

# "OUR JOURNEY THROUGH DISABILITY"

Newry Locality Planning Group

## REPORT

27/03/2019

Mourne Country Hotel,  
Newry





*All families should expect respect, to be listened to, to have regular and clear communication, valued as an integral part of the process.*



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# ACKNOWLEDGEMENTS

**We would like to thank the following for their time, efforts and sharing their expertise and stories to Our Journey Through Disability.**

## **MEMBERS OF THE PLANNING GROUP:**

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### **Parents & Carers**

Ashling Fitzmaurice  
Jim McDonnell  
Laura Kenny  
Martina McMahan  
Pauline McQuillan  
Peter Connolly  
Sheila Treacy  
Sinead Madigan

### **Staff**

Anne Marie Fegan (Clanrye Group)  
Blaine McCartney (SHSCT)  
Ciara Turley (SHSCT)  
Gael Bailie (SHSCT)  
Kerri Morrow (NMANDDDC)  
Lizzy Smith (Magnet YAC)  
Morgan Brannigan (SHSCT)  
Sinead Wadforth (Early Years Newry)

## **PARENTS WHOSE STORIES WERE RECORDED ON VIDEO:**

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Ashling Fitzmaurice  
Emma Hayes  
Martina McMahan  
John McCaul

Pauline McQuillan  
Jim McDonnell  
Sheila Treacy  
Sinead Madigan

### **Speakers on the day:**

Ashling Fitzmaurice (Parent), Jacinta Linden (SPACE/Chair Newry LPG), Paul Morgan (SHSCT Director of Children & Young People's Services), Cllr Mark Murnin (NMANDDDC)

### **Video contributors on the day:**

Kieran McShane (HSCB), June Wilkinson (Dept of Education NI)

Roger Gowdy (CiNI) for recording and editing our parents' videos

Joanne Patterson (CYPSP) for Admin support

Valerie Maxwell, Michael Hill, Yvonne Neill from CYPSP and Seaneen O'Donnell (HSCB) for admin support on the day

Newry Early Years for providing meeting a meeting place for the Planning Group

Facilitators and Scribes for the Group discussions for the event

Information stall holders for the Market Place session

*(Terminology: we have used the term Children to include children, young people and young adults, also recognising that when we use the term "with a disability", we include the term and/or additional needs. This was agreed by the Planning Group.)*

# EXECUTIVE SUMMARY

**On Wednesday 27<sup>th</sup> March 2019, Our Journey Through Disability took place at the Mourne Country Hotel, Newry.** In total 170 people attended: 64 parents/carers, 62 representatives of the voluntary and community sectors, with 44 from the statutory sector organisations.



**170 people**

**64** parents/carers

**62** representatives of the voluntary and community sectors

**44** from the statutory sector organisations

## The aims of the day were as follows:

- ✓ To inform parents of services available in the local area to help reduce their feeling of isolation
- ✓ To share video stories of their family journeys through local services
- ✓ To engage with service representatives and other parents to identify barriers and possible solutions to improve outcomes for children and young people with a disability, and
- ✓ To promote the importance of self-care for parents and carers.



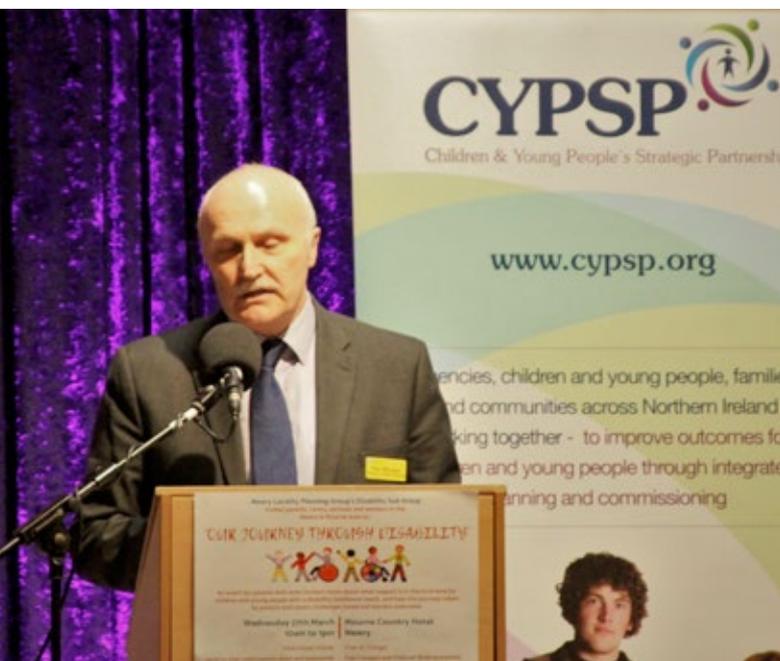
The word "Parents" refers to parents and carers of children/young people with a disability and/or additional needs.

Participants came together to discuss barriers and possible solutions faced by families of children with a disability with regards to all services affecting them. At the end of the day each table agreed on one statement saying what families should expect from services. These were as follows:

## "All families should expect..."

- » A named point of contact who signposts, clarifies, reassures in a supportive way, community based.
- » A one stop-shop for support. This may be through your social worker or key point of contact to support you and signpost you onwards.
- » A consistency of services, honesty about resources and to be listened to the very first time.
- » Expect respect, listen to what is being told, not have to fight for professionals to communicate on their behalf and with each other – cross departmental. Also more focus on self-care for parents/guardians.
- » To need to feel that they are being listened to and heard and action taken on what we say for our children.
- » To be listened to before a crisis occurs. A continuation of service. Better multi-disciplinary communication.
- » Circulate use of services to attendees.
- » Consistency, knowledge, coordination filling the gaps, respect/feeling believed/acknowledged, access to counsellor (family as a whole).
- » Support and updated information individual to each young person & family.
- » Knowledge about how to access the different services & refreshed and updated info, one point of contact to sign post to other services.
- » One point of contact to allow families to know what they have a right to e.g.an assessment, social worker and support (financial, emotional, physical).





Paul Morgan: Director of Children and Young People's Services, SHSCT and Chair of CYPSP's Southern Area Outcomes Group

- » Greater accurate communication & the use of PPI & co-production for carers/service users to participate in service developments. Families know what individuals need and creating centred & holistic pathways.
- » Respect, to be listened to, to have regular and clear communication, valued as an integral part of the process.
- » One point of contact, professionals should have all of the information; parents seem to be the experts on their own child's needs. Should be listened to and heard when they know there is an issue with their own child.
- » Effective listening, clear communication between professionals, clear direction and one point of contact. There should be transparency from all professionals and services.
- » A key point of contact to access key services to get the right information for their changing needs of their child and be listened to".

## Final recommendations

1. Professionals must realise parents are experts and **take responsibility to listen** to them closely. This demonstrates their commitment to value parents' knowledge.
2. Parents support a **person-led approach** where services place an individual and their family in the centre, assess need and build services around the family accordingly.
3. The Group recommends a **legislative change** regarding the process for transitioning to adult services. This should be on the basis of development rather than chronological age. Transition planning between children and adult services should commence at least 5 years before it occurs. The role of a key worker is of vital importance and families need more support initially at the start of their journey.
4. Health and education services need a more **joined-up approach** in terms of statementing, therapies and transitioning. This includes effective communication across Allied Health Professionals a recognition from services of the medical, social and educational models.
5. Families require a **single point of contact** from an early stage of diagnosis of disability for their child. This role should co-ordinate the process of services for families to inform and signpost to services and local support.
6. Information should be available for families through an **A-Z of services** online and packs which provide support services for families on a local level. Packs should also include information on a child's diagnosis.
7. Families require good communication. Whether formal diagnosis of disability or undiagnosed additional need, parents would like **information on what they should expect from services** and a timeline where appropriate.

