

# Ballymena Disability Engagement Event



Presented by: Moira Walsh  
Ballymena Locality Chair  
Ballymena SureStart

# Background

- Exit Questionnaire with a group of parents who had attended the Ballymena SureStart Little Acorns support for parents who have a child with a disability aged 0-4 years.
- Services for Parents / Child with a disability is included in the Ballymena Locality Action Plan. Feedback from the Questionnaires highlighted the extent of the need.
- Subgroup formed to plan for wider consultation with parents.
- Funding secured for a Disability engagement event to provide parents with the opportunity to have their voice heard regarding the needs of their child.

# Introduction

- Disability engagement event held on Thursday 20<sup>th</sup> June 2014 in Leighmohr hotel Ballymena.
- **Purpose to identify:**
  - Needs of the child / family at different stages?
  - What would have helped at these times?
- Consultation with 29 parents who had a child with a disability / additional needs.



# Disability Event – Programme

- Disability event involved;
  - Presentation 'A Parents Story' a child with autism
  - Celebration, display of children's art work from Little Acorns crèche and Castle Tower school
  - Castle Tower choir
  - Disability Timeline
  - Focus group discussions



# Celebration of Children

Artwork from Castle  
Tower pupils and Little  
Acorns SureStart crèche



Castle Tower Choir



# Disability Timeline

1. Identification of need
2. Diagnosis
- 3 Pre school Years
- 4 Primary Years
- 5 Post Primary Years
- 6 Preparation for Adulthood



# Focus Group Discussions



Parents engaging in focus group discussion



# Feedback from Disability Timeline

Disability Timeline	Need of Child / Family	What would have helped?
<b>Identification of Need</b>	<p>‘feeling lonely, isolated, despair, scared, fear, terrified’</p> <p>‘worrying - no diagnosis’</p> <p>‘no one to talk to’</p>	<p>‘someone to listen and understand my concerns’</p> <p>‘respite’</p> <p>‘not having to go to lots of clinics and repeat everything’</p>
<b>Diagnosis</b>	<p>‘people don’t how to react, avoided contact, ‘crossed to the other side of the street’</p> <p>‘fear of the unknown’</p> <p>‘what’s the future going to hold’</p> <p>‘More support on what the diagnosis means – still don’t fully understand it’</p> <p>‘lots of appointments’</p>	<p>‘face to face interview not a leaflet with no explanation’</p> <p>‘Understanding from Professionals who take eon the job of supporting families’</p> <p>‘parent support group’</p> <p>‘having a keyworker to explain things’</p>

# Feedback from Disability Timeline

Disability Timeline	Need of Child / Family	What would have helped?
<b>Pre-school Years</b>	<p><i>'no diagnosis – no support'</i></p> <p><i>'someone to speak to about my worries'</i></p> <p><i>'not to be judged on parenting skills'</i></p> <p><i>'need support as when your child is in nappies they don't get into nursery'</i></p> <p><i>'we had no support in early stages and do not what is out there for us'</i></p> <p><i>'a service that can actually help and don't disappear because of funding'</i></p> <p><i>'to get respite for yourself and to recharge your batteries for child and parents benefit'</i></p> <p><i>'to have contact with other parents who understand and can support you'</i></p> <p><i>'probably the most difficult time deciding on what school etc lots of tears'</i></p>	<p><i>'more information and support'</i></p> <p><i>'specialist health visitors that understand the disability / additional need'</i></p> <p><i>'advice on how to deal with certain behaviours'</i></p> <p><i>'I really struggled at home to the point of taking a mental health breakdown. If I had the support I was asking for it would not have got to this'</i></p> <p><i>'respite'</i></p> <p><i>'a special needs parents group that is inclusive despite the disability / additional need'</i></p> <p><i>'list of what local service are available'</i></p> <p><i>'getting a statement sooner'</i></p> <p><i>'</i></p>

# Feedback from Disability Timeline

Disability Timeline	Need of Child / Family	What would have helped?
<b>Primary Years</b>	<p><i>'need information about services available for families and children with additional needs'</i></p> <p><i>'social opportunities for children'</i></p> <p><i>'need support, someone to listen, to care,</i></p> <p><i>talk to someone who is in the same situation as us'</i></p>	<p><i>'support group for parents with older children'</i></p> <p><i>"social opportunities for children with disabilities and additional needs"</i></p> <p><i>'professionals to listen to what parents are saying their child's needs are'</i></p> <p><i>'All to realise the pressures that families are under'</i></p>
<b>Post Primary Years</b>	<p><i>'post 16 what happens next'</i></p> <p><i>'need a better structure for 16 plus and moving on'</i></p> <p><i>'preparation for moving on to life skills like making tea, showering etc'</i></p> <p><i>'issues around puberty / dealing with menstruation'</i></p>	<p><i>'ASD support'</i></p> <p><i>'help to explain puberty to children'</i></p> <p><i>'children with a disability no special support if they have a mental illness'</i></p> <p><i>'social outlets to take my child other than school has my child has nowhere to go to socialise'</i></p>

# Feedback from Disability Timeline

Disability Timeline	Need of Child / Family	What would have helped?
<b>Adulthood</b>	<p>'at 18 the children and families are left on their own with no back up support'</p> <p><i>'children need to be supported up to the aged of 21. They are aged 16 but mentally and physically they are 10'</i></p> <p><i>'children don't have the basic life skills to manage themselves, like getting a bus, making lunch etc. Children need supported up to age 21 years'</i></p> <p>'what happens at 18'</p> <p>'waiting on a time bomb'</p> <p>'worry about what the future will hold'</p> <p>'still have other children to think about in the family'</p>	

# Feedback from focus group discussions

- **Impact on family dynamics**

Parents discussed the challenges of trying to meet all their children's needs, the difficulties of family outings and the financial struggles;

*'difficult managing all children needs'*

*'financial issues, giving up work especially mothers down one wage'*

*'marriage changes'*

*'women blame themselves / feel guilty'*

*'men don't want to talk about it'*

*'personally took husband a long time to realise that anything was wrong'*

*'dad thinks he can fix them'*

One parent commented that family dynamics had changed in a positive way

*'our lives are richer and fuller – more tolerant'*



# Feedback from focus groups continued...

## ■ Impact on siblings

Parents discussed the impact on siblings

*'siblings feel like you love the other child more, they don't understand that they just have greater needs and need me more'*

*'other children feel left out and can lead to more arguments and fighting'*

*'never get the chance to spend quality time with the other children'*

*'brothers and sisters are aware of others staring at their siblings, especially when older'*

*'siblings don't understand the disability and what it means'*

*'siblings become good advocates for their brothers and sisters'*

Recommendation from parent;

*'an outsider (professional) explaining something to your child means more'*



# Recommendations

- More widespread Pan-Disability, Parent support groups – mindful of rural areas.
- Specialist health visitors in disabilities / additional needs.
- Consistency of care by health professionals.
- Local social outlets for children with a disability / additional need.
- Up to date directory of local services that are available to help them with their child and their additional needs.



# Questions



# Further Information

For further information on the Disability Engagement , contact:

- **Moir Walsh**  
Ballymena Locality Planning Group Chair
- **Sandra Anderson**  
Participation Development Officer for CYPSP

