

**Evaluation of two specific parent
education programmes for
parents and whānau of young
children (from 0 to starting
school age) with Autism
Spectrum Disorder**

FINAL Report

Prepared for Ministries of Health and Education
Manatū Hauora / Te Tāhuhu o te Mātauranga

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Executive Summary

1.1 Background

For the past 10 years the Ministries of Health and Education ('the Ministries') have co-purchased two autism spectrum disorder (ASD) parent education programmes for parents and whānau of young children (from 0 to starting school age) with ASD: the National Autistic Society (NAS) EarlyBird ('EarlyBird') and ASD Plus: Education for Families ('ASD Plus'). The current contracts for the programmes run for two years, until June 2011.

Litmus undertook concurrent evaluations of the programmes between 6 August 2010 and 10 November 2010. Evaluation data sources included:

- Provider reports to the Ministries, administration and monitoring data, and other relevant documents
- A quantitative self-completion survey of all families who had completed a programme since July 2009
- Qualitative interviews with key stakeholder audiences
- Background 'expert' interviews with two Ministry of Education personnel

Evaluation limitations included:

- A lack of monitoring and evaluation data, from both providers
- Outcomes data was indicative only, however, consistent findings triangulated across all data sources offer some confidence in the findings relating to programme impact
- The evaluation methodology included some risks around coercion, however Litmus took steps to minimise this risk. Evidence was highly consistent, and Litmus detected no evidence that coercion of any kind occurred.

1.2 EarlyBird

Specific requirements of the EarlyBird contract with the Ministries are as follows:

- Deliver to families situated in the North Island of New Zealand, excluding Northland
- Deliver to at least 120 families in each year of the contract
- Undertake for tripartite discussions with the NAS and Autism NZ within the first six months of the contract

Key evaluation findings

Autism NZ developed and delivered key programme outputs such as the Action Plan and the Cultural Responsiveness Plan, and established a Parent Consumer Advisory Group. Reporting targets were met. 104 families participated in EarlyBird in Year One of the contract. Key points to note for the period July 2009 – September 2010 are:

- 22 EarlyBird programmes were completed, involving a total of 124 participants. On average, 6 participants attended each programme
- The majority of programmes were run in Auckland (13 of the 22). 4 programmes were delivered in Wellington, 2 in Tauranga, and 1 in each of a number of other provincial centres (Hawkes Bay, New Plymouth and Gisborne)
- All programmes used the 'group' delivery format. However one family in New Plymouth had a 'modified' programme
- Three EarlyBird programmes were run in collaboration with Ohomairangi Trust (2 in South Auckland, 1 in Gisborne).

Key findings in relation to the EarlyBird **programme impact** are:

- There is consistent evidence across all data sources that EarlyBird is generating favourable outcomes for participants. Particular areas of strength are: improving participants' knowledge of autism; improving communication strategies; using play to interact and teach social interaction skills; and improving behaviour management
- Main changes seen in children, following EarlyBird, are: more interaction, better communication, and less frustration. Main changes in families/whānau include: better relationships, more relaxed households, more unified parenting and better routines/planning
- An unintended impact of the programme is providing some parents with a greater sense of empowerment and confidence *outside* the family, dealing with 'the system' and advocating on behalf of their child. Another unintended impact of the programme is the emotional benefit many parents derive from the group delivery format
- A small amount of negative feedback was received relating to programme logistics. The other criticism of EarlyBird is a lack of New Zealand-specific content. Follow-up contact, and finding ways to stay in touch with other parents to support each other over the longer term, is suggested as an improvement by some parents.

Evaluation conclusions

Key programme strengths

- There is clear evidence from the evaluation, reinforced by previous evaluations undertaken, that EarlyBird is highly valued by families who access the service, and that positive and intended outcomes are occurring for families who take part. For many participants, EarlyBird participation appears to be a turning

point in their journey with ASD, providing them with practical tools and strategies to improve communication with their child, and help deal with behaviour. Implications for the wider family are positive, with reduced stress and better relationships occurring as a result of one or more families attending the programme. The deeper understanding of ASD that parents achieve through the programme also empowers them to be more confident advocates for their children in the future.

- Autism NZ has delivered most key outputs and achieved a high volume of families participating in the programme, despite a slow start to the contract and substantial organisational change during Year One of the contract.
- The three collaborative programmes that have been run in partnership with Ohumairangi Trust appear to have increased level of participation for Māori and Pacific peoples families in EarlyBird, compared with previous years. Modifications to the core programme to deliver collaboratively (i.e. providing childcare, transport, co-facilitation with Ohumairangi staff, and so on) appear to have made the programme more accessible to Māori and Pacific peoples' cultures, and are valued by participants.

Key programme weaknesses

- The EarlyBird programme is not reaching those in rural and remote areas. The primary delivery format for EarlyBird of group sessions appears to be the key barrier to achieving higher levels of participation from rural families. While one programme in New Plymouth has been modified to allow some distance learning, further refinements are needed to provide flexibility which will make the programme more accessible.
- Internal monitoring and evaluation systems for EarlyBird by Autism NZ appear to be inadequate. While data is being collected for each programme, it seems to be incomplete, and Autism NZ head office does not appear to have access to all data that has been collected. The current parent evaluation sheet, combined with the 3-month follow up questionnaire, is not generating adequate outcomes data.
- While the collaborative programme has shown real promise, the programme requires more work to tailor it to a New Zealand context and to make it more culturally responsive. The planned DVD may help to provide a New Zealand 'flavour' to the materials. Workforce development strategies to recruit and train Māori and Pacific peoples facilitators need to be implemented, so that EarlyBird becomes more responsive 'from within'.

Priority questions

Priority questions were specified by the Ministries to be investigated for both evaluations. Based on the evidence available to the evaluation, Litmus' response to each question is summarised below.

1. How valuable/high quality is the ASD-specific parent education programme's content/design and delivery? Overall, there is strong evidence that EarlyBird is a high quality programme, as indicated by the evidence-basis from which it was developed, previous evaluations and outcomes data from the evaluation survey.

Planned work by Autism NZ to check that EarlyBird aligns with the NZ ASD Guideline would support the evidence about EarlyBird programme quality.

The programme could be improved to be more innovative and responsive in its delivery – particularly by offering a wider range of delivery formats. It could also be improved to become more family-centred – encouraging greater participation from the wider family, rather than mainly parents, and providing assistance to enable both parents to attend programmes where possible. Waiting list times may be an inherent result of co-ordinating group delivery, but there is a need for Autism NZ to minimise these to ensure parents receive EarlyBird in a timely manner.

On anecdotal evidence, the collaborative programme appears to have been successful in terms of ensuring cultural and contextual appropriateness for EarlyBird delivery, but more could be done across the programme as a whole to provide a programme that is appropriate for the specific New Zealand context and cultures. There is a need for Autism NZ to undertake the planned evaluation of the collaborative programme to provide further evidence and insights which can be used to improve delivery in future.

2. What changes are evident for the young child with ASD and their family/whānau/carer(s) that can reasonably be attributed to the programme (directly or indirectly)? There is evidence from the current evaluation that EarlyBird has a positive impact on the child and their family. Areas where families report improvement are around communication and social interaction skills for the child, and managing difficult behaviour. Enhanced confidence and relationships within the family are also evident as a result of EarlyBird participation.

Ongoing evaluation carried out by Autism NZ needs to ensure that it captures outcomes data, and longer-term outcomes for families.

3. How effectively are the participants applying and using their new knowledge? As noted above there is some evidence that participants are applying skills and knowledge after taking part in EarlyBird. There is a gap in the evidence-basis around longer term impacts for children and families.
4. What unexpected outcomes have resulted? Two unexpected outcomes are evident: Parents report a greater sense of empowerment and confidence outside the family, dealing with 'the system' and advocating on behalf of their child; and an emotional benefit derived from the group delivery format.
5. How effectively was the trade-off managed between the reach and intensity of the ASD-specific parent education programme, given the relevant constraints? In many ways Autism NZ appears to be managing the trade off between reach and intensity of the EarlyBird programme effectively – the programme is being delivered to a relatively large number of families in many parts of the North Island. However, EarlyBird has a notable gap in delivery to families in remote and rural areas.

The focus on a group delivery format appears to restrict the ability of EarlyBird to achieve greater geographic coverage. The emphasis on group delivery format also appears to limit participation from a wider range of cultures – while the

collaborative programme shows promise as a working model, the waiting times to assemble groups of particular cultural backgrounds may limit accessibility overall.

6. To what extent does this ASD-specific parent education programme represent the best possible use of resources? The evaluation provides clear evidence that EarlyBird is valued highly by participants, and it continues to contribute to positive outcomes for children with ASD and their families. There do not appear to be any alternative, comparable services for parents, suggesting that the absence of EarlyBird would mean poorer long term consequences for children with ASD and their families.

Taking into account factors that Autism NZ considers to have contributed to lower than expected delivery numbers in Year One of the contract, overall, EarlyBird is reaching a large number of North Island families in cities and provincial towns. The collaborative programme shows signs of being a successful model for improved participation rates in EarlyBird by Māori and Pacific peoples' families.

Programme delivery constraints mean that those in rural and remote areas are not accessing EarlyBird. Autism NZ reports that a 'modified' EarlyBird programme used with one family in New Plymouth will be reviewed as a potential alternative model for rural delivery of the programme – future monitoring and evaluation will be needed to determine whether this is a successful strategy.

Indepth costing analysis of EarlyBird programmes (including the collaborative programme vs the 'standard' EarlyBird programme) and other comparable services would be required to determine whether EarlyBird represents the *best possible* use of resources. This analysis would also need to take into account the longevity, location and wider organisational context of different programmes – that is, recognising that EarlyBird is a mature programme which has robust evidence of its efficacy, but there may be structural limitations on its ability to deliver to all audiences with funding currently available. Possible cost saving delivery innovations may include online components and use of distance technologies such as video conferencing. However, these innovations require further scoping to determine the extent to which they can successfully address current delivery limitations in reaching rural or isolated families.

1.3 ASD Plus

Aspects of the contract which are specific to ASD Plus are as follows:

- Design and set-up of the programme. Key outputs required included:
 - Designing a Project Development Plan (due 17 July 2009)
 - Establishing a Parent Consumer Advisory Group (by 2 November 2009)
 - Developing an Action Plan; Cultural Responsiveness Plan and Communications Plan (by 2 November 2009)
- Delivery to families situated in the South Island of New Zealand, and in Northland
- Delivery to 57 families in Year One of the contract, and 75 families in Year Two i.e. a total of 132 families over the period of the contract

Key evaluation findings

IDEA Services designed and developed the ASD Plus programme in Year One of the contract, delivery key outputs including an Action Plan and Cultural Responsiveness Plan. A Parent Consumer Advisory Group was established. All reporting targets were met. Key points to note for the period July 2009 – September 2010 are:

- 36 families participated in ASD Plus programmes, involving a total of 83 participants
- The majority of families were based in the South Island, including those based in cities, provincial towns and rural locations (31 families). 5 families from Northland have participated in ASD Plus since the programme began
- Most families received the 'individual' delivery format for ASD Plus (26 of the 36 families). Two group programmes were delivered, in two locations (Dunedin and Christchurch). 9 families received a 'combined' delivery method involving a mix of group, distance learning and individual delivery

Key findings in relation to the **programme impact** of ASD Plus are as follows:

- The evidence is consistent across all data sources that participants have been satisfied with the ASD Plus programme delivery. There is indicative evidence that the programme is achieving its objectives and having a positive impact on participants, children, the immediate and wider family. Particular areas of strength indicated by the data are: increasing participants' knowledge and understanding of ASD; increasing use of a range of strategies and tools to encourage improved communication and social interaction of the child with ASD; increasing parents' use of strategies to manage difficult behaviour
- Changes seen in children, following ASD Plus, include: Less frustration and improved communication. Changes for parents and families after ASD Plus participation include: More supportive attitudes, more relaxed households, unified parenting and a sense of being in control/more confident.
- ASD Plus facilitators receive very positive feedback from programme participants.
- An unintended, but positive impact is an ongoing sense of empowerment to be the ASD child's advocate. Other unintended impacts relate to emotional support and networking opportunities afforded by group delivery of the programme
- Negative feedback about ASD Plus is minimal. A few suggested improvements relate to changes in timing and logistics, more opportunity for interaction with other parents via group sessions (from those who did individual programmes), ongoing contact and advice about 'where to next'.

Evaluation conclusions

Programme strengths

- IDEA Services achieved all programme design and development outputs within Year One of operation, including a New Zealand-made DVD film resource which will be particularly beneficial in enabling distance learning options. Management and monitoring systems appear to be comprehensive, well

thought through, and functioning efficiently. The pool of facilitators seems adequate to cope with current and future demand, and supervision and workforce development activities are working well.

- The available evidence for ASD Plus indicates that this new programme is achieving positive, tangible short-term outcomes for participants and families in line with programme objectives. Participant satisfaction is consistently high, and there is evidence that most participants are applying ASD Plus-learnt strategies and tools in their households.
- The tailored, individual approach offered by ASD Plus is a real strength of the programme. Families respond positively to the opportunity to work in partnership with IDEA Services to determine both mode of delivery, and specific goals the family wishes to achieve. The evaluation also captured numerous examples of IDEA Services managers and facilitators 'going the extra mile' to ensure that families can participate and get the most out of ASD Plus.

While numbers are low, the flexible, family-centred approach appears to be driving participation across a wide range of families, in terms of geographic coverage, cultural backgrounds, and participation from the wider whānau as well as parents. The fact that ASD Plus resources are New Zealand-specific would appear to enhance the relevance of the programme to participants.

- Evaluation findings indicate that IDEA Services is highly responsive to feedback from participants and other sources. There are clear benefits in IDEA Services' ability to readily evolve and adapt the programme, particularly while it is in the inception phase
- The Service Leader for ASD Plus has personal expertise and in-depth understanding of ASD, and a long history of working in the field. The fact that he was involved in initial programme design and implementation, and continues to undertake and supervise delivery of the programme has positive quality control implications as he is able to modify delivery and content (as shown in the piloting of the programme) based on results and feedback.
- The monitoring and evaluation system that has been implemented by IDEA Services is thorough and includes the collection of outcomes data which will enable evidence-based evaluation of the programme over time.

Programme weaknesses

- The primary issue for ASD Plus is low referrals to the programme, which mean that the overall participation rate is well below contractual expectations, and the 'per family' cost is much higher. IDEA Services is well aware of this issue and has undertaken a range of communication and networking activities over the course of the contract to try and boost referrals, but the impact of specific activities on referral levels it is not clear.

To a degree, low referrals may reflect low awareness of a new programme in the inception phase. Other systemic issues may be in play – such as the lack of follow-up to families in the early post-diagnostic phase. The Christchurch earthquake also appears to have reduced expected referrals in the past couple of months.

It should be noted that Northland referrals, while initially low to non-existent, are now running at expected levels because the District Health Board has overcome capacity issues that meant young children were not being diagnosed.

Priority questions for the evaluation

The Ministries developed a series of priority questions to be investigated for both evaluations. Based on the evidence available to the evaluation, Litmus' response to each question is summarised below.

1. How valuable/high quality is the ASD-specific parent education programme's content/design and delivery? Evidence from the evaluation indicates that ASD Plus is a high-quality programme developed from a national and international evidence basis and in line with the NZ ASD Guideline. Early feedback suggests that programme participants find ASD Plus extremely valuable, as they perceive an absence of other support and education services post-diagnosis. The programme is innovative in the New Zealand context, in terms of offering a range of delivery modes including 'hybrid' delivery. The flexibility of delivery options, and the upfront involvement of families in selecting the most appropriate option for their unique needs, makes the programme highly person and family-centred. Participation from across a range of geographic areas and cultural backgrounds suggests that the programme is culturally and contextually appropriate.
2. What changes are evident for the young child with ASD and their family/whānau/carer(s) that can reasonably be attributed to the programme (directly or indirectly)? Early evidence suggests that ASD Plus is contributing directly to positive short-term outcomes for participants, their children, and wider family units. Participants report that they are applying a deeper understanding of ASD, and practical tools and strategies in their homes, with positive changes resulting. Changes noted include improved communication and social interaction skills for the child with ASD, a reduction in challenging behaviour (and/or improved coping mechanisms to deal with it), and enhanced relationships within the family as a whole. Longer-term data from IDEA Service's monitoring of families will determine whether these outcomes persist over time.
3. How effectively are the participants applying and using their new knowledge? As noted above, there is evidence that ASD Plus participants are applying their new knowledge and skills successfully in their homes. Further work is needed to determine how extensively and effectively this is occurring, and whether the programme has lasting impact.
4. What unexpected outcomes have resulted? There is a small amount of evidence that ASD Plus contributes to three unexpected positive outcomes: Some parents becoming more confident and empowered to communicate with others about their child's needs, and push to have these needs met; some deriving emotional benefit from participating in group sessions with other families; ongoing family support networks arising out of connections made through ASD Plus group sessions.

5. How effectively was the trade-off managed between the reach and intensity of the ASD-specific parent education programme, given the relevant constraints? On a per programme basis, the duration and intensity of ASD Plus appears to be about right to achieve the desired outcomes for participants. IDEA Services have already responded to feedback to change the length of some modules to ensure adequate coverage of content.

As a whole, ASD Plus is not achieving the expected reach to South Island and Northland families – the total number of families participating is considerably lower than expected, reflecting low referrals to the programme. IDEA Services has not found it feasible to deliver as many group programmes as expected, given the low referral numbers

6. To what extent does this ASD-specific parent education programme represent the best possible use of resources? Early evidence for ASD Plus suggests that parents and whānau of young children with ASD value the programme extremely highly, and that it directly contributes to positive outcomes in line with programme objectives. Parents' perception of an absence of other alternative services, particularly for those in rural areas, means that the programme appears to be hugely beneficial to those who take part.

The programme is currently running at below capacity levels. In this context, IDEA Services has been able to operate without a waiting list, delivering highly tailored programmes and catering well to those in rural areas. If referrals increase and IDEA Services can maintain the high quality of service provision seen to date across a larger number of families, then we could conclude that ASD Plus is maximising the use of Ministry resources available to the programme.

Indepth costing analysis of comparable programmes would be required to determine whether ASD Plus represents the *best possible* use of resources. This analysis would also need to take into account the longevity, location and wider health and education context of different programmes – that is, recognising that ASD Plus is in the inception stage, and that there may be systemic or sectoral issues beyond its control that impact on referrals.

2. Introduction

2.1 Background

“While autism is incurable, the right support at the right time can make an enormous difference to people’s lives”¹

A vast array of treatments and interventions have been developed to help people with Autism Spectrum Disorder (ASD) and expert opinion about ‘best practice’ is constantly evolving, reflecting the highly individual and complex nature of this condition.

In this context, the development of the New Zealand ASD Guideline is undoubtedly a major milestone for New Zealanders with ASD, their families and whānau, professionals and policymakers. Developed jointly by the Ministry of Health and the Ministry of Education, the Guideline provides a clear focal point for those making decisions relating to ASD – from an evidence-basis. It is intended that information and advice in the Guideline will be reviewed regularly to reflect new evidence that comes to light – the ‘Living Guideline’ approach.