8. **Better communication across services** is required to share information, saving families from giving the same information on a regular basis, and to avoid appointments occurring on the same day in different locations. This should serve as a Passport which is recognised among relevant services.
9. Support from key agencies is required **to bring parents, families and services together** through events such as Our Journey to provide the opportunity to share knowledge, experiences and support with others who have begun their journey. Services should endeavour to create opportunities to embed this into their practice and support this process.
10. Opportunities are needed to **build capacity with parents** through training opportunities and sessions to help complete forms which require specialist information such as PIP and DLA.
11. It is important for ALL children of all abilities to have **access** to a social group: **inclusion** with youth groups and similar organisations/ activities to build and maintain friendships and promote socialisation. These may be specific to disability/additional needs or universal and should cut across all sectors. Specialist equipment and support should be provided to ensure this.
12. **Out of Hours services and support including Short Breaks need to be increased:** these provide vital support to families who require support outside of office hours
13. All relevant professionals should be eligible to attend **CDC Clinics**, and parents should also have appropriate and effective representation at **MDT meetings**.
14. **Parents and siblings need time for self-care.** This is vital and should be supported in order to care for their child/siblings and themselves. Services should provide opportunities and resources for self-care through information and signposting.
15. Parents who had their journey recorded for videos which were used on the day have consented to having them used constructively to benefit families and improve their experiences with services. The event Planning Group has recommended that the **videos are used to help with induction of new staff and for students** in disciplines such as Social Work and Nursing.
16. There is a need to **train staff on daily issues** facing parents on navigating services, and to encourage better communication with other services.
17. Parents recommend a **better understanding of the issues** surrounding disability and additional needs: initiatives such as the JAM card should be supported and rolled out, as well as awareness raising on conditions across services and communities.
18. Members of the Planning Group have expressed an interest in **participating in training programmes** for staff in relevant services in order to relay their experiences in order to support the building skills and knowledge of staff.
19. Members of the Planning Group have agreed that **Co-Production as a process and ethos works well when done correctly**, and that services need to further embed Co-Production with families on a strategic and individual level.





# CYPSP: CHILDREN & YOUNG PEOPLE'S STRATEGIC PARTNERSHIP

**The Children (NI) Order 1995 provides the legislative base for cooperation and collaboration in the assessment of need and planning services for children on an inter-agency basis.**

The Health and Social Care Board (HSCB) has a statutory duty for Children's Services Planning which leads the integrated planning to coordinate integrated planning and commissioning to support outcomes based planning for children, young people and families through the Northern Ireland wide Children and Young People's Strategic Partnership (CYPSP). This duty is established by The Children (1995 Order) (Amendment) (Children's Services Planning) Order 1998

The Children and Young People's Strategic Partnership (CYPSP) was formed in 2011, it is a multiagency partnership which focuses on improving outcomes for children and young people and families (For further information about the CYPSP visit [www.cypsp.hscni.net](http://www.cypsp.hscni.net).)

**The purpose of the CYPSP is:**

- ✓ To put in place integrated planning and commissioning across agencies and sectors, through the Children and Young People's Plan, aimed at improving wellbeing and the realisation of rights of children in Northern Ireland, in relation to the 8 outcomes as set out in the draft Northern Ireland Executive Children and Young People's Strategy 2017-2027
- ✓ To ensure that the CYPSP will be informed by and inform individual organisational business, corporate and community plans
- ✓ To ensure the participation and involvement of children, young people, families and communities in the integrated planning process
- ✓ To ensure an effective and efficient, fully mandated structure which is representative of all key stakeholders is in place to carry out the work of the partnership.

# SOUTHERN OUTCOMES GROUP

**Outcomes Groups are a partnership of senior leaders across all sectors within each of the 5 HSCT areas of Northern Ireland.** The Southern HSCT area is represented by the Southern Outcomes Group and is chaired by the Director of Children Services. The focus is on Early Intervention, building preventative places and Improving outcomes for children and young people. The Southern Outcomes Group Reports to the CYPSP and is closely connected to 'Regional Task and Finish' groups as well as receiving regular reports from Locality Planning Groups and Family Support Hubs.



Outcomes Groups share information, knowledge and expertise about the Outcomes Group area, as well as identifying and removing barriers to more effective collaboration and partnership working, identifying opportunities to share budgets and make connections with other planning processes for children and young people.

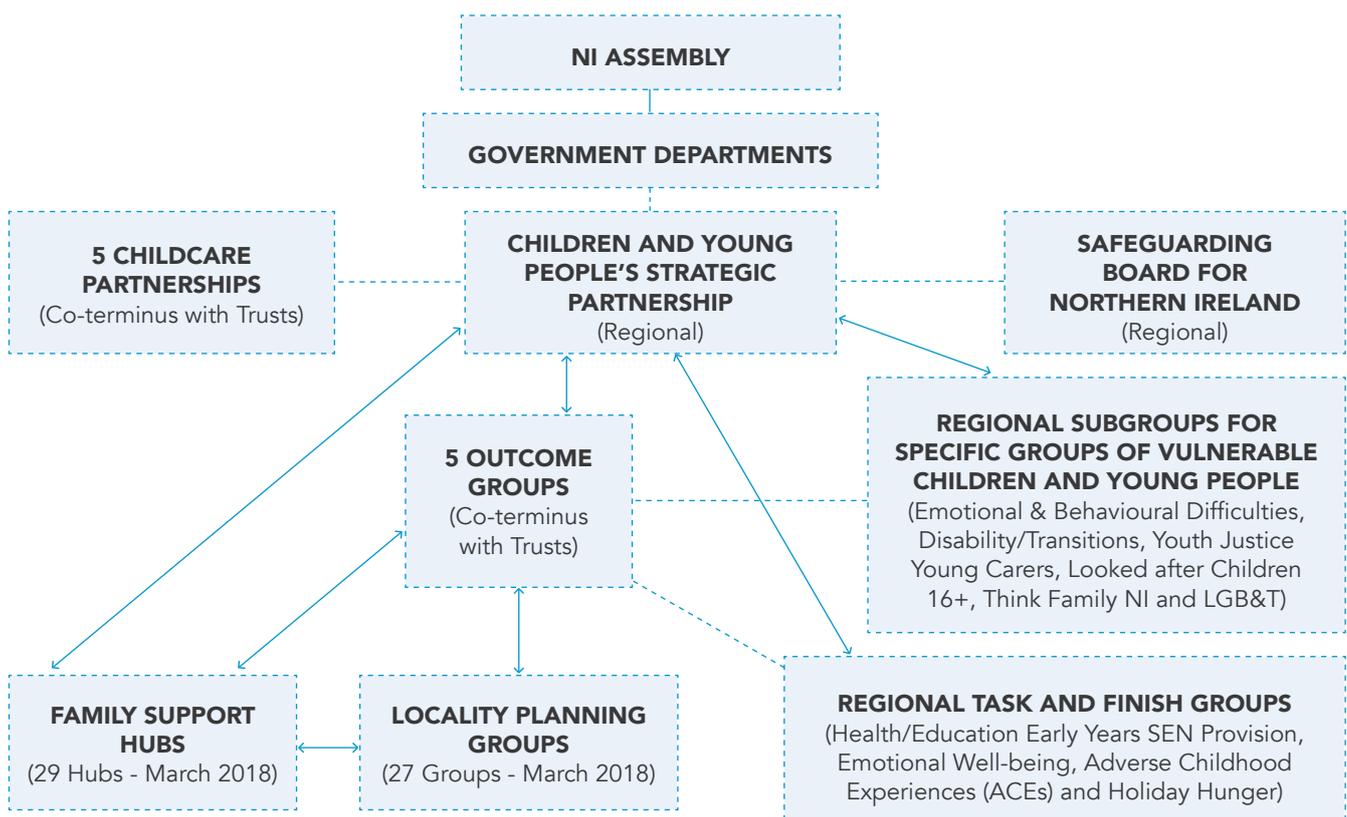
### Outcome Groups:

