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3 **Commentary on “What are the experiences of professionals working with parents with learning**
4 **disabilities? A meta-ethnography”**
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8 **Abstract**
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11 **Purpose**
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14 The purpose of this paper is to provide a commentary on Pytlowana and Stenfert Kroese’s article on
15 the experiences of professionals working with parents with learning disabilities by exploring
16 challenges and good practice in this area.
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21 **Design/ methodology/ approach**
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24 Key areas of practice were identified for further exploration by drawing on research studies with
25 parents with learning disabilities.
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29 **Findings**
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32 While there is growing evidence of good practice around working with parents with learning
33 disabilities, a number of challenges around communication and relationship-based practice remain.
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35 The paper recommends further training and education for those working in this complex area of
36 practice.
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42 **Originality/ Value**
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45 The paper adds value by bringing together evidence from across a number of studies to highlight good
46 practice.
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50 **Key words**
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53 Parenting, communication, relationship based practice, learning disability, intellectual disability, adult
54 social care
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58 **Introduction**
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3 The rights of parents with learning disabilities have gained prominence in recent years and are now
4 enshrined in international treaties and policy. For example, the UN Convention on the Rights of
5 Persons with Disabilities (UN General Assembly, 2007), in Article 23, provides that “state parties shall
6 take effective and appropriate measures to eliminate discrimination against persons with disabilities
7 in all matters relating to marriage, family, parenthood and relationships on an equal basis with
8 others”. This includes the right of disabled people to “decide freely and responsibly on the number
9 and spacing of their children” and to have access to information to ensure they can make informed
10 choices around this. At a national level, there are legislative frameworks in place that should support
11 these principles. In England the Care Act (UK Government, 2014) includes *developing and maintaining*
12 *family or other personal relationships and carrying out any caring responsibilities that an adult has for*
13 *a child* as eligible care and support needs. Similarly, in Scotland, Part 12 of the Children and Young
14 People (Scotland) Act (Scottish Government, 2014) states that Local Authorities have a duty to provide
15 support to children who are at risk of becoming looked after as well as to the significant adults in
16 relation to that child. Parents with learning disabilities should therefore be provided with legally
17 mandated support with their parenting role, should this be required.
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41 We know that parents with learning disabilities are significantly over-represented within the child
42 protection system (Collings *et al.*, 2017; Cox *et al.*, 2015) and are much less likely to have their children
43 living at home with them (Wilson *et al.*, 2013). Concerns often relate to neglect by omission rather
44 than intentional abuse. Parents with learning disabilities often live in extremely complex and
45 challenging circumstances which, combined with the parents’ learning disability, may present
46 particular challenges to parenting. Yet we know that people with learning disabilities can and do
47 become good enough parents when they have appropriate support (see for example MacIntyre *et al.*,
48 2019, Stewart *et al.*, 2016, Tarleton and Porter, 2012). To this end, the Scottish Commission for
49 Learning Disabilities produced *Good Practice Guidelines for Supporting Parents with Learning*
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3 *Disabilities* (SCLD, 2015). These guidelines were based on a series of principles including early
4 identification of parents with learning disabilities and early intervention so that preventative support
5 can be put in place; the provision of support on an ongoing basis, particularly at key points of
6 transition; support that respects the emotional bond between parent and child; whole family support;
7 and strengths based support that focuses on competence. Despite the publication of these guidelines,
8 professionals continue to report a number of difficult issues in their work supporting parents with
9 learning disabilities. This paper will focus on two of those challenges: communication issues and the
10 development of relationship based practice, drawing on our own research in this field.
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25 **Communication Issues**

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27 One of the key themes reported by Pytlowana and Stenfert Kroese related to concerns about
28 knowledge and experience of parents and professionals. Across the papers that were reviewed a
29 number of professionals questioned whether they had the necessary skills, knowledge and expertise
30 to work with parents with learning disabilities. Professionals felt they had expertise in their own field
31 (such as midwifery) but reported having limited contact with parents with learning disabilities. This
32 led to such work being perceived as the role of specialist learning disability staff. A lack of exposure
33 to parents with learning disabilities and a perception that working with this group requires specialist
34 expertise meant that professionals, at times, reported a lack of confidence in working with this group
35 of parents. This is exacerbated by those working in specialist learning disability teams feeling that
36 they do not always have the expertise or remit to carry out work that relates to parenting or child
37 protection, with the result that families where one or both parents have a learning disability often fall
38 in the gap between children's and adult services (MacIntyre *et al.*, 2019; Tarleton and Porter, 2012).
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3 An appraisal of the good practice guidance (SCLD, 2015) shows that good communication skills are
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5 essential when working with parents with learning disabilities. Indeed, the guidelines state that:
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8 *“good communication is vital in helping parents have as much control as possible. It helps families*
9 *engage with services and it helps services understand what each family wants and needs. Without*
10 *good communication, families feel powerless and frustrated”* (SCLD, 2015, p. 14).
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19 A central component of good communication is the provision of accessible information that is clear
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21 and easy to understand. This might include a range of formats including:
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- 24 - Easy read
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- 26 - Large print
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- 28 - CD or DVD
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- 30 - Accessible websites
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- 32 - Face to face meetings with people
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- 35 - Support from an advocate.
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41 We would argue that such forms of communication are good practice when working with families
42 generally, not just for those with learning disabilities. However, our research has found that
43 professionals do not always make these necessary, reasonable adjustments to communication when
44 working with parents with learning disabilities (MacIntyre and Stewart, 2012). There are numerous
45 examples of well-intentioned practitioners who are hampered by time pressure and a lack of
46 resources, as well as a limited understanding of the communication needs of parents with learning
47 disabilities. The child protection and court systems are particularly inaccessible for parents with
48 learning disabilities who often need significant levels of support to navigate their way through the
49 system and help to translate the information contained in formal reports. Support from an advocacy
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3 worker can be particularly helpful here (see for example Bauer *et al.*, 2014; Cox *et al.*, 2015; MacIntyre
4 and Stewart 2012).
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11 Parents' communication needs can also be overlooked during assessments of parenting capacity
12 (McGaw and Newman, 2005). Often parenting assessments have to be undertaken very quickly in
13 order to meet statutory timescales (Llewellyn and McConnell, 2010; MacBeth *et al.*, 2015;) and in our
14 research we have found examples of parents who have not understood the purpose of the assessment
15 or even that their parenting skills are being assessed (MacIntyre and Stewart 2012). There are a
16 number of accessible assessment tools available, for example the Parenting Assessment Manual
17 (PAMs) (McGaw, 2012). This assessment tool has been specifically designed for parents with learning
18 disabilities and assesses areas of strength as well as identifying deficits. Using the tool means that
19 support needs can be identified at an early stage and a range of interventions can be put in place
20 before a situation reaches crisis point. However, professionals have reported a lack of knowledge
21 about the existence of such tools and that they are not always readily available (Stewart *et al.*, 2016).
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40 **Development of Relationship Based Practice**