The Guideline currently indicates that parent education is associated with improved family outcomes for children with ASD – a finding that is widely accepted historically and internationally.

Reflecting this, for the past 10 years² the Ministries of Health and Education (‘the Ministries’) have co-purchased two ASD parent education programmes for parents and whānau of young children (from 0 to starting school age) with ASD:

1. **NAS EarlyBird** (‘EarlyBird’): A programme provided by Autism New Zealand Inc (Autism NZ) in the greater Auckland region and the lower two-thirds of the North Island. This programme was designed by the National Autistic Society (NAS) in Britain, and is offered by Autism NZ through a franchise agreement with the NAS.
2. **ASD Plus: Education for Families** (‘ASD Plus’): A programme provided by IDEA Specialist Services, covering the whole of the South Island and Northland. This programme was specifically developed for the New Zealand context.

The current contracts for EarlyBird and ASD Plus commenced in July 2009 and will run for two years, until June 2011. Before these contracts expire, the Ministries will be developing new procurement specifications and carrying out an open procurement process for ASD parent education programmes.

To this end, the Ministries required that an evaluation of both programmes be undertaken before November 2011. Litmus undertook these evaluations concurrently between 6 August 2010 and 10 November 2010. Evaluation findings are presented in this report.

¹ Rosenblatt, M (2008). *I Exist: the message from adults with autism in England*

² From 2009 the Ministries have co-purchased both ASD Plus and EarlyBird programmes; prior to 2009 EarlyBird was the sole ASD parent education programme.

Programme objectives and service specifications

The overall programme purpose and service specifications for both programmes were outlined in Joint Contract agreements between the Ministries and the providers at the commencement of the contracts. Key points to note are:

- The primary objective of the programmes is to provide quality-driven parent education that will improve knowledge of the impact of ASD and therefore enhance parents' and whānau abilities and confidence to help develop their children's communication, self-management and social interaction skills
- The programmes are expected to provide parent education as specified in the NZ ASD Guideline, which specifies that parent education should:
 - Be ongoing, for individual needs change according to the child's age and circumstances
 - Take a variety of forms (e.g. face-to-face, distance, video and online)
 - Take into consideration family needs, such as work commitments and access to respite care
 - Include shared professional learning and development with professionals in the field to lead to a common understanding of needs
 - Take into consideration the needs of rural families and whānau (e.g. distance education)
 - Consider cultural issues such as differing perceptions and management of disability and the impact of ASD on children's cultural development
 - Where possible, be available in the language of the participant family
 - Include services for siblings and other family members.
- The Ministries also expect the programmes to be truly reflective of the New Zealand environment, including meeting the expectations and aspirations of Māori and Pacific peoples, and reaching the more rural areas of New Zealand without reducing service quality. The programmes are also expected to align with other relevant key documents such as, but not limited to:
 - The New Zealand Disability Strategy (2001),
 - The Carer Strategy (2008), and
 - The New Zealand Autism Spectrum Disorder Guideline (2008).
- Specific requirements of the contract (discussed in more detail in the body of the report) also include:
 - Involving families and whānau in programme decision making, through the formation of a Parent Consumer Advisory Group
 - Ensuring that programme promotion and delivery are acceptable to, and effective for Māori (e.g. by recruiting and training Māori facilitators, providing cultural supervision to non-Māori facilitators, ensuring information and promotional material are appropriate for Māori, and using programme venues that are acceptable to Māori)
 - Accommodating Pacific and Asian peoples' health and specific disability issues (e.g. by promoting the programme in a culturally acceptable way,

ensuring it is effective for Pacific and Asian peoples, recruiting and training Pacific peoples and Asian facilitators, ensuring training incorporates learning about cultural differences)

- Geographic coverage – Delivering programmes as close as possible to where the child and their family lives, whether rural or urban
- Timing – Offering the programme at the earliest stage, ideally within 6 months of diagnosis of the child
- Processes – Ensuring programme methodology is evidence-based, and demonstrating robust quality assurance by implementing strong monitoring and evaluation processes
- Facilitators – Using qualified and competent staff from a range of professional backgrounds (e.g. speech-language therapists, specialist teachers, social workers, psychologists, etc.)
- Workforce development – Demonstrating commitment to staff professional learning and development, including supervision and peer review, performance management and professional registration of staff, as appropriate. Explicitly recruit, develop and retain Māori and Pacific peoples facilitators
- Key service linkages – Building and maintaining strong working relationships with other service providers and community agencies, and demonstrating evidence of these key linkages. (e.g. the Ministry of Education, Child Development Services (based in District Health Boards), Disability Information and Advocacy Services (DIAS), Needs Assessment and Service Co-ordination Services (NASC), support services, voluntary organisations, the Well Child / Tamariki Ora service, and other referrers such as family GPs).
- Quality requirements are as follows:
 - General – Programme provision from a family / whānau perspective; factually correct, evidence-based advice; high professional standards
 - Access – Including cultural and geographical accessibility, and timely delivery. Using client satisfaction surveys
 - Safety – Policies and protocols to ensure respect for family / whānau privacy, risk management, and compliance with Occupational Health and Safety Standards
- Key outputs are described in detail later in the report, as they apply to each of the programmes. Briefly, they include: Action Plan (including Programme Description; programme provision schedule; Communication Plan, Protocol on Management of Waiting Lists; Workplace Development Strategy; budget analysis); Cultural Responsiveness Plan; reporting (monthly; quarterly; annual).

2.2 Evaluation aims

The overall objective of this project was to evaluate the ASD Plus and EarlyBird programmes, and to provide the Ministries with information to develop future programme and service specifications.

The Ministries developed a series of **priority questions** to be investigated for both evaluations, as follows:

1. How valuable/high quality is the ASD-specific parent education programme's content/design and delivery? [Include validity/accuracy, match with participant needs, level-appropriateness, consistency with current evidence (including that in the New Zealand ASD Guideline), innovativeness, consistency with principles for adult learning, fidelity with design, person-centeredness, family-centeredness, cultural and contextual appropriateness and responsiveness and emphasis on community participation].
2. What changes are evident for the young child with ASD and their family/whānau/carer(s) that can reasonably be attributed to the programme (directly or indirectly)? How substantial and valuable are the changes / gains in participants' knowledge, skills, attitudes, confidence and other competencies as a result of the ASD-specific parent education programme?
3. How effectively are the participants applying and using their new knowledge, skills, attitudes, confidence and other competencies (i.e. evidence of changed behaviour)?
4. What unexpected outcomes (positive or negative) have resulted from the ASD-specific parent education programme?
5. How effectively was the trade-off managed between the reach and intensity of the ASD-specific parent education programme, given the relevant constraints? How in-depth was the programme, how many people were reached, at what intensity and for how long? And, what evidence is there that the duration and intensity was both feasible and sufficient to achieve meaningful impacts?
6. To what extent does this ASD-specific parent education programme represent the best possible use of resources to achieve outcomes of the greatest possible value for parents and whānau of young children with ASD?

2.3 Evaluation approach

The evaluation design was refined and agreed with the Ministries during an initial scoping phase, outlined in an Evaluation Plan which was approved by the Ministry of Education's Ethics Advisory Team. The two programmes were evaluated *concurrently*, to maximise efficiencies and value for money, and also to complete the work within the specified timeframe. The approach was *mixed methodology*, using a range of qualitative and quantitative data sources to provide an holistic picture of each programme.

Evaluation data sources included:

- **Provider reports to the Ministries, administration and monitoring data, and other relevant documents.** A complete list of documents and material reviewed and analysed by Litmus is included in Appendix 1.
- **A quantitative self-completion survey** of all families who had completed a programme since July 2009. The survey was mailed to 127 EarlyBird participants and 31 ASD Plus participants between 22 and 24 September 2010. A reminder survey was posted to the same participants on 22 October 2010 to increase the overall response rate. In total:

- 46 surveys were returned to Litmus from EarlyBird programme participants, representing a response rate of 36%
- 10 surveys were returned from ASD Plus programme participants, representing a response rate of 32%.

Questionnaire surveys and letters to participants are included in Appendix 2.

- **Qualitative interviews with key stakeholder audiences**, using a mix of ‘immersion visits’ to four locations, and indepth telephone interviews. Qualitative interviews were conducted between 6 October and 20 October 2010. The qualitative sample is summarised below:

Stakeholder Audience	Number of Qualitative Interviews	
	EarlyBird	ASD Plus
Parents/families/whānau	3 (Auckland, Wellington, rural North Island)	3 (South Island)
Programme facilitators	2 (Auckland)	2 (Dunedin, Christchurch)
Programme Leaders / Managers	2 (Wellington)	1 (Dunedin)

- **Background ‘expert’ interviews with two Ministry of Education personnel**, seeking advice/critical reflection on best practice for ASD parent education programmes.

A detailed description of Evaluation Methodology, including data collection tools is included in Appendix 2.

2.4 Expert perspectives

Litmus conducted background ‘expert’ interviews with two Ministry of Education personnel, seeking their advice/critical reflection on best practice for ASD parent education programmes.

These interviews provided Litmus evaluators with a deeper understanding of the NZ ASD Guideline, and factors that may enhance or limit the impact of ASD parent education programmes. The interviews highlighted in particular:

- The need for a flexible, tailored approach for individual families. This includes avoiding broad generalisations about ‘what works’ for broad geographical/cultural/religious groups – recognising that each family is unique
- The need for programmes to equip parents with skills to teach others, pass on their knowledge in the child’s support network, and to be an advocate for their child
- The need for delivery to occur at optimum times for parents. This includes running programmes at a time that suits parents (especially for those who are working). It also includes timing of delivery following ASD-diagnosis: balancing the need to provide parents with a service quickly (so they do not ‘go off and find something that is not evidence-based’), while recognising the grieving

process that may be occurring (which is not an optimum time to be bombarded with new information)

- A view that all delivery methods (group, individual, distance etc) have strengths and weaknesses, but face-to-face delivery is preferable where possible
- The view that a 'strengths-based' model of education (i.e. focusing on what the child and parents can do, rather than what they can't do), and a 'child-centred' model is valuable and preferable
- The need for 'cultural responsiveness' to be an integral aspect of programme design – i.e. designed in a way that reflects different 'world-views'. For example, a Māori world view might result in programme delivery which started with the individual child and then expanded to the ASD knowledge applicable to the whole group. Cultural responsiveness therefore extends *beyond* delivering the same programme in a variety of settings, and using facilitators of different cultural backgrounds
- The need for openness and good communication lines between programme providers, government and social service agencies, to create 'joined-up' services.

2.5 Evaluation limitations

The findings of this evaluation are an accurate presentation of the analysis across the multiple data streams detailed above. The findings have been triangulated across the data streams to validate the results presented. There are however, a number of limitations in relation to the data analysed, specifically:

- **A lack of monitoring and evaluation data, from both providers.** Provider contracts with the Ministries made reference to the need for 'ongoing monitoring and evaluation of the Services provided'. However, neither provider was able to provide Litmus with consistent, substantive data that had been collected over the duration of the current contract. The lack of internally collected and collated evaluation data places limitations on our ability to judge programme outcomes. It also meant Litmus needed to undertake separate quantitative surveying of families for the evaluation
- **Outcomes data is indicative only.** Neither provider has collected enough data from parents (and specifically data relating to programme outcomes) to provide a robust picture of programme impact. To this end, Litmus sought to measure programme outcomes by including the APQ battery³ within the self-completion survey that was mailed to parents as part of the evaluation. It needs to be borne in mind that the Litmus survey questionnaire was not scientifically validated. Quantitative data is based on small sample sizes

However, survey responses and highly consistent findings triangulated across all data sources offer some confidence in the evaluation findings relating to programme impact.

³ The APQ is the Autism: Parent Questionnaire developed by Auckland University as part of the evaluation of EarlyBird in 2006. The core part of the questionnaire consists of 25 items for ranking by the parent (a 'battery')

- **The evaluation methodology included some risks around coercion** – namely, that programme providers could influence who takes part in the evaluation, and/or their feedback. The final evaluation approach recommended by Litmus reflected the short timeframe we had for data collection. A staggered consent process (e.g. writing to parents and asking whether they allow Litmus access to their contact details) was ruled out due to the time this would involve. The recommended approach therefore relied on programme providers to inform participants about the evaluation, and take responsibility for the initial contact.

To minimise this risk, Litmus took a number of steps:

1. In all communication with participants we were explicit about the purpose of the evaluation, we reassured participants about the confidentiality Litmus offers, and we encouraged them to be free and frank in their feedback in order to improve the effectiveness of the programmes
2. We used our analytic and qualitative interviewing expertise to compare and triangulate perceptions of the programme as indicated via different information streams. If, for example, the evaluation revealed a significant difference between findings of the survey (e.g. highly positive) and findings of the interviews (e.g. highly negative) this would indicate that there may have been some influence on participants' responses.

Evidence from different data streams was generally highly consistent, and Litmus detected no evidence that coercion of any kind has occurred.

3. NAS EarlyBird Programme

3.1 Background to current NAS EarlyBird Programme contract

The National Autistic Society (NAS) EarlyBird programme ('EarlyBird') was introduced in the United Kingdom as an early intervention programme for parents of children with ASD. Its primary focus is to educate parents about ASD and how it affects their child. It also teaches parents strategies to improve communication and social interactions with their child, and deal with inappropriate or difficult behaviours. The programme was evaluated in the UK in 1999 and 2002, indicating positive outcomes resulting from the programme.⁴

The Ministries of Education and Health jointly and in partnership with Autism New Zealand (Autism NZ), piloted EarlyBird in this country in 2001. Data from the pilot study appeared to support UK findings. EarlyBird has continued to be delivered in New Zealand under a licensing agreement between the NAS and Autism NZ.

A formal evaluation of EarlyBird in New Zealand in 2006⁵ found that in many respects the programme was 'consistent with best principles, and utilises a range of therapies that have wide acceptance in the field'. The evaluation also provided evidence of the positive impact of EarlyBird: desired changes were observed amongst families, and *Autism: Parent Questionnaire (APQ)*⁶ scores improved. However, the evaluation recommended that EarlyBird become more accessible (e.g. to those in rural areas, or with limited child-care options), and more reflective of New Zealand's multicultural population. It also highlighted a need to reduce waiting times and enhance early identification, to ensure families receive EarlyBird at the optimum time.

Programme description

EarlyBird is a two month programme working with up to six families at a time. It brings parents together for group daytime training sessions. It involves families being visited regularly in their own homes. It also involves video feedback to help parents apply what they learn, whilst working with their child.

Parents and caregivers need to commit to four six-hour training sessions held fortnightly, and four half-hour home visits, as well as ongoing work with their child during the programme. Modules cover a range of the following topics, interspersed with home visits, delivered in the following order:

- What is autism
- Autism and communication
- Working with your child
- Home Visit A
- Visuals and structure
- Preventing problems
- Home visit B
- Understanding behaviour

4 Hardy, 1999; Macniven, 2002

5 Anderson, A., Birkin, C., Seymour, F., & Moore, D. (2006). EarlyBird evaluation. Wellington: Ministry of Education

6 A 25-item questionnaire designed specifically for the 2005 evaluation, with established validity and sensitivity to changes over time from participation in EarlyBird.

- Managing behaviour A
- Home visit C
- Managing behaviour B.

Families should live within two hours travelling distance of the project base and generally need to make their own travel and childcare arrangements. Funding may be provided to assist with travel and childcare in cases of hardship. (Note: Participants in EarlyBird 'collaborative' programmes, run in partnership with the Ohumairangi Trust in South Auckland and Gisborne to date, are provided with childcare as a matter of course.)

Current contract

The current contract between the Ministries and Autism New Zealand for providing EarlyBird officially commenced on 1 August 2009, and will run until 30 June 2011. Aspects of the contract which are specific to EarlyBird are as follows:

- Deliver to families situated in the North Island of New Zealand, excluding Northland
- Deliver to at least 120 families in each year of the contract, i.e. a total of 240 families over the period of the contract
- Undertake for tripartite discussions with the NAS and Autism NZ within the first six months of the contract (to focus on how recommendations of the 2006 evaluation can be implemented)

Outputs delivered, as required by contract

An Action Plan was developed for EarlyBird, with key actions planned for the first year of the contract including: Management of waiting lists; improve communications; delivering to remote areas; development of the workforce; increase cultural relevance; and ongoing evaluation and improvement. Autism NZ uses the Action Plan to report against when providing updates to the Ministries.

A Parent Consumer Advisory Group was established and the Group met twice in the first year of the EarlyBird contract and signed off the Action Plan. It is considered by Autism NZ to be 'well on the way to being of great support to both Autism NZ and the EarlyBird programme'. Autism NZ intends that the Parent Consumer Advisory Group will meet every second month in the second year of the contract.

A Cultural Responsiveness Plan was also developed. Further details of objectives and action points from the Action Plan and Cultural Responsiveness Plan are provided in following sections, where relevant.

Autism NZ met reporting targets as required by the contract.

104 families participated in EarlyBird in Year One of the contract.

3.2 Programme management

The contract between the Ministries and Autism NZ was drafted in June 2009, but not finalised and signed until October 2009. Autism NZ reports that the process was protracted due to negotiations around technical terms in the contract (e.g. definitions

of rural and remote) and concerns about changes to funding (per family, rather than per programme). Autism NZ also attributes delays to the Ministries determining how they wished to split delivery of ASD parent education programmes between EarlyBird and ASD Plus. However, the Ministries dispute this perception.

Autism NZ considers that the contract negotiation process caused a number of delays in it achieving some core outputs, including the establishment of the Parent Consumer Advisory Group and completion of the Action and Cultural Responsiveness Plans. Changes to programme management were also delayed, for example implementing a fees rationalisation strategy with trainers.

Autism NZ underwent significant internal change and restructuring over the first year of the EarlyBird contract. Organisational changes included the arrival of a new Chief Executive in June 2009 and a move of the national office to Wellington in September 2009 (with associated changes in staffing). The existing EarlyBird Programme Manager was made redundant (in October 2009) and a new Programme Manager began in December 2009. Autism NZ has also developed a new Strategic Plan. Autism NZ considers that these changes had some impact on the organisation's ability to achieve all of the EarlyBird programme objectives.

Autism NZ had minimal contact with NAS UK in Year One of the contract, reflecting its focus on internal structural changes. From April 2010 the Autism NZ CEO has had contact with Jo Stephens of NAS UK. This contact has been 'productive', and Autism NZ reports that NAS UK is 'open' to a conference call with the Ministries and Autism NZ.

During the first year of the contract, Autism NZ changed the way that EarlyBird trainers are paid, from an hourly rate to a flat 'per programme' fee. This change was primarily budget-driven, but also an effort to ensure consistency of payments to trainers - who had been invoicing different total hours per programme. The change initially met with some resistance and concern amongst trainers – one supervisor is reported to have resigned over the issue. Autism NZ believes the new fee structure it is 'now well established and trainers appear to have accepted it'. Autism NZ also sought to reduce EarlyBird programme delivery costs by specifying that trainers use more modest venues and catering, and using more effective travel and accommodation arrangements.