- Belfast
- Northern
- Southern
- South Eastern
- Western



(For further information about the Southern Outcomes Group visit <http://www.cypsp.hscni.net/outcomes-groups/southern-outcomes-group/>)

## CYPSP Structure:



# LPG'S – LOCALITY PLANNING GROUPS



*Locality Planning is about understanding community assets and strengths and ensuring that service delivery organisations seek to support those assets/strengths.*

**Locality Planning is part of the CYPSP focus on developing and supporting multi-agency early intervention approaches. Its aim is to improving outcomes for children, young people and families at a local level.**

Locality Planning focusses on how service delivery organisations can engage more effectively with the community to better understand local issues and to work together to produce more effective responses to those issues.

Locality Planning is about understanding community assets and strengths and ensuring that service delivery organisations seek to support those assets/strengths. It does this by:

- » Developing shared information, knowledge base and expertise about the local area
- » Identifying opportunities to improve outcomes for children and young people by working better together
- » Building a commitment to early intervention
- » Building an effective partnership

The Locality Planning Groups report to the Southern Outcomes Group who meet bi-monthly.

In the Southern Area, we have 6 Locality Planning Groups: Armagh, Banbridge, Craigavon, Dungannon, Newry and South Armagh. These groups meet bi-monthly and report back on their individual Action Plans, share relevant local information on their own services and other activities in the area, identify Emerging Needs on local issues to escalate to the Southern Outcomes Group, and receive regular updates on the 3 Family Support Hubs in the Southern Area.

- 1 Armagh
- 2 Banbridge
- 3 Craigavon
- 4 Dungannon
- 5 Newry
- 6 South Armagh



# NEWRY LOCALITY PLANNING GROUP

**Newry LPG was established in 2016.** Membership of the group includes a range of community, statutory and voluntary organisations with a remit for children and young people in the area. The group aims to improve the well-being of children and young people through a multiagency planning approach.

## Membership of Newry LPG includes the following:

Action for Children	Advocacy VSV	Ascert	CAWT MACE Programme
Centred Soul	Changing Lives Initiative & facilitated discussions	Clanrye Group	Confederation of Community Groups
EANI FLARE Project	EANI Youth Service	Early Years Toybox	Home Start Newry
i-Recovery	Magnet Young Adult's Centre	Newry Early Years	Newry Gateway Club
Newry Mourne & Down District Council DEA	NMDDC Health inequalities	NMDDC PCSP	Newry Therapy Centre
NIACRO	NIHE	Parent Action	PIPS Hope & Support
SHSCT Children With Disabilities Team	SHSCT Promoting Wellbeing	Silvery Light Sailing	SPACE
Start 360	St John Bosco Youth Centre	The Changing Lives Initiative	Women's Aid Armagh Down
Youth Action NI	Youth Justice Agency		





*Parents/carers should be an integral part of the process through the planning and attendance.*

# NEWRY LPG DISABILITY SUB GROUP

**Newry LPG has an Action Plan for 2018-21 which is based on evidence through the CYPSP mapping system and local evidence from member organisations and other relevant information.** One of the top priorities for the Newry LPG is to improve outcomes for children and young people with a disability, which falls under the heading of Family Support

A Disability Sub-Group was established in January 2018 to plan for an event which would bring together services and organisations working in the locality area for children and young people with a disability and/or additional needs. The aims of the day were to gain a fuller understanding of issues for those working with children and young people with a disability through networking and sharing good practice, and to undertake an Outcomes Based Approach process to identify actions for the Newry LPG Disability Sub Group to take forward.

## Disability Inclusion Workshop

1. Speed Networking Event
2. Key Speakers sharing good practice:
  - Ruth Purdy, SHSCT Transitions Team
  - Ciara Lowe, N MandDD Council Disability Liaison & Sports Development
  - Conor Keenan, Confederation of Community Groups
3. Introduction to Outcomes Based Accountability (OBA) by Nicola Doran, SAIL
4. Facilitated session on Action Planning using the OBA "Turning the Curve" exercise

As a result of this workshop, one of the key actions agreed was to organise and facilitate an event in order to support families of children/young people with a disability and/or additional needs. It was agreed that parents/carers should be an integral part of the process through the planning and attendance.

# "OUR JOURNEY THROUGH DISABILITY"



# A Co-Production Approach

**Due to agreement at the Disability Inclusion Workshop that an event should be organised to support families of children/young people with a disability and/or additional needs, it was agreed at the review of the event that a Co-Production approach would be the most effective way to achieve positive outcomes.**

The Planning Group of the Newry LPG Disability Sub-Group at this stage included representatives from the Southern Health & Social Care Trust (Promoting Wellbeing Team, Community Development), Newry, Mourne & Down District Council District Electoral Area (Newry), Early Years Newry, Magnet Young Adults Centre and CYPSP. They reported to the larger Disability Sub-Group and also to the whole of Newry Locality Planning Group at their bi-monthly meetings, to ensure the work was open and accountable, with consensus about what it was doing, why and how.

A Co-Production approach was agreed upon for a number of reasons. When done properly:

1. The underlying principle of Co-Production, as described by Boyle et al (2010) is that "People's needs are better met when they are involved in an equal and reciprocal relationship with professionals and others, working together to get things done" (RIGHT HERE, RIGHT NOW: Taking Co-Production into the Mainstream Discussion Paper, NEF 2010).
2. It fits with the Values and Principles of Community Development as described in the Expansion of Community Development Approaches Report to Transformation Implementation Group (DoH, HSCB, 2018):
3. The Planning Group recognised that engagement with Health Services plays a key major role in the lives of families of children/young people with a disability and/or additional needs. The Group adopted a Co-production approach as recommended by the Dept of Health's Co-production Guide: Connecting and Realising Value Through People (2018). Co-producing means working together as partners in order to improve health and wellbeing outcomes.
4. The Co-Production approach fitted well with the approaches of Planning Group members and the Newry Locality Planning Group as a whole.
5. Members of the Planning Group had extensive experience of engaging with communities and working collaboratively together to hold a skill set enabling them to embark on a key piece of work as Co-Production.
6. It was an opportunity to be creative, take some risks and work towards an important and key piece of work with families.