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42 Alongside an appropriate communication strategy, we argue that establishing trusted relationships
43 between professionals and parents with learning disabilities is crucial if best practice is to be achieved.
44 Relationship based practice in social work and social care more generally has long been considered
45 the gold standard in service provision (Trevithick, 2003; Ruch, 2005). The literature provides evidence
46 of the importance of relationship based practice over a longer period of time with recurrent support
47 for parents with learning disabilities to achieve positive outcomes (MacIntyre and Stewart, 2019;
48 Tarleton and Turney 2020; McGaw and Newman, 2005). However, concerns over austerity measures
49 and the impact of political changes such as Brexit have led commentators to consider the challenges
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3 to relationship based practice in the current context (Bryan *et al.*, 2016). The same authors suggested
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5 that austerity measures have brought with them less staff, less time and less resources to provide
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7 support to service users including parents with learning disabilities alongside fewer opportunities for
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9 education and training for staff.
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15 Opportunities for developing effective and trusting relationships with parents can be limited for a
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17 number of reasons including a lack of knowledge of learning disabilities, limited flexibility of provision,
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19 poor information provision and constraints on time. Much of the existing literature (e.g. McGaw and
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21 Newman, 2005; Emerson and Hatton, 2008) identifies the need for parents with learning disabilities
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23 to have ongoing rather than time-limited support to enhance their parenting based on trusting
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25 relationships with professionals. This reflects the complex and multi-faceted problems parents with
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27 learning disabilities face in everyday life such as poverty, poor health, poor housing and complex legal
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29 issues (Cleaver and Nicholson, 2007) alongside any perceived or actual deficits in their parenting. In
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31 addition many parents with learning disabilities will require to hear messages repeatedly and be
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33 prompted on specific actions on a regular basis in order to ensure that their parenting reaches a 'good
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35 enough' standard (MacIntyre and Stewart, 2012). This creates significant challenges for statutory
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37 services such as health and social work who have specific legislative requirements to meet. For
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39 example, timeframes for Child Protection inquiries may restrict opportunities for long-standing
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41 involvement as well as the opportunity to develop trusting relationships. However, this is not to
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43 suggest that good practice with parents with learning disabilities cannot be effectively undertaken
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45 both within statutory and third sector organisations.
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55 A recent study undertaken by the authors with women with learning disabilities who have experienced
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57 domestic violence or childhood sexual abuse (MacIntyre and Stewart, 2019), where the majority of
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59 participants were parents, suggests that collaborative working between health and social care
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3 professionals alongside third sector staff (in this case advocacy staff) is crucial. This approach can
4 support relationship based practice which can contribute to good outcomes for the women both in
5 terms of their parenting and in securing a safer future for themselves with regard to intimate
6 relationships. It was acknowledged, however, that this requires significant time, knowledge of
7 learning disability, flexibility of provision and the willingness and ability to work co-productively with
8 the women to enhance their confidence, self-esteem and participation in their own support. It was
9 further noted, often by practitioners themselves, that they were not always able to practise in this
10 way due to challenges of time, lack of knowledge of learning disability and role constraints. The
11 flexibility and specialist knowledge offered by third sector advocacy staff on the other hand helped to
12 secure the engagement and participation of women and was viewed as unique. The independent
13 nature of the advocacy provision was also highly valued. These findings support those of Tarleton and
14 Turney (2020) who point out the need for ongoing relationship based practice if successful outcomes
15 are to be maintained on a longer term basis.

36 **Conclusion**

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38 In this commentary it is argued that issues surrounding communication and challenges to developing
39 relationship based practice may combine, particularly within statutory services, to limit opportunities
40 for good practice to develop and that consequently opportunities for parents with learning disabilities
41 to assert their right to a family life may be reduced. This is not to suggest an unwillingness on the part
42 of professionals to support parents with learning disabilities to parent. Rather, existing education and
43 training provision, and statutory responsibilities may make this more challenging to be realised. It is
44 hoped that some of the good practice suggested above and in the more detailed guidance cited,
45 alongside additional training for professionals around the needs of parents with learning disabilities,
46 may aid professionals in supporting this group of adults to achieve their wish to have a family life.
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3 Given the expertise resulting from their own experiences, parents with learning disabilities should be
4 involved as partners in the development and delivery of the training that professionals require.
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