in the partnership (Wall, 2003).

An in-depth examination of parents’ comments also revealed that parents were dissatisfied with the quantity of therapy sessions their child received. Indeed, 56.7 per cent of participants in the questionnaire strongly disagreed/disagreed to some extent that the amount of input was insufficient. Robards (1994) explains that if parents are more involved in the decisions made about the services to be delivered to their child, ultimately they will be more open to negotiate. A Final Comment

‘Parent-Professional Partnership’ has been defined as a process whereby both professionals and parents communicate effectively and problem-solve in cooperation (Dale, 1996). It is characterised by various features such as mutual trust and respect (Turnbull, Turbiville and Turnbull, 2000). In the Republic of Ireland, working in partnership with parents has been recommended as an effective method of providing service to children with special educational needs (National Parents Council Primary, 2004). Working in partnership with parents is important as ultimately it will lead to a more effective method of delivering services to children and their families (Boot and Macdonald, 2006).

The parents in this study identified that the professionals communicated information to them in frequent, positive, honest and understandable approaches. The importance of not leaving parents feeling overloaded with information was stressed by some parents. Results also indicated that parents and professionals worked together as equal partners. For example, the children’s therapy goals were determined in cooperation with the professionals. However, parents felt that they were not given an opportunity to decide how the services were to be delivered to their child. Parents acknowledged that mutual respect and trust was demonstrated between the partners. Professionals demonstrated interpersonal skills, such as listening and understanding, which helped parents to work effectively with the professionals. A sense of commitment was also demonstrated by the professionals by being devoted to both the child and the family. Parents spoke about their dissatisfaction with the amount of support provided and felt that other services were required, such as counselling services to assist the family to cope with the child’s diagnosis.

The identification of the various characteristics displayed by the professionals is a positive indication that the professionals were in many ways responsive to parents’ requests and needs in the formation of good working relationships. Despite the literature suggesting that parent-professional partnerships often fail (Pinkus, 2003), the majority of the parents indicated that overall, there was a positive relationship between the parents and the professionals. Literature recommends various characteristics in order to promote partnership (Turnbull et al., 2000). However, it does not advice professionals on how much collaboration between parents and professionals is required, except that it is important to work in partnership with parents (Dale, 1996). Although it can be concluded that the professionals
did exhibit certain characteristics which helped parents to work effectively with the professionals, it is hard to conclude whether parents perceived their relationship with professionals as a true partnership. Literature has tended to focus on qualitative studies describing the interpersonal characteristics required for partnerships to work, thus making it difficult to assess the degree to which parents perceived their relationship with professionals as a partnership. For example, Park and Turnbull (2003) suggest factors such as respect and communication in order to promote parent-professional partnership. The development of a measure of positive partnerships is an area deserving of research as it may be useful to use in environments where models of intervention for children with disabilities and their families need to be assessed. Nevertheless, this study indicates that the service’s attempt to work more effectively with parents has had a positive effect on the relationship between parents and professionals.

It should be acknowledged that this research study encompasses the views of a relatively small sample of parents. Therefore, it is hard to generalise these findings beyond the limits of this study. Consequently, significantly more research needs to be undertaken, to obtain the views of a larger sample of parents working with professionals in an ASD service. However, the results are consistent with the work of Bailey, Hebbeler, Scarborough, Spiker and Mallik (2004), who found that a high degree of parents were satisfied with the way they worked with early intervention professionals. Professionals in the field of special education or those working with parents of children with disabilities, who are willing to work in partnership, may wish to consider these factors when attempting to form effective and constructive relationships with parents. The barriers identified by the parents also highlight the need for professionals to re-examine some of their methods of working. Highly-motivated and committed professionals need to acknowledge that training in effective communication skills is required. This should enhance their communication and interaction with parents, thus promoting parent-professional partnerships.