

Evaluation of the Early Intervention Readiness Program (EIRP): A post-autism diagnosis family support program

Autism is a lifelong developmental condition that affects how an individual communicates and interacts with people and their environment. A child's diagnosis with autism is often a very stressful and confusing time for families. Parents can find it difficult to locate the information needed for them to understand the diagnosis and to develop an awareness of available support options. **Key Aspect Personnel:** Rhiannon Tolmie, Susan Bruck and Rachel Kerslake.

Executive Summary

Background

Autism is a lifelong developmental condition that affects how an individual communicates and interacts with people and their environment. A child's diagnosis with autism is often a very stressful and confusing time for families. Parents can find it difficult to locate the information needed for them to understand the diagnosis and develop awareness of available support options.

The Early Intervention Readiness Program (EIRP) is a family support service offered during the challenging post-autism diagnosis period. The EIRP is delivered within the family home and aims to strengthen family capacity to facilitate a smooth transition into appropriate early intervention and support services. Throughout the program, support and management strategies related to autism associated behaviours, and information about available intervention services are provided. Participation in the program involves an initial consultation and a series of follow-up visits, based on individual family needs.

This report presents the findings of an evaluation of the effectiveness of the EIRP. Outcomes are based on the information received from a total of 62 families who completed the program within a twenty month period.

Conclusions

Findings from this research project provide evidence that the EIRP is a useful and valued family support resource following a child's diagnosis with autism. This report also provides further evidence for the value of professional support during the challenging post-autism diagnosis period.

Key Findings

Family Confidence

Families used a 5-point scale to indicate their perceived confidence, prior and subsequent to involvement in the EIRP. Following involvement in the EIRP, participants perceived a significant increase in their confidence in their:

- » Understanding of autism behaviours;
- » Knowledge and level of access of service and support options;
- » Capacity to independently make decisions about services;
- » Knowledge of practical strategies to manage their child's behaviours at home; and
- » Current family support network.

Program Evaluation

A post-program survey was used to evaluate participant perceptions of the usefulness of the EIRP. The majority of the families reported the EIRP was very or extremely useful in:

- » Enhancing their understanding of autism;
- » Expanding on their knowledge of services and funding options;
- » Increasing their current level of access of services and funding options;
- » Developing their ability to independently make decisions about and access services;
- » Building on their knowledge of practical management strategies to use with their child at home; and
- » Increasing their current family support network.

Introduction

Autism is characterised by persistent difficulties with communication and social interaction, with accompanying restricted or repetitive behaviours (APA, 2013). The prevalence of autism diagnosis is continuing to rise, with a parallel increase in the demand for appropriate intervention and support services (Nedft, et al., 2010).

A child's diagnosis with autism is an event that is rarely forgotten by families due to the stressful nature of the process of autism assessment and diagnosis (Braiden, et al., 2010; Keenan, et al., 2010). A range of emotions often ensue as families begin to adapt to their child's diagnosis and contemplate the future (Poslawsky, et al., 2014; Wachtel & Carter, 2008). Families also begin to search for information about autism and explore support and treatment options. Individualised information is vital to help families understand their child's diagnosis and to promote subsequent informed decision-making about intervention services (Valentine, et al., 2010).

Whilst it is recognised that the provision of specialised information and support immediately following a child's autism diagnosis is crucial (Cassidy, et al., 2008; Cutress & Muncer, 2014; Keen, et al., 2010), it is also evident that professional guidance at this time can often be limited (Dunst, et al., 2007; Mansell & Morris, 2004; Shields, 2001). Parental stress can intensify as a result of the challenges of independently sourcing reliable autism specific information whilst awaiting the commencement of intervention (Mackintosh, et al., 2005; Pisula, 2011).

