Austprem Ink

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Early Intervention

Jodi Crompton

Many parents of children born prematurely will recognize the term 'early childhood intervention' but not fully understand what it means for them. Early childhood intervention (ECI) is a system for providing services to infants and young children with developmental delays/disabilities and their families (Odom SL and Wolery M 2003). They operate in each state and territory. Children are referred to these services when they have developmental delay/ disability, irrespective of whether they were born prematurely.

Parents are presented with many challenges when raising children but there can be additional challenges when a child has a developmental delay/disability. It is the role of the ECI service to work collaboratively with parents and provide them with information and available resources to meet the needs of their child and family. Staff at ECI services have training in the areas of health or education such as physiotherapy, occupational therapy, speech pathology, social work, psychology and teaching.

The way in which ECI services work with families can differ but the focus will be on supporting the whole family and not just the child with the special needs (McWilliam RA et al 1998). The type of help will also depend on the problems or issues identified by the families. Some parents might be concerned that their child is not yet walking or using words to talk but for others it might be that they are exhausted from providing the extra care for their child. To help address these issues some families might attend groups or have one-to-one sessions to learn how to help with their child's particular developmental problem. Others might prefer strategies and advice be provided to the staff at their child's childcare centre or kindergarten to promote inclusion.

ECI agencies also offer a place to meet other parents of children with developmental delay/ disabilities (Moore T 2000). Other parents can be a good source of practical ideas and support as you deal with the issues of raising your own children – with and without special needs!

You should speak to your child's doctor or maternal and child health nurse if you are concerned about your child's development. If required, they can help you find an ECI service in your local area.

Jodi Crompton

Physiotherapist

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6th Biennial National ECIA Conference

Early Childhood Intervention Australia

Grand Hyatt Melbourne, Victoria

25 - 27 July 2004

Broadening the Vision : Building cohesive communities for children and families

See the Program and Registration information online at

http://www.cdesign.com.au/ecia2004/

Accessing Early Intervention

Early Intervention can be a great support to both the child and their family. Some children show a need for a bit of extra help quite early, where others are older before the need for specialist help becomes a consideration.

Once the need is recognized, however, most families want Early Intervention to begin immediately. The difficulty here is that many of the centres have waiting lists, some of which can be VERY long. There may be a different waiting period, depending on the specific therapy required. Usually the services on offer include physiotherapy, speech therapy and occupational therapy. There will often be a psychologist available too, to help with assessments and provide advice and suggestions.

You are usually only able to access one Early Intervention service at a time; it may be possible to be on several waiting lists however, so that your child can get some help as soon as possible.

Most Early Intervention services will usually take referrals directly from parents; you may also be referred by your GP, paediatrician, child health nurse or other professional that you encounter in your prem journey.

> Early Intervention may be required for just a few months, or for a number of years.

Early Intervention services are provided for children with a wide range of issues, ranging from mild to more severe disabilities. Early Intervention may be required for just a few months, or for a number of years.

The various professionals you deal with would probably be in the best position to recommend the most suitable service for your family, but if you wish to make a start, below are some links that might help you to find Early Intervention Services in your area.

ACT:
http://www.parentlink.act.gov.au/directory/directory_3.htm

NSW:
http://www.parenting.nsw.gov.au
Click on “Parenting Service Directory” then “Children’s Services” then “Resource Project” (on the right)

QLD:
http://www.disability.qld.gov.au/idial/search.cfm
try searching on “early intervention”

SA:
http://www.cyh.com/cyh/parentopics/usr_index0.stm?topic_id=1675
The resources at the bottom of the page are what you are after—they are not specific to intellectual disability but provide assistance to children with other delays too.

TAS:
http://www.dhhs.tas.gov.au/familychildandyouthhealth/parenting/childdevelopment/

VIC:
http://www.ecis.vic.gov.au/bhcv2/bhcsite.nsf/ecis/ecis_our_services?Open

Your Story - Kate's experiences with EI

Rob was born at 30 weeks due to haemorrhaging of placenta previa. He was 1665g (3lb 11oz) and suffered from hyaline membrane disease. He was high-frequency ventilated for about a week, then a relatively trouble-free 6 weeks before he was discharged at 37 weeks (on my birthday yippee!!), no monitors or oxygen required. Rob achieved the normal milestones roughly at the corrected age, if a little behind. After Rob's 6 month check, his paediatrician didn't want to see him again unless we had any concerns.

Rob at two days old, with Kate, David and big brother Ben looking on

At 7 months corrected, he was verbalising mum-mum and da-da sounds, but at his 12 month check-up with the M&CH nurse, the words had gone. My husband and I were quite concerned, but were told that he might take a while to talk (lots of babies do) and that we shouldn't compare Rob's development to our first son (Ben, 41 weeks). As such, she didn't recommend seeing his paed just yet. As the next couple of months passed, David and I became more and more concerned that Rob's only communication was grunts and squeals. Our concerns were dismissed by friends and family; the standard responses were "Don't worry, he'll be fine", "I'm sure it's because his brother speaks for him" (he didn't) and, our favourite, "I knew someone who had a child that didn't speak until he turned four and then spoke in complete sentences".

