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Information Sheet 53

Parent/family involvement in early childhood intervention

*This article is from a presentation by Lizzie Eakin, Early Childhood Special Educator**

My aim today is to talk about parent/family involvement in early childhood intervention, the importance and benefit of it and what professionals and parents can do to support it. I will also address some of the challenges or barriers that may impact on parent involvement in early childhood intervention.

I'd like to begin by talking a little about myself and my personal experience. I was diagnosed with a profound hearing loss when I was 15 months old. It is believed that a viral infection when I was three months old was the cause. Once Mum said to me, that when I was diagnosed, the audiologist showed her a school-aged girl who was speaking with difficulties using a loud and unusual pitch and she couldn't form her lips properly to make the right sounds. Mum said she was shocked and decided right there and then that it wasn't going to be like that for me.

So Mum invested a lot of time and energy in me to help me to learn to listen and to talk so that I could be included in mainstream society. She was aware of some of the challenges children with hearing impairment face especially with speech and language development.

Mum enrolled me into an Auditory-Oral Early Intervention Program at the Catholic Centre for Hearing Impaired Children at Strathfield where the service is still provided today. The Auditory-Oral Program's aim was to help children with hearing impairment to listen and talk through using their residual hearing and lip reading.

Mum spent a lot of time with me outside of this program.

She spent a lot of time talking to me at home and everywhere else we went providing me with a verbal model from which to learn. She would put me on the sink when doing the washing up and talk to me. She would put my fingers on her voice box so I could feel the vibrations of the sounds she made and she would make me look at her lips so I could watch how sounds and words were formed.

Mum was also aware that literacy is a challenge for children with hearing impairment so she took me to the local library where I attended story time and she would read tons of books to me. As a result, she has instilled in me an extreme love of reading and writing.

My parents decided to send me to mainstream preschool, primary school and high school and I received itinerant support during my schooling years. I went on to university and completed two bachelor degrees as well as a post graduate certificate.

The nine years of my working life have been dedicated to young children particularly those with special or additional needs.

In all this time, I've always believed that if it wasn't for the dedication of my parents, particularly my mother, I wouldn't have come this far. This has inspired me to explore and promote parent/family involvement in early childhood intervention which brings me here today.

When I talk about parent involvement, I am applying it to any family members who have regular contact/involvement with the child who has additional needs. So mums, dads, step parents, foster parents, grandmas, grandpas, aunts, uncles, cousins, brothers, sisters and close family friends because all these people are a huge part of a child's life.

When I talk about a child, I am applying this term to cover any child with a disability in one or more areas. So a child who has a vision impairment, a child who has autism, a child who has Down syndrome, regardless of the degree of the child's disability, the importance of parent involvement in the child's early childhood intervention remains the same.

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When I talk about professionals I apply this term to educators, therapists, nurses, doctors, childcare workers, counsellors and anyone else who is providing an early childhood intervention program.

I have used the following methods to prepare this paper. These are:

- documenting my personal experience,
- documenting my work experience,
- conducting written and video interviews with family members of children with additional needs using a set of questions formulated by myself,
- reviewing a range of journal articles, text books and websites, and
- casual discussions with family members at home and at work and with professionals in the early childhood intervention field.

What is parent involvement in early childhood intervention?

Parent involvement in early childhood intervention is not a new concept.

From my literature review I have found articles and readings dating back to the early seventies. There is extensive literature on parent involvement in special education.

It is not easy to define the meaning of parent involvement in a single sentence because there are many aspects to it.

From my reading, experience and talking with other professionals and parents I can narrow the definition of parent involvement in early childhood intervention into the following three main points.

- It includes parent participation in many different forms in the child's intervention program and plan.
- It includes parents taking an active role in controlling and making decisions about their child's intervention plan such as what program to enroll their child in, the goals to work on, what therapy services the child may need and so on. It is important to note that parents have a **legal right** to make decisions about their child's educational placement and treatment plan.
- It includes parents advocating for their child.

Why is parent involvement important in early childhood intervention?

A young child spends the greater part of their early childhood with their parents. So it makes sense for a parent to assume the role of the child's first teacher.

I know this is a tired old cliché but its value can not be ignored especially when there is consistent evidence from a wide range of research that the impact of parent involvement has a major positive influence on their child's achievements in their intervention and throughout life.

One such qualitative research that demonstrates this is 'Involvement of Portuguese Speaking Parents in the Education of their Special Needs Children' by Dora Tellier-Robinson (2000).