Studies have acknowledged the scarcity of post-autism diagnosis support, and have questioned parents about the information and resources they felt were, or would have been most useful immediately after the diagnosis. This research highlighted the need for professional, comprehensive and reliable information about autism (Osborne & Reed, 2008). Information that is individualised to suit the unique difficulties of each child is vital to assist parents in developing an enhanced understanding and appreciation of the different ways their child experiences the world (Pakenham, et al., 2004). The availability of comprehensible, autism-specific resources has also been linked to enhanced family well-being and improvements in parent-child relationships and interactions (Wachtel & Carter, 2008). Families have explicitly acknowledged the value of guidance with navigating region-specific supports (Mulligan, et al., 2010). The provision of practical strategies to implement at home to support communication and interaction (Whitaker, 2002) and behaviour (Ludlow, et al., 2012), in addition to 'next step' information (Valentine, et al., 2010) has also been prioritised by families.

Given the immediate information needs of families and the limited availability of comprehensive and individualised support following a child's diagnosis of autism, the Early Intervention Readiness Program (EIRP) family support service was developed. The

emphasised need for a more seamless transition from autism diagnosis through to the commencement of relevant interventions (Valentine, et al., 2010) was carefully considered in the design of the program. The EIRP is therefore offered during the challenging post-autism diagnosis period to strengthen family capacity to independently coordinate and commence appropriate early intervention and support services.

The core components of the EIRP have been derived from past research findings and recommendations, in addition to prior informal discussions with parents of children previously diagnosed with autism. Information about autism and associated behaviours is offered to parents to enhance their understanding of the unique way their child thinks and learns (Osborne & Reed, 2008; Whitaker, 2002). Local intervention, education and support options are identified and professional guidance is offered to facilitate effective service transitions and ongoing family engagement (Mulligan, et al., 2010; Russa, et al., 2014). Whilst awaiting the commencement of relevant support services, families are offered practical resources and strategies to assist their child's skill development and manage their behaviours (Farmer & Reupert, 2013; Ludlow, et al., 2012; Valentine, et al., 2010). Through the provision of relevant resources, supports and the establishment of collaborative relationships between the program staff and parents, the EIRP endeavours to promote informed decision making, the strengthening of family functioning and the expansion of family support networks.

The EIRP endeavours to promote informed decision making, the strengthening of family functioning and the expansion of family support networks

The aim of the current study was to evaluate the effectiveness of the EIRP in supporting families following their child's diagnosis with autism. Research questions were divided into two sections; family confidence and program evaluation. Specifically, the following research questions were examined:

Family Confidence

1. Did families identify an increase in their confidence in their understanding of autism?
2. Did families perceive a change in their confidence in their knowledge of services, supports and funding options?
3. Did families recognise an increase in their confidence in their level of access of services, supports and funding options?

4. Did families perceive a change in their confidence in their ability to independently make decisions about and access services and supports?
5. Did families indicate an increase in their confidence in their knowledge of practical management strategies to implement with their child at home?
6. Did families identify enhanced confidence in their current family support network?

Program Evaluation

1. Did families feel the EIRP was useful in enhancing their understanding of autism?
2. Did families recognise the EIRP to be useful in increasing their awareness of services, supports and funding options?
3. Did families identify the EIRP as useful in expanding on their level of access of services, supports and funding options?
4. Did families acknowledge the EIRP was useful in enhancing their ability to independently make decisions about and access services and supports?
5. Did families identify the EIRP as useful in improving their knowledge of practical management strategies to implement with their child at home?
6. Did families indicate the EIRP was useful in increasing their family support network?

Method

This study was granted ethics approval by the Autism Spectrum Australia (Aspect) Research Approvals Committee. Informed consent was gained from all participating families prior to the inclusion of their data in the study. Participation in the research was not a criterion for involvement in the EIRP. This was clearly stated to all families.

Participants

Participants involved in this project were families from the Hunter Region, New South Wales, Australia. All children involved in the EIRP had either recently been diagnosed with autism, or were identified by the referral source as displaying characteristics of autism with a confirmed diagnosis yet to be received.

Eligibility

To be eligible for an initial EIRP consult, families needed to confirm they felt they had limited awareness and level of access of appropriate early intervention or support services for their child and family. Eligibility was established during an initial phone call which was made subsequent to the family's referral to the program.

