Early Identification Group

Terms of Reference Revised November 2016

This document describes the purpose of this group, its membership, aims, way of working and the outcomes it hope to achieve.

Background

The Early Identification Group was established in 2014, as a result of recognising the importance of identifying families where one or both parents have a learning disability.

It was recognised that this issue of early identification was complex, and concerned a number of different agencies and Scottish Government Departments. An effective response would require the active involvement of a significant number of people with the remit to develop, influence or implement policy at a national level.

On 17th November 2106, a report commissioned on behalf of the Scottish Government was presented by academics from the University of Strathclyde. The report was called '**Supporting Parents with Learning Disabilities in Scotland: Challenges and Opportunities.'**

The report made a number of recommendations which will form the basis of an Implementation Plan. It is proposed that a Task Group oversees the delivery of the Implementation Plan. The membership of the group is similar to that of the Early Identification Group because of its national focus and spread of agencies involved. It is further proposed, therefore, that The Early Identification Group assumes the role of this Task Group. The Group shall be called The Keys to life Parenting Task Group

Purpose and vision

The overall purpose of the Task Group is to oversee the development and delivery of the 'Supporting Parents with Learning Disabilities' report Implementation Plan. It will continue with its original purpose of addressing the issue of identifying at an early stage, parents with learning disabilities that need support to parent effectively. The group aims to influence and improve how this is done, by sharing information, by identifying policy opportunities, and by deciding on collective action.

The vision of the group is that any parent with a learning disability that needs extra support to parent will have this need recognised and addressed at an early stage.

Scope and Objectives

‘Supporting Parents…’ is an independent report commissioned on behalf of the Scottish Government. The Implementation Plan names a range of organisations as having Lead Responsibility for its various recommendations. The group will consider what support and encouragement from the Scottish Government and other members of the Group can ensure that the Plan is delivered as effectively as possible.

What We Want to Do

Many group members have a role in developing or implementing national policy. Some group members have a locality focus e.g. health board, but are doing work in this area that has national significance. The Group will support the delivery of the Plan by:

- Developing the content of the Implementation Plan
- Overseeing the consultation on the Implementation Plan
- Reviewing progress of individual stakeholders
- Identifying support that can be offered to delivery partners by the Scottish Government
- Ensuring that the views of parents with learning disabilities is central to the implementation of the report’s recommendations

The Group will continue to

- Influence mainstream parenting/family/Early Years policy that explicitly or implicitly addresses the requirements of families with parental learning disability, through consultations etc.
- Share information about policy developments, policy implementation, events, initiatives that will benefit the Working Together With Parents Network
- Influence the development of good practice, resources etc., with a view to national promotion/rollout
- Identify gaps in good practice, resources etc., with a view to addressing these gaps
- Facilitate communication between Scottish Government departments and Health and Social Care Partnerships

Membership

The Group will be chaired by Clare Simpson, Director of Parenting Across Scotland.

The membership of the group should reflect the wide range of professions and agencies whose work includes the support of families where parents have a learning disability. Current membership includes representation from:

- NHS Health Scotland
- NHS Education for Scotland (NES)
- Royal College of Midwives
- Social Work Scotland - Adult Learning Disability Social Work
- Social Work Scotland – Children and Families
- Parents (People First Scotland)
- The voluntary sector
- Children and Families Directorate, Scottish Government
- Chief Nursing Officer’s Directorate, Scottish Government
- Care, Support and Rights Division, Scottish Government
- GIRFEC Team, Scottish Government
- Early Years, Policy Delivery Unit, Scottish Government
- COSLA

It is anticipated that the membership will need to be increased, including representation from

- Health and Social care Integration Directorate, Scottish Government
- Integration Joint Boards/Health and Social Care Partnerships

And from other organisations deemed useful for achieving the aims of the Group.

Future Meetings

Future meetings will be held quarterly at least until the end of 2017.

Report Recommendations

Prevalence

1. There is a need to establish more accurate prevalence rates of parents with learning disability currently living in Scotland to allow for more effective service planning and delivery. This process may include consideration of standardised coding and reporting across the key stakeholders.

2. A better understanding of the different definitions of learning disability in use is needed in order to gain a clearer sense of the population in question. Targeting identification of those individuals most at risk of receiving little or inadequate support (likely to have an IQ of just above 70) is required. This would help to ensure that a model of crisis intervention is avoided, allowing for intervention at an earlier stage.

Support provision

3. A clear, evidence-based pre and post-natal care pathway, which can measure impact and improvement and has been tested by parents should be established. This will minimise the current complex, geographically variable and ad hoc provision that is available.

4. Longer-term, parent centred support that is reflective of individual child development milestones should be developed. This support is likely to be intensive at times, particularly at points of transition, for example during the transition from baby to toddler when a range of new parenting skills and support requirements will be necessary. The current lack of effective long term postnatal support has the potential to undermine the good practice that has been established prenatally and in the early days following the birth of the child.

5. This support should take a whole family approach that focuses on the needs of both the parent and the child. This support must take account of the broader structural and social factors that impact on a person's ability to parent effectively.

6. The best way to structure and organise whole family support is via the creation of jointly funded multi-disciplinary teams involving social workers, community learning disability nurses, nursery nurses, health visitors, midwives, psychologists and occupational therapists. The teams should work in partnership with experienced third sector providers. Such an approach would help to prevent families affected by parental learning disability from falling between the gaps in service provision and should promote better use of early intervention strategies . Existing models of jointly funded support for families should be explored and lessons for good practice identified and disseminated.

7. It is essential to build on the knowledge and expertise that has been established in this area, particularly by third sector organisations. While it is recognised that parents with learning disabilities should be supported to access mainstream services where appropriate, their very specific support needs as well as the value

of working together with parents who are experiencing similar issues must be acknowledged and specific targeted interventions developed.

8. A clear, adequately funded accessible information strategy should be put in place to help better meet the information needs of parents with learning disabilities. This strategy should acknowledge the excellent work that has been carried out by individual practitioners and organisations to translate information but should also recognise the piecemeal way in which this work has developed. The strategy should have a governance framework and utilise evidence based materials, where available.

Awareness raising

9. Greater awareness of the very specific support needs that parents with learning disabilities have is required. This includes the need for specialist tools to assess parenting capacity, accessible information, flexibility, repetition and the modelling of good practice. The good practice identified in this report should be disseminated widely.

10. Specialist training on the needs of parents with learning disabilities and their families should be provided to frontline practitioners, many of whom have limited experience of working with this group. This training should be offered as part of qualifying programmes for social workers, midwives and health visitors but should also be offered as CPD for those professionals wishing to develop additional specialist knowledge.

Further research

11. Further research is required to establish long term outcomes for families affected by parental learning disability. However careful consideration and discussion of the outcomes to be measured will be required beforehand to ensure that indicators of successful are reasonable and realistic.

12. Additional research is required to elicit the views of parents with learning disabilities about the factors that promote or hinder their ability to parent at a national level.