Consider a child going to a weekly therapy session who lasts only an hour without the parent being there. Would you deem this to be influential and substantial in the child's intervention treatment?

If a child went to a weekly therapy session with their parent and the parent learnt some strategies from the therapist to use at home, do you think this would have more of an impact than the aforementioned scenario? Yes, I think so. And the child will be learning in a comfortable and secure environment.

The impact of intervention will be greater if a parent is exposed to child development, strategies and activities.

The more active a parent is in their child's early intervention the more likely a child will be successful compared to a child whose parent takes a passive role. Parents have the opportunity to engage their children in a "rich array of everyday learning experiences" (Council for Exceptional Children: The Voice and Vision of Special Children, 2007).

This statement by a parent of a child with a disability sums up the answer to this question beautifully. "It is very important to be involved in your child's education, especially if you have a handicapped child. If we are not involved, they won't do anything. They will be passive and uninterested in the world and the people around them. If all children, including handicapped children, had the support of parents, they would do much better and they would achieve more. We as parents must be involved in all phases of our children's lives, whether they are handicapped or not." (Robinson, 2000)

Another School of Thought

Of course parent involvement in early childhood intervention is not without its opposition. It continues to be a complex and controversial issue (Morrissette, 1999). One example of reading that supports this is 'Rethinking Parental Participation in Special Education' (Morrissette: 1999).

Issues that arose in the above reading by Morrissette (1999) about parent involvement in early childhood intervention included the following.

- The parent-child relationship may be affected when the parent assumes the role of 'teacher' therefore affecting child rearing practices.
- Professionals may assume that parents have the skills to observe, identify and plan educational goals for their child.
- If parents possess the above skills then there may not be a need for professionals in the early childhood intervention field.
- The process of partnership may set parents up to fail. It creates disillusionment with professionals as they have certain expectations how parents should be involved.
- It questions the abilities of parents to be involved in the Individual Family Service Plan (IFSP) and Individual Education Plan (IEP) processes.
- It states that the benefits of parent involvement in early childhood education remain unconfirmed and that the view of parent involvement is unbalanced.

These are issues that professionals and parents may need to consider and whether it applies to them and their practices. The extent of one's belief in parent involvement in early childhood intervention obviously will impact on the practise and promotion of parent involvement.

The benefits of parent involvement in early childhood intervention

There are so many benefits of parent involvement in early childhood intervention. Not just to the child, but to the parent as well as the professionals who work with the child and the parent.

Aside from the obvious – that the child is more likely to be successful in achieving proposed intervention goals, the benefits of parent involvement in early childhood intervention include the following.

- The child, the parent and the professionals adopt a positive attitude and behaviour.
- There are high but not unrealistic expectations for the child.
- The parent gains an understanding of and becomes interested in their child's learning and why he/she is learning it.
- The parent gains greater confidence in themselves as a parent and in their ability to help their child at home.
- Parents become confident in choosing and participating in the program they access for their child.
- Professionals gain more confidence in the child's likely progress and outcomes as they know the parents are keen to be involved. Professionals only take on responsibility as guided by parents. Parents develop self-determination as they gain control of their child's intervention program.
- Professionals respect the role of the parents who become involved in their children's early childhood intervention.
- There is mutual support between parents and professionals therefore increasing the morale for both.
- Lastly and most importantly parents become empowered to decide on their child's education and treatment plan thus ensuring continuity of support throughout the child's life.
- Parents can be involved in a support group – a perfect example of this is most of the families who have a child with Down syndrome at Learning Links have started up a monthly morning tea. They each take turns to host the morning tea. Experienced parents can act to mentor or support parents who are new to the early childhood intervention field.
- Parents can learn all they can about their child's disabilities to understand their child and the issues/challenges he/she may face. This may involve researching and/or attending workshops specific to their child's needs. One great example I love sharing with people is a family who decided that they all should attend a Makaton course to learn key word signing so that the role didn't fall on just one person in the family unit.
- Parents can confer/collaborate with therapists, special educators, pediatricians and social workers to receive support and gain ideas about strategies and activities and also to make informed decisions about the services they can access for their child.
- Parents can be actively involved in the wider community in order to educate the community about their child's disability. A fantastic example is a mother with a daughter who has Down syndrome held a fundraising open day at her house on National Down Syndrome Day last year. She asked a number of people in the local community to set up 'stalls' in her house and she sent out invitations to a lot of people in the community. The day was very successful with people coming and going all day long. She raised a substantial amount of money for the Down Syndrome Association, educated the public about the disability and was also in the local paper.

