

Phil Harding,
Parent Representative for the Autism Strategy
and Steering Group for Cardiff and the Vale,
Parents Participation Group (Additional Needs),
c/o Cardiff and Vale Parents Federation,
435 Cowbridge Road East,
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21st May 2014

To Elected Politicians and LA Officers,

Hello,

I hope all is well with you in your busy schedules and demanding roles.

My name is Phil Harding and as part of my activities to help children and adults with Learning Disabilities (LD), I am a member of a number of groups within the Cardiff and Vale area, including the Cardiff and Vale Parents Federation and the Autism Strategy Steering Group for Cardiff and the Vale. Another group that I contribute to is the Parents Participation Group (PPG) (Additional Needs) and I have volunteered to write to you on behalf of the members of that Group.

The PPG is a group that, under the umbrella of the Cardiff Parents Network, has been set up with the assistance of funding initially from Cymorth, followed by a reduced grant for 2013/14 from Families First, and has been facilitated by Action for Children and supported by Rachel Kelly.

The PPG (Additional Needs) seeks to support children with LD and other disabilities, as well as their families and carers. Via myself and Corrina Raessi, it feeds into the agenda of the **Autism Strategy Steering Group for Cardiff and the Vale**; and in turn we report back to the PPG on the issues of interest.

But the group also links into:

- the **Disabled Children and Young People's Workstream** via its representatives Jane Bailey and Bina Khan – with the recent upheavals concerning Children's Services I would have thought that the Local Authorities can ill afford to lose the depth of experience and knowledge that our parents have already supplied to help originally design the Disabled Children and Young People's Strategy.
- The **Children's Hearing Impairment Working Group (CHISWG)**. 2 parents from the PPG, who also work full time, have contributed to this working group for more than 2 years.
- **Grandparents Raising Grandchildren (GRG)**

The funding for the Cardiff Parents Network ended as of 31st March 2014, and the PPG now finds itself without administrative support and facilitation.

The Group members wrote to Families First in November. 2012 when they first heard of the proposal to cease funding and I enclose some excerpts from that letter, which eloquently sum up the strength of feeling:

“Our Network feeds into all of the seven strategic outcomes in the “What Matters” strategy. You have a ready-made forum for asking these questions - why would you want to destroy it? Groups like Cardiff Parent Network take a long time to build and cannot just be discarded and assumed to restart as and when. You need to build confidence, knowledge, trust and friendship for these groups to be effective. Groups like us cannot be turned on and off like taps.

As well as all of that, we benefit personally from the group in many ways. The grandparents amongst us wanted particularly to say how valuable the group has been to them, and that they wish it had been available when they were younger. All of our members have had opportunities to attend training courses and develop skills that have made us more effective at providing our input.

Without the support of paid staff individual members of our network will remain isolated, in the dark, impossible to find and coordinate - and simply unable to provide you with the input that you say you need.”

It is perhaps useful to point out that we hear so much about “co-production” these days - involving service users in the design of services - but it seems to be increasingly difficult to find anyone interested in making that happen. It seems such a pity to us all that an established group that was proving its worth in so many areas is under threat due to lack of support. The authorities need to understand that many of the parents involved face a hugely challenging juggling act of trying to plug the increasingly large gaps in public provision whilst holding down jobs etc.

We are still hoping for support from groups such as the Autism Strategy Steering Group for Cardiff and the Vale, and Local Health Boards. In principle the Autism Strategy Steering Group want to support the PPG but their resources are intended for people on the autistic spectrum and there is a tension between that aspiration and the wider remit of the PPG, so support from other areas will be needed.

But we wanted to bring to your attention the dire predicament that groups such as the Cardiff Parents Network and the PPG find themselves in when funding for support and facilitation disappear; and the gaping wound that it leaves with committed parents and carers when they see all their hard work and commitment appear to be cast aside as of no value.

Your consideration and good offices would be most welcome and we look forward to your response.

Yours sincerely,

Members of the Parents Participation Group (Additional Needs)

Phil Harding
Corrina Raessi
Sue Hurrell
Jane Bailey
Bina Khan
Hayley Norris