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Postgraduate Conference

- When: 30th July 2018, 1.30pm – 3.30pm
- What: Post-doctorate funding workshop: Life after the PhD
- Who: Two experienced speakers who have gained funding after their PhDs, one of whom now works for a funding body.
- Where: Anglia Ruskin University, Cambridge
- Contact: Hannah.belcher@pgr.anglia.ac.uk)

Research article

An Intellectual Disability Service and Children's Social Care joint parenting pathway: the experiences of parents, and health and local authority practitioners.

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Abstract

Parents with intellectual disabilities can face multiple challenges. They often receive help simultaneously from Intellectual Disability Services and Children's Services. This service evaluation explored the views of parents and practitioners, of an inter-agency pathway between Children's Social Care Services and an Intellectual Disability Service. The results led to recommendations for service improvement including structures to support interagency communication, consistency, and person-centred working.

Introduction

There is an increasing knowledge base about the experiences of parents with intellectual disabilities (ID) (eg Booth & Booth, 2005; Tarleton & Ward, 2007). Effective support for parents with ID is a national policy objective (DoH, 2009; United Nations, 2006). There have been a number of reviews of practice and guides to effective support (Baum, Gray, & Stevens, 2010; Baum, 2014; Department of Health & Department for education and skills, 2007; Goodinge, 2000; The Baring Foundation, Tarleton, Ward, & Howarth, 2006; Theodore, Raszka & Kleinberg, 2014).

However, parents with ID continue to experience high rates of Child Protection (CP) involvement and child removal (Booth, 2004; Collings & Llewellyn, 2012). They remain a disadvantaged social group, commonly experiencing multiple factors, such as isolation and poor housing, known to impact on parent and child outcomes. It is difficult to distinguish the relative influences of a parent's ID and these multiple social factors (Collings & Llewellyn, 2012).

Guidance on service provision

Practice guidance in this area has several themes. Effective services are family centred (rather than parent or child focused); preventative; strength focused; and flexibly tailored to families' needs (The Baring Foundation et al., 2006). Long term support should be available, based on an assessment of needs and strengths. Effective services have clear and coordinated referral and care pathways, provide accessible information, and access to advocacy (Working Together with Parents Network (WTPN), 2016).

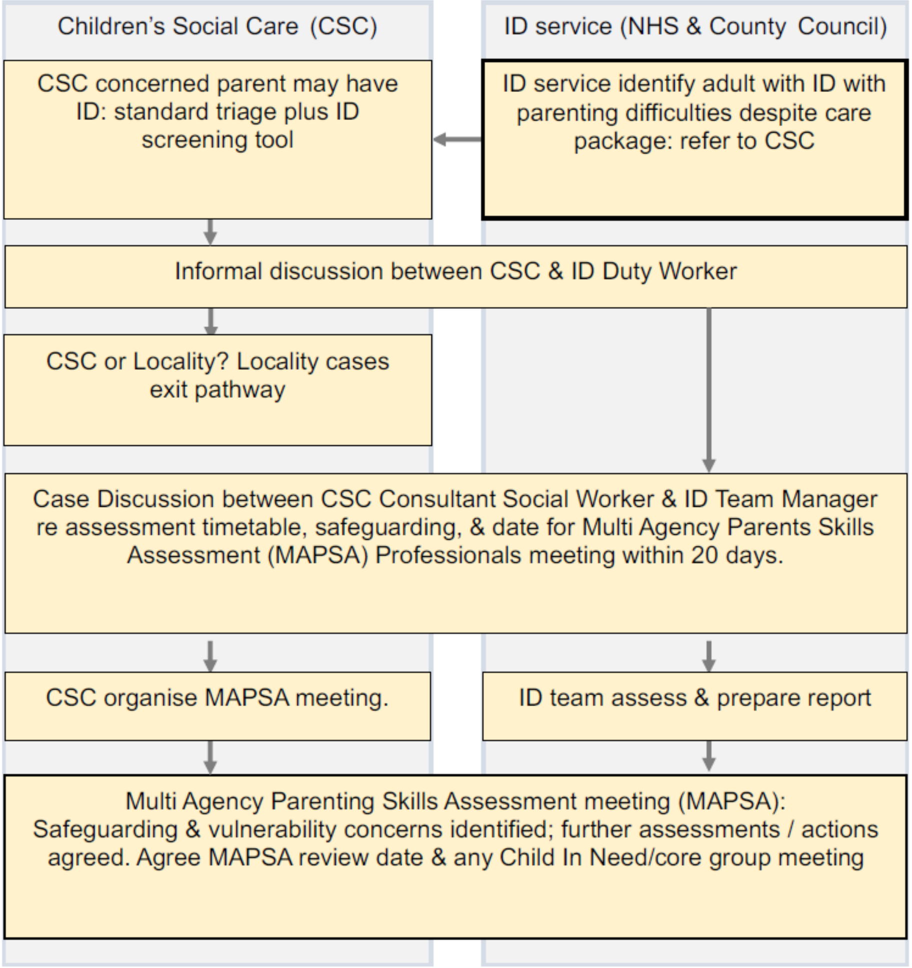
However, service provision for parents with ID often fails to adhere to these principles. The WTPN suggested that this failure can amount to a breach of the child and parent's rights (Working Together with Parents Network (WTPN), 2016).