VALUE	PRINCIPLE
Working and Learning Together	Identify own needs and actions
Community Empowerment	Develop confidence, skills and knowledge
Collective Action	Take collective action using strengths and resources
Anti-Discrimination	Challenge unequal power relationships
Social Justice and Equality	Promote social justice, equality and inclusion

## Planning Group

**The Planning Group needed to expand to include parents and carers of children with a disability.** Another Organisation from the LPG became involved with the Group, Clanrye Group, so it was agreed to invite up to 98 parents to the group to join the 6 staff on the LPG. The rationale for this was that staff were more likely to make the meetings as part of their working day, however parents may find it more difficult due to family pressures or work commitments.

2 parents were recruited due to being active member already of the Newry LPG through their work, however for the purposes of the group, attended as parents and outside of their working hours. This gave them the opportunity to speak more open and honestly as a parent and not as a representative of a statutory service or community organisation.

6 parents were recruited through Newry Early Years, who were an active member of the Planning Group and offered to host meetings. Their existing work is built on strong links and support for families and parents of children with a disability felt able to engage with the process due to this positive relationship. The importance of a familiar and trusted face and supporter was key to the engagement of parents with the process.

## Early Stages of the Group

**As is the case for any new group forming, there were a lot of questions asked and limited answers available, especially due to the co-production aspect of the process.** For the first meeting the staff (representatives of Newry LPG member organisations) agreed to give a very brief presentation on Co-Production values and principles, however not to get too in-depth as the agreed message was that the recommendation was to work together, make collective decisions and use all expertise in the room to agree how best to support families of children with a disability in the Newry & Mourne area, in their engagement with services across their lives.

The Presentation given on the first meeting showed a short 5 minute video of The Ladder of Co-Production from TLAP (Think Local Act Personal) which is available on the You Tube link:

<https://www.youtube.com/watch?v=kEgsJXLo7M8&feature=youtu.be> .



**THE LADDER OF CO-PRODUCTION**



Scan barcode to view the video

Consensus by the end of the meeting was that everyone agreed they wanted to be involved with an initiative, event or piece of work to support parents/carers of children with a disability, in the Newry and Mourne area.

Parent representation on the Planning Group initially assumed the staff member held more experience and expertise in the Co-Production process, and the statement "Well, what do you think as you're the experts?" was mentioned by a parent. This was raised by the group and assurance given that parents were equal partners in the process as the work was to focus on the experiences of families with services.



## Aims of the Project

**From personal experiences, parents felt strongly that an event should initially reassure others they were not on their own, with regards to children diagnosed with a disability or with additional needs, in terms of existing services.** An event would reassure, support and inform other parents using experiences by the Planning Group and other parents on the day. Services and support would be on offer to those to inform and make links with from that point onward.

The event would be open to parents of children with any disability or additional need: there would be no stipulation of any type of disability or how prominent it was.

Parents would have the chance to have their stories heard by other parents and by services who would also be invited to the event. They would also be able to agree on standards which families should expect from services.

An element to the day would also to give parents a voice: to increase capacity building to advocate on behalf of their children and their families. Lastly, there would be an emphasis on self-care for parents: to support those who have to constantly battle for their own family.



*An element to the day would also to give parents a voice: to increase capacity building to advocate on behalf of their children and their families.*

## Format and Structure of Meetings



### 11 meetings

took place between November 2018 and March 2019s

**Meetings would be held when agreed by all members, as and when required.** They would be informal however included agreed notes taken of decisions and actions. Decisions could only be taken when there was representation from BOTH staff and parents, and enough to make it representative.

Each meeting, although an Agenda was produced, allowed space for discussions to carry on slightly off the Agenda. It was quickly observed that these discussions allowed parents to share their stories, contacts and opportunities for others, and this was recognised to be of great benefit to the process as it emerged that the event would act as a larger version of these meetings insofar as there would be opportunities for parents to discuss matters important to their family lives.

Meetings were held at Early Years Newry, as the majority of parents knew the venue and child minding was also provided by Early Years. They took place at 10 in the morning after children were brought to the Centre so parents did not have to travel elsewhere.

There were 11 preparatory meetings in total, including 2 visits to the venue for the event. These took place between November 2018 and March 2019.

# Format of the event

## INFORMATION STALLS



Members of the Planning Group identified a number of local organisations and services who had a remit to provide support for families with a child with a disability, in the Newry and Mourne area. This criteria was applied to ensure appropriate services were represented and parents could gain information of relevance to their family. In total 39 services had an information stall at the event.

The information stalls were allocated the first hour of the day, where parents were free to chat informally and obtain information at their convenience.

## PARENT'S VIDEOS

The Planning Group agreed that any speakers should be appropriate to the audience, who would consist of parents and staff from services. It was agreed that parents themselves would tell their story of their own particular journey, from birth to transition to adult services. It was agreed that parents would make short videos about their journeys for 3 main reasons:

1. This would ensure time would not run over during the day so groups would have time to have table discussions
2. It would take pressure off parents from speaking in front of a large audience, and ensure their message was clear and supported
3. The videos could be used for further sessions and information to get the message across from the event

## TABLE DISCUSSIONS



The third aspect to the day was to hold facilitated discussions at each table which consisted of a mixture of parents and staff. There was a clear briefing given to Table Facilitators to keep the discussion positive and to highlight barriers faced by parents with regards to services, and to also identify potential solutions to these.

All Table Groups were asked at the end of their session to agree on a statement which started with "All families should expect..." with regards to local services. These would be read out at the end.

## Self Care

Lastly, the importance of self care for parents would be emphasised throughout the day. A short session was included during the break of the videos to provide practical activities for parents to help with their self care. This would be facilitated by Sinead Wadforth from Early Years Newry.



# THE EVENT: OUR JOURNEY THROUGH DISABILITY

**On Wednesday 27<sup>th</sup> March 2019, Our Journey Through Disability took place at the Mourn Country Hotel, Newry.** In total 170 people attended: 64 parents/carers, 62 representatives of the voluntary and community sectors, with 44 from the statutory sector organisations.



**170 people**

**64** parents/carers

**62** representatives of the voluntary and community sectors

**44** from the statutory sector organisations

The format of the day as described above aimed to ensure that all participants had the opportunity to engage with peers and service representatives, and to keep the discussions constructive. Table facilitators were given a briefing to ensure positive discussions due to this unique opportunity to engage directly with services and families, and to identify possible ways forward to help improve service provision for families.

**Feedback from the discussions are listed below and as follows:**

- 1.** Statements given ad verbatim by each 16 tables, starting with the same phrase "Families should expect...".
- 2.** Summary of the table discussions by theme, identifying barriers and possible solutions given.
- 3.** Final recommendations as agreed by the Planning Group at a following meeting, based on feedback from the day.

**The aims of the day were as follows:**

- ✓ To inform parents of services available in the local area to help reduce their feeling of isolation
- ✓ To share video stories of their family journeys through local services
- ✓ To engage with service representatives and other parents to identify barriers and possible solutions to improve outcomes for children and young people with a disability, and
- ✓ To promote the importance of self-care for parents and carers.







# NOTES FROM ROUND TABLE DISCUSSIONS

## 1. "Listen to us!"



### BARRIER(S)

#### Parents reported...

We do not feel listened to, believed, taken seriously or understood. We are asking for the same things over and over again, going around in circles before we are either listened to or else nothing changes anyway.

Everything is a fight: we have to cry out yet we feel we are not believed and "professionals know best", needing to see it before they believe.

We need to speak up otherwise services don't realise we are here. By this stage we are already at breaking point.

It's difficult trying to get someone to listen Nobody asks us. We have to explain our concerns at every appointment.