Workforce Development

Autism NZ describe the over-arching criteria to become an EarlyBird trainer as: 1) a professional background in ASD; and 2) experience as a presenter/deliverer of education.

When Autism NZ first began delivering EarlyBird in New Zealand, two New Zealand trainers went to the UK and were trained there as EarlyBird 'Trainer of Trainers'. These two individuals then provided training to the other New Zealand trainers.

EarlyBird currently has 12 trainers, working on a peripatetic, contractual basis. All have been involved in delivering EarlyBird since the commencement of the current contract. All received formal EarlyBird training from New Zealand-based Supervisors (the 'Trainers of Trainers') and have been awarded a licence to deliver the programme. All have maintained their licence by delivering the required number of programmes, as well as receiving feedback from Supervisors. Supervisors undertake an annual evaluation of each trainer.

No new trainers were identified or employed by EarlyBird in the first year of the contract. Autism NZ reports in the June 2010 Annual Report that this 'reflects the stability of the group and the uncertainty of the programme over its two-year period...[and] the cost and priority has been on ensuring successful delivery this year with the available resources'.

Recently however, Autism NZ has identified a need for more trainers. Five new trainers have been recruited through networks / word of mouth. These new trainers will take part in a Professional Development Day in Wellington in December 2010, delivered by the two Supervisors who have trained as 'Train the Trainers'.

The two Supervisors resigned around the end of June 2010, however both agreed to stay on as trainers. Autism NZ planned to work on a proposal for operational supervision in the July/August period – this has not been reported, to date.

Autism NZ describes communication with trainers as having been 'somewhat problematic' in the first year of the contract, due to organisational changes within Autism NZ.

'Development of the workforce' is highlighted as an area of focus in EarlyBird's Action Plan. Action points agreed include: Meeting with all trainers annually and workshopping areas for improvement; encouraging trainers to attend the Autism NZ 2-yearly national conference; encouraging trainers to attend training programmes run by Autism NZ and other bodies; providing supervision and mentoring to each trainer and providing written feedback on the evaluations from programmes they have facilitated; actively recruiting Māori and Pacific peoples trainers; supporting all trainers to attend culturally specific training; providing trainers with information and up-to-date research that is relevant.

According to Autism NZ's reports to the Ministries, many of the action points relating to workforce development are being implemented successfully:

- Trainers met in March 2010 for the annual Professional Development Day. Key areas of discussion were the evaluation form, planning for future programmes, the best use of supervision time (with a suggestion for video feedback) and the fees proposal
- Trainers were offered free registration to the Autism NZ conference, and have been encouraged to attend other training opportunities. Each trainer has received contact from the supervisor (prior to the supervisor's resignation) and two-way feedback was provided. Trainers have been provided with information and latest research through regular emails from Autism NZ
- Autism NZ participated in a Parent Education Providers Workshop in September 2010, in Wellington
- The main gap in workforce development activity is around Māori and Pacific peoples trainers. None have been recruited – although it should be noted that *no* new trainers were recruited in Year One of the contract. None of the five new recruits are Māori or Pacific peoples. No trainers have attended culturally specific training and this has not been asked for by trainers.

Communications / Networking

'Improving communications' is a key area of focus specified in the EarlyBird Action Plan. Agreed action points include: Notifying all relevant organisations and providers of courses planned in their area; advertising courses in newsletters and websites (e.g. Autism NZ and Altogether Autism) as well as in monthly e-news; including information on EarlyBird in Autism NZ parent information packs and new Disability Information and Advocacy Services (DIAS) information packs; meeting with the Parent Advisory Group regularly; working with rural agencies and diagnosticians to ensure a process for appropriate and timely referrals; utilising existing communication channels for Māori and Pacific peoples.

Many of these action points are being implemented by Autism NZ. Communication with rural agencies and diagnosticians appears to be an area where further action could be undertaken. Autism NZ has had several meetings with REAP (Rural Education Activities Programme) to discuss how best to provide information to families, and branches are reported to be 'working with their local networks to ensure that families are aware of events in their areas'. Wider communication to Māori and Pacific peoples audiences is another area where further action could be undertaken (this is discussed further in the section below on Cultural Responsiveness).

Monitoring and Evaluation

Autism NZ currently provides parents with an evaluation sheet which is completed on a 'rolling basis' through the programme. The evaluation sheet form asks parents to rate each module and each home visit with a score of 1-5, and to provide comments if they wish (about what they learnt, anything that was useful, any problems/comments/suggestions). The current evaluation sheet has been in use since around March 2010 – prior to this time parents completed a separate sheet after each session. Parents also complete a pre-programme questionnaire, and a 3-month follow up questionnaire.

Trainers report back to the EarlyBird Programme Manager verbally. They do one written report for each family, using a 'Preliminary Home Visit Sheet'.

Autism NZ does not use the APQ questionnaire (developed by Auckland University for the 2006 evaluation) as part of its own monitoring tools. It appears that the APQ was used for a period of time (prior to the current contract), but Autism NZ received feedback that the APQ information being collected was not being used by the Ministries and was not needed. The Ministries strongly dispute this assertion.

'Ongoing evaluation and improvement' is a key area of focus from the EarlyBird Action Plan. Key action points include:

- Continue to provide evaluation forms to families after every session and analyse responses
- Send a summary of the evaluation feedback to NAS UK. Work with NAS UK to develop a feedback loop that includes Autism NZ, Ministries of Health and Education and NAS UK
- Provide feedback to trainers. Address any issues as they arise with individual trainers
- Discuss evaluation summaries with Parent Consumer Advisory Group.

These action points have been implemented to some extent, but there appear to be gaps in this area:

- In the June 2010 Annual Report Autism NZ reports that evaluation occurs in every programme, however Autism NZ was only able to provide limited data to Litmus (from 17 programme participants who took part in programmes between March and August 2010). Autism NZ consider that this reflects that not all parents complete their evaluation sheets, and very few complete the 3-month follow-up questionnaires. In addition, for most of the first year of the contract, monitoring and evaluation data was on paper files and is difficult and time-consuming to access. Autism NZ reports that data has been stored electronically since March 2010, as part of the organisations systems improvements (and this data has been provided to Litmus for the evaluation)
- Autism NZ reports that NAS UK has indicated that they would like feedback information, and Autism NZ plans to send their Annual Report and thereafter Quarterly Reports rather than after every programme
- Feedback to trainers was reported to have occurred throughout Year One, via Supervisors
- Autism NZ plans to discuss evaluation summaries with the Parent Consumer Advisory Group in 2011.

One of the action points from the EarlyBird Cultural Responsiveness Plan was to undertake a review of the collaborative programme with Ohumairangi Trust. The reason provided by Autism NZ is that there was not enough time, given the structural changes that have occurred within the organisation.

“An improvement I would suggest is less parental assessment forms to fill in after every module and home visit – it felt onerous.” (Parent)

3.3 Programme delivery and reach

Programme participation: Overview

Autism NZ has provided the Ministries with quarterly reports of data summarising how, where and to whom, EarlyBird has been delivered. The most recent quarterly report covered the period July – September 2010. An Annual Report was also submitted for the period July 2009 – June 2010.

Key points to note for the period July 2009 – September 2010 are:

- 22 EarlyBird programmes were completed, involving a total of 124 participants. On average, 6 participants attended each programme
- The majority of programmes were run in Auckland (13 of the 22). 4 programmes were delivered in Wellington, 2 in Tauranga, and 1 in each of a number of other provincial centres (Hawkes Bay, New Plymouth and Gisborne)
- All programmes used the ‘group’ delivery format. However one family in New Plymouth had a ‘modified’ programme
- Three EarlyBird programmes have been run in collaboration with Ohomairangi Trust (2 in South Auckland, 1 in Gisborne).

Geographic coverage

The majority of programmes were run in Auckland (13 of the 22). 4 programmes were delivered in Wellington, 2 in Tauranga, and 1 in each of a number of provincial centres (Hawkes Bay, New Plymouth and Gisborne).

All programmes used the 'group' delivery format. However one family in New Plymouth had a 'modified' programme as they couldn't travel for family reasons. The modified programme involved extended home visits to make up for lack of session time and putting the family in contact with families who did the group programme. In the June 2010 Annual Report, Autism NZ notes that it plans to use this example as a way of modifying the programme in future to better meet the needs of rural families.

'Delivering to remote areas' is an area of focus in EarlyBird's Action Plan. Key action points agreed include: Ensuring all relevant rural organisations are informed about the EarlyBird programme; tagging families who register an interest in the programme with a 'rural' tag as appropriate; working with rural organisations such as REAP to develop a version of EarlyBird that meets the needs of rural families; utilising distance learning techniques where appropriate to; considering the development of a web-based programme; ensuring that at least 30% of programmes are offered in rural towns; arranging for transport support where necessary.

As yet, only a few of the action points relating to extending the reach of EarlyBird to families in remote areas have been implemented. Autism NZ reports that it has worked with several agencies at a national level and all information on programmes is sent to agencies in that region prior to the start of the programme. Rural families are 'tagged' as part of waiting list management. Transport support has been provided to some families on request. While 5 of the 22 programmes have been run in provincial towns, none have been run in rural towns. Autism NZ reports that it plans to work on potential alternative ways of delivering EarlyBird to make it more accessible to rural people in December 2010 and 2011.

Referrals

Autism NZ reports that most families access the EarlyBird programme via self-referral, often after 'Googling' and finding the Autism New Zealand website. A small proportion are referred by:

- Diagnosticians, who may discuss services available and/or provide parents with a 'New parent pack' which includes the EarlyBird brochure. However Autism NZ reports that many diagnosticians do not have packs, and others may be reluctant to diagnose autism
- Autism NZ Outreach workers, who sometimes refer families when they do 'home-visits' with families who recently had a child diagnosed with ASD
- Ministry of Education, Special Education
- Kindergartens
- Speech-language therapists.

Autism NZ's collaboration with Ohomairangi Trust is considered to have increased Māori referrals – this is discussed later in the report.

Waiting lists

The number of families on waiting lists has fluctuated over the course of the contract, as has the average length of time spent by families on the waiting list. The waiting list dropped to a low of 24 families in the April – June 2010, but rose to a high of 65 families in July – September 2010. The average number of days on the waiting list ranged between 219 to 113 days.

Autism NZ points out that a waiting list is inevitable due to the inherent delay in forming a group and working out the logistics. As such, Autism NZ would prefer to call it a 'registration of interest' list rather than a waiting list. Autism NZ reports a number of factors that can affect waiting lists:

- If logistics (e.g. childcare, parents' work commitments) don't work out for a family, despite being offered programmes in their area, they stay on the 'waiting list'. In the June 2010 Annual Report, Autism NZ noted that the average time on the waiting list was somewhat skewed by a small number of families who had been on the waiting list over 200 days – all of whom had declined at least two programmes for a variety of reasons. The average time on the waiting list declined to 68 days, when these families were excluded from the calculation
- In some cases families may be placed on the waiting list when their children are close to five years of age. If a programme happens to have been run in their area recently, they may stay on the waiting list or miss out altogether.

Waiting lists were identified as a key focus area for EarlyBird in the Action Plan. Action points agreed in the Action Plan included: Ensuring 30% of courses are not scheduled at the beginning of the year and there is flexibility to respond to pockets of unforeseen demand; maintaining the waiting list so cancellations can be quickly filled and following up non-attendees to information evenings to confirm (or not) commitment to attend courses; developing a population-based map to ensure courses are directed in most likely areas; maintaining a record of all incidences where families did not attend a course within 6 months; and reporting these cases to the Ministries.

These key action points have largely been implemented, with the exception of developing a population-based map. Autism NZ believes that this is 'not yet required as demand is being met' but may consider using this tool in the second year of the contract. Strategies used by Autism NZ to reduce waiting lists since July 2009 have included:

- All families being contacted 'often' with a phone call and informed of when they can expect to receive an invitation to participate in an EarlyBird programme
- All families also being contacted by email
- Where families decline programmes repeatedly Autism NZ attempts to ascertain the reasons for this, and help the family gain access to another programme
- A particular focus on improving the Auckland waiting list by providing families with direct contact from new staff, and an improved Auckland branch response. These strategies appear to have been successful, with the number of families on the Auckland waiting list dropping from 37 in June 2009 to 13 in June 2010.

Autism NZ has also made changes to the way programmes are allocated, with programmes now being allocated as soon as families have expressed an interest.

Cultural Responsiveness

Three EarlyBird programmes have been run in collaboration with Ohomairangi Trust (2 in South Auckland, 1 in Gisborne). Autism NZ considers that the delivery for these programmes has been modified to be more culturally responsive by including child-minding, provision of food for all family members, an extra trainer in some circumstances and a wider group than just the parents attending.

Autism NZ developed a Cultural Responsiveness Plan for EarlyBird in Year One of the contract and reports that it received 'some very positive feedback' about the Plan from both Māori Board members and staff. Key areas of focus for the Cultural Responsiveness Plan are summarised below, together with Autism NZ's progress towards implementing key action points:

1. Commitment to the Treaty of Waitangi: Review the evaluation for the Outreach programme (March/April 2010); consider how the collaborative approach can be replicated around the country (April/May 2010)
 - The review of Outreach has not been undertaken. Autism NZ aims to undertake the evaluation in the second year of the contract. Autism NZ has not yet formally documented the differences around the two approaches
 - A collaborative programme was run in Gisborne in July 2010.
2. Communications strategy: In consultation with Ohomairangi Trust and the Parent Consumer Advisory Group, develop EarlyBird resources so they have a more appropriate cultural context; target Māori and Pacific peoples' diagnosticians and other referrers (March 2010 and ongoing); ensure communications remain on the agenda for the Parent Consumer Advisory Group
 - Consultation around programme information and resources for EarlyBird to make them more culturally appropriate had not occurred at the time of annual reporting. Autism NZ reports that the approach taken by EarlyBird trainers when working with Māori and Pacific peoples has been to discuss the information face-to-face as well as leaving the information for families to consider. Autism NZ expects that the new DVD will take account of the need to include a more culturally appropriate view
 - There has been no specific targeting of Māori and Pacific peoples' diagnosticians, but Autism NZ note that Outreach staff are working indirectly with them and have made a number of extra referrals as a consequence. Autism NZ plans to gather data on this in the second year of the contract
 - Communications has been on the Agenda for the Parent Consumer Advisory Group, and will remain so in future meetings.
3. Workforce development strategy: Review current peer review format to ensure it meets the needs of all trainers and is modified if necessary for Māori and Pacific peoples trainers; identify possible future Māori and Pacific peoples trainers; receive advice from Parent Consumer Advisory Group regarding improving trainer skills

- Autism NZ modified its peer review format to take account of the different cultural needs of Māori trainers. Specifically, the supervisor met with Māori trainers to give collated feedback rather than written individual feedback. Autism NZ reports that 'this appeared to be well received' and that a report was provided but there has been no further follow up
 - No new trainers (of any ethnicity) were identified or employed in the first year of the contract. None of the five new trainers recently recruited are Māori or Pacific peoples
 - The Parent Consumer Advisory Group was informed about changes that have occurred to EarlyBird, and offered advice relating to the second year of the contract. Autism NZ notes that 'the different experiences of the group have also helped us consider how best to deliver professional development to the trainers in the next 12 months'
4. Programme design: Develop and implement an evaluation process for the collaborative programme; document process so that it can be replicated; offer at least one collaborative course in another area of New Zealand
- The collaboration was not reviewed in the first year of the contract. Autism NZ reported that this was due to 'the need to put in place structural changes this year' and intended to formalise the evaluation process in the first quarter of the second year of the contract. This has not occurred as yet. Autism NZ identifies a need to 'continue to work in different ways to ensure that communication is improved'. In the June 2010 Annual Report Autism NZ reported that they were in discussions with the Trust about price and the parent feedback process. A Memorandum of Understanding (MoU) between Ohomairangi Trust and Autism NZ has not been signed but has been rescheduled to September 2010.
5. Monitoring processes
- Autism NZ reported in June 2010 that standard monitoring processes have been used for the collaborative programmes run to date, and that it intended to have 'discussions to consider how best health gains can be measured in this context. These will be implemented (where necessary in the third quarter of 2010).' Autism NZ also notes however that 'there is still some sensitivity around effecting change within the collaborative programme. This is an ongoing matter and will continue into the second year.' Discussions with Autism NZ about sensitivities within this relationship indicated difficulties in forging a genuine partnership, when Autism NZ holds the funding for programme delivery.

'Increasing cultural relevance' is also a key area of focus for EarlyBird's Action Plan. Action points include: Growing the existing external network; using the external network to identify and to find solutions to address any barriers with the programme; using the external network and waiting list information to identify areas of cultural need; linking with external and local networks and developing a response (e.g. marae-based programmes, using translators, etc.); using the internal resource (EarlyBird trainers) to make local links with Māori and Pasifika groups.

The desired action points around cultural responsiveness have been implemented to some degree:

- The Gisborne programme was a consequence of Autism NZ identifying an area of need in the area.
- The Parent Consumer Advisory Group and EarlyBird trainers have discussed potential cultural barriers to the programme, and Autism NZ reports that they are 'comfortable that these are being addressed during the normal course of business'
- Autism NZ reports that EarlyBird trainers have been making local links with Māori and Pasifika groups.

3.4 Programme Impact

A range of data sources have been used to inform the evaluation about the impact of the EarlyBird programme on participants and their families, including:

- Results from the self-completion survey of parents (46 responses, from a mail-out to 127 families)
- Feedback from qualitative interviews with Autism NZ managers, 2 facilitators and 3 parents
- Monitoring data from Autism NZ, from 17 parents who took part in programmes between March – August 2010.

Data tables summarising the quantitative data sources are provided in the following pages. Verbatim comments from surveys are included in Appendix 3.

Key findings

All data sources, and the qualitative interviews in particular highlight that many parents feel isolated after the initial ASD diagnosis, and struggle to get practical support and advice from any sources, particularly those living in rural areas. In this context they are hugely grateful to have the opportunity to take part in EarlyBird. In most cases, their actual experience of EarlyBird exceeds expectations, with its practical focus contributing to long term positive outcomes in the family.

Key findings in relation to EarlyBird's impact are as follows:

- **There is consistent evidence across all data sources that EarlyBird is generating favourable outcomes for participants**, in line with programme objectives. Almost all participant feedback is positive, with a considerable proportion saying that there was 'nothing' they disliked about the programme
- Particular areas of **strength** indicated by the data are:
 - Improving participants' knowledge of autism – The majority of participants report that since taking part in EarlyBird, they have 'a lot more' understanding of how their child experiences the world differently from children without autism, how autism influences their child's learning, and why their child communicates the way she/he does
 - Improving communication strategies – Many participants say that since taking part in EarlyBird, they are 'a lot' more likely to reflect on how they communicate with their child and change this accordingly, warn their child before introducing something new, and give one instruction at a time.

- Learning about, and using play to interact with the child and teach social interaction skills – Many participants report that they are ‘a lot’ more likely since EarlyBird to know games that they can play with their child to teach social interaction skills, and that there are some games their child enjoys playing with them.
- Improving behaviour management – In particular, many participants report that they are ‘a lot’ more likely since EarlyBird to look at the triggers and results of their child’s behaviour and to find this helpful in managing him/her.

