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## We must do all we can to support parents with learning disabilities

## AGENDA

Clare Simpson,
Parenting across Scotland

HE good news for first-time parents is the arrival of their baby will change only one thing. Bad news? That one thing is, of course, everything. Their lives will be turned inside out, upside down and, for those first, exhilarating but exhausting months, become a dizzying whirl of new challenges, changed priorities, utter confusion and endless uncertainty. Every parent needs support at times, a bit of advice, a helping hand, some reassurance, a little encouragement. Some need that support more than others, Arguably, parents with learning disabilities need it most of

Estimates, a finger in the air, suggest there are around 5,000 parents with learning disabilities in Scotland, but there are almost certainly many more. When such fundamental data is missing, it is hardly surprising that support for these parents can be so patchy. There is a need for a clearer but more flexible definition of learning disability because, currently, a few IQ points above or below 70 can mean the difference between concerted, consistent support and none at all. These parents face many of the same issues, and challenges as others but the consequences of them failing to meet those challenges can be life-changing. Around 40 per cent of parents with learning disabilities

no longer live with their children, underlining concerns that some are not getting the support they need when they need it. A quick fix, a sudden intervention when a family is already in or facing crisis, will often only postpone another crisis. Continuity founded on early intervention and prevention is key. Get it right for parents with learning disabilities and we will get it right for many, many other parents.

Support services must be planned, designed and built on the fullest possible information. Generally, we need better data and greater consistency in how we identify and record parents with learning disabilities from region to region and service to service. Specifically, for each family, we must carefully assess the ability and potential of parents to care for their child and better respond to their needs and wishes. The support needed by parents and their children may be different and provided in different ways by different teams. They must work together to assess and deliver what is best for the whole family.

Getting it right will need a concerted effort from everyone

involved, from midwives and health visitors to social workers and psychologists. In particular, we must build on the expertise of the third sector. Charities have been providing some of the most innovative, effective support for parents with learning disabilities and have a wealth of experience and expertise.

The children's charity, Aberlour, has been supporting parents with learning disabilities throughout Scotland, and its Girvan project in South Ayrshire reveals the potential benefits. Children have stayed with their parents, families have stayed

intact and are healthier, safer, and achieve more. The value to society is priceless but can also be measured in pounds and pence. A recent evaluation suggests the service, which has so far supported 42 families, is saving taxpayers £1.4million a year.

There are, of course, many difficult questions to be asked and issues to be addressed when assessing a family's needs but, most fundamentally, support teams must decide if parents can care for their child. If so, how can they help them do that? When it comes to parents

with learning disabilities, it seems that too often the first question is given too little serious consideration and the second then becomes irrelevant.

A careful assessment of parenting capacity which is responsive to the needs and wishes of parents is essential. There will always be parents who cannot care for their children and some of them will have learning disabilities. They need longterm support from before their baby is born, in the months after birth and, often, for many years to come. Often they will need particular support at milestones in their child's lives, at times of transition, from baby to toddler, nursery to primary from primary to secondary. They need to know help is there and how to find it - the door must be left open. There must be a number to call and a named person to talk to.

Sometimes, of course, it is not enough and, for their own welfare and protection, children can no



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longer be allowed to live with their parents despite our best possible efforts. However, we can and must do more to ensure our efforts are indeed the best possible. These children deserve it. Their parents deserve it too.

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## We must do all we can to support parents with learning disabilities We must do all we can to support parents with learning disabilities. By Clare

We must do all we can to support parents with learning disabilities. By Clare Simpson, Parenting across Scotland

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Their lives will be turned inside out, upside down and, for those first, exhilarating but exhausting months, become a dizzying whirl of new challenges, changed priorities, utter confusion and endless uncertainty. Every parent needs support at times, a bit of advice, a helping hand, some reassurance, a little encouragement. Some need that support more than others, Arguably, parents with learning disabilities need it most of all. Estimates, a finger in the air, suggest there are around 5,000 parents with learning disabilities in Scotland, but there are almost certainly many more. When such fundamental data is missing, it is hardly surprising that support for these parents can be so patchy. There is a need for a clearer but more flexible definition of learning disability because, currently, a few IQ points above or below 70 can mean the difference between concerted, consistent support and none at all.

These parents face many of the same issues, and challenges as others but the consequences of them failing to meet those challenges can be life-changing. Around 40 per cent of parents with learning disabilities no longer live with their children, underlining concerns that some are not getting the support they need when they need it. A quick fix, a sudden intervention when a family is already in or facing crisis, will often only postpone another crisis. Continuity founded on early intervention and prevention is key. Get it right for parents with learning disabilities and we will get it right for many, many other parents.

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Sometimes, of course, it is not enough and, for their own welfare and protection, children can no longer be allowed to live with their parents despite our best possible efforts. However, we can and must do more to ensure our efforts are indeed the best possible. These children deserve it. Their parents deserve it too.

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