How can parents become involved in their child's early childhood intervention?

There is no set formula for parent involvement in early childhood intervention. Based on my experience, literature review and listening to professionals and parents, these are some examples that have been suggested.

- Parents choosing, attending and participating in an early childhood intervention program with their child is a good place to start.
- Parents can also attend therapy sessions with their child with the intention of learning some strategies to use at home.
- Parents can volunteer at the preschool their child attends.
- Parents can be involved on the board of the organisation or a committee.



- Parents can use ‘teachable moments’ in their daily lives and routine with their child. A teachable moment can happen almost anywhere – at the shops, in the car, in the bath, when going for a walk. It is an unplanned event that a parent can use as a learning opportunity for their child. It is an opportunity to extend or expand the child’s learning. It is a meaningful and functional experience for the child because the child is interested right there and then and parents should capitalise on that. For example, when going for a walk, a child may be looking at a bird on the grass. His mother may use that opportunity to say “bird”, bringing the child’s language goal into it.
- Parents can have an active role in the process of an IFSP or an IEP. Parents can organise the meeting with all the professionals involved as well as family members or friends and host it. Parents can contribute to the plan by making decisions and suggesting goals and strategies for their child as well as a plan for themselves.
- Parents can assume an active role in advocating for their child. This will include all of the above strategies but also includes knowing what rights the parents and the child have and understanding the ‘system’ such as school systems, intervention services and community services so the parents can campaign for their child’s right to access these. One example I’d like to share with you is when I was transitioning to school the Catholic Centre for Hearing Impaired Children felt that I would be better off in a unit within a mainstream school called Opportunity of the Deaf as the professionals there felt that I would not make it through kindergarten. Mum and Dad refused this and wanted to give me a chance in mainstream and luckily they did because I don’t think I would be here now.

These are just some ideas of how parents can become involved in their child’s early childhood intervention. Some parents will of course find lots of creative ways to become involved and this should be encouraged.

How can professionals support parent involvement in early childhood intervention?

Professionals in the early childhood field can support parent involvement in early childhood intervention by encouraging them to engage in the strategies discussed above. However, professionals can do more to pave the way and promote parent involvement in early childhood intervention by including the following strategies in their workplace.

1. Educating Parents

- Providing information/training in the child’s disability/diagnosis.
- Providing information/training on the issues and challenges their child may encounter in their lives.
- Providing information/training about child development, strategies and activities to increase their awareness of play-based therapy and teachable moments.
- Role modeling to parents during the intervention program (such as playgroup or therapy sessions) how to interact with their child. At Learning Links’ playgroups the special educator and therapists encourage parents to follow their child’s lead, get down on the floor with them and play. The professionals will guide the parents if they want assistance with implementing strategies relevant to their child.
- Educate parents on the process of the IFSP or the IEP so they can gain the necessary knowledge and skills to contribute to the meeting, come up with goals and suggest strategies. The more control parents have over their child’s IFSP or IEP the greater the chance of goals being achieved by the child (and the parents!).

2. Empowering Parents

- Allowing parents to have a say in the running of the intervention program – asking them what they would like to have happen, ideas and other suggestions. Put these suggestions into practice! Parents need to feel that what they say is valuable and this promotes empowerment. A recent example I can provide involves myself and the family counsellor at Learning Links when we held a morning tea for the parents and asked them how they felt about the

playgroups, what support they would like, what they would like to see happening, what changes they want and so on. It was very positive and allowed me to share with the therapy team what the parents want from the playgroups and the staff providing the service. I know as a professional, I like to know exactly what parents want for their child so I can provide them with the right service. Of course, there may be limitations with this as there is only so much a service or support an intervention program can provide a parent.

- Encourage parents to be a part of the program; for example, helping with cleaning up, singing songs, setting up activities, assisting the special educator/teacher to do an art and craft activity or volunteering to help with the sports program just to name a few ideas.
- Start off a support group for parents. Your workplace may need to start it off and host it but eventually the reins can be handed over to the parents.
- Be aware of keeping IFSP and IEP goals simple and short. It is overwhelming when a parent has a 52 page IFSP/IEP for their child to work on over the year. This is a confidence killer. Parents need to feel that goals are achievable and manageable. I had a parent who only wanted this one single goal. It was her biggest priority over everything else. This goal was for her child to walk. She told me she couldn’t focus on anything else until her child achieved this goal. Within six weeks the goal was achieved and I feel it was because the family, the preschool and the intervention service all focused on that one goal in all aspects of the child’s daily routine and life. The mum said to me later that she felt like she was in control and she was so motivated because there was no pressure to work on 20 goals at once. She was so excited and so motivated to have another IFSP to set down the next goal for her child.

