EARLY INTERVENTION AND PARENTAL INVOLVEMENT

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Early Intervention in Ireland – where do we go from here?
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Acknowledgements

Parents who participated in focus groups, interviews and surveys

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Overview

- Parental involvement in Early Intervention Services
- Methodology
- Key findings – parents’ perspectives on:
  - Information
  - Key-working
  - Connections to other services
  - Decision-making
    - Assessment
    - Intervention
  - Evaluation of services
Family-centred
Parental involvement in Early Intervention for children with disabilities

- Progress in ECCE with parental involvement through Siolta & Aistear
- Disability policy endorses family-centred services
- What does this mean in practice?
- Lack of coherence in EI settings about parental involvement

- Without parental involvement early childhood intervention does not work (Pretis, 2011)
Parental involvement in Early Intervention for children with intellectual disabilities

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<th>Benefits for parents</th>
<th>Barriers</th>
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<td>- Enhance capacity to support their child</td>
<td>- Individual; family; child; societal</td>
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<td>- Counteract isolation, stress and professional dominance</td>
<td>- Parent-professional</td>
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<td>- Transitions from early intervention to other services</td>
<td>- Professionals that are oriented towards their professional practice (Pretis, 2011)</td>
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<td>- Decision-makers as child’s advocate on uncertain education and care trajectory</td>
<td>- EI services delivered by multiple disciplines</td>
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# Methodology

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<th>Aim</th>
<th>Method</th>
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| To examine parents’ experience of their child’s EIS | Parent questionnaire (n=42)  
3 parent focus groups (n=14)  
One-to-one parent interviews (n=10) |
| Focus Group and interview topics |  
• Information  
• Parental involvement in child’s care  
• Referral and assessment process  
• Services’ strengths and limitations  
• Key worker role  
• Involvement in programmes  
• Parents’ evaluation of services |
| Survey – European Parental Satisfaction Survey about Early Intervention |  
• Assistance for parents  
• Assistance for children  
• Social environment  
• Relationships between parents and EIS  
• Model of assistance  
• Parental rights  
• Other community services |
Parent sample (survey)

- 42 parents completed survey – 60% response rate
- Majority mothers
- 86% aged 36-45
- Two-thirds of children of these parents attending for less than 3 years
- 40% of children under 3 years; 60% aged 3-to-6 years
- Majority children with difficulties in speech and language, and intellectual development
Assessment and intervention

- Received EI from multidisciplinary team: OT, Physio, SLT, ID nurses; play therapist; pre-school teacher, social worker
- 70% satisfied with the assessment process
- Lack of satisfaction: those with children with multiple and complex needs
- Many examples of home-based assessment, but formal and centre-based more common
- Parent concerns about timing and receipt of assessment reports
If something comes out of this focus group I’d love it to be that the assessment is more child-friendly.

(Parent Focus Group 2)

Should be giving information prior to the assessment, in order to know where the child should be at or what are they expecting.

(Parent Focus Group 2)
Service experience and involvement

With key worker
- Essential in a MD team context
  - Families reported that they have key workers
  - Lack of clarity about the role of key worker

In home
- Parents encouraged to support their child’s ongoing intervention in home-setting

In training
- Speech and language
- Toilet training
- Parenting programmes
- High degree of satisfaction

In organisational aspects
- Parents involved in fundraising
Parental Satisfaction Survey

- Assistance for parents, mean = 3.4
- Assistance for children, mean = 3.7
- Social environment, mean = 4.1
- Relationships between parents and EIS, mean = 4
- Model of assistance, mean = 3.7
- Parental rights, mean = 3.7
- Other community services, mean = 3.1

Examination of individual scale items reveals that services are personalised and professional
The assistance provided by the service helped me to feel more secure in dealing and handling my child.

- Strongly Agree: 19
- Agree: 57
- Neither: 17
- Disagree: 5
- Strongly Disagree: 0
She was just so warm and caring, you know, which is huge...

Our minds at ease like when we got the visit from ( ) that was fantastic because we really got a sense of two other really caring people in this room

It was kind of protective

Parent interview 1

Parent interview 2

Parent focus group 2
The support provided by the service helped me to see both, my child’s possibilities and difficulties.

- Strongly Agree: 24%
- Agree: 50%
- Neither: 19%
- Disagree: 7%
- Strongly Disagree: 0%
Maybe it’s just me but I think they genuinely care. Your child is not just a client to them, it’s a little person that needs help... I’ve seen people and they are treated just as clients and it’s just whatever, you are a number this is my job and I have to do it, it’s not. And I have seen that, so for me the fact that they treat [child’s name] as a little person and they genuinely care about her which is huge.

Parent interview 6

They helped us as a family do better our own behaviours especially dealing with the other children in the family (siblings) and again great progress too.

Parent survey 17

They’ve taught me how to take the therapies, how to adapt them to my child, how to look at them with the right objectives they’ve really helped because at the end of the day you’re educating more than the therapists, you’re taking guidance but you’re the one who is going to really drive the child forward.

Parent interview 4
The way staff from the Early Intervention Service interact with my child is

- Very good: 65%
- Good: 25%
- Neither good nor poor: 8%
- Poor: 3%
- Very poor: 0%
Contact with other parents

The contact I have with other parents facilitated by the EIS is helping me

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<th>Opinion</th>
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I would like to see more group work with other parents

I have never had any contact with any other parents

I remember saying to them that I’d love to meet other parents and they didn’t encourage me to meet other parents at that time

Parent survey 11

Parent Survey 12

Parent focus group 1
Information on community services

The EIS informs parents about different community services available for my child

- Strongly Agree: 5
- Agree: 12
- Neither: 29
- Disagree: 45
- Strongly Disagree: 10
The EIS informs parents about different community services available for my child.
Private alternatives are not encouraged or mentioned such as Down Syndrome Ireland

Parent survey 10

My child has not yet been offered external organisational assistance

Parent survey 21

[We] received no information on community services

Parent survey 12

Parent survey 21
Reliance on verbal information

- 52% of parents were not informed in writing of their child’s progress:
  - ‘Verbal conversations with individual therapists’ (Parent Survey 04)
  - ‘Not in writing, but have regular meetings and updates with EIS team and team leader’ (Parent Survey 28)
  - ‘Very infrequently; in five years maybe around twice for all therapies’ (Parent Survey 41)
  - There is no communication […] they know what they are aiming for and then we should be working together to achieve those goals but we don’t know […] it would be good to know the goals and at what stage they should be (Parent Focus Group 1)
Information provision: what is going to happen?

I think there is an opportunity to give maybe an outline of what you are going to experience for the next 12 months. I think if I didn’t have (name) at the end of the phone I would have been lost. You kind of take the appointments as they come, you go, you do what you are told to do. It would have been very helpful just at the beginning for somebody to sit down, (other than the keyworkers), but somebody outside of that relationship, who can say to you “here are the steps, here are the two key people in your life, here are the different therapies you are going to do, here’s what you can expect when you go into these therapies and after 18 months you will have a full assessment of what you have experienced so far and then you will decide from there.
Decision-making

‘We believe a team meeting should be held annually between parents and E.I team to chart our child’s development and future plan’ (Parent, Survey 15)

‘Kind of what I was saying earlier in terms of the different therapists, and as I said there is a very good chance that they do meet regularly to discuss, but I just don’t get that feeling back. I am almost sure they do, don’t they?’ (Parent, Interview 2)

‘You know we are not health care professionals but we have more contact with [child’s name] and know a lot more about her than anybody else, and I’d certainly if decisions will be taken about her future given the way they have progressed since she’s been with them I’d have thought we’ve been asked a lot more questions than we’ve been asked so far (Parent, Interview 7)
EIS model and approach: involvement in monitoring and evaluation

• ‘understanding what service users want and how they evaluate services is critical to the delivery of a quality service’ Quality Standards in Human Services in Ireland: Disability Services’ (NESC, 2012, pxix).

But parents may be cautious of speaking out:
‘You do have a sense sometimes that you are very lucky to get what you got and you know, you should be happy with that and I just think that is a pity but I don’t know where that comes from and I am actually, I was going to bring it up actually with them later today I have never discuss it with them because I feel we are so appreciative of everything we do get. I don’t want that to go against us or to certainly not against him you know I wouldn’t like it.’ (Parent, Interview 2)
Conclusions

- Parents positive about personalised, professional services
- Gratitude and fear of being critical
- Personal and professional is welcomed
- But need to be combined with parental involvement standards on:
  - Information provision
  - Joint goal setting, planning, transitions
  - Involvement of parents in team decision-making
  - Reporting and evaluation
- Dilemma of personalised professional services and parent empowerment