The tools, techniques and strategies taught in EarlyBird are cited by many parents as the ‘best thing’ about the programme. The use of home video is mentioned as a particularly valuable teaching mechanism.

- **Main changes seen in children, following EarlyBird, are:** more interaction, better communication, and less frustration.
- **There is evidence that EarlyBird improves parents’ confidence and family functioning. Main changes in families/whānau, following EarlyBird, include:** Better understanding/more supportive relationships, more relaxed/less stressed/calmer households, more unified parenting and better routines/planning.
- **An unintended impact of the programme is providing some parents with a greater sense of empowerment and confidence *outside* the family, dealing with ‘the system’ and advocating on behalf of their child.**
- **Another unintended impact of the programme is the emotional benefit many parents derive from the group delivery format.** Meeting others in a similar situation is cited by a considerable proportion of participants as the ‘best’ aspect of the programme. Many welcome the opportunity to meet others and share experiences, taking comfort in the fact they are ‘not the only ones’ in this situation.
- **A small amount of negative feedback was received relating to programme logistics:** length of programme, time management, waiting lists, locations, travel, etc. Lack of assistance with travel and childcare means that some families can only send one parent to take part, when they would prefer to have both parents, or other family members participating. Feedback from one participant from the Gisborne collaborative programme highlighted the benefits of being able to bring children and family members to the programme.
- **The other criticism of EarlyBird is a lack of New Zealand-specific content** – this appears mainly driven by the video, and is the most frequently suggested area for change to the programme.
- **Follow-up contact, and finding ways to stay in touch with other parents to support each other over the longer term, is suggested as an improvement by some parents,** reflecting that longer term issues still remain after completion of the programme. Many report that their child with autism still ‘dominates their life’, and they face new challenges entering the school-age years.

“It was marvellous, really, really good. By the end I felt I really knew [the strategies]... I now know more about ASD than our GP and more about A’s ASD than the psychiatrist. ... There were no gaps, and EarlyBird helped me to look for further information in other places like the

internet. ... The facilitator was able to give strong, effective guidance that was immediately applicable. There was a home video filming interaction between us and A [that was particularly useful]. ... A lot of fear has gone out of our heads. ... Most important was the exposure to other parents ... we initially kept in touch... But the question really is: how can parents continue to share their specific experience with each other over time. Could Autism NZ facilitate this?" (Parent)

"On an everyday basis we have a lot more tools to help L deal with life. And we have things we can teach her siblings that help them to develop a relationship with their sister. Our quality of life is definitely increased after doing EarlyBird. We actually have some answers now. ... It's been great for reducing frustration and anger of all involved. Our days are not spent on battles now, but achievements. ... Also, meeting others on 'common ground' and entirely non-threatening... Our family has been unlucky with the health system, less unlucky with the education system, we've really had to fight to get something out of the system. It was nice to spend time with others who are in the same boat and who get it. ... It was time consuming ... we had a childcare issue which meant I did it without my partner. This had a cost impact on us because of the loss of income." (Parent)

"There was childcare at the Gisborne venue where we did the sessions. This was great as my kids were there with their Dad and I could see him during the day of the session... The movie worked well especially for learners who don't process information through a written medium like a lot of Māori don't... The facilitator was great ... the group really knitted together and gelled, we all became more courageous in sharing our personal stories ... We're still networking with the other parents to do the ongoing learning and strategies... The children played together and networked too! One month after the programme we were at the beach and my daughter refused to get out of the car. Then she saw a little boy from EarlyBird and remembered him and wanted to get out of the car then. Most of us were Māori parents 80%. I can't take my daughter on the marae [she just can't cope with the sensory overload]... We were grateful and thankful to do the programme... The movies were foreign, British, but that didn't matter, it was universal, the child experience.... After the early diagnosis there's really not that much out there, especially rurally. The information available is miniscule in comparison to what you need. EarlyBird gives you working information, practical strategies about how as well as what." (Parent)

Data from Self-completion Survey undertaken by Litmus for the Evaluation

Q 1: As a result of completing the EarlyBird Programme, this statement applies to me						
Respondents (n=46); Figures in tables are 'raw numbers'						
	A lot more	A little more	About the same	A little less	A lot less	Did not answer
I understand ways in which my child experiences the world differently from children without autism	38	8	0	0	0	0
I understand how autism influences my child's learning	36	10	0	0	0	0
I have a good understanding of why my child communicates the way he/she does	36	7	2	0	0	1
I can reflect on how I communicate with my child and change this accordingly	34	9	2	1	0	0
I warn my child before introducing something new	31	10	3	1	1	0
I match my language to a level my child understands	34	10	2	0	0	0
I wait until my child responds before I say something else	28	16	2	0	0	0
When I talk to my child I give him/her one instruction at a time	32	12	1	1	0	0
I use my facial expression and body language to encourage my child to take turns	27	14	4	1	0	0
I know some games that I can play with my child that will teach him/her social interaction skills	30	13	3	0	0	0
There are some games my child enjoys playing with me	30	13	2	1	0	0
I have a good understanding of why my child misbehaves	31	13	2	0	0	0
I use structure and visual cues to prevent or minimise problem behaviour	25	16	5	0	0	0
I structure daily activities to minimise problem behaviour	27	16	3	0	0	0
When my child has a tantrum I have a number of effective strategies	20	19	5	1	1	0
I am able to change my child's behaviour by the way I react to it	18	22	5	1	0	0
Looking at the triggers and results of my child's behaviour is helpful in managing him/her	32	11	3	0	0	0
My child with autism doesn't dominate my life	6	9	19	7	5	0
I feel I can cope with the long-term responsibility of having a child with autism	23	13	8	1	0	1
I feel confident that things will improve as I learn more about how to deal with my child	29	15	2	0	0	0
I believe I have enough help with parenting my child with autism	11	15	14	1	3	2
I believe that I have some control over the future outcomes for my child	22	15	7	0	2	0
I feel I can improve my child's condition and future prospects	25	14	6	0	1	0
My family functions well as a unit	22	15	9	0	0	0
My child with autism doesn't dominate family life	8	11	19	4	2	2
The needs of other family members are met most of the time	12	13	19	0	1	1
The people involved in my child's care are in agreement with how to help or manage him/her	19	9	13	3	1	1

Q2: What changes, if any, have you noticed in your <u>child</u> with ASD, as a result of you taking part in the EarlyBird programme? Figures in tables are 'raw numbers'	Respondents (n=46) Responses (n=69) ⁷
More interaction	16
More understanding (from the parent)	14
Less frustration	12
Responding better	12
Improved communication	10
More settled	2
No answer	2
Other	1

Q3: What changes, if any, have you noticed in your <u>family/whānau</u>, as a result of you taking part in the EarlyBird programme? Figures in tables are 'raw numbers'	Respondents (n=46) Responses (n=63)
Better understanding/more supportive	17
More relaxed/less stressed/calmer	9
Unified parenting	8
Better prepared/interaction/	7
Better manage daily routine	6
Given right tools	5
Feel in control more/more confident	4
Other (No family support and adjusted lifestyle)	4
No difference	2
No answer	1

Q 4: What was the best thing about the EarlyBird programme? Figures in tables are 'raw numbers'	Respondents (n=46) Responses (n=81)
Others in same / similar situation	23
Tools/Techniques/Strategies	21
Facilitator	8
Understanding Autism/behaviour	8
Group work/Social interaction/	7
Feeling normal	6
Content	5
Other	3

Q5: What, if anything, did you not like about the EarlyBird programme? Figures in tables are 'raw numbers'	Respondents (n=46) Responses (n=49)
Could be longer/shorter	6
Content not offered/not NZ specific	5
Logistics/rooms/time mgmt./waiting list	4
Location/distance/travel	3
More discussion/child participation	3
Need follow-up	2
Nothing	12
No answer	13

⁷ Respondents could make more than one response.

Other	1
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Q6: What would you suggest to improve the Early Bird programme for the future?	Respondents (n=46) Responses (n=49)
Figures in tables are 'raw numbers'	
Content/NZ content/content specifics	16
Follow-up contact	8
Timing/make longer/shorter	7
More interaction	4
Other	2
Nothing	5
No answer	7

Data from Evaluation of EarlyBird undertaken by Autism NZ

Collated data from EarlyBird Parent Feedback Forms (from Programmes run between July – December 2009)		
Feedback	Jul-Sep 09 (24 families completed)	Oct-Dec 09 (39 families completed)
Parents are now more able to explain autism to others	100%	100%
Material covered in the course was useful and valuable	95%	95%
Sharing of experiences with other parents was valuable	74%	74%
Parents feel more confident about managing their child	100%	100%
Parents have changed the way they communicate with their child	100%	100%
The programme came at a good time for the family	100%	98%
Recommend the programme to other parents	100%	96%
Better understanding of how autism influences their child's behaviour	93%	91%

Collated scores from EarlyBird Parent Feedback Forms (from Programmes run between March and August 2010)					
Training Sessions / Home Visits	1	2	3	4	5
Figures in tables are 'raw numbers'	'Very helpful'		'Helpful'		'Not helpful'
1. What is autism?	7	8	1	0	0
2. Autism and communication	10	6	1	0	0
3. Working with your child (People Games)	9	4	3	0	0
Home Visit A (People Games)	11	6	0	0	0
4. Visuals and structure (Self Help Routines)	11	5	1	0	0
5. Preventing Problems (Play Routines)	13	3	1	0	0
Home visit B (Play Routines)	12	4	1	0	0
6. Understanding Behaviour	14	2	1	0	0
7. Managing Behaviour (A)	11	4	0	0	0
Home Visit C (Your Choice)	12	3	0	0	0
8. Managing Behaviour (B)	3	2	0	0	0

3.5 Conclusions

Key programme strengths

- There is clear evidence from the evaluation, reinforced by previous evaluations undertaken, that EarlyBird is highly valued by families who access the service, and that positive and intended outcomes are occurring for families who take part. For many participants, EarlyBird participation appears to be a turning point in their journey with ASD, providing them with practical tools and strategies to improve communication with their child, and help deal with behaviour. Implications for the wider family are positive, with reduced stress and better relationships occurring as a result of one or more families attending the programme. The deeper understanding of ASD that parents achieve through the programme also empowers them to be more confident advocates for their children in the future.
- Autism NZ has delivered most key outputs and achieved a high volume of families participating in the programme, despite a slow start to the contract and substantial organisational change during Year One of the contract.
- The three collaborative programmes that have been run in partnership with Ohomairangi Trust appear to have increased level of participation for Māori and Pacific peoples families in EarlyBird, compared with previous years. Modifications to the core programme to deliver collaboratively (i.e. providing childcare, transport, co-facilitation with Ohomairangi staff, and so on) appear to have made the programme more accessible to Māori and Pacific peoples' cultures, and are valued by participants.

Key programme weaknesses

- The EarlyBird programme is not reaching those in rural and remote areas. The primary delivery format for EarlyBird of group sessions appears to be the key barrier to achieving higher levels of participation from rural families. While one programme in New Plymouth has been modified to allow some distance learning, further refinements are needed to provide flexibility which will make the programme more accessible.
- Internal monitoring and evaluation systems for EarlyBird by Autism NZ appear to be inadequate. While data is being collected for each programme, it seems to be incomplete, and Autism NZ head office does not appear to have access to all data that has been collected. The current parent evaluation sheet, combined with the 3-month follow up questionnaire, is not generating adequate outcomes data.
- While the collaborative programme has shown real promise, the programme requires more work to tailor it to a New Zealand context and to make it more culturally responsive. The planned DVD may help to provide a New Zealand 'flavour' to the materials. Workforce development strategies to recruit and train Māori and Pacific peoples facilitators need to be implemented, so that EarlyBird becomes more responsive 'from within'.

Priority questions

The Ministries developed a series of priority questions to be investigated for both evaluations. Based on the evidence available to the evaluation, Litmus' response to each question is summarised below.

1. How valuable/high quality is the ASD-specific parent education programme's content/design and delivery? [Include validity/accuracy, match with participant needs, level-appropriateness, consistency with current evidence (including that in the New Zealand ASD Guideline), innovativeness, consistency with principles for adult learning, fidelity with design, person-centeredness, family-centeredness, cultural and contextual appropriateness and responsiveness and emphasis on community participation].

Overall, there is strong evidence that EarlyBird is a high quality programme, as indicated by the evidence-basis from which it was developed, previous evaluations and outcomes data from the evaluation survey. Planned work by Autism NZ to check that EarlyBird aligns with the NZ ASD Guideline would support the evidence about EarlyBird programme quality.

The programme could be improved to be more innovative and responsive in its delivery – particularly by offering a wider range of delivery formats. It could also be improved to become more family-centred – encouraging greater participation from the wider family, rather than mainly parents, and providing assistance to enable both parents to attend programmes where possible. Waiting list times may be an inherent result of co-ordinating group delivery, but there is a need for Autism NZ to minimise these to ensure parents receive EarlyBird in a timely manner.

On anecdotal evidence, the collaborative programme appears to have been successful in terms of ensuring cultural and contextual appropriateness for EarlyBird delivery, but more could be done across the programme as a whole to provide a programme that is appropriate for the specific New Zealand context and cultures. There is a need for Autism NZ to undertake the planned evaluation of the collaborative programme to provide further evidence and insights which can be used to improve delivery in future.

2. What changes are evident for the young child with ASD and their family/whānau/carer(s) that can reasonably be attributed to the programme (directly or indirectly)? How substantial and valuable are the changes / gains in participants' knowledge, skills, attitudes, confidence and other competencies as a result of the ASD-specific parent education programme?

There is evidence from the current evaluation that EarlyBird has a positive impact on the child and their family. Areas where families report improvement are around communication and social interaction skills for the child, and managing difficult behaviour. Enhanced confidence and relationships within the family are also evident as a result of EarlyBird participation.

Ongoing evaluation carried out by Autism NZ needs to ensure that it captures outcomes data, and longer-term outcomes for families.

3. How effectively are the participants applying and using their new knowledge, skills, attitudes, confidence and other competencies (i.e. evidence of changed behaviour)?

As noted above there is some evidence that participants are applying skills and knowledge after taking part in EarlyBird. There is a gap in the evidence-basis around longer term impacts for children and families.

4. What unexpected outcomes (positive or negative) have resulted from the ASD-specific parent education programme?

Two unexpected outcomes are evident: Parents report a greater sense of empowerment and confidence outside the family, dealing with 'the system' and advocating on behalf of their child; and an emotional benefit derived from the group delivery format.

5. How effectively was the trade-off managed between the reach and intensity of the ASD-specific parent education programme, given the relevant constraints? How in-depth was the programme, how many people were reached, at what intensity and for how long? And, what evidence is there that the duration and intensity was both feasible and sufficient to achieve meaningful impacts?

In many ways Autism NZ appears to be managing the trade off between reach and intensity of the EarlyBird programme effectively – the programme is being delivered to a relatively large number of families in many parts of the North Island. However, EarlyBird has a notable gap in delivery to families in remote and rural areas.

The focus on a group delivery format appears to restrict the ability of EarlyBird to achieve greater geographic coverage. The emphasis on group delivery format also appears to limit participation from a wider range of cultures – while the collaborative programme shows promise as a working model, the waiting times to assemble groups of particular cultural backgrounds may limit accessibility overall.

6. To what extent does this ASD-specific parent education programme represent the best possible use of resources to achieve outcomes of the greatest possible value for parents and whānau of young children with ASD?

The evaluation provides clear evidence that EarlyBird is valued highly by participants, and it continues to contribute to positive outcomes for children with ASD and their families. There do not appear to be any alternative, comparable services for parents, suggesting that the absence of EarlyBird would mean poorer long term consequences for children with ASD and their families.

Taking into account factors that Autism NZ considers to have contributed to lower than expected delivery numbers in Year One of the contract, overall, EarlyBird is reaching a large number of North Island families in cities and provincial towns. The collaborative programme shows signs of being a successful model for improved participation rates in EarlyBird by Māori and Pacific peoples' families.

Programme delivery constraints mean that those in rural and remote areas are not accessing EarlyBird. Autism NZ reports that a 'modified' EarlyBird programme used with one family in New Plymouth will be reviewed as a potential alternative model for rural delivery of the programme – future monitoring and evaluation will be needed to determine whether this is a successful strategy.

Indepth costing analysis of EarlyBird programmes (including the collaborative programme vs the 'standard' EarlyBird programme) and other comparable services would be required to determine whether EarlyBird represents the *best possible* use of resources. This analysis would also need to take into account the longevity, location and wider organisational context of different programmes – that is, recognising that EarlyBird is a mature programme which has robust evidence of its efficacy, but there may be structural limitations on its ability to deliver to all audiences with funding currently available.

4. ASD Plus: Education for Families Programme

4.1 Overview of ASD Plus contract

In June 2009 IDEA Specialist Services ('IDEA Services'), a service provision arm of IHC, was awarded the contract to provide the ASD Plus: Education for Families programme ('ASD Plus').

The contract between the Ministries and Idea Services officially commenced on 1 July 2009, and will run until 30 June 2011. Aspects of the contract which are specific to ASD Plus are as follows:

- Design and set-up of the programme. Key outputs required included:
 - Designing a Project Development Plan (due 17 July 2009)
 - Establishing a Parent Consumer Advisory Group (by 2 November 2009)
 - Developing an Action Plan; Cultural Responsiveness Plan and Communications Plan (by 2 November 2009)
- Delivery to families situated in the South Island of New Zealand, and in Northland
- Delivery to 57 families in Year One of the contract, and 75 families in Year Two i.e. a total of 132 families over the period of the contract

Outputs delivered, as required by contract

An Action Plan was developed for ASD Plus in the first 6 months of the contract, finalised on 18 January 2010. The Action Plan includes:

- Programme Description
- Workforce Development Strategy
- Communications Plan
- Programme Provision Schedule Year One
- Protocol for the management of waiting lists

A Cultural Responsiveness Plan was also developed, dated 18 January 2010.

A Parent Consumer Advisory Group was established and held its first meeting on 15 December 2009.

4.2 Programme development and implementation

The ASD Plus programme was developed and designed by IDEA Services staff with a background in ASD and training/development.

To input to the programme design, IDEA Services undertook a literature search of a range of delivery models for parent education programmes relating to children's behaviour. Programmes explored in depth included Triple P Parenting Programme (Australian), Incredible Years (USA), Early Days (Australia), EarlyBird (UK/NZ) and Jump Start (USA).

The Jump Start programme was considered by IDEA Services to be a particularly worthwhile programme as it combined both education and intervention components, but it was found to be very costly. IDEA Services endeavoured to combine these two components in ASD Plus but for a lower cost.

IDEA Services also wanted to develop a flexible programme that would cater for families unable to take part in group programmes, due to rural, childcare, transport or other issues. To this end, the Service Manager notes that "one-on-one delivery was a design consideration right from the start". IDEA Services also noted some support in the literature that there are families (e.g. from lower socio-economic groups) for whom one-on-one delivery has better outcomes.

Pilot testing of the group programme was undertaken with families and some content adjustments were made to Modules 4 and 6. Changes included a greater focus within the modules about learning styles (specifically for children with ASD) and more examples of different learning styles. The July – September 2010 report notes that these changes are 'now being used in practice by facilitators'.

Film resource

IDEA Services received funding from the Ministries during the first year of the contract, to develop a New Zealand-based, filmed resource (DVD) for ASD Plus. The film shows a range of New Zealand families talking about their experiences with ASD. The film was completed on time toward the end of June 2010, and IDEA Services is 'delighted' with the end product.

In the latest quarterly report for ASD Plus (July–September 2010), IDEA Services reports that the film is now being used in delivery to all families involved in the programme, and that 'feedback from facilitators about its usefulness in showing the issues and successes of other families has been very positive'.

Programme Description

“ASD Plus is not just an educational programme, but also very much a practical application of learning. Without this, outcomes are much more limited.” (Service Leader, ASD, IDEA Specialist Services)

A Programme Description for ASD Plus is included in the Action Plan. IDEA Services describes ASD Plus as ‘person-centred and individualised’. The programme has seven modules: Introduction to ASD; understanding my child’s communication; how my child senses the world; my child’s learning style; stress, anxiety and routines: reducing child and family stress through good planning; understanding behaviour – why does my child do that?; managing into the future – a roadmap. Each module includes an intervention element – a practical application of the information provided (for example, developing a communication tool to use with the child).

Families are first visited at home (the ‘pre-education visit’). A learning plan is developed with the family - content and methods of delivery are chosen together. There are three delivery mechanisms for the programme:

- Group sessions involving a small number of families – usually once a fortnight
- Individualised sessions for a particular family or whānau group delivered to suit each family
- Distance learning – via internet, DVD, reading material, and phone/email/face-to-face contact, depending on the needs and location of each family.

Families attending group sessions have the option of a Follow-up Visit after every module. For Distance Learning, there is one initial home visit/phone call and then IDEA Services follow with a “hybrid” of distance learning and one-on-one home visits.

Workforce Development

A Workforce Development Strategy is an area of focus in the ASD Plus Action Plan. Action points agreed include:

- Supervision of existing facilitators: First delivery of module content to be observed by Idea Services staff who developed the programme; further delivery to be observed at least once per year; co-delivery of group sessions to be arranged as often as possible; facilitators to use a Facilitation Skills Self-Reflection tool throughout delivery; for group delivery programmes, the Service Leader ASD to facilitate group/individual supervision after module 3 home support, and after completion of all modules; any needs or issues arising for facilitators to be discussed with Service Leader ASD via additional face to face or telephone supervision sessions at any point in the programme
- Professional development of existing facilitators: All encouraged and supported in their professional development in ASD, working with families; and delivery of training/education; All to be linked to the IHC library and to receive a Table of Contents for relevant journals to access online or hard-copy from the library; a once-yearly professional development meeting of facilitators to occur, with a focus on issues of relevance to the team, and areas of learning that have been identified through supervision and feedback

- Potential Māori and Pacific peoples facilitators: Potential facilitators identified (as per Cultural Responsiveness Plan) and kept informed of ASD Plus, particularly those from Māori and Pacific peoples families; invite appropriate individuals to participate in professional development events that other facilitators may be involved in; invite appropriate individuals to co-deliver certain portions of the programme, or to provide support to facilitators on pre-education or follow-up visits with families; support potential facilitators to meet the competence measures required of facilitators, and to participate in 'Train-the-trainer' events.

In the June 2010 Annual Report, Idea Services reports that 15 facilitators had been trained to deliver ASD Plus, based in a range of locations (5 in Christchurch, 4 in Dunedin, 1 in Timaru, 2 in Nelson/Marlborough and 1 in Northland). Idea Services considers that this pool of facilitators enables it to deliver good geographic coverage (particularly as facilitators travel regularly for other work), and is big enough to cater for current and 'significantly larger' numbers of families.

Facilitators are considered by IDEA Services to 'have a good understanding of programme content and processes [and] subsequent delivery has been closely monitored with all group sessions involving co-delivery with an experienced facilitator. Individual programme delivery has been supported by careful supervision'. IDEA Services considers that this number of facilitators is ideal to cover for all geographical areas.

Reflecting low referrals to ASD Plus, as of June 2010, four trained facilitators had not yet delivered a programme.

IDEA Services has sub-contracted Southern Behaviour Specialists to provide facilitator services in Southland. The July – September 2010 report notes that this organisation is 'experiencing capacity difficulties in Southland and is no longer able to provide cover in this region'. However, all referred families received ASD Plus via IDEA Services facilitators.

In September 2010, facilitators attended a Parent Education Professional Development Day in Wellington, along with representatives from Autism NZ, and the Ministry of Education. Seven IDEA Services facilitators attended (all were eligible to attend but some weren't able to, for example a Christchurch-based facilitator could not attend because of disruption following the Christchurch earthquake).

Communications / Networking

A Communications Plan is part of the ASD Plus Action Plan. The Communications Plan outlines a range of actions for communicating with different target audiences, summarised as follows:

- Families waiting for service at time contract taken over from previous provider: Access by post or phone
- Families who will potentially access the service in future: Provide them with information via: Altogether Autism website and e-tools; Autism NZ brochures and electronic information; IHC website; brochures and information from other networks (Needs Assessment and Service Co-ordination Services (NASC), Child Development Teams, Early Intervention providers, early childhood

education providers; information sessions in local environments; 0800 phone numbers and specific email address

- Referring agents (NASC, Child Development Teams, Early Intervention providers, early childhood education services, Plunket nurses): Provide them with information via post and email in the first instance (within a week of the Ministries making the joint announcement), then provide printed brochures and electronic information to follow up; hold information sessions in some locations, arrange meetings with larger agencies
- Autism NZ: Make initial phone contact, meet in person, then ongoing regular contact, including brochures and electronic resources
- Internal audiences (Service General Managers, Family/Whānau Services, Specialist Services staff; wider IDEA/IHC: A variety of methods as appropriate
- Autism Community networks (DIAS, Altogether Autism, Parent to Parent, Autism NZ branches: Personal contact with Altogether Autism and Parent to Parent, followed up by brochures and electronic materials; Autism NZ branches: Send written information, invitations to Information Sessions, attend committee meeting and share information in person. At some point, develop a MoU with Altogether Autism and Parent to Parent.

IDEA Services reported establishing communications and commencing relationship development with Autism NZ, Altogether Autism and other referring agencies in the September – December 2009 quarter, and was 'pleased with the reciprocity of these relationships'.

Communication activities remained a focus through the first year of operation and the June 2010 Annual Report states that IDEA Services is 'confident that our promotional and marketing activities have ensured that the majority of referring agents (or information providers) are aware of the service and are sharing information about ASD Plus with appropriate families, and are working hard to increase awareness of the service and corresponding referrals'.

The latest quarterly report for ASD Plus (July – September 2010) notes that 'extensive' promotion of the service was carried out during this period. Activities included:

- Promotion via the Altogether Autism organisation: Advertising ASD Plus on the Altogether Autism website; advertising specific course details through its e-newsletters; and attending, or providing promotional materials to local network meetings in relevant locations
- Working with Autism NZ's local area coordinators and email networks
- Regular email contact and sending information to IDEA Services' own networks of paediatricians, early intervention providers, support groups, and family health services
- Meeting with Northland groups and service providers
- Responding to queries from clinicians/practitioners.

A conference presentation about ASD Plus was delivered at the Autism NZ conference in September 2010. IDEA Services reports that it got 'great feedback from delegates'.

Despite the attention and energy being put into raising the profile of ASD Plus, current referrals are still lower than desirable, and this is a source of frustration for IDEA Services:

“We have just upped our promotional activities yet again, with a new poster for GPs, Plunket, Early Childhood Centres etc, and are doing a round of presentations at other services and professional forums in Christchurch, Dunedin and Invercargill, but it is really hard to forecast the impact of this with any accuracy.” IDEA Services ASD Service Leader, November 2010

Monitoring and Evaluation

IDEA Services implemented an internal evaluation programme for ASD Plus in March 2010. It involved three levels of evaluation including: 1) Participants' views of programme delivery; 2) Changes in at-home practice; and 3) Progress toward family goals. Specifically, ASD participants:

- Set family goals together with IDEA Services at the pre-education visit
- Complete a feedback form at the end of the programme
- Complete an APQ questionnaire at commencement of the programme, at completion, and 6-months after programme completion.

Internal evaluation data for ASD Plus is limited at this point in time, due to the small number of families who have completed the forms, and the fact that no families have completed the 6-month follow-up for the APQ component.

IDEA Services have provided participants with the opportunity to give preliminary consent to take part in external evaluations since March 2010. However, at the time that parent feedback was being sought for the current evaluation (in August-September 2010), no ASD Plus parents had given preliminary consent *and* completed a programme.

The first formal family feedback was received by IDEA Services in April – June 2010, and was positive (see Section 4.4 for further details). On the basis of this first wave of feedback, IDEA Services responded to a small number of parents' suggestions to increase the time allowed for group sessions, increasing each group session by 30 minutes.

4.3 Programme delivery and reach

The Action Plan for ASD Plus includes a Programme Provision Schedule for Year One of the Contract, summarised below:

ASD Plus Programme Provision Schedule – Year One	
Location and programme type	Number of families expected to participate
Urban South Island - 5 group programmes: 2 in Christchurch, 1 in Dunedin, Invercargill and Nelson - 3 individual programmes	25 (5 families per group) 3
Rural South Island - 7 individual programmes	7
South Island (all areas) - 10 distance learning programmes	10
Northland - 6 individual programmes - 6 distance learning programmes	12
TOTAL	57

Idea Services has provided the Ministries with quarterly reports of data summarising how, where and to whom, ASD Plus been delivered. The most recent quarterly report covered the period July – September 2010. An Annual Report was also submitted for the period July 2009 – June 2010.

Key points to note for the period July 2009 – September 2010 are:

- 36 families participated in ASD Plus programmes, involving a total of 83 participants
- The majority of families were based in the South Island, including those based in cities, provincial towns and rural locations (31 families). 5 families from Northland have participated in ASD Plus since the programme began
- Most families received the ‘individual’ delivery format for ASD Plus (26 of the 36 families). Two group programmes were delivered, in two locations (Dunedin and Christchurch). 9 families received a ‘combined’ delivery method involving a mix of group, distance learning and individual delivery
- The majority of children whose families participated were NZ European or European (22 children), 3 were NZ Māori, 11 of other ethnicities. No Pacific peoples took part in ASD Plus
- The age of children whose families participated is not a reporting requirement for ASD Plus. Anecdotally, IDEA Services considers that most of the children whose families did ASD Plus were 4 or 5 years old.

Delivery numbers increased steadily during the first year of operation, with 17 families completing the programme in the April – June 2010 quarter. As noted in its June 2010 Annual Report, this is approximately the level of delivery that would be required for IDEA Services to achieve its target of 75 families in the second year of operation. However, only 4 families completed ASD Plus in July – September 2010, with group programmes cancelled due to low referrals. IDEA Services notes that families scheduled for group delivery were all offered an individual or distance programme as an alternative. In Christchurch, all further group programmes have been cancelled this year, following the earthquake.

Referrals

The overall volume of referrals to ASD Plus in the first year of operation was lower than anticipated. IDEA Services attributes this to the fact that the programme is new, and it has 'taken time to build awareness and trust in something that was previously unknown'.

In September – December 2009 all referrals were self-referred except one referral from an occupational therapist in Whangarei. Families at that time reported to IDEA Services that they were hearing about the service from 3 key sources: a) Paediatricians or health-based assessment teams (usually around the time of diagnosis); b) Early intervention team members (such as Ministry of Education, Special Education, Vera Haywood Centre, Beacon House, etc.); and c) Autism NZ.

In the first year of operation, most families referred to ASD Plus were self-referred. One family was referred by a health professional, one by a DHB child health service, and one by Ministry of Education staff.

IDEA Services notes that by June 2010 it had started to receive word-of-mouth referrals from families who found out about ASD Plus from other families, and hoped that this will be a good source of referrals in future.

IDEA Services reported an issue affecting referrals in the April – June 2010 report, as follows:

"Through discussion with paediatricians we have become aware of an issue that may influence referral to this service – limited follow-up support after immediate diagnosis. Most families are reportedly given information about ASD Plus at the time of diagnosis, but for many families it is a time of confusion, grief, and distress, and many are unlikely to remember the information given to them, or feel able to participate in an education programme at that time. Unless they are able to access other support services quickly (such as Early Intervention, for which there is often a long wait) it is likely that they will have forgotten about ASD Plus (or many other supports), and not informed of it again until much further down the track. We do not have a way to contact these families or even know who they are. We are looking forward to the implementation of the DHB-related co-ordination services, as this should provide contact with families after diagnosis, that will help remind them of what is available and how it can be accessed."

The latest quarterly report for ASD Plus (July – September 2010) notes that although all families currently referred to the programme are self-referred, IDEA Services is 'starting to see a wider range of professionals informing families' about the programme. Ministry of Education, Special Education early intervention teams in Nelson/Marlborough and Southland are considered by IDEA Services to have been particularly active in promoting ASD Plus. IDEA Services intends to contact other agencies who give families ASD Plus information in October/November 2010, to discuss follow-up with those families to identify any 'roadblocks' to accessing the programme.

The Programme Manager for ASD Plus mentioned that the link between ASD Plus and 'IHC branding' might possibly be problematic in that it could be seen to have negative connotations of severe impairment.

South Island

IDEA Services reported that discussions with Autism NZ coordinators in Otago and Canterbury in June – September 2010 revealed concerns that families get limited follow-up post-diagnosis, including from Autism NZ. IDEA Services plans to work further with Autism NZ coordinators in October and November 2010 to identify how both organisations can follow-up families who receive ASD Plus information to try and increase uptake of the programme.

Although IDEA Services was optimistic that referrals were steadily rising up until June 2010, referral numbers in Christchurch and Dunedin were low in July – September 2010, and scheduled group programmes had to be cancelled. IDEA Services believes that Christchurch referrals may have been affected by the impact of the earthquake.

Northland

5 Northland families participated in ASD Plus between July 2009 – September 2010.

IDEA Services reports that despite efforts to increase awareness of the programme and build community and agency relationships in Northland through the first year of operation, low levels of referrals have continued. An explanation of the referral issue is included in the June 2010 Annual Report: as follows:

"We contacted the Child Health Service at Northland District Health Board and were informed that very few pre-school children had received an ASD Diagnosis in the past 18 months. This is largely because of a change to the diagnostic process (now following the more thorough process outlined in the NZ ASD Guideline) used by the team led to a backlog of assessments, and school-age children have been seen first as a way of managing this... We anticipate an increase in referrals once diagnosis starts to focus on pre-school children in future."

In July – September 2010 IDEA Services reports that 'referrals for Northland are now being received and that IDEA Services has increased its contact with other services in the area' (including REAP), and during the interview for the evaluation the Service Leader told Litmus that the facilitator is now at capacity.

Although numbers are small, there appears to be a greater issue with delays, cancellations and withdrawals from ASD Plus in Northland, than in other parts of the country. IDEA Services appears to be working hard to overcome difficulties families may face. For example, in July – September 2010 one family in the Far North had cancelled planned sessions and was having difficulties rescheduling due to distance and lack of a phone. IDEA Services loaned the family a telephone to try and overcome these barriers.

Waiting lists

A Protocol on the Management of Waiting Lists is a key action area in the ASD Plus Action Plan. The Protocol was discussed with the Parents Consumer Advisory Group at its first meeting in December 2009. Action points agreed in the Action Plan include:

- Referral acceptance: Families meeting entry criteria will receive ASD Plus on a 'first-in first-served basis
- Prioritising programme type: Group delivery will be encouraged for the majority of families. Distance learning will generally be the second option, and individual programmes (for which there is limited capacity) will be prioritised carefully. (Factors influencing prioritisation for individual delivery include: no group option in that location; language/learning/cultural barriers; young child; personal circumstances which make group involvement difficult; significant transport difficulties; significant childcare difficulties)
- Waiting list capacity: Waiting list managed by the Service Manager, ASD Plus; pre-education visits to occur within 1 month of acceptance, and programme to commence within 3 months of acceptance; families to be informed of waiting time at pre-education visit, and provided with information about other support services that may be available during the wait; distance learning to be offered when wait for other programme types will be lengthy; Ministries to be informed on numbers/capacity, particularly if unable to accept further referrals.

IDEA Services has been able to provide ASD Plus to almost all families who were referred and were eligible for participation. Only one family, in the July – September 2010 quarter has ever waited for any length of time (the Dunedin-based family prefers a group-delivery format so is waiting for a group to be formed).

In the first reporting period (September – December 2009), the average wait between the pre-education visit and scheduled programme start was 69 days, i.e. significantly longer than specified in the Protocol above. However IDEA Services points out that most referrals were received in October 2009 and there was not sufficient time to gather sufficient numbers and complete groups before the Christmas 2009 break, so families referred during this time had to wait until 2010 for their programme to start.

Cultural Responsiveness

The Cultural Responsiveness Plan for ASD Plus was finalised on 18 January 2010, and is a key action area in the ASD Plus Action Plan. Action points outlined in the Cultural Responsiveness Plan include:

- Demonstrate commitment to Te Tiriti o Waitangi: Use a model that promotes whakamana; recognise whānau as the foundation of Māori society; acknowledge the importance of working in a consultative, collaborative manner; continually build understanding of te Ao Māori; recognise unique family needs, spend time establishing relationships before beginning 'work', adapt the programme (using Te Reo in delivery, using Māori staff and advisors where possible)
- Develop a communication strategy for communications with Māori and Pacific peoples: meet with people already working with Māori and Pacific peoples' communities to: a) provide information to be disseminated through existing networks; b) discuss adapting delivery to best suit the needs of Māori and Pacific peoples' communities; c) seek advice about sharing information and engaging with local communities; and d) working together once families are engaged

- Provide information in face-to-face contacts (4 meetings by end of March 2010)
- Make regular contact with identified people who can link with Māori and Pacific peoples (ASD Plus database) by early March 2010
- Receive referrals via informal conversations and face to face meetings as necessary
- Use interpreters and elders to support communications as appropriate
- Develop and implement a Māori and Pacific peoples' workforce development strategy: Meet with related groups (as above) and establish ongoing relationships over time; identify individuals with interest and expertise in ASD who have potential to be involved in delivery of the programme, include these individuals in the programme's communication loop, invite them to co-present relevant parts of the programme as appropriate, invite them to professional development activities for programme facilitators, provide support for them to complete facilitator competency requirements, with mentoring and support from appropriate facilitators
- Provide a programme that meets the expectations and aspirations of Māori and Pacific peoples: Individualise delivery to take account of specific family needs, for example:
 - Pre-education visits – allowing additional time/visits to establish relationships with families before beginning the programme
 - Work with families/whānau/aiga to determine what their expectations and aspirations are, so these can be incorporated into programme delivery
 - Encourage and invite participation of the wider family/whānau/aiga e.g. Saturday or evening sessions
 - Seek support from advisors or local community elders where necessary
 - Adopt a more interactive and oral style of delivery where appropriate
 - Discuss evaluation of the programme with each family and be prepared to alter the evaluation format (e.g. use informal interview/conversation, rather than written forms)

Monitor processes to measure the health gains of the programme for Māori and Pacific peoples: Discuss individual family goals so these can be measured at programme completion (as for all families); carry out APQI and questionnaire measures AFTER relationships have been established; alter evaluation format if needed (as above).