### POSSIBLE SOLUTION(S)

#### Parents recommended...

Take our information on board. Listen to us, support us and inform us about waiting lists. Trust our instinct: we know our child. Find out what is a priority for our family by asking us.

Professionals must realise we are experts and listen to us. Take responsibility to value our knowledge and listen more closely.

## 2. The “System”



### **BARRIER(S)**

#### **Parents reported...**

Parents feel they are battling against the system, with constant and new referrals back and forward. This causes stress to them and their child. The child gets lost in the system and there seems to be no clear pathway of what to do and who to speak to.

Groups reported seeing poor integration and co-ordination of services – a lack of joined up working and consistency and poor communication between departments and across services. 8 groups raised communication as a barrier.

Groups talked about a lack of consistency among and across services. Examples included Dept of Health and schools not working closely together, too much distance between commissioning and service providers, and huge multidisciplinary teams with different messages. Parent reported having to be the link between all the different professionals/services involved.

Barriers faced by parents also included the length of waiting lists, services operating 9-5 Monday-Friday, no clear pathway for referral, no help unless a diagnosis has been made and lack of resources in the system. Bureaucracy creates delays to access and one group added things have not gotten any better over the last 10 years.

Groups acknowledged the lack of resources in the system and that services were not able to offer things to everyone. Help is only available in many cases to those who have had a diagnosis for their child. Conversely, pathways are complicated for those children with a multiple diagnosis.

Parents reported finding it difficult asking for help and support due to the stigma attached and fear of being judged as a parent.

Other statements shared by groups include:

- » “Why does it take so long?”
- » “Why do I have to fight for a school place for my child?”
- » “Nobody asks us”





## POSSIBLE SOLUTION(S)

### Parents recommended...

Groups agreed communication is key. Parents would appreciate a timeline of what is to come and what to expect, key information on services and support, including peer support groups and local contacts. Parents would like to see more peer support from other parents.

Groups identified a person-centred approach where professionals find out what is a priority for a family. This is a needs-led, not service-led approach where needs are assessed and services built around them.

A very clear message from the day from all groups was the clear need for someone to co-ordinate the process around services for families. This person was described as a co-ordinator, "go-to" person, navigator, link person, key worker, main, central or single point of contact. Ideas for this role include supporting and directing parents to the correct professionals/services.

3 groups recommended a "This is Me" passport and/or JAM card, which will give important information for their child in order to help people understand the person and their support needs, and to take a step back to give extra time for communication and everyday interactions in the community.

Groups recognised a good Disability Social Worker provides appropriate access to services and care, and shares information with parents before they have to push or fight for it. Suggestions to maintain quality included training for Social Workers on daily issues facing parents in navigating services and systems, and to encourage better communication with other services.

Further ideas/suggestions made by single groups included:

- » Try to avoid conflicting appointments!
- » Link Autism and Sensory services
- » Services should be for development not chronological age
- » Why can't the diagnosis travel to professionals instead of having to repeat all our information?
- » Develop appointments based on service locations
- » Different ways of working

### 3. “I felt alone and isolated – we need to join the dots”



#### BARRIER(S)

##### Parents reported...

Parents reported a lack of knowledge of services in the local area, where to get help, who to speak to, and where to access support and up-to-date information.

Further difficulties reported included support groups being limited to a particular condition rather than issues, need for more resources for family support groups, peer support (e.g. signposting to a helpline for parents) and asking for help due to a lack of trust.

Parents reported a fear of the unknown particularly at the point of diagnosis, and also of being overwhelmed with all the information at this point too.

Many groups reported guilt and concern for siblings of children with a disability and/or additional needs, as they may feel neglected due to the lack of meaningful time their parents and carers can offer them, as well as having caring duties themselves. Siblings can experience bullying and find it difficult to ask for help. Parents also reported resilience of their other children too.



#### POSSIBLE SOLUTION(S)

##### Parents recommended...

Groups again suggested a navigator to help co-ordinate information and support for families. Information should be relevant and kept up-to-date. One group recommended each Department in a service had one representative who was a point of contact for signposting.

Groups suggested automatic information distributed to services, a postal drop every Quarter on services or an A-Z of services for children and young people with a disability/additional needs on a website.

A common theme in discussions was peer support amongst parents and local support groups, who were able to access training and capacity building to provide support for each other. Examples identified included Down Right Brilliant, Autism Support Kilkeel (ASK).

Groups appreciated events like today's Our Journey Through Disability where services could inform what is on offer and give advice. Parents would also have the chance to network to share experiences and further contacts to their peers, and be offered the chance to talk about their journey. This should happen on a regular basis.

Groups recognised the importance of children to have a social group: involvement with youth groups and similar organisations/activities to build and maintain friendships and promote socialisation.

Other ideas included:

- » Get more business involved through volunteering
- » More support for rare conditions
- » A directory of services for parents – better information that suits individuals.



## 4. “Transitions: the process or a period of changing from one state or condition to another”



### BARRIER(S)

#### Parents reported...

*When discussing transitions, we acknowledge that although the event focuses on all services in a family's life, this theme predominantly refers to transitions within health services.*

Transition to adult services from children's services was agreed by groups to be difficult due to various reasons. Parents reported fear of the 'unknown' in services for their children and family support. The move into adulthood, although based on age, is difficult due to the developmental age of the young person/adult. Continuity of services stops, to be replaced by another which many parents felt was like "starting over from scratch again", where they had to once again re-educate professionals about their child and learn about new services.

Those parents who attended and had experienced transition reported the process as "not good" or "not smooth". Parents reported a delay in the start of transitions and that a 5 years transition plan was in place however not happening in reality. One group reported there was no clear process to the stages of transition.

Parents reported a lack of understanding what is available as part of the transition process, and what happens when their child turns 18 and is "pushed out into the big, bad world". Feedback given suggested 18 is too young an age for transition into adult services.



### POSSIBLE SOLUTION(S)

#### How can we make this process better?

Feedback identified a need to review the age for transitioning to adult services at 25 years, however also indicated the need to begin the process at 14 years, adhering to a clear plan at least 5 years prior to transition. There was agreement that individuality needs to be considered as a factor with developmental needs taking precedence over age.

During this preparatory period, groups agreed again that one main point of contact was available consistently and equipped with appropriate knowledge to signpost to further support services as well as providing relevant and timely information: information should be automatically available on a range of issues.

## 5. Gaps in Service Provision



### BARRIER(S)



### POSSIBLE SOLUTION(S)

#### Parents reported...

Parents are worried about further gaps in services which brings about uncertainty and worry. Gaps identified include:

- » Lack of Disability Social Workers
- » Reduced capacity in schools with an increase in class numbers
- » Time limited support
- » Lack of adult short breaks in Newry & Mourne
- » Delay in diagnosis which restricts available services
- » Insufficient local short breaks provision for adults and children in short break units (will only go up to age 16/17, long waiting lists and lack of information on the service)
- » Lack of childcare for children with a disability
- » Access to mental health services
- » You feel like you have to be grateful for what you are offered
- » People not 'joining the dots'
- » Length of waiting lists
- » Services operating 9-5 Monday-Friday
- » No clear pathway for referral
- » No help unless a diagnosis has been made
- » Lack of resources in the system
- » Bureaucracy creates delays to access
- » Social workers have retired and not been replaced
- » Transport
- » Lack of support in primary schools
- » Lack of learning support units
- » Links and relationships between statutory and community voluntary services.