Service delivery

The EIRP was offered at no cost to families and delivered within the family home or early childhood

education setting. The program was delivered by early intervention specialists, specifically speech pathologists and occupational therapists.

Program Outline

Families who participated in the EIRP first received a two-hour initial consult (home-visit). This involved completion of a Family Service Profile which summarised their current level of access of intervention and support services and available funding options. Through guided discussion, families also outlined their individual information needs, including those related to autism and their child's specific difficulties, region-specific services and practical strategies for supporting their child. If these discussions highlighted a need for further information and support, the program staff member made a collaborative decision with the family to schedule ongoing EIRP sessions. In instances where a family stated that no further information or support needs were necessary, the EIRP was discontinued.

Only families who received support through EIRP sessions subsequent to their initial consult were invited to participate in the current research project. A maximum of 10 sessions were offered to each family with the exact number primarily dependent upon individual family information needs and service engagement. In line with the program aims, EIRP sessions involved the provision of information about autism, local early intervention and family support service options and relevant funding entitlements. Support was also provided to assist families with decision-making about appropriate services and facilitate their subsequent capacity to access these. Practical strategies were provided throughout family involvement in the program to enable parents to support their child whilst waiting to commence relevant intervention services. The decision to conclude EIRP service provision was made in close collaboration with families and predominantly based on families' perceived understanding of their child's diagnosis and successful engagement in available service and support options.

Data Collection

Family Confidence

A Family Confidence Scale was generated for the purpose of this project and used to examine families' pre- and post-program confidence. The measurement tool incorporated six questions, consistent with program aims. Parents rated their responses on a 5-point Likert scale, from 'not at all confident' (1) to 'extremely confident' (5).

Program Evaluation

The usefulness of the program was evaluated by parents using a post-program survey. The survey incorporated six questions, consistent with both the program aims and the key areas addressed within the family confidence measurement tool. Parents rated their responses on a 5-point Likert scale, from 'not at all useful' to 'extremely useful'.

Results

One hundred and thirty-five (135) families were referred to the Early Intervention Readiness Program (EIRP) during the research project period. These referral sources included local early intervention referral or support agencies, public allied health staff and other non-autism specific early intervention services. Children referred to the program were aged between 0-7 years, with a mean age of 3.8 years. Seventy-eight percent of the children who were referred were male. Seventy-one percent of the children had a confirmed diagnosis of autism prior to their referral to the program. The remaining 29% of the families were awaiting a diagnosis assessment for their child or required support to arrange assessment with a diagnostic professional. The mean number of service delivery sessions conducted with families was 5.8 sessions.

Forty-six (34%) of the families who participated in the EIRP had both parents involved in service delivery. Two participating families (1%) included the father only, with eighty-three (61%) involving participation of the mother only. In four families (3%) one additional family member (i.e. grandparent or school representative) participated in the program alongside a child's mother.