> ...they were tears of relief that finally someone was listening to us

We didn't agree and insisted our GP gave us a referral to see his paed. She agreed that there were some speech delays and some gross motor concerns but thankfully ruled out cerebral palsy. She referred us to the local EI program at our community health centre. First thing they did was a speech assessment. When the ST had spent some time with Rob, she agreed that there were some concerns. I promptly burst into tears at which she started to reassure me that it wasn't that serious, that it was good we had recognised the delays early enough etc. etc., and I had to explain that they were tears of relief that finally someone was listening to us.

From there, we had an OT assessment and a discussion with the EI coordinator, a wonderful woman called Chris. We talked about our concerns, their impressions of Rob, and what we wanted to do. We decided to start Rob with individual speech therapy as none of us were overly concerned about his very slight physical developmental delays. After about 3 months of fantastic ST and my participation in a speech therapy program for parents (called Hanen, run by the Community Health Centre), our everyday life was much improved with a much happier little boy who could at last communicate. At this point, we had more discussions with the ST and EI coordinator and a decision was made to include Rob in one of the EI playgroups to encourage some physical development as well as continue ST in a group environment (as Rob was losing interest in his individual sessions).

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Your Story - Kate's experiences with EI (cont)

Rob attended EI playgroup for 2 terms. He was probably the least affected child who attended: the group included a severe CP girl, 2 autistic kids, a Down Syndrome boy, and a couple of kids like Rob: some developmental delays with speech issues. It was fantastic. 6 workers (including ST, Chris, PT, OT, etc) worked with the group of up to 7 kids each week while the parents (mostly mums, but sometimes a dad or grand-parents) had a support group meeting which involved coffee and biscuits with the EI counsellor directing our chats. We sat in a room that had a two-way mirror between us and our kids so we could see them at all times. The EI program also offered weekly support sessions of a more formal nature that provided information and help on specific issues like toilet-training, respite care and how to get it, dealing with siblings etc. At our informal chats we often had guest speakers, which included members from the local parents support group who offered a range of services from help filling out Centrelink forms to discount tickets for carers.

> I have felt supported, informed and helped by the wonderful group of women who make up the team

Also on offer was individual counselling, of which I am still availing myself!! At the end of each session, the staff gave each of us run-down on how the session went and we received a copy of the previous week's notes from their files.

Rob hasn't attended the EI program this year, we had an assessment late last year and then a discussion at which we decided to have a break and see how he went. This week, we will have two follow-up re-assessments with the EI Team and take things from there. At every stage of my involvement with the EI program, I have felt supported, informed and helped by the wonderful group of women who make up the team. I cannot recommend highly enough the level of care and professionalism that have been afforded to both Rob and myself from the EI program.

Kate Gordon

Ben (5) with Rob (3 1/2) January 2004

Book and Website Reviews

Through the Maze

A guide to benefits and services for families of children with a disability

Association for Children with a Disability

Although this is a Victorian based publication, much of the information would give families in any state some places to start looking for extra assistance they might need.

The section on Centrelink gives some ideas of what payments you may be entitled to. The "Advocacy Tips" section is also relevant to anyone needing some advice on how to approach agencies to get the services your child requires.

ACD is looking at producing version for the other States and Territories (although the link doesn't seem to be working yet), so you might want to check back now and again and see how this is progressing.

"Through the Maze" is available to download free from the internet. You will need Acrobat Reader.

http://www.acd.org.au/information/ttm.htm

The Association for Children with a Disability website in general provides some great information and is well worth a look. Although it is a Victorian organisation, there are contacts for all States and Territories (listed under "National Network").

http://www.acd.org.au

Early Intervention article references (from page 1):

McWilliam R A, Tocci L and Harbin G L (1998): Family-centred services: Service provider's discourse and behaviour. Topics in Early Childhood Special Education 18: 206-221.

Moore T (2000): The importance of early childhood intervention: recent developments. Conference Paper

Odom S L and Wolery M (2003): A unified theory of practice in early intervention/ early childhood special education: Evidence-based practices. The Journal of Special Education 37: 164-173.

Pathways Awareness Foundation

http://www.pathwaysawareness.org/

An excellent website giving information on what to expect from your child at different stages, including typical speech, physical and play development; as well as signs to watch out for.

Developmental milestones specifically for children born prematurely

http://med.emory.edu/PEDIATRICS/NEONATOLOGY/DPC/mileston.htm

The author of this website recognises that being born prematurely may impact on development. Developmental milestones are given for different age groups, along with sections on "exceptions" and "concerns".

Early intervention in premature infants (2002)
Vivienne Bernath

http://www.med.monash.edu.au/healthservices/cce/evidence/pdf/b/767.pdf

This was a search done on the available evidence to answer the request "Does early intervention or physiotherapy improve the motor developmental outcome of premature infants?". The best available evidence is looked for and a number of databases were searched. Nine suitable references were found, showing conflicting results. The paper provides full citations for each of the references, and looks at each of the studies in some detail.