#### Plugging the Gaps...

Resources (both funding and time) to support:

- » More units for "challenging behaviour"
- » Training and time for workers to upskill and share expertise with other services
- » Pilot projects with smart timeframes
- » Professionals/workers to keep in contact with parents more
- » Early intervention
- » Giving more support to families at the start of their journey
- » Referral to someone who has expertise/knowledge (professional or peer)
- » Services becoming better informed
- » Support for rare conditions
- » More short breaks
- » Counselling facilities
- » Information packs to promote services and support
- » Trust services to develop services using PPI & co production which involves everyone
- » Out of hours services
- » Better inclusion of parents in MDT meetings
- » Potential for teachers and EANI to attend CDC clinics
- » Proper diagnosis to avoid re-diagnosis.

Parents reported that it is difficult when trying to get help from professionals and it should not be so hard to get. Honesty and transparency is key.



## 6. Gaps in knowledge and understanding



### BARRIER(S)

#### Parents reported...

Groups identified gaps in knowledge and understanding among both professionals and the wider community. With professionals it was identified a need to become more aware or knowledgeable on conditions such as ASD, additional needs in the classroom, recognising learning difficulties and disabilities, and to become familiar with more rare disorders or diagnosis when starting to provide a service for a family.

Within the wider community, groups identified a need to address a wider societal attitude and promote a more empathetic approach. Employers still may have limited understanding which further perpetuates stigma, and there is a need to challenge the focus on what a child with a disability can do instead of what they cannot do. Parents also reported a greater lack of acceptance and tolerance towards their child if their disability was more visible.



### POSSIBLE SOLUTION(S)

#### Parents recommended...

Groups recommended more training and awareness raising among professionals on conditions which include more rare diagnosis /complex needs.

Parents again suggested the JAM Card and This is Me to help communities better understand their child. More positive media coverage and awareness raising by charities would help too. One group suggested to take time to get to know a child and their family.

Local support groups were identified as a very good source of provision of knowledge and understanding. Parents can share their experiences and expertise to others, including their peers, services and the wider community.

## 7. Advice, information & support for families



### BARRIER(S)



### POSSIBLE SOLUTION(S)

#### Parents reported...

This has been included in some of the themes above, however more areas were identified and are listed below:

Parents/families may need further advice, information and support on:

- » Employment rights for parents.
- » Form completion (e.g. PIP) – support workshops
- » Reducing stigma attached to asking/getting help (capacity building)
- » Getting people to listen (capacity building)
- » Knowing what support is available/who to contact
- » Grief loss of the child you expected
- » Counselling options
- » Family support groups
- » What happens next (particularly post diagnosis)
- » Overcoming fear of asking for help from services
- » Need for peer support – signposting to a helpline for parents etc.
- » Accessing support for siblings (young carers, groups, activities)
- » Support for carers
- » Support for parents for Direct Payments
- » Advice on family support.

#### Parents recommended...

- » Peer support –from other parents (trained to help or support groups)
- » Community Advice
- » Having one main point of contact to connect families to services and who know the individuals
- » Workshops for parents in filling in PIP/DLA forms
- » Networking opportunities
- » Info events like todays can help access services and information
- » There should be a clear outline of entitlements for every parent
- » Knowledge of and support for rare conditions
- » More events to happen on a regular basis
- » More awareness of charities and resources that are available for parents/careers
- » Financial/Emotional/Physical support
- » Information packs that promote services/support
- » Need to make process of direct payments easier.
- » Social support
- » Services advertised at this event: opportunities for families
- » Champion needed
- » Open space/room in leisure centre to facilitate
- » Develop support units
- » Communicate more with parents/carers.



## 8. Self Care: Look After Yourself



### BARRIER(S)



### POSSIBLE SOLUTION(S)

#### Parents reported...

A large focus on the event was to promote self-care and remind attendees that in order to care for their child and family, we need to look after ourselves.

Factors impacting on parents' self-care included the agreement that they have to fight for everything, and the consensus that help only comes when they are at breaking point. Parents recognise the stigma attached to asking for help from services however are aware that they will be fighting for their children all their lives.

Parents spoke of the grief they felt of the loss of the child they thought they would have and the lack of support (counselling) around this. It is hard to approach services to admit they cannot cope or do everything on their own. They put on a brave face to hide what is going on with them as they need to fight for their child.

Parents reported feeling overwhelmed at the information overload once their child has received a diagnosis, and the guilt around neglecting their other children as they devote the majority of their time around their child with additional needs.

Parents are physically, emotionally and mentally tired fighting for their family, navigating around services and not feeling listened to. Many experience sleep deprivation too, leaving them exhausted and neglecting their own self care.

#### Parents recommended...

Peer support was the overwhelming suggestion to overcome this barrier: the understanding and knowledge of a peer's journey gives immense support. Other feedback included support for couples as relationships can be strained and taking time out for yourself.

Support services such as Health Visitors can help parents feel supported and in the "right frame of mind".

One group offered: "If we can get together we can make change"

# END STATEMENTS



**All discussion tables agreed on one collective statement each.  
These were read out at the end of the day.  
There are the statements.**

## “All families should expect...”

- » A named point of contact who signposts, clarifies, reassures in a supportive way, community based.
- » A one stop-shop for support. This may be through your social worker or key point of contact to support you and signpost you onwards.
- » A consistency of services, honesty about resources and to be listened to the very first time.
- » Expect respect, listen to what is being told, not have to fight for professionals to communicate on their behalf and with each other – cross departmental. Also more focus on self-care for parents/guardians.
- » To need to feel that they are being listened to and heard and action taken on what we say for our children.
- » To be listened to before a crisis occurs. A continuation of service. Better multi-disciplinary communication.
- » Circulate use of services to attendees.
- » Consistency, knowledge, coordination filling the gaps, respect/feeling believed/acknowledged, access to counsellor (family as a whole).
- » Support and updated information individual to each young person & family.
- » Knowledge about how to access the different services & refreshed and updated info, one point of contact to sign post to other services.
- » One point of contact to allow families to know what they have a right to e.g.an assessment, social worker and support (financial, emotional, physical).
- » Greater accurate communication & the use of PPI & co-production for carers/service users to participate in service developments. Families know what individuals need and creating centred & holistic pathways.
- » Respect, to be listened to, to have regular and clear communication, valued as an integral part of the process.
- » One point of contact, professionals should have all of the information; parents seem to be the experts on their own child's needs. Should be listened to and heard when they know there is an issue with their own child.
- » Effective listening, clear communication between professionals, clear direction and one point of contact. There should be transparency from all professionals and services.
- » A key point of contact to access key services to get the right information for their changing needs of their child and be listened to”.