IDEA Services reported ongoing activities in relation to cultural responsiveness in its quarterly reports to the Ministries. Key activities include:

- Ensuring that every delivery is individualised; encouraging wider family participation and community support for every family; offering flexible delivery to all families; Identifying unique family goals for each family
- Taking a 'slower approach' to relationship building with Māori families

- Meeting with Pacific Trust Canterbury, on a number of occasions to share information about the two services and invite a representative from the Trust to join the Advisory Group
- Meeting with a range of other relevant organisations including Northland Hau Ora services, Ministry of Education Kaitakawaenga Canterbury, Vaka Tautua
- Contacting all relevant parties on the IDEA Services database at least monthly

4.4 Programme Impact

A range of data sources have been used to inform the evaluation about the impact of the ASD Plus programme on participants and their families, including:

- Results from the self-completion survey of parents (10 responses, from a mail-out to 31 families)
- Feedback from qualitative interviews with the ASD manager, 2 facilitators and 3 parents
- Monitoring data from IDEA Services, from 17 participants who have taken part in programmes since monitoring began in March 2010.

Data tables summarising the quantitative data sources are provided in the following pages. Verbatim comments from surveys are included in the Appendix.

Key findings

The total sample size of ASD Plus participants who provided feedback about the programme is small. However, given that only 36 families have participated in ASD Plus since the programme began, we can be reasonably confident the views expressed represent about 50% of participants. While findings are indicative of participants' views, there is a high degree of consistency of feedback across the three data sources.

Analysis of participant feedback highlights the relief and gratitude that families feel to have received the ASD Plus programme. It clearly fills a need amongst parents that is not offered through any alternative services in the South Island or Northland. Feedback indicates that family expectations are surpassed, and the programme contributes to immediate and longer-term benefits for families.

Key findings in relation to the impact of ASD Plus are as follows:

- **The evidence is consistent across all data sources that participants have been satisfied with the ASD Plus programme delivery. There is indicative evidence that the programme is achieving its objectives and having a positive impact on participants, children, the immediate and wider family.**
- Particular areas of **strength** indicated by the data are:
 - Increasing participants' knowledge and understanding of ASD: Most survey respondents report that ASD Plus has helped them understand 'a lot more' about how their child with autism understands the world, how autism influences their child's learning, why their child communicates the way they do and why their child 'misbehaves'⁸

All respondents to the IDEA Services' feedback forms say they understood the information given, and that the information covered and resources would be useful when they got back home.

⁸ While the word misbehaves has negative connotations, it is the word used in the validated APQ questionnaire

- Increasing use of a range of strategies and tools to encourage improved communication and social interaction of the child with ASD: Most parents who responded to the survey say they are more likely since taking part in ASD Plus to give one instruction at a time and wait until the child responds before saying anything else
- Increasing parents' use of strategies to manage difficult behaviour: Most survey respondents report being more likely since ASD Plus to use structure and visual cues to prevent or minimise 'problem'⁹ behaviour, and to look at triggers and results of their child's behaviour.
- **Changes seen in children, following ASD Plus, include**: Less frustration and improved communication.
- **Changes for parents and families after ASD Plus participation include**: More understanding and supportive attitudes, more relaxed and calmer households, unified parenting and a sense of being in control/more confident.
- **ASD Plus facilitators receive very positive feedback from programme participants**. Most ratings for different aspects of programme delivery and facilitation on the IDEA Services' parent feedback forms are 'very satisfied', and a range of enthusiastic comments about ASD Plus delivery reflect this. Half of those who completed an evaluation survey rate the facilitator(s) as the 'best thing' about the programme.
- **An unintended, but positive impact of ASD Plus reported in the qualitative interviews is an ongoing sense of empowerment to be the ASD child's advocate**, negotiating the education and health systems in particular.
- **Other unintended impacts relate to group delivery**, and include the emotional benefit of seeing others 'in the same boat' who can relate to each other and share experience. One individual mentioned the creation of a support network that arose from her ASD Plus group sessions.
- **Negative feedback about ASD Plus is minimal. A few suggested improvements relate to**:
 - Changes in timing and logistics (the small number of suggestions does not indicate any pattern of response in this area)
 - A few participants who took part in one-one-one delivery say they would like to have the opportunity for interaction with other parents via group sessions
 - Ongoing contact and advice about 'where to next' is suggested by a small number of participants.

"We do routines now. We didn't do this before. Also J listens to more music now – this was a suggestion that we learnt from the course. His language and vocabulary have improved. He listens to nursery rhymes and orchestra; he really likes Mozart. Another strategy we learned on the programme was the star chart. ... Another thing that came out of the programme was the 'About Me' book that I put together on J. This is all about his likes and dislikes and has been really helpful for taking to school to share with J's teacher. ... I didn't know that there would be other mothers there, it was good to meet parents with children the same age as J. Before that I didn't know any others in the area. We exchanged phone

⁹ 'Problem' is the word used in the validated APQ questionnaire

numbers and will get together. ... I would like there to be follow-up courses. We both felt like we wanted to do more... The only thing was it was a long day 8.30-4.30 to sit at a table like a board meeting – some comfy chairs or even beanbags would have been better, more comfortable.” (Parent)

“[ASD Plus was] fantastic, completely tailored to what we especially were looking for. We did at home. ... We started in May because my whole family wanted to take part. My parents, my grandparents, my uncle, my great grandmother, and my great aunty. IDEA Services really worked to make the scheduling happen. We had constant contact with IDEA Services. ... The most useful part was learning about managing sensory issues. Managing what people think is bad behaviour... We’ve learnt a lot about managing his behaviour, we have tools and strategies that enable us to go out into the community and full members. ... If we go out, we feel more confident to handle S’s behaviour, he’s sensitive to light and noise. We were like hermits in our home because we just didn’t know how to deal with it... We felt more empowered coming away from ASD Plus. My mantra has been “knowledge is power” – I don’t want to bury my head in the sand and ASD Plus sets you on your way ... This is also true for the wider family, they support me to look after S, they’re the only ones I trust to look after my son. Another thing is that my husband and I were sad to see that marriages break up over ASD and we’ve vowed to keep building on a really strong partnership because we can see how ASD affects marriages. ASD Plus really helped to emphasise the importance of marriage and managing your stress levels. ... It would be a real shame if it wasn’t there. It’d be dire for some parents. It was a lifeline for us to be taught by such knowledgeable people. We had ASD Plus at the start of our journey with ASD – diagnosis can be a very isolating experience, we got nothing of any real help from the paediatrician, he didn’t really explain, we were left to our own devices to figure out what next.” (Parent)

“We did the programme in my house, this was really good, my sister-in-law who is quite involved in R’s life, joined in the sessions. It was more comfortable and relaxed in the home setting. Also, we were able to really focus on R in that one-to-one set up. ... The facilitators delivered it in a way that I could translate to R’s older brothers; giving some ideas about how things could run better for the whole family. It helped me to explain to them how they can help R. ... I knew a lot about ASD but the Programme was great for the practical examples and strategies. We all [as a family] have a better understanding of R’s world...and...seeing things from his point of view. We’ve learnt to understand him a lot better [mum, aunt and brothers]. ... One skill in particular, R doesn’t like touching new things and the programme taught me more about how to handle this. Also, I really learnt from the programme to pick my battles. I do feel more confident – and I still have the notes from the programme and refer to them when new things come up which has been really helpful. ... If this programme hadn’t existed, I would feel extremely isolated as the two organisations here [Altogether Autism and Autism NZ] don’t seem to do a lot. ... The two facilitators had a genuine interest and in-depth knowledge; they could answer every question on the spot and this was very helpful. Both invited me to contact them if I needed to ... Although the one to one had its advantages, doing it in a group would mean I could meet other parents. ... The only thing that could be thought of as a gap would be something about where we go from here i.e. after the programme ends. It would be good if the programme could point parents in the direction of where they can access ongoing support.” (Parent)

Data from Self-completion Survey undertaken by Litmus for the Evaluation

Q 1: As a result of completing the ASD Plus Programme, this statement applies to me						
Respondents (n=10); Figures in tables are 'raw numbers'						
	A lot more	A little more	About the same	A little less	A lot less	Did not answer
I understand ways in which my child experiences the world differently from children without autism	9	0	0	0	0	1
I understand how autism influences my child's learning	8	0	1	0	0	1
I have a good understanding of why my child communicates the way he/she does	6	1	2	0	0	1
I can reflect on how I communicate with my child and change this accordingly	4	4	1	0	0	1
I warn my child before introducing something new	4	3	2	0	0	1
I match my language to a level my child understands	5	2	2	0	0	1
I wait until my child responds before I say something else	4	4	1	0	0	1
When I talk to my child I give him/her one instruction at a time	8	0	1	0	0	1
I use my facial expression and body language to encourage my child to take turns	4	3	2	0	0	1
I know some games that I can play with my child that will teach him/her social interaction skills	4	2	3	0	0	1
There are some games my child enjoys playing with me	4	2	3	0	0	1
I have a good understanding of why my child misbehaves	5	4	0	0	0	1
I use structure and visual cues to prevent or minimise problem behaviour	4	5	0	0	0	1
I structure daily activities to minimise problem behaviour	4	4	1	0	0	1
When my child has a tantrum I have a number of effective strategies	3	5	1	0	0	1
I am able to change my child's behaviour by the way I react to it	3	5	1	0	0	1
Looking at the triggers and results of my child's behaviour is helpful in managing him/her	6	2	1	0	0	1
My child with autism doesn't dominate my life	1	0	7	1	0	1
I feel I can cope with the long-term responsibility of having a child with autism	2	3	4	0	0	1
I feel confident that things will improve as I learn more about how to deal with my child	4	3	2	0	0	1
I believe I have enough help with parenting my child with autism	2	4	3	0	0	1
I believe that I have some control over the future outcomes for my child	3	3	3	0	0	1
I feel I can improve my child's condition and future prospects	4	1	4	0	0	1
My family functions well as a unit	3	3	3	0	0	1
My child with autism doesn't dominate family life	1	3	4	1	0	1
The needs of other family members are met most of the time	1	4	3	0	1	1
The people involved in my child's care are in agreement with how to help or manage him/her	3	3	3	0	0	1

Q2: What changes, if any, have you noticed in your <u>child</u> with ASD, as a result of you taking part in the ASD Plus programme? Figures in tables are 'raw numbers'	Respondents (n=10) Responses (n=11)
Less frustration	3
Improved communication	2
More understanding (from the parent)	1
Responding better	1
No changes	1
No answer	3

Q3: What changes, if any, have you noticed in your <u>family/whānau</u>, as a result of you taking part in the ASD Plus programme? Figures in tables are 'raw numbers'	Respondents (n=10) Responses (n=13)
Better understanding/more supportive	2
More relaxed/less stressed/calmer	2
Unified parenting	2
Feel in control more/more confident	2
Given right tools	2
No difference	2
No answer	1

Q 4: What was the <u>best thing</u> about the ASD Plus programme? Figures in tables are 'raw numbers'	Respondents (n=10) Responses (n=18)
Excellent presenter	5
Content/One-to-one	4
Group work/Discussion/Social Interaction	3
Gaining understanding of Autism/behaviour	2
Tools/Techniques/Strategies	2
Feeling normal/comfort/hope	1
Others in same / similar situation	1

Q5: What, if anything, did you <u>not like</u> about the ASD Plus programme? Figures in tables are 'raw numbers'	Respondents (n=10) Responses (n=10)
Could be longer/shorter	1
Location/distance/travel	1
Other	1
Nothing	3
No answer	4

Q 6: What would you suggest to <u>improve</u> the ASD Plus programme for the future? Figures in tables are 'raw numbers'	Respondents (n=10) Responses (n=13)
Timing/logistics/equipment	3
Content	2
More interaction	2
No answer	2
Other	2
Follow-up contact	1

Nothing	1
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Data from Evaluation of ASD Plus undertaken by IDEA Services

ASD Plus Feedback Form – Modules 1-2 (n=7: Course G002; I015); Figures in tables are 'raw numbers'	V.S ¹⁰	S	N	D	NA
Content					
I understood the objectives of the session	4	3			
We covered everything I expected to cover	2	5			
I understand the information I was given	4	2	1		
The information covered will be useful to me when I get back home	3	4			
Comments - None					
Format					
I will be able to use the things handed out	3	4			
Activities and worksheets were useful / helped me understand	3	4			
The visuals / resources were useful / helped me to understand	2	5			
There was enough variety within the modules	2	5			
I will be able to use the resources again at home	4	3			
Comments - None					
Venue (if outside home)					
I liked the place where the session was held	4	1			2
Comments - <i>Good place. Cold outside</i> - <i>Nice and quiet and relaxing</i>					
Delivery The person/people who delivered the modules ...					
Made things easy to understand	6	1			
Was knowledgeable about the topic	6	1			
Presented in a way that helped me to understand the topic	4	3			
Encouraged discussion and involvement of group members	4	3			
Answered questions appropriately	4	3			
Managed the group well	4	3			
Kept the modules focused on the topic	4	3			
Made me feel comfortable	5	2			
Comments about the delivery - <i>Relaxed and friendly; Present things quite clearly to understand</i>					
Write down anything you would have changed about the session					
No comments					
Write down one thing you enjoyed most about the session					
- <i>Easy to contribute</i> - <i>Listening to other comments</i> - <i>Learning a bit more about ASD</i> - <i>Discussing about sign language</i>					

¹⁰ IDEA Services uses a visual 'smiley-face' scale to collect feedback, which we have equated to 'Very Satisfied' (V.S., above); 'Satisfied' (S); 'Neutral' (N); 'Dissatisfied' (D); and Not applicable (NA)

ASD Plus Feedback Form – Modules 3-7 (n=3: Course G002)	V.S	S	N	D	NA
Content					
I understood the objectives of the session	2	1			
We covered everything I expected to cover	2	1			
I understand the information I was given	2	1			
The information covered will be useful to me when I get back home	2	1			
Comments - <i>Up-to-date (not like the old EarlyBird). More relevant for Christchurch / Aotearoa</i> - <i>It was very useful information for my partner and I for use at home</i>					
Format					
I will be able to use the things handed out	2	1			
Activities and worksheets were useful / helped me understand	2	1			
The visuals / resources were useful / helped me to understand	2	1			
There was enough variety within the modules	2	1			
I will be able to use the resources again at home	2	1			
Comments - <i>Good use of DVDs. International best practice followed</i> - <i>Very good resources made to help me understand</i>					
Venue (if outside home)					
I liked the place where the session was held	3				
Comments - <i>Wonderful caring environment</i> - <i>Nice and quiet apart from small sounds around</i>					
Delivery The person/people who delivered the modules ...					
Made things easy to understand	3				
Was knowledgeable about the topic	3				
Presented in a way that helped me to understand the topic	3				
Encouraged discussion and involvement of group members	2	1			
Answered questions appropriately	3				
Managed the group well	2	1			
Kept the modules focused on the topic	3				
Made me feel comfortable	3				
Comments about the delivery - <i>A little rushed to keep to time (keeping to time is <u>great</u>) – not able to have quite enough discussions (which was tangential)</i> - <i>Very good</i>					
Write down anything you would have changed about the session					
- <i>Too much information in Session 1 (2 module). Need time to digest. Hence leave a long gap (between 2-3 weeks) so that the parent can bring the material back, read through it, maybe practice it before the next session</i>					
Write down one thing you enjoyed most about the session					
- <i>Cutting edge research/technology</i> - <i>Enthusiastic facilitators</i> - <i>I liked group discussion which parents share their experiences and learn a lot from it</i> - <i>Everything about the whole session which was all good to take in for my own knowledge</i>					

ASD Plus Feedback Form – Modules 1-7					
(n=10: Course I005; Goo1; I014)					
	V.S	S	N	D	NA
Content					
I understood the objectives of the session	8	2			
We covered everything I expected to cover	9	1			
I understand the information I was given	10				
The information covered will be useful to me when I get back home	10				
Comments - <i>We covered everything I expected to cover, and more</i> - <i>A lot of the information provided helped me understand my child's behaviour</i> - <i>ASD is such a complex subject but I found the content of the course a great starting platform of base information from which we could branch out and discuss in more detail areas that were relevant to us</i>					
Format					
I will be able to use the things handed out	5	5			
Activities and worksheets were useful / helped me understand	7	3			
The visuals / resources were useful / helped me to understand	9	1			
There was enough variety within the modules	9	1			
I will be able to use the resources again at home	7	3			
Comments - <i>The information in the folders was set out in a clear, easy to understand and follow manner, with space to add thoughts or additional notes, which was great</i>					
Venue (if outside home)					
I liked the place where the session was held	7	1			2
Comments - <i>Great lunch</i> - <i>Didn't get cold feet during the flood. Good venue</i> - <i>Excellent</i> - <i>Being held at my own home, I think it gave the facilitators a better understanding of my unique situation</i>					
Delivery The person/people who delivered the modules ...					
Made things easy to understand	10				
Was knowledgeable about the topic	10				
Presented in a way that helped me to understand the topic	9	1			
Encouraged discussion and involvement of group members	9	1			
Answered questions appropriately	10				
Managed the group well	10				
Kept the modules focused on the topic	9	1			
Made me feel comfortable	10				
Comments about the delivery - <i>Enjoyed the one-on-one delivery</i> - <i>The facilitator was awesome. She gave us so much help and knew her stuff well. We are so thankful for all she has done to help us</i> - <i>[The facilitators] were great! It is nice to be able to chat with people who understand and can provide clarification of various aspects of ASD</i>					
Write down anything you would have changed about the session					
- <i>Cakes with cream</i> - <i>More encouragement for discussion of group members</i> - <i>4 more days/weekends</i> - <i>Not enough sessions to cover everything in depth</i>					
Write down one thing you enjoyed most about the session					
- <i>Relaxed, friendly. Really nice people</i> - <i>Enjoyed everyone's company</i> - <i>To be informed and met by competent teach and other families in same situation. Thanks</i> - <i>Meeting other families</i> - <i>Friendliness</i> - <i>It was great that the facilitator could meet xxx (my 'autist') and give her professional opinion, which I value</i>					

4.5 Conclusions

Programme strengths

- IDEA Services achieved all programme design and development outputs within Year One of operation, including a New Zealand-made DVD film resource which will be particularly beneficial in enabling distance learning options. Management and monitoring systems appear to be comprehensive, well thought through, and functioning efficiently. The pool of facilitators seems adequate to cope with current and future demand, and supervision and workforce development activities are working well.
- The available evidence for ASD Plus indicates that this new programme is achieving positive, tangible short-term outcomes for participants and families in line with programme objectives. Participant satisfaction is consistently high, and there is evidence that most participants are applying ASD Plus-learnt strategies and tools in their households.
- The tailored, individual approach offered by ASD Plus is a real strength of the programme. Families respond positively to the opportunity to work in partnership with IDEA Services to determine both mode of delivery, and specific goals the family wishes to achieve. The evaluation also captured numerous examples of IDEA Services managers and facilitators 'going the extra mile' to ensure that families can participate and get the most out of ASD Plus.