How do services work at present?

Parents with ID are most often supported by mainstream services with input from ID services where necessary (The Baring Foundation et al., 2006). In some services, parents' views have been used alongside good practice guidance in the development of inter-agency pathways (Theodore, Raszka & Kleinberg, 2014).

However, many practitioners lack confidence, or specialist skills, for working with parents with ID (Goodinge, 2000; The Baring Foundation et al., 2006; Working Together with Parents Network (WTPN), 2016). There are barriers to close communication between adult and children's services, with Children's Services practitioners concerned about ID practitioners' attention to Child welfare, and ID practitioners believing that Children's Services staff do not understand ID sufficiently (Working Together with Parents Network (WTPN), 2016). Service criteria for some NHS ID teams are restrictive, so some parents whose needs cannot be met by generic services cannot access ID team support (Goodinge, 2000; Working Together with Parents Network (WTPN), 2016). Services often provide repeated, short term interventions which are a poor fit for ID parents' needs (Booth, McConnell, & Booth, 2006). Booth et al consider this "temporal discrimination", and implicate it in the high levels of CP involvement and child removal for this client group. The focus of work is usually either the parent *or* the child, rather than the whole family's needs (Goodinge, 2000).

Fig 1: Simplified ID and CSC joint pathway



Aims of the current study

- To examine the experiences of parents with an ID, and health and local authority practitioners, of an inter-agency pathway between Children's Social Care Services and an adult ID service.
- To make recommendations to improve inter-agency working.

Method

Context: The adult ID service consists of integrated community teams of NHS healthcare practitioners, and County Council social workers and adult support coordinators. Services for children are provided by the County Council's Children, Adults and Families directorate.

In 2012, a joint care pathway was developed between the ID Service and Children's Social Care Services. This was based on WTPN Good Practice Guidance (Department of Health & Department for education and skills, 2007) (See Figure 1).

This pathway formalised referral routes, clarified each service's responsibilities for initial assessment, and provided a forum and documentation for interagency information-sharing and risk assessment through a Multi-Agency Parenting Skills Assessment meeting (MAPSA). This pathway was piloted in two ID teams between 2012-16. A qualitative service evaluation was carried out using semi-structured interviews. Detailed notes were taken with key phrases recorded verbatim (Redley et al, 2012). The written interview records were examined using Thematic Networks Analysis

(Attridge-Stirling, 2001) an established qualitative method that uses diagrams to structure themes during analysis.

Ethics: Ethical issues were given serious consideration at all times during this project. Maintaining anonymity was emphasised, as participants from a small population were commenting on service delivery. Direct quotations were checked with participants and used very sparingly. The local NHS Research and Development department advised that ethical approval would not be required for a service evaluation.

Participants: The five parent participants were all mothers. They all met community learning disability team service criteria. One woman was living with her partner at the time of interview, and four were single parents. All had been involved at least once in Child Protection proceedings. Four of these mothers had at least some of their children resident with them at the time of interview. Four mothers had had one or more children removed from their care; two of these mothers had experienced the removal of several children.

There were four Children's Services participants, who were practitioners from teams at Children's Social Care and Locality levels. ID service participants were two healthcare practitioners, and two county council practitioners.

Reliability and trustworthiness: Concurrent analysis and data collection allowed ideas to be confirmed by further data collection (Morse, Barrett, Mayan, Olson, & Spiers, 2008). Sections of data were rated independently by another practitioner (Barbour, 2001). Some level of data saturation was achieved as new codes were not produced from later data collection. The researcher's positions as an LDP practitioner will have affected the data gathered. To try to elicit more critical views, service improvement suggestions were directly requested.

Results

In this analysis, 15 organising themes were identified, then linked into five global themes using Thematic Network Analysis techniques (Attridge-Stirling, 2001).

1. *"What helps"*

Service users referred little to the process but emphasised the importance of practical help, such as:

- Translating CP concerns into concrete tasks with visual aids
- Help with routine practical tasks
- Help to reduce isolation
- Accessing advocacy for CP meetings

Parents and practitioners valued the longer term input provided by the ID service.

2. *"Joined-up-ness"*

Practitioners reported that the most useful part of the pathway was the MAPSA multi-agency meeting, because it had increased "joined-up-ness". Other parts of the pathway were rarely mentioned. Practitioners thought time pressures could prevent colleagues understanding or fully following the pathway. Service users and practitioners told us that support packages could be more joined up; currently they support either the parent's or child's needs. "Me and (my child) come as a package. (Support Workers) can't come into a house with a child to help and not help with the child."