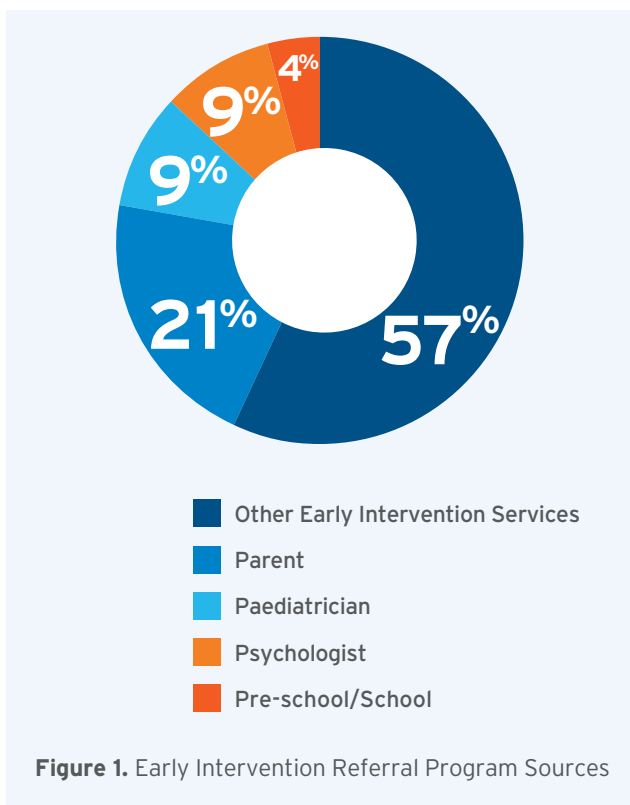


Figure 1 shows that a majority (57%) of the 135 referrals were received from other early intervention service providers. Direct referrals from parents (21%) who had independently learned about the service (e.g. via website or another parent) were also received. The remainder of the referrals were received from diagnostic professionals, psychologists (9%), and paediatricians (9%) and from early education setting and school staff (4%).

Of the 135 families referred to the program during the research project period, 114 families met the criteria for inclusion in the program following an initial phone call. Four families withdrew from the program prior to the collection of post-program data. The data obtained from these families was therefore not included in the analysis. The findings outlined and discussed within this article are based on the data from 62 families who completed the program during the research data collection period.

Family Confidence

Pre- and post-program responses to each of the six questions addressed in the Family Confidence Scale (see Table 1) were compared to determine whether there was significant change in family ratings. As illustrated in Figure 2, the EIRP was associated with significantly;

- » Increased parent understanding of autism;
- » Enhanced knowledge of services and funding options;
- » Increase level of parent access of services and funding options;
- » Improved parent ability to independently make decisions about and engage in services;
- » Increased parent knowledge of practical management strategies at home; and
- » Improved family support network.

Table 1. Likert scale questions on pre- and post-parent confidence measurement tool.

Q1	How confident do you feel about your understanding of autism?
Q2	How confident do you feel about your knowledge of services and funding options?
Q3	How confident do you feel about your current access of services and funding options?
Q4	How confident do you feel about your ability to independently make decisions about/access services?
Q5	How confident do you feel about your knowledge of practical management strategies at home?
Q6	How confident do you feel about your current family support network?

Program Evaluation

Of the 62 families who finished the program during the research data collection period, 55 families also completed a post-program survey to evaluate the usefulness of the EIRP. Table 2 shows the specific questions parents were asked within this survey. As Figure 3 identifies, the majority of the families reported the EIRP was very or extremely useful in:

- » Enhancing their understanding of autism;

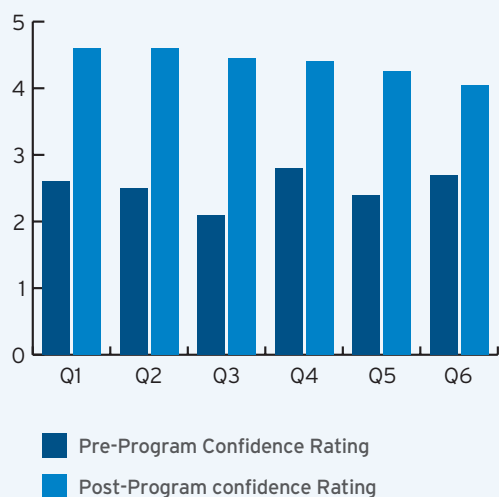


Figure 2. Mean pre- and post-program parent confidence ratings on 6 questions (n=62).

- » Expanding on their knowledge of services and funding options;
- » Increasing their current level of access of services and funding options;
- » Developing their ability to independently make decisions about and access services;
- » Building on their knowledge of practical management strategies to use with their child at home; and
- » Increasing their current family support network.

Table 2. Likert scale questions on post-program parent survey

Q1	How useful do you rate the EIRP in increasing your understanding of autism?
Q2	How useful do you rate the EIRP in increasing your knowledge of services and funding options?
Q3	How useful do you rate the EIRP in increasing your current access of services and funding options?
Q4	How useful do you rate the EIRP in increasing your ability to independently make decisions about/access services?
Q5	How useful do you rate the EIRP in increasing your knowledge of practical management strategies at home?
Q6	How useful do you rate the EIRP in increasing your current family support network?