While numbers are low, the flexible, family-centred approach appears to be driving participation across a wide range of families, in terms of geographic coverage, cultural backgrounds, and participation from the wider whānau as well as parents. The fact that ASD Plus resources are New Zealand-specific would appear to enhance the relevance of the programme to participants.

- Evaluation findings indicate that IDEA Services is highly responsive to feedback from participants and other sources. There are clear benefits in IDEA Services' ability to readily evolve and adapt the programme, particularly while it is in the inception phase
- The Service Leader for ASD Plus has personal expertise and in-depth understanding of ASD, and a long history of working in the field. The fact that he was involved in initial programme design and implementation, and continues to undertake and supervise delivery of the programme has positive quality control implications due to his ability and willingness to incorporate results and feedback.
- The monitoring and evaluation system that has been implemented by IDEA Services is thorough and includes the collection of outcomes data which will enable evidence-based evaluation of the programme over time.

Programme weaknesses

- The primary issue for ASD Plus is low referrals to the programme, which mean that the overall participation rate is well below contractual expectations, and the 'per family' cost is much higher. IDEA Services is well aware of this issue and

has undertaken a range of communication and networking activities over the course of the contract to try and boost referrals, but the impact of specific activities on referral levels it is not clear.

To a degree, low referrals may reflect low awareness of a new programme in the inception phase. Other systemic issues may be in play – such as the lack of follow-up to families in the early post-diagnostic phase. The Christchurch earthquake also appears to have reduced expected referrals in the past couple of months.

It should be noted that Northland referrals, while initially low to non-existent, are now running at expected levels because the District Health Board has overcome capacity issues that meant pre-school children were not being diagnosed.

Priority questions for the evaluation

The Ministries developed a series of priority questions to be investigated for both evaluations. Based on the evidence available to the evaluation, Litmus' response to each question is summarised below.

1. How valuable/high quality is the ASD-specific parent education programme's content/design and delivery? [Include validity/accuracy, match with participant needs, level-appropriateness, consistency with current evidence (including that in the New Zealand ASD Guideline), innovativeness, consistency with principles for adult learning, fidelity with design, person-centeredness, family-centeredness, cultural and contextual appropriateness and responsiveness and emphasis on community participation].

Evidence from the evaluation indicates that ASD Plus is a high-quality programme developed from a national and international evidence basis and in line with the NZ ASD Guideline. Early feedback suggests that programme participants find ASD Plus extremely valuable, especially in the absence of other support and education services post-diagnosis. The programme is innovative in the New Zealand context, in terms of offering a range of delivery modes including 'hybrid' delivery. The flexibility of delivery options, and the upfront involvement of families in selecting the most appropriate option for their unique needs, makes the programme highly person and family-centred. Participation from across a range of geographic areas and cultural backgrounds suggests that the programme is culturally and contextually appropriate.

2. What changes are evident for the young child with ASD and their family/whānau/carer(s) that can reasonably be attributed to the programme (directly or indirectly)? How substantial and valuable are the changes / gains in participants' knowledge, skills, attitudes, confidence and other competencies as a result of the ASD-specific parent education programme?

Early evidence suggests that ASD Plus is contributing directly to positive short-term outcomes for participants, their children, and wider family units. Participants report that they are applying a deeper understanding of ASD, and practical tools and strategies in their homes, with positive changes resulting. Changes noted include improved communication and social interaction skills for the child with ASD, a reduction in challenging behaviour (and/or improved coping mechanisms

to deal with it), and enhanced relationships within the family as a whole. Longer-term data from IDEA Services' monitoring of families will determine whether these outcomes persist over time.

3. How effectively are the participants applying and using their new knowledge, skills, attitudes, confidence and other competencies (i.e. evidence of changed behaviour)?

As noted above, there is evidence that ASD Plus participants are applying their new knowledge and skills successfully in their homes. Further work is needed to determine how extensively and effectively this is occurring, and whether the programme has lasting impact.

4. What unexpected outcomes (positive or negative) have resulted from the ASD-specific parent education programme?

There is a small amount of evidence that ASD Plus contributes to three unexpected positive outcomes:

- Some parents becoming more confident and empowered to communicate with others about their child's needs, and push to have these needs met
- Some parents deriving emotional benefit from participating in group sessions with other families
- Ongoing family support networks arising out of connections made through ASD Plus group sessions.

5. How effectively was the trade-off managed between the reach and intensity of the ASD-specific parent education programme, given the relevant constraints? How in-depth was the programme, how many people were reached, at what intensity and for how long? And, what evidence is there that the duration and intensity was both feasible and sufficient to achieve meaningful impacts?

On a per programme basis, the duration and intensity of ASD Plus appears to be about right to achieve the desired outcomes for participants. IDEA Services have already responded to feedback to change the length of some modules to ensure adequate coverage of content.

As a whole, ASD Plus is not achieving the expected reach to South Island and Northland families – the total number of families participating is considerably lower than expected, reflecting low referrals to the programme. IDEA Services has not found it feasible to deliver as many group programmes as expected, given the low referral numbers.

6. To what extent does this ASD-specific parent education programme represent the best possible use of resources to achieve outcomes of the greatest possible value for parents and whānau of young children with ASD?

Early evidence for ASD Plus suggests that parents and whānau of young children with ASD value the programme extremely highly, and that it directly contributes to positive outcomes in line with programme objectives. In the absence of other alternative services, particularly for those in rural areas, it appears to be hugely beneficial to those who take part.

The programme is currently running at below capacity levels. In this context, IDEA Services has been able to operate without a waiting list, delivering highly tailored programmes and catering well to those in rural areas. If referrals increase and IDEA Services can maintain the high quality of service provision seen to date across a larger number of families, then we could conclude that ASD Plus is maximising the use of Ministry resources available to the programme.

Indepth costing analysis of comparable programmes would be required to determine whether ASD Plus represents the *best possible* use of resources. This analysis would also need to take into account the longevity, location and wider health and education context of different programmes – that is, recognising that ASD Plus is in the inception stage, and that there may be systemic or sectoral issues beyond its control that impact on referrals.

5. Future Areas for Exploration

Litmus has identified a number of issues that sit outside the scope of the current evaluation, but which we believe warrant further investigation. We believe that a deeper understanding of these areas would be highly valuable in helping to determine the best way to maximise resources invested in ASD parent education programmes in future.

Areas that might be considered by the Ministries for future investigation are:

- The ASD parent education referral process: Seeking to understand the different pathways through which parents come to the parent education programme, the role of key players and gatekeepers, and the triggers and barriers that exist at various points in the pathway
- Ongoing monitoring and evaluation of the programmes: Reviewing current monitoring and evaluation processes (including reporting to Ministries) to determine whether these are adequate, useful, workable, consistent and comparable
- Further analysis of financial data by programme providers to provide a greater understanding of how resources are being used. This could include analysis to determine more clearly the different costs of alternative programme delivery modes.

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Appendix 1: Documents reviewed

Data and documentation from EarlyBird

- Service Agreement with Ministries of Education and Health, dated 1 August 2009
- Performance Monitoring Return, for period 1 October – 31 December 2009
- Quarterly Narrative Reports: 1 October – 31 December 2009; 1 January – 31 March 2010; 1 April – 30 June 2010; 1 July – 30 September 2010
- Annual Report: June 2010
- Programme materials: Parent Book; Parent application form; Family code sheet; Preliminary home visit sheet; Home visit sheet; Post-programme questionnaire; 3 month follow-up questionnaire; Parent feedback form; Consent to access for evaluation form.

Data and documentation from ASD Plus

- Service Agreement with Ministries of Education and Health
- Action Plan (dated 18 January 2010; including Protocol on Management of Waiting Lists; Communication Plan; Programme Description; Workforce Development Strategy; Programme Provision Schedule Year One; Budget Analysis (heading only - not detailed)
- Cultural Responsiveness Plan (dated 18 January 2010)
- Quarterly Narrative Reports: September 31 – December 31 2009; 1 January – 31 March 2010; 1 April – 30 June 2010
- Quarterly Report (data only): 1 July – 30 September 2010
- Annual Report: 1 July 2009 – 30 June 2010
- Programme materials: Distance Learning Workbook; Facilitator notes; DVD resource; Family feedback forms; Pre-programme family questionnaire

Other documents

- Request for Proposal for programmes, by Ministries of Education and Health (dated 26 January 2009)
- Anderson, A., Birkin, C., Seymour, F., & Moore, D. (2006). *EarlyBird evaluation*. Wellington: Ministry of Education
- Ministries of Health and Education. (2008). *New Zealand Autism Spectrum Disorder Guideline*. Wellington: Ministry of Health
- Ministries of Health and Education. (2008). *New Zealand Autism Spectrum Disorder Guideline Summary*. Wellington: Ministry of Health.

Appendix 2: Detailed evaluation methodology

Rationale for Approach

Litmus outlined an initial approach for the evaluation in the proposal response to the Ministries' RFP. The approach was revised based on a range of factors highlighted in preliminary scoping:

- Programme providers had only collected internal evaluation data from programme participants since March 2010. *In the absence of earlier data, Litmus considered it was vital that the evaluation included a quantitative component*
- Overall, the number of programme participants was relatively small, so quantitative data would be indicative rather than robust. *Litmus recommended retaining a qualitative component to data collection, to ensure depth of understanding and insights. We reduced the scope of qualitative work from the original proposal to reflect the inclusion of both qualitative and quantitative components*
- Preliminary consent to take part in the evaluation had only been sought from programme participants since March 2010. The short timeframe for the evaluation would have made it difficult to undertake a staggered consent process (e.g. writing to parents and asking whether they would allow Litmus access to their contact details). *Litmus therefore recommended that programme providers inform participants about the evaluation, and take responsibility for the survey mailout*
- The EarlyBird programme has partnerships in Auckland and Gisborne with Maori providers to provide 'collaborative' programmes, some of which may run during the evaluation period. *Litmus recommended that the 'Immersion Visit' locations for Early Bird include Auckland and if possible, participants of a collaborative programme. Unfortunately the eventual timing of the 'Immersion Visit' did not make this a feasible option, but one participant in a collaborative programme was interviewed by telephone*
- The ASD Plus programme had only involved a small number of families in Northland (four between July 2009 and June 2010). *We aimed to interview one or more Northland participants by telephone. However, no Northland participants completed a response form to take part in this component of the evaluation.*

The Ministry of Education's internal Ethics Advisory Committee reviewed the revised approach and provided approval for Litmus to proceed.

Approach

The evaluation drew on a range of data sources, as follows:

A. Analysis of existing data

Litmus collated and analysed the administration and monitoring information and data relating to the implementation and impacts/outcomes of each Programme. We also analysed contextual documentation to understand other factors that may have influenced, or be influencing implementation or impacts/outcomes.

B. Data collection

This component involved targeted data collection from a range of audiences, to supplement existing data. It include expert interviews, a self-completion survey, 360 immersion visits and telephone interviews, as detailed below.

Expert stakeholder interviews

Two interviews were conducted with people qualified to give expert opinion about the quality of ASD parent education programmes.

Quantitative self-completion survey

This was recommended due to the lack of monitoring and evaluation data that currently exists, for both programmes. It provided a cost-effective means for as many participants to contribute to the evaluations as possible, including from all locations (urban and rural/remote). The 'opt-in' approach, and the fact that Litmus was not be provided with contact details for parents, was recommended to fully protect parents' privacy and confidentiality. Survey specifications were as follows:

- The survey took a 'census' approach – that is, all those who had participated in a programme since July 2009 were invited to respond
- The survey used a self-completion methodology, whereby participants were sent a survey to complete, with a pre-paid envelope for sending back their responses to Litmus. The survey pack also included a cover letter from the programme provider to explain the purpose of the survey and provide reassurances about the credibility and confidentiality of the process
- Programme providers assisted Litmus to administer the survey, using their contact databases to send surveys to participants
- To avoid over-burdening participants, and to encourage participation, the survey was designed to take no more than 5-10 minutes to complete
- Litmus developed a structured questionnaire addressing key research questions. The questionnaire included a mix of closed and open questions. The Autism Parent Questionnaire (the 'APQ', developed for the 2006 EarlyBird evaluation) was used in the design of the survey questionnaire, to enable consistency with the previous evaluation and some internal evaluation that has been undertaken since then
- The survey pack also included a separate form asking participants whether they were happy to be contacted by Litmus to take part in subsequent face-to-face or telephone interview. If so, they were asked to provide contact details. A copy of the form is included later in this section.

Immersion Visits and Telephone Interviews

Following completion of the survey, Litmus sought qualitative feedback from the full spectrum of perspectives:

- *Programme managers and administrators:* Programme managers provided an overall perspective of how the programme had been delivered since July 2009 and why, including key successes and challenges. Clarifications about monitoring and evaluation documentation were put to programme managers at these meetings (and in subsequent phone calls and emails)
- *Parents/family/whānau:* Parents and family provided feedback about their experiences and perceptions of the programmes. We aimed to include a mix of ethnicities, genders, locations and backgrounds. We will also aimed to include a mix of participants in terms of in terms of programme delivery method (e.g. distance learning vs venue-based)
- *Programme facilitators:* Again, we aimed for a mix of ethnicities, genders, locations and backgrounds.

Participants were invited to take part in this component of the evaluation when they receive the self completion survey. The exact mix of our qualitative sample was therefore limited to those who indicated a willingness to take part.

Litmus used a **360 Immersion approach** to complete the bulk of qualitative interviews. This involved visiting three locations and undertaking fieldwork within a specified timeframe (1-2 days). The process to undertake the 360° Immersion was as follows:

- Interviews and discussions lasted 30-90 minutes and were conducted in neutral venues provided by the Ministries and programme providers (e.g. in head offices, or venues used for the programme) or in participants' homes
- Litmus developed qualitative interview/discussion guides to guide the flow of discussion, and ensure that key areas of investigation are addressed. The guides were tailored as appropriate for each of the different stakeholder audiences and will reflect research questions. Litmus recruited all interviews
- Parents/whānau received a small koha (\$30 gift certificate) as recognition for their time and contribution to the evaluation
- Informed consent forms were provided to participants (along with verbal explanations about the process)..

A small number of **telephone interviews** were also conducted, focussing on participants from rural areas, and to enable flexibility to talk to participants who were keen to take part but not available during the time of a visit.

The sample achieved reflected the timing of programmes and parents' willingness to take part, and was as follows:

- **Qualitative interviews with key stakeholder audiences**, using a mix of 'immersion visits' to four locations, and indepth telephone interviews. Qualitative interviews were conducted between 6 October and 20 October 2010. The qualitative sample is summarised below:

	Number of Qualitative Interviews	
Stakeholder Audience	EarlyBird	ASD Plus
Parents/families/whānau	3 (Auckland, Wellington, rural North Island)	3 (South Island)
Programme facilitators	2 (Auckland)	2 (Dunedin, Christchurch)
Programme Leaders / Managers	2 (Wellington)	1 (Dunedin)

Evaluation tools

Cover letter for self-completion survey

Dear (Name)

The Ministry of Health and the Ministry of Education are conducting an evaluation of the (ASD Plus or EarlyBird Programme) that you attended, and they would like you to take part. The purpose of the evaluation is to understand what is working well and what could be done differently. The evaluation is being conducted by Litmus, an independent consultancy.

1. We enclose a short **survey** that has been designed by Litmus for people who have participated in the (ASD Plus or EarlyBird Programme). If you wish to take part, please complete the survey and return to Litmus in the pre-paid envelope.
2. We also enclose a **form** asking if you would like to take part in a face-to-face or telephone interview with Litmus (in addition to completing the survey). Please also return this form to Litmus if you are interested.

Please be assured that your feedback will be entirely confidential to Litmus, and will in no way affect your relationship with (Autism New Zealand or Idea Services) the Ministries, or any other Government agency. Litmus will group your results with those of other (ASD Plus or EarlyBird Programme) participants. No individuals will be identified in any reports from Litmus to the Ministries. You are under no obligation to take part.

We do hope you will take part in the evaluation, as results will be used to improve the (ASD Plus or EarlyBird Programme) for the future. If you have any questions, please contact Kiri Milne at Litmus or Leigh Sturgiss at the Ministry of Health (phone number).

Best wishes

(Alison Molloy / Martyn Matthews)

(Autism New Zealand / Idea Services)

Survey reminder letter

Dear Parents

SURVEY REMINDER

The Ministry of Health and the Ministry of Education are conducting an evaluation of the (EarlyBird/ASD Plus) Programme. The evaluation will provide information to guide future programme development and Ministerial funding decisions. The evaluation is being conducted by Litmus, an independent consultancy.

We recently sent families a survey to provide feedback about (EarlyBird/ASD Plus) for the evaluation. We understand how busy parents are, and we are very grateful to those people who completed the survey. Overall, however, the number of replies was quite low. We are therefore re-sending the survey to provide a second opportunity for families to take part.

- | |
|---|
| <ul style="list-style-type: none">- If you did not complete the survey in September, <u>please consider doing so now</u>. We appreciate the demands on your time, but the survey should take no longer than 10 minutes to complete. <u>Your feedback will be used to determine the future of programmes like ASD Plus.</u>- If you completed the survey in September, thank you very much for doing so, there is no need to re-complete the enclosed survey. |
|---|

Your feedback will be entirely confidential to Litmus, and will in no way affect your relationship with Idea Specialist Services, the Ministries, or any other Government agency. Litmus will group your results with other participants, and no individuals will be identified in any reports by Litmus. You are under no obligation to take part.

If you have any questions, please contact Kiri Milne at Litmus (04 473 3880) or Leigh Sturgiss at the Ministry of Health (phone number).

Best wishes

(Alison Molloy / Martyn Matthews)

(Autism New Zealand / Idea Services)

Survey questionnaire

Participant feedback on the EarlyBird/ASD Plus Programme

The questionnaire should take around 10-15 minutes to complete. There are no right or wrong answers. Please be assured that your responses are completely confidential to Litmus. If you have any questions about completing the survey, please call **Kiri Milne at Litmus 04 473 3880**.