# FINAL RECOMMENDATIONS



*The word "Parents" refers to parents and carers of children/young people with a disability and/or additional needs.*



**Following the event the Planning Group held 2 meetings in April and May 2019 to process the wide amount of information and issues raised at the Our Journey event, and agreed on the following recommendations from the day:**

1. Professionals must realise parents are experts and listen to them. Take responsibility to value their knowledge and listen more closely.
2. Families need a single point of contact from an early stage to co-ordinate the process of services for families. They should have a co-ordinating role for families for informing and signposting to services and local support.
3. Families value good communication. Whether formal diagnosis of disability or undiagnosed additional need, parents would like information on what they can expect from services and a timeline where appropriate.
4. Parents support a person-led approach where services place an individual and their family in the centre, assess need and build services around the family and their needs
5. Parents recommend a better understanding of the issues surrounding disability and additional needs: initiatives such as the JAM card should be supported and rolled out, as well as awareness raising on conditions across services and communities.
6. Groups identified the need for training service staff on daily issues facing parents on navigating services, and to encourage better communication with other services.
7. Parents recommend better communication among services to share information which saves families from giving the same information on a regular basis, and to avoid appointments occurring on the same day in different locations.
8. Parents strongly recommended support to bring parents, families and services together through events such as Our Journey, and opportunities for capacity building for parents through training opportunities and sessions to help complete forms such as PIP and DLA.
9. Parents want the opportunity to share their knowledge, experiences and support with others who have begun their journey. Services should endeavour to create opportunities to embed this into their practice and support this process.
10. Groups recognised the importance of children to have a social group: involvement with youth groups and similar organisations/activities to build and maintain friendships and promote socialisation. These may be specific to disability/ additional needs or universal.
11. Participants identified the need to review the process for transitioning to adult services. This should be on the basis of development rather than chronological age. Feedback also recommended the need to begin planned at least 5 years before transitioning takes place within services. The role of a key worker again is of vital importance and families need more support initially at the start of their journey.
12. Information should be available for families through an A-Z of services online and packs which provide support services for families on a local level. Packs should also include information on a child's diagnosis.
13. Out of Hours services and support need to be increased.
14. All relevant professionals should be eligible to attend CDC Clinics, and parents should also have better representation at MDT meetings.
15. Parents need time for self-care. This is vital and should be supported in order to care for their child and themselves.
16. Parents who had their journey recorded for videos which were used on the day have consented to having them used constructively to benefit families and improve their experiences with services. The event Planning Group has recommended that the videos are used to help with induction of new staff and for students in disciplines such as Social Work and Nursing.
17. Members of the Planning Group have also expressed an interest in training programmes for staff in relevant services.
18. Members of the Planning Group have agreed that Co-Production as a process and ethos works well when done correctly, and that services need to further embed Co-Production with families on a strategic and individual level.



# APPENDIX 1:

## List of Attendees

Aiden Burns	Deirdre Shields	LeeAnn Archer	Paul Morgan
Aislinn Mooney	Denise Graham	Lesley Richardson	Paula Loughran
Alison Rice	Donna Barr	Lesley Waugh	Pauline Leeson
Amy Black	Donna Gaffney	Lindsay Holmes	Peter Connolly
Ana Patricia Correia	Edel Brennan	Lindsey Clarke	Peter McKinney
Andrea Doyle	Eileen Costello Rawat	Lisa Bennett	Roisin Doran
Andrea Toal	Eileen McKevitt	Lisa McIntyre	Roisin McGowan
Angela Tinney	Elaine Mooney	Lisa Preece	Roisin Meagher
Angelina McKeown	Emma Hayes	Lizzy Smith	Russell Smith
Ann McCann	Emma Johnstone	Louise Maguire	Ruth Allen
Anna Rodgers	Emma Scullion	Lynn Phun	Ryan O'Callaghan
Anne Marie Fegan	Gavin McGee	Maeve Grant	Sallianne Giles
Anne Marie McKinless	Gemma Finn	Mairead McEvoy	Sandra Jenkinson
Anne McAlmeel	Gemma Mc Keown	Mal O'Hare	Sara Gilpin
Anne Smith	Gemma McKinney	Margaret Convery	Seaneen O'Donnell
Ashley Brown	Gerald Donnelly	Margaret McShane	Sharon Donnelly
Ashling Fitzmaurice	Helen O'Neill	Maria Walker	Sharon Hillen
Avril Annett	Imelda Haughey	Marie McGonnell	Sheila Treacy
Bernie Cousins	Isobell McDonnell	Marie Murphy	Shirley Lilburn
Billy Stewart	Jacinta Linden	Martin McIntyre	Simone Farrell
Blaine McCartney	Jan Charman	Martina McCooley	Sinead Hughes
Brenda Maxwell	Janice Montgomery Watkins	Martina McMahan	Sinead Madigan
Bridget Smith	Jean Kelly	Megan Lennon	Sinead Wadforth
Carol Mackin	Jennifer Duffy	Merrisa McGeary	Siobhan Gibson
Catherine Lynch	Jennifer Hamilton	Michael Hill	Siobhan Harshaw
Catherine Mc Anuff	Jim McDonnell	Michael Vaughan	Stacey Hickman-Robinson
Catherine McCartan	Joan Brolly	Morgan Brannigan	Suzanne McStravick
Chloe Davis	Joanne Hardy	Naimh Howe	Suzanne Turner
Christina Ryan	Jodie Anne Douglas	Naimh McNamee	Una McCrory
Ciara Lowe	John Flett	Naomi O'Hare	Valerie Maxwell
Ciara Matthews	Joyce Holmes	Natalie Robinson	Valerie Hayes
Clare McDonald	June Wilkinson	Necha Falkalel	William Lilburn
Cllr Charlie Casey	Katherin Fearon	Olive Donnan	Yvonne Curran
Cllr Liz Kimmins	Kathy Wilson	Olive McCormick	Yvonne Neill
Cllr Mark Murnin	Kellie Arguelles	Orla Murtagh	
Cllr Valerie Harte	Kerri Morrow	Orla Watt	
Colleen Guinness	Kerrie Cartmill	Paddy Hughes	
Conor Keenan	Kevin Duggan	Pamela Hazely	
Dara Jacks	Kieran McShane	Parycja Teszbir	
Darren Curtis	Kyle Duncan	Patricia Byrne	
David McKenna	Kyleigh Lough	Patrick Murray	

# APPENDIX 2:

## Programme for the Event

Newry Locality Planning Group Presents...

### “Our Journey Through Disability”

Wednesday 27<sup>th</sup> March  
at Mourne Country Hotel

#### Programme:

- 10am Registration & Information Stalls (Kilmorey Suite)**  
(Please make sure you register and spend time making connections and getting vital information)
- 11am Our Journeys...(Carlingford Suite)**
- Welcome**  
Jacinta Linden, LPG Chair  
Paul Morgan, Southern Outcomes Group Chair
- Background to event**  
Ashling Fitzmaurice and Darren Curtis, Planning Group
- Our Journey: DVD and table discussions**
- Self Care and it's importance**  
Sinead Wadforth, Planning Group
- Feedback**
- Next Steps, evaluations and close**  
Ashling Fitzmaurice and Darren Curtis, Planning Group
- 1pm Lunch and networking**

**Please turn page over for important information about Our Journey session**



## Newry Locality Planning Group Presents...

### “Our Journey Through Disability”

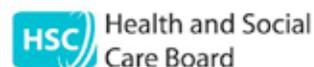
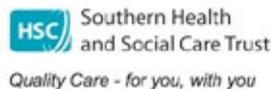
Thank you for your interest and participation in today's event. We recognise the importance of parents and carers of children/young people with a disability/additional needs to be able to express their experiences whether positive or negative. We have representatives from key services in families' lives who have come to participate in the day.

During the table discussions we need to make it clear what we expect:

- We do want to hear the honest, and often difficult, issues faced by families with regards to services.
- We do want as honest feedback as possible. Inevitably families will have faced challenges and barriers. Please focus on solutions for change. What can be changed? What would have or can help? What can be done better?
- We do want respect for everyone involved. This is not an opportunity to target any individual in an open and public forum: if there are any problems or criticisms with individual staff we have briefed the facilitators to focus back to the constructive discussions.
- We encourage you all to get involved: it will make the day so much more productive.