Prematurity in the Press

This is a new Austprem group - an online forum where summaries/ abstracts of articles in journals, print/online media and book reviews etc that feature issues about prematurity will be posted. Where possible links to the full text of the article will also be included, but this depends on the availability of the article and Copyright. This group will be a semi-public group, non-members will be able to read forum, but only members can post articles to the group and join in any subsequent discussions.

For information on joining see http://www.austprem.org.au/pip.html

Pregnancy Support Group

The Austprem – Pregnancy Support Group has been set up for those who are contemplating or experiencing a pregnancy following a preterm birth, and for those at risk of giving birth prematurely.

Everyone is welcome to join Austprem – Pregnancy Support Group. You might be pregnant again, you might just be thinking about another pregnancy or you might have already completed a subsequent pregnancy and want to support someone else who is just starting on the journey. Sharing your thoughts and experiences might just help another mother, and support is what Austprem is all about.

You can find information about joining Austprem – Pregnancy Support Group at

http://www.austprem.org.au/psg.html

Your Austprem Committee

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	Cathryne McDonagh
	Junelle Rhodes

Contacting the Committee

If you need to contact any of the Committee, please email them by clicking on their name in the Members list of the mc2 group, or send an email to

austprem@austprem.org.au

and it will be forwarded to the appropriate person.

WA Get-Together!

Advance notice that our Western Australian members will be invited to attend a Christmas in July Get-Together on Sunday 25th July

ALL WELCOME

Watch the Forum for details as it gets closer to the day.

Maybe some of the other States would like to organize something too?

Chats

Chats are a great way to get to know other members better. They are usually held on Thursdays and Sunday nights from about 9pm (EST).

> "You can turn up in your pj's and you don't need a babysitter"

A reminder is posted to the Austprem Forum the day before a chat, so check there for the exact time. The chats are held in the Austprem Chat Room on the mc2 site, so only Austprem members are able to attend.

Chats are very informal—you can turn up in your pj's (who's going to know?) and you don't need a babysitter. But you can still receive great support and understanding from other parents, or just have a social chat—a bonus if you have been isolated at home all day.

Special Topic Chats

Watch the forum for announcements about upcoming chats on "breastfeeding and increasing supply" and "reflux"!

Birthdays

June

5 Amy (1)
13 James (9)
15 Jacob (5)
21 Cullen (2)
21 Nina (1)
21 Xavier (1)
26 Thaddeus (11)

If you would like your children (full term and prem) added to the Birthdays page at http://www.austprem.org.au/journey/superheroes/birthdays.html or to be listed in the Newsletter, please email kirsten@austprem.org.au

July

1 Mitchell (2)
3 Taylor (5)
3 Brooke (1)
6 Esther (1)
9 Molly (7)
18 Angelo (4)
20 David (4)
20 Nicholas (4)
21 Micayla (6)
22 Alexander (9)
24 Belinda (2)
25 Sheldon (5)
25 Kylara (3)

August

6 Jayden (6)
7 Kate (7)
13 Elizabeth (12)
16 Nicholas (4)
19 Imogen (4)
22 Lachlan (8)
24 Charllee (7)
25 Benjamin (3)
26 Daniel (7)
29 Saffron (4)
29 Hayley (1)

Your support helps Austprem Inc. to grow and improve.

Donations

Austprem Inc. is a non-profit organization with no on-going funding.

If you would like to make a donation to Austprem Inc., please send your cheque or money order to:

Austprem Inc.
P.O. Box 2157
Sunbury VIC 3429

Please include you name and address so that a receipt can be posted to you.

Donations $2 and over are tax deductible.

Your support is greatly appreciated.

Joining Austprem

Austprem is an Internet based support group. To join Austprem Inc., you will need to go to http://www.austprem.org.au/join.html and fill out the online membership form. To access the online forums and chats (where most of the Austprem "action" happens), you will also need to follow the steps at http://www.austprem.org.au/forums.html to register with mc2 and subscribe to an Austprem group.

Join now - it is a great opportunity to share with others who have "been there" and who can understand your experiences

Membership is FREE!

Any information provided to Austprem is held in confidence and will not be used for any other purpose or given out to any third party without your permission.

Austprem Inc.

Providing friendship, information and support for families of premature babies and children.

Visit our website

www.austprem.org.au

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Newsletter

Suggestions and Comments?

newsletter@austprem.org.au

Coming Up in the Next Issue...

- Reflux and distressed infants

Copies of Austprem Ink may be downloaded from:

http://www.austprem.org.au/newsletters.html

PremiePress is a publication for those who are interested in the development of premature infants and prematurely born children.

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Disclaimer

Please note that Austprem Inc. does not recommend that any interventions are made to any baby or child without the knowledge and assent of the child's doctor or other health care provider.

Austprem Inc. cannot be held liable for the actions of any person based on information that Austprem Inc. has provided.

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Please support those that support us.

Please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby.