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Developing a Joint-Working Pathway to parenthood: Learning from the lived experiences of mothers with learning disabilities

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Working Together with Parents Network
London & South East Conference

“I think it would have been more helpful when I had the first problems with my children to have come and got help with my children, not just pushed everyone away like I did first of all... Yeah, it was very hard to ask for help in the beginning.”



- There are an increasing number of parents with known or suspected Learning Disabilities presenting to services (BPS, 2011).
- These parents face multiple disadvantages in parenting their children successfully, and are still more likely than other groups to have their children removed from their care (Tarleton et al., 2006).
- 40 – 60% parents with LD are not living with their children (Emerson et al, 2005; DoH & DfES, 2007).
- There are a number of key documents and Good Practice Guidance available regarding supporting parents with learning disabilities (e.g. DoH & DfES; 2007).

- Locally in West London, there has been a move to improve joint working between agencies
- This project aimed to ensure that future service development and joint working protocols were informed by the voices and experiences of parents with learning disabilities who live locally.
- At the time of the study, there were 28 parents with learning disabilities known to the H&F LD Service.

Stage One:

- Gathered representative views from mothers with learning disabilities.
- In-depth qualitative interviews were conducted with five of these mothers (aged between 23 and 38 years)
- The women interviewed had 16 children (aged less than 1 year to 17 years old) between them.
- Three of the five mothers were still living with at least some of their children, and the other two mothers' children had been removed from their care.
- Interviews were analysed using thematic analysis (Braun & Clarke, 2006).

‘It was a shock, I didn’t even know I was pregnant’

“I said I’m pregnant innit and they said yeah and they said to me I have two options, I can have abortion or I can have adopting. I don’t believe in those.”

“you know like they make like mock of people who have learning difficulties”

“I was, ok in my head I was this disabled person...then when I had my children it gave me strength...”

“I used to feel like they were all against me kind of thing but now I feel like they’ve helped me get through a lot”

“They actually listen to me and supported me and asked me what sort of support I need.”

“They’ve [services] got to work around me “

“It was always about what I couldn’t do”

“... always under watch all the time... I felt like everything was just a mistake.”

- Desire for parenthood - yet felt unprepared, and frequently experienced negative reactions and even victimisation from others.
- Mothers whose children had been removed from their care, described their significant loss.
- Mothers also described a dilemma between their desire for support from services to develop their skills as a parent, conflicting with the intrusive and evaluative nature of this support, and the danger that it brought in terms of potential for child removal.

Messages of Support



- Parents also expressed a desire to give messages of support to other parents with Learning disabilities.

“Just that they should keep their head up because the services are there to help them at the end of the day”

“.... and now I just feel like, I just, I feel like I don't really need too much help now, I feel like I'm getting there. And I feel like they will get there too.”

Two main themes emerged:

Theme 1: Experiences of becoming a mother

"On all my pregnancies I could say my children were planned to have but not to have so close together, to have far away but it just didn't happen like that."

Feeling unprepared

"It was a shock, I didn't even know I was pregnant"

Discourses of others

"I said I'm pregnant innit and they said yeah and they said to me I have two options, I can have abortion or I can have adopting. I don't believe in those."

"You know like they make like mock of people who have learning difficulties"

Fulfilling a desire for motherhood

"I was, ok in my head I was this disabled person...then when I had my children it gave me strength..."

Theme 2: Mothers' experiences of support from others: Dilemma of support versus intrusion

"I used to feel like they were all against me kind of thing but now I feel like they've helped me get through a lot"

What was more helpful?

"They actually listen to me and supported me and asked me what sort of support I need."

"They've [services] got to work around me"

Qualities of helpful support

Developing parenting skills

Support Networks in place

What was less helpful?

"It was always about what I couldn't do"

"... always under watch all the time... I felt like everything was just a mistake."

Stage 2: Developing the Pathway



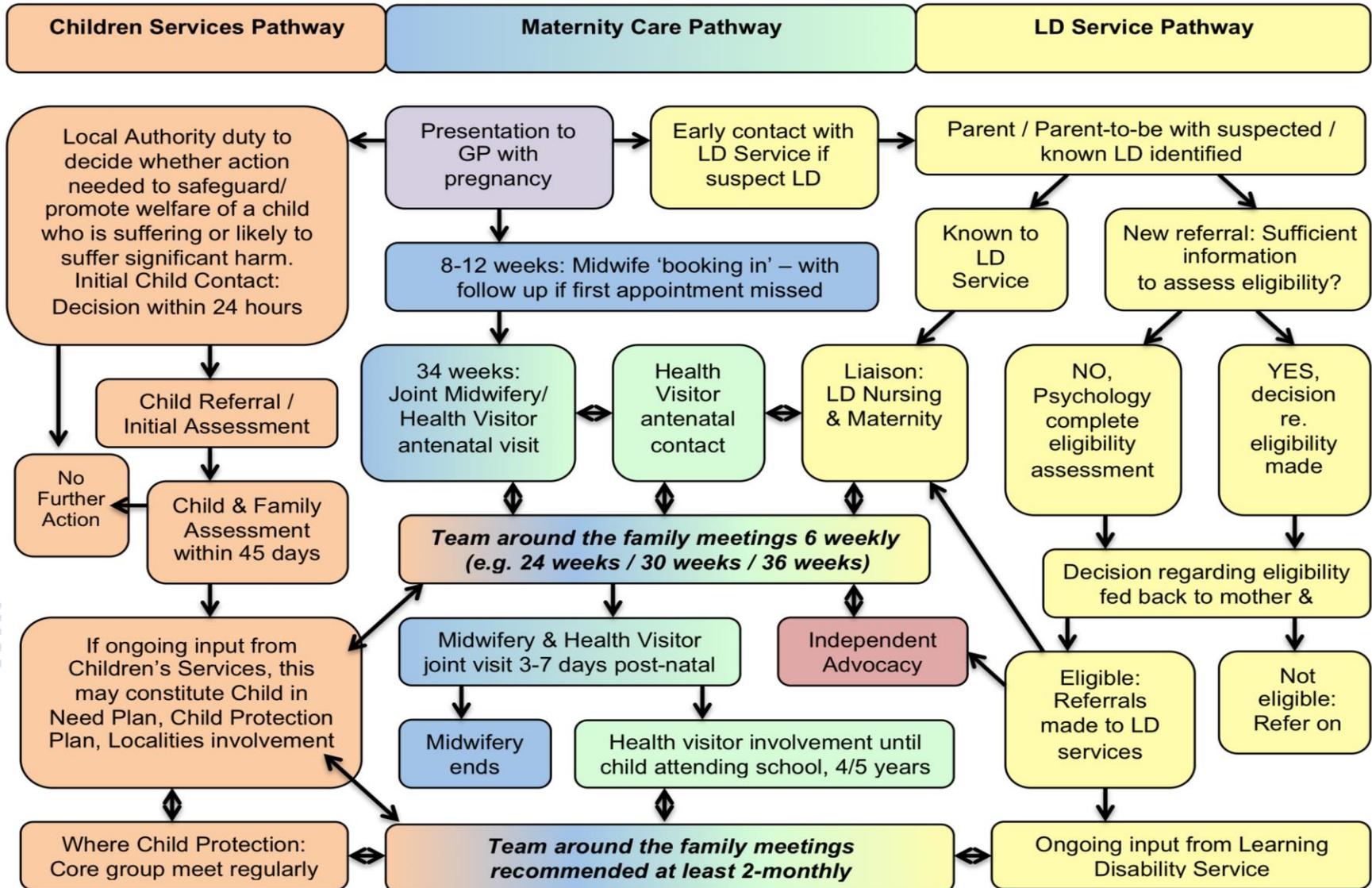
- The mothers' lived experiences informed the development of a joint-working pathway for services supporting parents and parents-to-be with learning disabilities.
- The themes described were shared with key stakeholders.
- A working party including:
 - Adult Learning Disability Service
 - Children's Services,
 - Midwifery,
 - Health visiting,
 - Advocacy services
- Developed a joint working service pathway for parents-to-be with learning disabilities, drawing on the lived experience of the mothers interviewed, together with good practice guidance available.

Stage 2: The Pathway



- The pathway shows three key parallel pathways:
 1. the central pathway being maternity care services (including GP, midwifery and health visiting), with parallel processes either side
 2. the Children Services procedures in place to assess welfare of the child,
 3. assessment and support for the parent as provided by the Learning Disability Services.
- Within these pathways, reasonable adjustments required to effectively support parents with learning disabilities have been specified.

The Pathway



Reasonable Adjustments:



- Be proactive:
 - Recognise support needs and implement services at early stages
- Be flexible and responsive:
 - Allow more frequent appointments, longer appointment times, home visits, and provide individualised, person-centred care
- Include support networks where appropriate:
 - Consider all aspects of the support system, and family strengths as well as deficits
- Work collaboratively:
 - Avoid multiple assessments and including specialist learning disability input
 - Consider parents' anxiety about role of professionals, and support needed to prevent anxiety becoming a barrier
- Use accessible information
- Provide access to independent advocacy for parents

(Also in line with good practice guidance e.g. DoH & DfES, 2007)

Summary & Next Steps:



- The completion of this qualitative project with mothers has allowed a rich and powerful narrative of their experiences to emerge.
- Small-scale study, but also builds on the literature already available to develop a joint-working pathway based on local mothers' experiences as well as good practice guidance
- Highlighted areas for cohesive joint-working across the multiple services involved; an area highlighted by many as still lacking (MacIntyre and Stewart, 2011).
- Leading to further group work for parents with LD

“The True Story of Mothers with Learning Disability – We CAN Do It!”

| | |
|---|---|
|  | <p>My message to other mothers:</p> <p>Don't let disability be a disability, fight it if you can, especially if you've got one like mine. Just see it as, all it is, is a shell, I'm just exactly like you but just for me it's just a shadow, a shell.</p> |
|  | <p>I want to share this message because...</p> <p>Sometimes society is selfish. People say disabled people can't do things when they can. Society makes us disabled.</p> |
|  | <p>I have done / thought about... My skills, achievements and ideas</p> <ul style="list-style-type: none">• I don't judge.• I think <i>I can do it</i>.• I have choice.• I write songs.• I had 3 children.• I say what I can't do. I explain what is difficult.• I have a sense of humour. |

- Small group work with mothers with ID using a Narrative Therapy model
- Development of a booklet summarising conversations with the mothers, sharing their messages, values, skills and achievements
- Audio-visual CD to accompany the booklet
- Booklet available at:
<http://www.londonparents.net/news.html>

Kleinberg & Theodore, 2013

Thank you!



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