- Also consider the wording of IFSP/ IEP goals – avoid jargon. If jargon must be used then take the time to explain what each term means. It would be preferable to avoid writing goals in a ‘therapy format’, for example “Matthew will put his cup on the target on the table 75% of the time”. I know this is for measuring progress of the goal but is it going to be relevant to the parent? Wouldn’t it be better to write “Matthew will put his cup on the table consistently”?
- Tap into the family and child’s strengths and integrate the IFSP/IEP goals into what they do in their daily lives and routine. This is much more family friendly and practical. The goals stand a greater chance of being achieved and the learning experiences are much more meaningful to the child. Barry Carpenter stated in the book ‘Team Around the Child: working together in early childhood intervention’ (Sue Davies, 2007) that “if we are to work effectively with families, it is important that we [professionals] value their context – the home environment – and are prepared to work with the network of family support which sustains them” (Apple and Minchom, 1991). “The demands of the multiprofessional team on parenting and family life are often intrusive and need to be reconciled with the family’s daily functioning” (Carpenter, 2005; Porter, 2002; Redmond and Todd, 2003).

3. Partnership with Parents

- Both parents and professionals should be able to determine goals and strategies together at an IFSP/ IEP meeting as well as evaluating the goals. A fantastic statement from a book called ‘The Strengths Approach’ explains the process of working in partnership as “... clients and workers are colleagues who enter into partnerships as equals: sharing expertise, knowledge, ideas, skills and other resources. They learn from each other” (McCashen, 2005).
- Listen to what parents want and act accordingly. Make recommendations where appropriate and offer alternatives because what a parent wants may take priority over your recommendations.

- Respect the parents you work with and their decisions. Remember that they are the expert on their child.

Professionals in the early childhood intervention field are also essential. Their expertise is important.

As Sue Davies said in her book ‘Team Around the Child: working together in early childhood intervention’ (2007) “[Professionals] as experts in their discipline area, they complement the parent’s expertise on their family and child”. Effective early childhood intervention is not possible without parents and professionals working together.

Challenges/Barriers of/to parent involvement in early childhood intervention

We need to address the challenges of and barriers to parent involvement in early childhood intervention so we can be aware and come up with strategies to minimise these. Some of the challenges or barriers include the following.

- It can be time consuming for families who have other priorities in their lives (such as financial commitments) which require them to work or other children who need their time too. I had one parent say to me once that she gave up working because she wanted to put in all her time with her daughter so that she can “have a better life”. However, this is not always possible so professionals need to be sensitive to this.
- Financial situations of parents can affect their ability to access support for their child. As we all know, early childhood intervention is not always free. There are costs involved with programs such as playgroups, therapy sessions, equipment, traveling expenses and so on. At Learning Links we offer subsidies to our parents when funds are available to help them access our services. We also have a bus that is funded by donations from our supporters including registered clubs. This bus picks up the families who do not have transport to access our programs.

- Some parents may not feel confident making suggestions and decisions about their child’s intervention. Professionals need to be sensitive to parents who may feel this way and assist them to become confident by letting them know that their input into their child’s early intervention program is valuable. It is essential to remember as a professional that you are responsible for preventing an environment where the professionals have the ‘answers’ to everything and parents are made to feel that they have nothing to contribute. This is a true sense of disempowerment and no one has the right to do this to any parents.
- Some parents may find the stress of having a child with a disability too much and this impacts on their ability to seek support. Parents suffering depression or health issues may not be in a position to be fully involved in their child’s early childhood intervention. In these circumstances referring the parent to a family counsellor or social worker would be the best course of action (with the parent’s permission of course).
- Parents from culturally and linguistically diverse (CALD) backgrounds may not be aware of what’s available for their child or have a set of beliefs that may impact on them becoming involved with their child’s early childhood intervention programs. They may not understand what early childhood intervention is. They may not understand the intervention program that their child is attending or the strategies involved. Parents may have difficulties communicating with professionals. Some people can define disabilities in medical terms but there are some people who believe a disability can be caught or is a punishment for the parents. I had one parent who told me once she believed she was being punished for her sins as she has a child with a disability. Some parents can have enormous respect for professionals and will happily leave the professional to do whatever is necessary for the child as they tell me that the professional knows best.

A colleague of mine experienced this recently when she was approached by a mother who had a son who was almost three years old. She said to my colleague, "He's not speaking. You fix him". Professionals can empower these parents by becoming culturally competent. Cultural competence means "systems, agencies, and practitioners that have the capacity, skills, and knowledge to respond to the unique needs of populations whose cultures are different than that which might be called dominant or mainstream" (CASAnet Resources, 1995-1996). Professionals need to accept and accommodate the uniqueness of each parent.

- Parents who speak English as a second language or cannot speak English at all can have difficulty accessing intervention. Some examples of how we try to address these challenges at Learning Links include the use of telephone interpreters to talk with parents and access interpreters for meetings. At one of the playgroups I facilitate in Fairfield there is a large number of parents who speak Vietnamese as a first language so I have an English/Vietnamese dictionary at hand so we can communicate with each other and I also included songs in Vietnamese so that they can feel a part of the group. There are many agencies and resources professionals can use to help their organisations to accommodate these parents. One such agency is the Multicultural Disability Advocacy Association of NSW (MDAA).
- Parents' attachment with their child who has a disability is something to consider. Attachment between the parent and the child is much more challenging and parents have to work harder to create a secure attachment. It is difficult because a child who may be developmentally delayed may not smile at their parents at the typical age range or a child with autism may not want mum near his trucks. A parent needs to make extra effort to understand their child. This alone is hard work and if the attachment between the parents and their child is not secure it impacts on parent involvement in early childhood intervention.

This is an area where the parent may need to seek support from a psychologist or a parent training such as programs from the Hanen Centre in Canada (www.hanen.org). Last year I helped a Speech Pathologist from Learning Links to run The Hanen Program – More Than Words for parents of children with autism. The program provided parents with strategies to help their children to communicate and develop their social and play skills. This program involved videoing the parents interacting with their children before the program started and near the end of the program. Some parents in the beginning struggled to establish joint attention with their child and had difficulties engaging in play with them. Their body postures in the video and facial expressions showed how they felt uncertain about interacting with their child. However, towards the end of the program the videos of the same parents showed them engaging their child in play, communicating with each other, happy and confident. The changes in both the parents and their children were amazing.

- Conflict between parents and professionals can be a problem. Some parents have come across professionals who assumed that they know more than the parents. This can affect the parents' confidence and relationship with the professionals of the service their child may be accessing. This also may make parents feel disempowered. I have heard countless stories from parents who have accessed other services and have had arguments with professionals about IEP/IFSP goals, programs, behaviour management, strategies and so on. These parents left the services with a 'bad taste in their mouth'. One parent reported feeling very disheartened about her child's intervention program after a meeting with a team of therapists. They had already set goals before the meeting and formulated strategies without discussing them with the parent. She tried to talk about what goals she had in mind but they told her that they weren't realistic.

That parent admitted that it affected her enthusiasm and confidence to keep working with her child for a while. Professionals need to come to meetings prepared but parents need to be given the opportunity to speak about their ideas, their goals and strategies.

- Sometimes parents may feel pressured to be involved at a high level and feel anxious or guilty if they feel they are not spending enough time with their child. This can add to the stress of family life. Professionals need to be aware that when a parent chooses to become less involved it does not mean that a parent is disinterested in their child. Professionals need to acknowledge parents' priorities and make parents feel that it is O.K. to change their level of involvement.

These are just some of the challenges or barriers that I have observed in my workplaces, heard or read about. There are probably many other challenges that you as professionals or parents may have come across. Professionals have a responsibility to minimise the challenges/barriers that may impact on parent involvement in early childhood intervention.

Conclusion

I am biased I admit, in my opinion of parent involvement in early childhood intervention but it's personal to me. If it wasn't for the model of parent involvement I truly feel I wouldn't have come this far. There is extensive research that shows that a high level of parent involvement positively influences a child's achievement. From my experience at work, I have found it to be an enjoyable experience to promote parent involvement.

Imagine, if we didn't give parent involvement a go, how many children will miss out on the opportunity to reach their potential? Shouldn't we all challenge ourselves to reflect on the extent to which we promote effective and active parent involvement?

There is a bibliography available for this article.

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