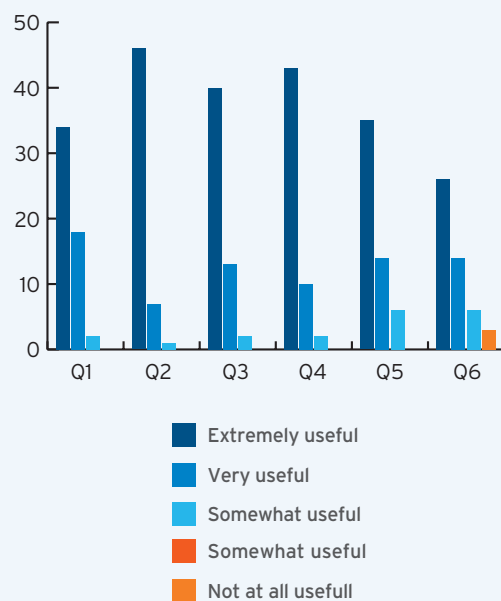


Figure 3. Post-program survey parent responses (n=55).

Discussion

This project aimed to investigate the outcomes for families who participated in the Early Intervention Readiness Program (EIRP) and their perceptions of the usefulness of the program. Results indicated there was a significant difference in parent pre- and post-program ratings of their confidence in their understanding of autism associated behaviours and difficulties, their knowledge of available early intervention services and funding options and their current level of access of these supports. Results also revealed a significant difference in participants' confidence in their ability to independently make decisions about and engage in services, their knowledge of practical management strategies to implement with their child at home and their current family support network. Parents who completed a post-program evaluation most commonly identified the EIRP as an extremely useful support in increasing their understanding of autism, their knowledge of services and funding options and their current level of access of these supports. Parents also frequently recognised the EIRP as being extremely useful in increasing their ability to make independent decisions about and access services, their knowledge of practical home-management strategies and their current family support network.

The period immediately following a child's autism diagnosis is a key time for professionals to introduce relevant resources related to the nature of autism (Mulligan, et al., 2010). The reality for most families is that it can be difficult to find relevant information and support, without professional direction in the post-diagnosis period (Gaspar de Alba & Bodfish, 2011; Gray, et al., 2008). The results from the current study indicate the effectiveness of the EIRP in delivering this important information. Findings showed that the parents reported a significant increase in their

confidence in their understanding of autism as a result of the tailored information they received.

Access to reliable information about autism and how this relates to their individual child's behaviours and difficulties is the most frequently described unmet need of parents (Whitaker, 2002). It has also been identified that limited availability of appropriate information not only compounds parent stress, but can have a subsequent impact on the intensity and effectiveness of the early intervention and education programs that a family chooses to engage in (Osborne, et al., 2008; Siller, et al., 2014). The results from the EIRP post-program survey confirmed that the EIRP was useful in developing the parents' understanding of their child's diagnosis.

Following confirmation of their child's autism diagnosis, parents have indicated that it is difficult to distinguish which interventions are available and most appropriate (Valentine, et al., 2010). Past studies have highlighted a clear need for the provision of region-specific information detailing available support options and intervention services (Mulligan, et al., 2010; Osborne & Reed, 2008). Results from this study showed that following involvement in the EIRP, participants identified a significant increase in their confidence in their knowledge of local services and funding options. Additionally, in their post-evaluation of the program, almost all participants recognised the EIRP to be at least very useful in enhancing their knowledge of available supports.

It is well documented that early intervention is crucial for children with autism to promote essential skill development and support their integration into mainstream programs (Corsello, 2005). Whilst it is acknowledged that children should commence appropriate intervention as soon as possible, it is also recognised that the family foundation and knowledge base must be strong enough to facilitate a child's smooth transition into these services (Miller, et al., 2012; Osborne, et al., 2008). Results from the current study showed parents who participated in the EIRP identified a significant increase in their confidence in their ability to access relevant services and funding options. This is proposed to be directly related to the emphasis the EIRP placed on the prior provision of information about autism, discussion of region-specific support options and tailored guidance with navigating these services. Post-program survey results verify parents' perceived usefulness of the program in enhancing their current level of access of services and funding opportunities.