3. *"Being human"*

Parents said that practitioners "being human" and less formal was important in building a trusting relationship. Being human involved things like smiling, appearing to enjoy the parent's company, limited self-disclosure, and flexibility about venues. Both parents and practitioners valued having a named person to ask for when telephoning. Practitioners thought regular communication helped to reduce "them and us" tensions and maintain relationships between agencies.

4. *Tensions*

Service users and practitioners observed tensions that impede coordinated working. Service users mostly focused on how views on acceptable living standards can vary between practitioners, and services. Practitioners raised this issue, and also tensions between time-limited service structures and ID parents' long term needs, and between the taken-for-granted knowledge of LDP and CSC practitioners (most frequently regarding CSC practitioners' ID communication skills and LDP staff's knowledge of CP legislation).

5. *Seeking clarity*

Practitioners found that the MAPSA meeting's focus on evidence could help resolve some tensions and achieve clarity. "The (MAPSA) risk matrix takes away people's opinion and looks at fact!" Service users also wanted services to be clear about their needs, and more specific about what changes were required.

Implications for service development

The joint pathway provided a structure (the MAPSA meeting) for inter-agency working, but time pressures affected adherence to the pathway, and working relationships. The ID service has now produced a booklet to help practitioners follow the pathway. This specifies a named contact person for each case to make access to the service more person centred. The ID service has introduced an inter-agency case discussion group as a structure to maintain inter-agency communication (Working Together with Parents Network (WTPN), 2016) and share knowledge.

Participants thought that direct support staff should be able to support the whole family (The Baring Foundation et al., 2006). Pooling budgets for more effective family based support is recommended by the Care Act (Department of Health, 2014). The ID and Children's services are exploring employing support staff from the same agency as a simple practical solution.

Social support has been shown to buffer stress for mothers with ID (Feldman, Varghese, & Ramsay, 2002), as long as it is acceptable to the parent, and builds their confidence (James, 2004). The ID service now assesses social networks in more depth. Devising strategies to help parents find social and community support is an area for service development.

As there is no exact definition of "good enough" parenting (McGaw & Sturmey, 1994; Morgan, 2017), standards can vary between practitioners. Parents are often not clear what is required or how this is assessed (Booth & Booth 2005). Higher standards are expected of parents with ID than of non-disabled parents (The Baring Foundation et al., 2006). There is growing evidence around factors predictive of parental difficulties, for example, the parent or child having additional needs, the parent having a history of childhood trauma, an IQ below 60, or a partner with a forensic history (Morgan, 2017). Other factors are considered protective, such as the child having a consistent supportive adult relationship (The Baring Foundation et al., 2006), a smaller family size, and a parent having had positive childhood experiences (James, 2004). Services could use the evidence base on risk and protective factors to aid decision making about what constitutes acceptable parenting.

In recent years financial constraints on councils have increased time pressures for teams. In this context, services may focus on legal requirements and immediate risk management, rather than on good practice based service development. However, a review of literature and case studies (Bauer, 2015) found that good practice recommendations (specifically early referral and involvement of children's services, and longer term but decreasing levels of support) can prevent negative child outcomes, and save costs to services in comparison to episodes of foster care. Understanding how potential cost savings are linked to different models of support may enable practitioners and commissioners to implement these changes.

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Endnote - Please contact the authors if further information on methodology, data analysis and results is required.

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An introduction

Introducing you to the Positive Ageing Research Institute – Rebecca Chandler

Anglia Ruskin University

Who are we?

The Positive Ageing Research Institute (PARI) is a cross-faculty multidisciplinary institute based at Anglia Ruskin University. We are a diverse team from academia, older adult forums, healthcare practice, local authorities, industry, and voluntary organisations. Together we represent many disciplines and purposes, but are united by our common interest in ageing and emphasis on ageing well.

What do we do?

PARI aims to develop research and innovations that support positive ageing, improve quality of life and foster independent living, even in the presence of age-related conditions. To achieve this we take a collaborative approach in the development of our work, in which we place older adults at the center. We view older adults as valuable assets of society who should be empowered to engage with their healthcare, as such we have developed technology based projects which allow older adults to control their own conditions in their own home.

One example of our projects which we successfully co-created with older adults is the PainAdviser™. This system acts an "interactive expert" on chronic pain management via PC or tablet providing 24 hour support on pain management. The PainAdviser™ engages older adults in a conversation about their pain and makes treatment recommendations based on the older adult's response. Treatment recommendations are based on algorisms created with pain experts and guidelines. The PainAdviser ™ allows older adults to seek immediate treatment, placing them in control of their condition and potentially avoiding the need for further help-seeking from healthcare services. The PainAdviser™ continues to be developed and considered for its uses in other chronic conditions of