Q1. **As a result of completing the EarlyBird/ASD Plus Programme**, please rate the extent to which the following statements apply to you:

As a result of completing the EarlyBird/ASD Plus Programme, this statement applies to me					
	A lot more	A little more	About the same	A little less	A lot less
I understand ways in which my child experiences the world differently from children without autism					
I understand how autism influences my child's learning					
I have a good understanding of why my child communicates the way he/she does					
I can reflect on how I communicate with my child and change this accordingly					
I warn my child before introducing something new					
I match my language to a level my child understands					
I wait until my child responds before I say something else					
When I talk to my child I give him/her one instruction at a time					
I use my facial expression and body language to encourage my child to take turns					
I know some games that I can play with my child that will teach him/her social interaction skills					
There are some games my child enjoys playing with me					
I have a good understanding of why my child misbehaves					
I use structure and visual cues to prevent or minimise problem behaviour					
I structure daily activities to minimise problem behaviour					
When my child has a tantrum I have a number of effective strategies					
I am able to change my child's behaviour by the way I react to it					
Looking at the triggers and results of my child's behaviour is helpful in managing him/her					
My child with autism doesn't dominate my life					

As a result of completing the EarlyBird/ASD Plus Programme, this statement applies to me					
	A lot more	A little more	About the same	A little less	A lot less
I feel I can cope with the long-term responsibility of having a child with autism					
I feel confident that things will improve as I learn more about how to deal with my child					
I believe I have enough help with parenting my child with autism					
I believe that I have some control over the future outcomes for my child					
I feel I can improve my child's condition and future prospects					
My family functions well as a unit					
My child with autism doesn't dominate family life					
The needs of other family members are met most of the time					
The people involved in my child's care are in agreement with how to help or manage him/her					

Q2. **What changes, if any, have you noticed in your child with ASD,** as a result of you taking part in the EarlyBird/ASD Plus Programme?

Q3. **What changes, if any, have you noticed in your family/whānau,** as a result of you taking part in the EarlyBird/ASD Plus Programme?

Q4. What was the **best thing** about the EarlyBird/ASD Plus programme?

Q5. What, if anything, did you **not like** about the EarlyBird/ASD Plus Programme?

Q6. What would you suggest to **improve** this Programme for the future?

Thank you very much for taking the time to complete the survey.

Please return to Litmus in the pre-paid, addressed envelope enclosed. Please also enclose the form indicating whether you may be contacted again in future.

Form seeking contact details for immersion visits / telephone interviews

Taking Part in a Face-to-face or Telephone Interview with Litmus

As well as conducting this survey, Litmus would like to personally speak to some participants of (ASD Plus or EarlyBird Programme).

This would involve taking part in a face-to-face interview or a telephone interview with a Litmus researcher between mid-September and mid-October 2010. Your feedback would be completely confidential to Litmus – this means that no individual comments will be reported to (ASD Plus or EarlyBird Programme) or the Ministries.

Those who take part will receive a small koha/gift in appreciation of their time and contribution, of a \$30 gift certificate.

If you would be happy to be contacted to take part in an interview, please provide your contact details for Litmus below. Thank you.

Name: _____

Address: _____

Contact phone number (day): _____

Contact phone number (evening): _____

Date you commenced (ASD Plus or EarlyBird Programme): _____

Location of (ASD Plus or EarlyBird Programme): _____

Please enclose this form with your survey in the pre-paid envelope, and post back to Litmus by 5 October 2010.

Recruitment script (immersion visits and telephone interviews)

Hello, can I please speak to (name)? My name is (name) from Litmus, an independent consultancy. I am calling following up a letter and survey you recently received requesting your participation in the evaluation of the (ASD Plus or EarlyBird Programme).

We have received your form indicating that you would be able to take part in an interview with one of our staff.

- One of our team will be visiting (location) on (dates), OR we would like to interview you over the telephone some time between (date) and (date).
- The process followed by Litmus will keep your information confidential. This means that no information in the evaluation report will be attributed to you. You may request any of your information to be withdrawn at any time up until the reporting stage, and returned to you or destroyed.
- With your permission the interview will be taped, and may be transcribed. You have the right to request a copy of the audio or transcript of your discussion. Digital recordings, notes, and summaries will be stored securely at Litmus and will not identify you
- Those who take part will receive a small koha/gift in appreciation of their time and contribution, of a \$30 gift certificate.

Are you willing to participate in the evaluation of the Programme?

If needed:

- The interview will last around (minutes).

If agree:

- Agree date and time of interview against scheduled interview times
- Confirm location if face-to-face interview or contact number if phone interview
- Confirm who will be conducting the interview
- Inform we will send confirmation letter
- Confirm they have contact details in case need to reschedule the interview
- Check we have correct contact details.

Close with thanks.

Confirmation letter (for immersion visits and telephone interviews)

Dear (name)

Thank you very much for agreeing to take part in an interview with Litmus, as part of Litmus' evaluation of the (ASD Plus or EarlyBird Programme).

To confirm, your interview will be on (date) at (time), at location. (Name) from Litmus will be interviewing you.

The interview will be informal and relaxed, with no right or wrong answers. We just want to hear your feedback about the (ASD Plus or EarlyBird Programme).

The process followed by Litmus will keep your information confidential and no information in the report will be attributed to you. With your permission the interview will be taped, and may be transcribed. You have the right to request a copy of the audio or transcript of your interview. Digital recordings, notes, and summaries will be stored securely at Litmus and will not identify you. You may request any of your information to be withdrawn at any time up until the reporting stage, and returned to you or destroyed.

In appreciation of your time and contribution, you will receive a small koha/gift of a \$30 gift certificate. If you have any questions about the interview, or find that you need to change this appointment for any reason, please call (name) on (phone number).

We look forward to meeting you soon.

Yours sincerely

(Name)

Litmus

Consent Form (given to participants at immersion visits)

I (insert name)

of (insert address)agree to participate in this project, as outlined in the information provided to me by Litmus. I understand that:

- My participation in the project is voluntary and I can withdraw at any time
- Whether or not I participate will not affect any current or future relationships with (ASD Plus or EarlyBird Programme) or other government agencies
- The process followed by Litmus will seek to keep my information confidential. No information in the evaluation report will be attributed to me
- I can request any information collected from me to be withdrawn at any time up until the reporting stage
- If I withdraw, I can request that any information collected from me to be returned or destroyed
- The interview with my permission will be taped, and may be transcribed
- I have the right to request a copy of the audio or transcript of my discussion
- Digital recordings, notes, and summaries will be stored securely at Litmus and will not identify me.

I have read the information sheet and this consent form, and been given the opportunity to ask questions. I give my consent to participate in this evaluation.

Participant's signature: _____

Date: _____

Discussion guide – Programme managers

Evaluation of Autism Spectrum Disorder parent education programmes FINAL PROGRAMME MANAGERS DISCUSSION GUIDE. 5 October 2010

Introductions

- Introduce self/Litmus
- Review purpose/how MoE/MoH will use findings – to improve programmes for the future
- Informed consent

Personal background

- How long have you been involved in ASD / ASD education?
- How long have you been involved in delivering EarlyBird/ASD Plus through your organisation? *If necessary:* What has been your involvement delivering EarlyBird/ASD Plus since July 2009?

Overview

- How has the EarlyBird/ASD Plus been delivered since July 2009? Has delivery met the contract requirements?
 - *Probe – to clarify / check monitoring data, data analysis*
- What have been the key successes? What have been the key challenges?
- For ASD Plus only:
 - How was the Programme developed?
 - What have been the key successes and challenges in relation to developing the programme?

Programme Reach

- Overall how well do you think the Programme reaches people that would benefit from taking part?
 - How do most people get referred to the Programme? Why is that?
 - Do you think anybody / or any particular groups have missed out on EarlyBird/ASD Plus? (i.e. are there any gaps in provision?) *Probe – rural/cultural/SES issues*
 - Does the method(s) of Programme delivery work well, in terms of who wants to take part? *Probe – rural/cultural/SES issues*
 - Do you think programme has achieved an optimum balance between the number of people reached and the length of courses/modules? If not, why not?

Programme Design and Delivery

- What do you think most families are seeking from taking part in EarlyBird/ASD Plus?
 - What do they hope to achieve?
 - What are their concerns?
 - How are expectations set/managed?

- What are your views of the different delivery methods available to participants? (i.e. venue based vs. distance learning)
 - Which are most beneficial to parents, and why?
 - What are specific benefits/drawbacks of different delivery mechanisms?
 - Does participation tend to happen at the right time for families?
 - Is the delivery of the programmes consistent with their design? Has there been any innovation of design/content?
- Overall, do you think the content of the programme is suitable for parents/whānau needs?
 - How valid and accurate is the information in the EarlyBird/ASD Plus modules?
 - Is the content level appropriate for parents and family/whānau ? Are there any aspects that people struggle to understand?
 - Do participants find it useful / informative? Does it cover everything they want to know? Which parts are most/least useful?
 - Is the programme both person *and* family centred? In what way?
 - Is there an element of community participation? What does this look like?
 - Is it appropriate and responsive to different cultures? How does it ensure this? Why/why not?
 - Overall, does it meet the needs of parents/whānau – if not, why not?
- Do you believe the programme aligns with principles for adult learning? How?
- Do you believe the programme aligns with the NZ Disability Strategy (2001)? The Carer Strategy (2008)? The NZ ASD Guideline (2008)? How?

Training, support and management of facilitators

- How do you recruit facilitators? What works well / what does not?
- What training and support is provided, to assist with facilitators skills and professional development? What has worked well / what could have been done differently? Any gaps?
- How do you tend to communicate with facilitators: frequency, mode etc. What works well / what is more challenging?
- Have there been any issues in relation to facilitators?

Effectiveness and outcomes of EarlyBird/ASD Plus

How do you monitor the effectiveness and outcomes of the Programme?

What evidence is there that participating in the EarlyBird/ASD Plus programme achieves the intended Programme outcomes?

What changes tend to occur for parents/whānau , the child, and the family as a whole? (unprompted)?

- Does EarlyBird/ASD Plus increase families/whānau 's knowledge of ASD and its impact?
- Does EarlyBird/ASD Plus enhance the families/whānau 's ability and confidence to help their child's ASD-specific development needs? (e.g. communication, self-management and social interaction skills)?

- Do family/whānau 's attitudes and approaches to their child's ASD specific needs change because of EarlyBird/ASD Plus?

Probe for examples of the above (i.e. indicators of achievement) – use APQ battery as a checklist if necessary (attached).

Probe for unexpected outcomes

Value for money

- Is the Programme running to budget? Why / why not?
- Is the cost per family higher/lower than expected? Why?
- Given the activities undertaken and the outcomes achieved, does EarlyBird/ASD Plus offer value for money?
- Could this money be better spent to achieve better outcomes for parents and whānau of young children with ASD?
- If EarlyBird/ASD Plus were no longer around, what would happen? How would it change things?

Wrap Up

- What is the best thing about EarlyBird/ASD Plus?
- What changes could be made to the EarlyBird/ASD Plus programme to better meet its key goals?
- What could be done to assist your organisation to deliver this programme more successfully?

Close with thanks.

CHECK SHEET (used in all qualitative interviews as appropriate)

- I understand ways in which my child experiences the world differently from children without autism
- I understand how autism influences my child's learning
- I have a good understanding of why my child communicates the way he/she does
- I can reflect on how I communicate with my child and change this accordingly
- I warn my child before introducing something new
- I match my language to a level my child understands
- I wait until my child responds before I say something else
- When I talk to my child I give him/her one instruction at a time
- I use my facial expression and body language to encourage my child to take turns
- I know some games that I can play with my child that will teach him/her social interaction skills
- There are some games my child enjoys playing with me
- I have a good understanding of why my child misbehaves
- I use structure and visual cues to prevent or minimise problem behaviour
- I structure daily activities to minimise problem behaviour
- When my child has a tantrum I have a number of effective strategies
- I am able to change my child's behaviour by the way I react to it
- Looking at the triggers and results of my child's behaviour is helpful in managing him/her
- My child with autism doesn't dominate my life
- I feel I can cope with the long-term responsibility of having a child with autism
- I feel confident that things will improve as I learn more about how to deal with my child
- I believe I have enough help with parenting my child with autism
- I believe that I have some control over the future outcomes for my child
- I feel I can improve my child's condition and future prospects
- My family functions well as a unit

- My child with autism doesn't dominate family life
- The needs of other family members are met most of the time
- The people involved in my child's care are in agreement with how to help or manage him/her

Discussion guide – Facilitators

Evaluation of Autism Spectrum Disorder parent education programmes Final FACILITATOR DISCUSSION GUIDE. 5 October 2010

Introductions

- Introduce self/Litmus
- Review purpose/how MoH/MoE will use findings – using feedback to improve programmes for the future
- Informed consent

Personal background

- How long have you been involved in ASD education?
- How long have you been delivering EarlyBird/ASD Plus programmes? *If necessary:* What has been your involvement delivering EarlyBird/ASD Plus since July 2009?
- What did you know about EarlyBird/ASD Plus before you started working as a facilitator?

Training, support and management

- When/how did you receive initial training to become a facilitator? What worked well / what could have been done differently? Any gaps?
- Since the initial training, what further training and support has been provided, to assist with your professional development as a facilitator? What has worked well / what could have been done differently? Any gaps?
- Before we discuss the Programme itself, what can you tell us about your impressions of the Programme's administration and management
 - Is communication from Autism NZ / Idea Specialist Services adequate, clear, timely? (*Probe: pre, during and post-Programme*)
 - Did you have a clear sense of what to expect, what you should achieve?
 - Did you understand what should be happening when, and why?

Understanding

- What do you consider to be the overall programme objectives?
- How well do you understand the content / training materials? Are there any areas you struggle with?
- Are you familiar with principles for adult learning? If so - Are the programmes consistent with principles for adult learning? Why? Why not?
- Are you familiar with the NZ Disability Strategy (2001)? Does the programme align with this Strategy?
- Are you familiar with the Carer Strategy (2008)? Does the programme align with this Strategy?
- Are you familiar with the NZ ASD Guideline (2008)? Does the programme align with this Strategy?

Design and delivery of EarlyBird/ASD Plus

- How do most people get referred to the Programme? Why is that?
- Overall how well do you think the Programme reaches people that would benefit from taking part?

- Do you think anybody has missed out on EarlyBird/ASD Plus? (i.e. are there any gaps in provision?)
 - Does the method(s) of Programme delivery work well, in terms of who wants to take part? Probe – rural/cultural/SES issues
 - Do you think programme has achieved an optimum balance between the number of people reached and the length of courses/modules? If not, why not?
- What do you think most families are seeking from taking part in EarlyBird/ASD Plus?
 - What do they hope to achieve?
 - What are their concerns?
 - How are expectations set/managed?
- Overall, what has worked well in delivering EarlyBird/ASD Plus education for parents and family/whānau ? What has not worked so well?
- What are your views of the different delivery methods available to participants? (i.e. venue based vs. distance learning)
 - Which are most beneficial to parents, and why?
 - What are specific benefits/drawbacks of different delivery mechanisms?
 - Does participation tend to happen at the right time for families?
 - Is the delivery of the programmes consistent with their design? Has there been any innovation of design/content?
- Overall, do you think the content of the programme is suitable for parents/whānau needs?
 - How valid and accurate is the information in the EarlyBird/ASD Plus modules?
 - Is the content level appropriate for parents and family/whānau ? Are there any aspects that people struggle to understand?
 - Do participants find it useful / informative? Does it cover everything they want to know? Which parts are most/least useful?
 - Is the programme both person *and* family centred? In what way?
 - Is there an element of community participation? What does this look like?
 - Is it appropriate and responsive to different cultures? How does it ensure this? Why/why not?
 - Overall, does it meet the needs of parents/whānau – if not, why not?

Effectiveness and outcomes of EarlyBird/ASD Plus

As a result of participating in the EarlyBird/ASD Plus programme, what changes tend to occur for parents/whānau , the child, and the family as a whole? (unprompted)?

- Does EarlyBird/ASD Plus increase families/whānau 's knowledge of ASD and its impact?
- Does EarlyBird/ASD Plus enhance the families/whānau 's ability and confidence to help their child's ASD-specific development needs? (e.g. communication, self-management and social interaction skills)?
- Do family/whānau 's attitudes and approaches to their child's ASD specific needs change because of EarlyBird/ASD Plus?
- If EarlyBird/ASD Plus were no longer around, what would happen? How would it change things?

Probe for examples of the above (i.e. indicators of achievement) – use APQ battery as a checklist if necessary (attached).

Probe for unexpected outcomes

Wrap Up

- What is the best thing about EarlyBird/ASD Plus?
- What changes could be made to EarlyBird/ASD Plus to better meet its key goals?
- What could be done to assist your performance as a facilitator, or the performance of other facilitators?

Close with thanks.

Discussion guide – Parent/whānau

Evaluation of Autism Spectrum Disorder parent education programmes FINAL PARENT/WHĀNAU DISCUSSION GUIDE. 5 October 2010

Introductions

- Introduce self/Litmus
- Review purpose/how MoH/MoE will use findings – to improve programmes for the future
- Informed consent

Family background

- Firstly, can you please tell me a little about your family? (length of time in area, working/not working, how many children, which child/ren has ASD etc)
- How old was xxx when ASD was confirmed/diagnosed?

Experience of EarlyBird/ASD Plus (Design and delivery)

- How did you hear about the programme?
 - What were you told?
- What did you expect from the programme?
 - What did you hope to learn - for you, for xxx, for the family as a whole?
 - Were there any other things you thought the Programme might achieve?
 - What, if any, were your fears and concerns?
- Before we discuss the Programme itself, what can you tell us about your experiences of the Programme's administration
 - Was the communication from Autism NZ / Idea Specialist Services adequate, clear, timely? (*Probe: pre, during and post-Programme*)
 - Did you spend any time on a waiting list? If so: Was the waiting process / preliminary communication handled well?
 - Did you have a clear sense of what to expect, what you should achieve?
 - Did you understand what would be happening when, and why?
- What was your actual experience of doing the EarlyBird/ASD Plus programme?

- Did the overall delivery method work for you? (i.e. venue based vs. distance learning)
 - Was it useful / informative? Did it cover everything that you felt you needed to know? Which parts were most/least useful?
 - Was the material clear and easy to understand?
 - How effective was the facilitator, in delivering the programme?
 - Did your participation happen at the right time for you?
 - Was the programme both person *and* family centred? In what way?
 - Was it appropriate and responsive to your family's culture?
 - Overall, did it meet the needs of you and your family/whānau – if not, why not?
-
- Did what you learnt in EarlyBird/ASD Plus line up with information received from other sources e.g. health care professionals, specialist school teachers?

Effectiveness and outcomes of EarlyBird/ASD Plus

As a result of participating in the EarlyBird/ASD Plus programme, what has changed for your child and your family/whānau ? (unprompted)?

- Has EarlyBird/ASD Plus increased your/your family/whānau 's knowledge of ASD and its impact?
- Has EarlyBird/ASD Plus enhanced your/your family/whānau 's ability and confidence to help your child's ASD-specific development needs? (e.g. communication, self-management and social interaction skills)?
- Do you/your family/whānau do anything differently now you've attended EarlyBird/ASD Plus?
- Do you feel that your/your family/whānau 's attitudes and approach to your child's ASD specific needs have changed because of EarlyBird/ASD Plus?
- If EarlyBird/ASD Plus were no longer around, what would happen? How would it change things?

Probe for examples of the above (i.e. indicators of achievement) – use APQ battery as a checklist if necessary (attached).

Probe for unexpected outcomes

Wrap Up

- Finally, what would you say was the best thing about doing the programme?
- What could be changed or improved to better meet families' needs? (e.g. content/design, delivery)

Close with thanks, give koha.