In the post-diagnosis period, families have described increased feelings of worry and hopelessness, accompanied by a need for guided decision support about which interventions and supports are most suitable for their child (Osborne & Reed, 2008). Following involvement in the EIRP, parents reported a significant increase in their confidence in making independent decisions about commencing relevant support and interventions. Furthermore, almost all participating families also directly identified the

program to be at least very useful in increasing their capacity to make autonomous decisions about services to explore for their child and family.

Whilst many parents are aware of the benefits of early intervention for children with autism, it is not uncommon for families to experience long periods of waiting before the commencement of services (Renty & Roeyers, 2006). Families also often report that they feel 'lost' as a result of the limited availability of information about how to support their child whilst waiting for intervention to begin (Mulligan, et al., 2010). In addition to identifying growth in their confidence and competence in sourcing appropriate supports for their child, EIRP participants also indicated a significant increase in their confidence in their knowledge of strategies for managing their child's behaviours at home. Similar outcomes have been reported in research into other post-autism diagnosis support programs (Keen, et al., 2010; Shields, 2001; Stuttard, et al., 2014) where following program involvement, parents have indicated improvements in their knowledge of effective strategies and self-management of their child's challenges and behaviours. Within the EIRP post-program evaluations, parents most commonly perceived the EIRP to be extremely useful in building their awareness of practical strategies to implement with their child.

Parents with a child diagnosed with autism have been shown to experience significantly higher levels of stress and frustration when compared to those with a typically developing child (Dykens, et al., 2014; Russa, et al., 2014) or a child with another disability or ongoing health problem (Baker-Ericzen, et al., 2005; Dabrowska & Pisula, 2010; Sayyed, et al., 2012). Research has suggested during this post-diagnosis period, parents with children who exhibit challenging behaviour often seek support from their family network as a way of managing their emotional and physical health and overall wellbeing (Hall & Graff, 2011). It is therefore important to note that participants within the present study reported a significant increase in their confidence in their current family support network following engagement in the EIRP.

Past studies have shown that the strongest predictor of depression and anxiety in mothers of children with autism is a lack of social supports and networks (Boyd, 2002; Gray & Holden, 1992). In this study, the post-program evaluation indicated that the majority of the participants considered that the EIRP to be at least very useful in increasing their family support network. These findings therefore suggest that the EIRP has a positive impact on parents' ability to cope during this stressful post-diagnosis period.

It is important to note that over one-third of families who participated in the EIRP had both parents directly involved in program service delivery. The benefits of involving additional family members in program delivery are frequently highlighted and include shared understanding of information and consistency of strategy implementation (Farmer & Reupert, 2013).

Conclusion

Outcomes of this study suggest the EIRP was effective in providing support to families following their child's diagnosis with autism. Following involvement in the program, families perceived improvements in their confidence in their understanding of autism and their knowledge of and capacity to access available service, support and funding options. Participants also indicated they felt more confident in their ability to independently make decisions about services for their child and reported improvements in their knowledge of practical management strategies at home. Additionally, the majority of parents reported an increase in their overall family support network. Results of a post-program survey explicitly highlighted the usefulness of the EIRP as a post-autism diagnosis support.

Whilst further research is warranted, the overall outcomes of this study provide further support for the need and value of support programs for families with a child recently diagnosed with autism.

Recommendations

Based on the outcomes of this project, the following is recommended:

- » Continuation of the program within the current trial site (Hunter Region of NSW, Australia);
- » Consideration of the replication of the program in other regions of Australia where similar gaps in family support services exist;
- » Maintenance of the information content and approach to service delivery during future delivery of the program; and
- » Inclusion of objective measures of parent and child outcomes following participation in the EIRP (e.g. impact on parent stress and child behaviour) during future evaluations of the program.

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