



“I refuse not to have quality of life” (parent quote with permission)

***What parents expect from early childhood intervention services.
ECIA(VC) Parent Focus Group Report – April, 2005***

Introduction:

ECIA(VC) has been conducting a range of activities regarding defining desirable outcomes of early childhood intervention services. Material from these activities is being used to develop an *ECIA(VC) Outcome Statement* (draft is available www.eciavic.org.au).

It is important that parents are involved in the development of the Outcome Statement, and also that parents and professionals agree on what services are trying to achieve. Professionals have valued and appreciated parent opinions at recent forums and workshops. Ongoing consultation and discussion between parents and professionals regarding service development is recommended best practise.

As part of the development of the Outcome Statement, a parent only focus group was organised in February to consider the topic: *Keeping the End in Mind – What Should Services be Aiming to Achieve?*

Participants:

There were 15 places available, and 13 parents attended on the day, from all metropolitan regions. The group included one father and a fairly even mix from parents who were currently receiving ECI services and those who had attended in the past. There were a number apologies from those who wanted to be involved and informed of the results – this included parents from rural regions and 2 other fathers.

Purpose:

The focus group was an opportunity for parents to:

- 1) discuss their own ideas of what the goals of early childhood intervention should be, and
- 2) compare these ideas to the proposed *ECIA(VC) Outcome Statement*.

The Outcomes Parents Want

At the end of early childhood intervention, the overall outcome was that parents wanted to *feel satisfied that they had used the maximum opportunities to achieve what they could for their children*. This included:

- Children being seen as children.
- Children being happy.
- Children achieving goals and progressing towards their potential.
- Parents understanding any diagnosis, causes and contributions.
- Parents guided by and working with professionals on goals and strategies.
- Parents gaining skills and knowledge through experience and training.
- Parents having their say in partnership with services.
- Parents being able to represent the interests of their child in the future.
- Other services educated regarding the needs of their child.
- Family needs responded to at the time, with services considerate of family energy, resources, lifestyles and routines.
- Families have received assistance with home and family support needs.
- Families linked with other parents and families.
- A good quality of life.

There was agreement among the parents that outcomes evolve as children get older and family priorities change. Families with older children talked about a progression where expectations in the beginning are very much focussed on the child, and then expand to a family focus and lifespan focus. One example: *"I shut my other children in another room so that I could do therapy with my child. My husband was the one to pull me up and say, 'what are we doing here?', and we looked at every one's needs."*

Other Issues Raised by Parents:

You ask for these services, but why?for what reasons?

The level of services received was an issue for parents and this sometimes clouded the discussion about outcomes. At times, parents struggled with the distinction between what services offer on a daily basis and what the overall aim of the service should be. The exercise of teasing out the difference resulted in an active discussion. Parents could identify what they wanted for their children and why they wanted those outcomes. It was slightly harder for parents to say what they wanted for their family. There was not enough time to fully explore this, on this occasion.

I want to say my child and family had a great experience at the EI centre I attended.

The group reported a range of current and past experiences of early childhood intervention. There were reports of positive experience and satisfaction with services, and also reports of disappointment in those expectations to do with parent involvement and parent training. System issues were raised with regard to staff training and experience. One discussion example was of a mother withdrawing her child from an early childhood intervention service, because there was *no parent access to or involvement in the program*, and therefore no benefits of parent training and extension of strategies into the home.

While not directly on the agenda, it is evident that services are consistent in providing programs for children, but practise is variable with regard to parent involvement and family support. The degree of these experiences and further feedback from families is reserved for another possible forum: *what has worked for your family, and why?*

Just one more example before we move on with the agenda.....

We ran out of time for a detailed discussion of the proposed *ECIA(VC) Outcome Statement*. However, the group did look briefly at the statement, and gave the general impression that the statements were in line with the thinking of the group. The focus group allowed a rich discussion and sharing, but more time would allow a more detailed discussion of the proposal (eg: level of agreement with family and community statements, readability etc.). The group of 13 was enough for this task and format – other sorts of activities would be necessary for a larger group of parents.

Overall the group were positive about the opportunity to discuss their experiences and suggestions for services. Members expressed an interest in similar events in the future, with suggestions such as an email group for future responses.

What next for parents?

- The day was a good starting point for ECIA(VC) to establish ongoing contact with families. ECIA(VC) is committed to continuing the dialogue with parents.
- Future events need to consider more time for each topic, or a combination of activities for parents to provide feedback.
- Professionals at the March forum were highly interested in what parents had to say – more opportunity for frank dialogue between parents and service providers should be promoted.
- The list that parents came up with does coincide with the ECIA list. From the March forum, there is still a need to ‘tweak’ the language to be less academic in places.
- The information will be used to inform the 3 planned documents – the ECIA(VC) Outcome Statement, a document about implementation and evaluation, and a parent information booklet.

Implications for professionals:

- Parents, like professionals, find it easier to talk about goals for their children than for their families.
- Parents, like professionals, can be caught up with issues to do with service delivery focus and find it hard to focus on outcomes. The service is a means to an end, and not an end in itself.
- Parent goals evolve over time and professionals need to be alert and responsive to those changes.
- Parents clearly want to be involved (and not excluded) from programs.
- The outcomes that ECIA(VC) have developed are broadly compatible with those identified by parents.
- Parents have a valuable role in the development of policy and practice in early childhood intervention services, and should be involved in every stage of planning and service development.

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