



APPENDIX 3

COSMOS (COMMUNITY OF SEND MOTHERS OBTAINING SOLUTIONS) – Terms of Reference and Aims and Objectives

At the last meeting of this board in December, 2024 a public statement was made by the Community, Voluntary and Faith Reference Group (CVF-RG) on behalf of the Community of SEND Mothers Obtaining Solutions (COSMOS). The board welcomed the formation of COSMOS and it was agreed that “the Health and Wellbeing Board would look at the Terms of Reference and Aims and Objectives of COSMOS and advise on which meeting any future report should come to”.

This appendix relates to the formation, growth and development of COSMOS in providing a structure working in partnership with all service providers, for an improved and more effective delivery of SEND services to Wirral’s families.

The principal aim of COSMOS is to give a structured involvement and voice to mothers (and fathers) with children diagnosed with SEND to enable the many challenges facing those children and their parents to be addressed more effectively through strong local partnerships with service providers.

COSMOS seeks the full support of the Health and Wellbeing Board in supporting its principal aim which is “to work in full partnership with all relevant service providers to improve the delivery of SEND services to ensure all SEND parents receive help and support in a timely manner”.

BACKGROUND INFORMATION

In June 2024 a SEND mother expressed the frustration with the current service provision with the following words: -

“It’s the point you become a Care Co-ordinator instead of a mum to your child. It’s hard enough dealing with the anxiety of looking after a child who needs more support, the walking on eggshells at times because you know there’s anxiety in your kid of unmet need and then the million and one phone calls you need to make to get anywhere.

And then none of the professionals you’re doing the job of and co-ordinating, actually pick up the phone. And every email, letter, call or meeting is bad news because of the barriers to ensuring SEND children have what they need. And because they don’t talk to each other no one knows what the unmet needs are.

Nothing is transparent and simple to understand.

SEND provision feels like people tap you on the shoulder and say it's going to be ok, we have provision but there's the door, go out of it and don't expect us to fund the provision needed"

Further to this and following regular meetings with mothers of SEND children, Community Voice, CVF Reference Group and the Director of Children's Services action was taken to establish and structure COSMOS (Wirral).

Since July 2024 COSMOS has been active in setting up a committee, run by SEND mothers and has agreed a set of aims and objectives, terms of reference, a logo and established a website.

Many councils have realised that the inadequacies in the provision of SEND services need to be addressed through the full engagement with communities and residents and more specifically with the SEND community.

COSMOS (Wirral) has met with local MP's and they wish to be fully supportive of this initiative.

SUPPORTING INFORMATION

COSMOS (Wirral), as much as is possible, aims to work in partnership with all service providers by creating a structure which provides ready access to an improved and refreshed system for meeting the needs of parents and carers with SEND challenges.

COSMOS (Wirral), in achieving this aim, is working to establish Cosmos Local organisations in communities across the Wirral peninsula.

In principle and recognising the importance of the Family Hubs when working in partnership, the COSMOS Locals will be prominent and readily available to parents and carers, within each community for when advice and guidance is needed.

Key components in the establishment of the organisation COSMOS, Community of SEND Mothers Obtaining Solutions, was agreed in September 2024.

AIMS AND OBJECTIVES

The principal aim is to give a structured voice to mothers (and fathers/carers) with Children with SEND, on pathways to diagnosis or with suspected SEND to enable, the many challenges facing those children and their parents to be addressed more effectively through strong local partnerships with service providers.

To establish the structured voice ('the voice') will require the development of local infrastructure on a community-by-community basis and/or through the 'coming together' of SEND families with children of similar SEND characteristics.

To fully utilise 'the voice' will require the establishment of a broadly representative COSMOS organisation for Wirral to whom the role of developing and sustaining partnership working will be assigned.

To establish a fully operational COSMOS model, that in time is a stand-alone organisation, will require the formation of a temporary COSMOS organisation to work in partnership with communities and service providers, The aim would be to achieve this position by the end of July 2025 or earlier.

In its final form it is envisaged that local COSMOS organisations linked to a central COSMOS (Wirral), will be able to fully engage with service provision and their Elected Members as they work together in the interests of SEND children

COSMOS Local will have the responsibility in establishing best practices in discussions with their Elected Members, service providers and knowledge provided by practitioners across the UK.

COSMOS (Wirral) will work within its principal goals, to liaise and work with parents/carers to enable voices to be heard by the local authority and SEND providers on the Wirral. The primary goal to establish improvement within SEND provision on the Wirral. It will not act as representatives for individual SEND cases and will provide information to individual parents/carers of where advocacy, mediation, representation can be found.

Best practice systems further adapted to the COSMOS (Wirral) model, on an area-by-area basis should, should be encouraged within the framework above as it is clear there is 'no one size that fits all'.

TERMS OF REFERENCE

- Each local COSMOS should meet at a frequency appropriate to their specific circumstances but not less than six times per annum. The meeting frequency should be dictated by the needs of the SEND children. Meetings once per month are recommended.
- Each local COSMOS should elect a Chairperson, a Secretary and a Treasurer. The meetings should be open to all parents with SEND children.
- COSMOS (Wirral) should elect a Chairperson and a Secretary through a process in which all SEND parents can participate. The current status of COSMOS (Wirral) is it is completely voluntary with no desire or need to work with financial remits, so no treasurer is needed under its current structure.
- Up to nine ordinary members may also be appointed to COSMOS (Wirral) core group made up of SEND parents, representation from the Community Voice brokerage and key partners.
- Officers and members of COSMOS (Wirral) will serve for two years. Further service will need to be agreed.
- COSMOS (Wirral) must meet at a frequency of at least once per month with provision for additional meetings, when necessary.
- COSMOS (Wirral) is responsible for arranging regular and irregular meetings to work in partnership with all Service Providers, when appropriate.
- Both COSMOS (Wirral) and Cosmos Locals **must** keep full records of activities, outcomes, progress and plans.