**\*During the day there will be photographs and video taken for social media and related work which will be accessible to the public. Please inform Registration staff at the start of the day if you do not wish your image to be used in either media.**

Event Planning Group and key contributors:



# APPENDIX 3:

## Scorecard for the Event:

**An Outcomes Based Accountability tool to document evaluation of the day which includes information on what we did, how well we did it and what changed as a result of the event.**



**BACKGROUND**

A priority for Newry Locality Planning Group (LPG) is to improve outcomes for children and young people with a disability. In May 2018 Newry LPG held a Disability Inclusion Workshop which brought services together to share information and plan for how they can best respond to need in the local area. It was agreed to further work with parents and carers of children/young people with a disability to improve outcomes for families in the Newry locality, supported by the Southern Area Outcomes Group's "Best Start in Life" Task & Finish Group.

The Newry LPG Disability Sub Group first met with parents/carers in November 2019 and they agreed to hold an event in March 2019 which would meet the following aims:

- Inform parents of services available in the local area to reduce their feeling of isolation
- Share video stories of their family journeys through local services
- Engage with service representatives and other parents to identify barriers and possible solutions to improve outcomes for children and young people with a disability.

Our Journey Through Disability was held at the Mourne Country Hotel, Newry, on Wednesday 27<sup>th</sup> March 2019.

Making a contribution to all 8 **High Level Outcomes** for Children:

- ✓ Physical & Mental Health
- ✓ Enjoyment of Play & Leisure
- ✓ Learning & Achieving
- ✓ Living in Safety & with Stability
- ✓ Economic & Environmental Wellbeing
- ✓ Positive Contribution to Society
- ✓ Respect for their Rights
- ✓ Promotion of Equality & Good Relations



**How much did we do?**

- Planning Group partnership held 11 preparatory meetings, including 1 initial presentation on Co-production and 2 site visits to Mourne Country Hotel
- Invitations to all services & organisations supporting families with children/young people with a disability and/or additional needs
- Invitations open to local and regional-wide services/organisations
- Invitations publicised through existing LPG networks and social media methods (Facebook & Twitter)
- 8 x 5 minute videos made of parents describing their family's journey through services
- 4 hour event at Mourne Country Hotel:
  - 1 hour information stalls session
  - 2 x Parent's Journey films shown of 8 journeys
    - Self Care session
    - 2 x facilitated discussion workshops: 16 tables of parents/carers, and service representatives.



**Newry Locality Planning Group Presents...**  
**"Our Journey Through Disability"**

**Wednesday 27<sup>th</sup> March**  
**at Mourne Country Hotel**

**Programme:**

**10am**     **Registration & Information Stalls (Kilmorey Suite)**  
(Please make sure you register and spend time making connections and getting vital information)

**11am**     **Our Journeys...(Carlingford Suite)**

**Welcome**  
Jacinta Linden, LPG Chair  
Cllr Mark Murnin, Chair, NM&DDC  
Paul Morgan, Southern Outcomes Group Chair

**Background to event**  
Ashling Fitzmaurice and Darren Curtis, Planning Group

**Our Journey: DVD and table discussions**

**Self Care and it's importance**  
Sinead Wadforth, Planning Group

**Feedback**

**Next Steps, evaluations and close**  
Ashling Fitzmaurice and Darren Curtis, Planning Group

**1pm**     **Lunch and networking**



## How well did we do it?

❑ A total of 170 people attended the event

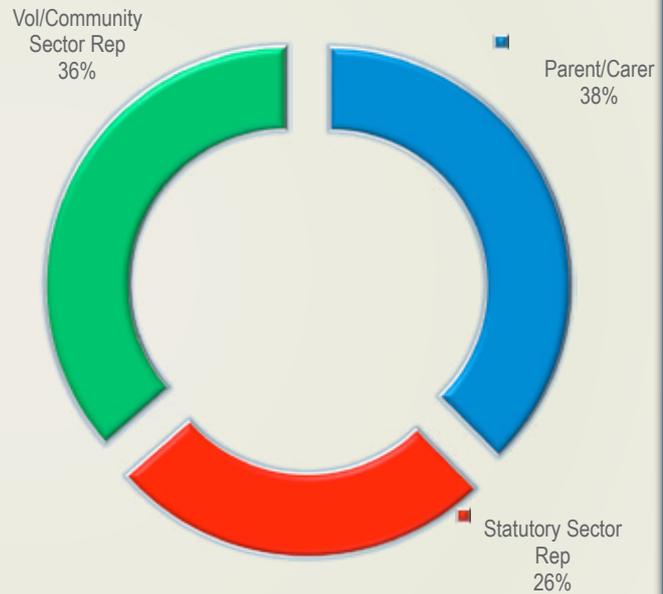
❑ 64 (38%) of attendees were parents/carers, 62 (36%) from the voluntary/community sectors and 44 (26%) from the statutory sector.

❑ Planning Group organisation members were CYPSP/CiNI, Newry Early Years, Magnet Young Adults Centre, Newry, Mourne & Down District Council, Southern Health & Social Care Board Promoting WellBeing Team, SPACE and Clanrye Group.

❑ 103 (63.2%) participants completed Evaluation Forms

❑ 39 Services & Organisations had an Information Stand

### Attendance Breakdown



## How well did we do it?

81 people quantified the number of connections made

### The Information Stalls

639 connections were reported to have been made on the day



Average connections made was around 8 per person

7 people said "Lots/lost count" or "Not enough"



## How well did we do it?

### Social Media Coverage on Facebook:



46 Shares for the promotional flyer on CYPSP Facebook Page



2,921 Reactions, Comments & Shares

60,144 People reached

28,768 Views

6 Parents shared their journeys on the CiNI Facebook Page

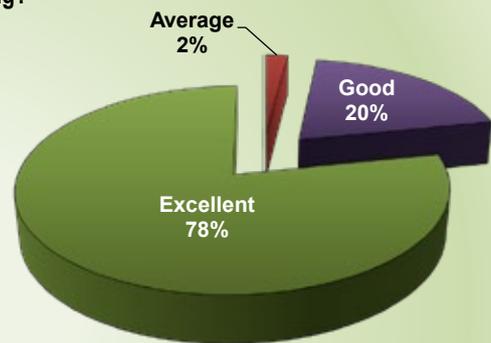
## How well did we do it?

### Evaluation Responses

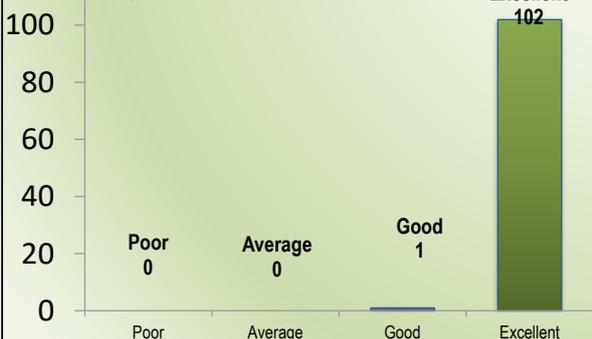
How beneficial did you find today in making connections with parents/carers and services?



How useful did you find the information stalls in the morning?



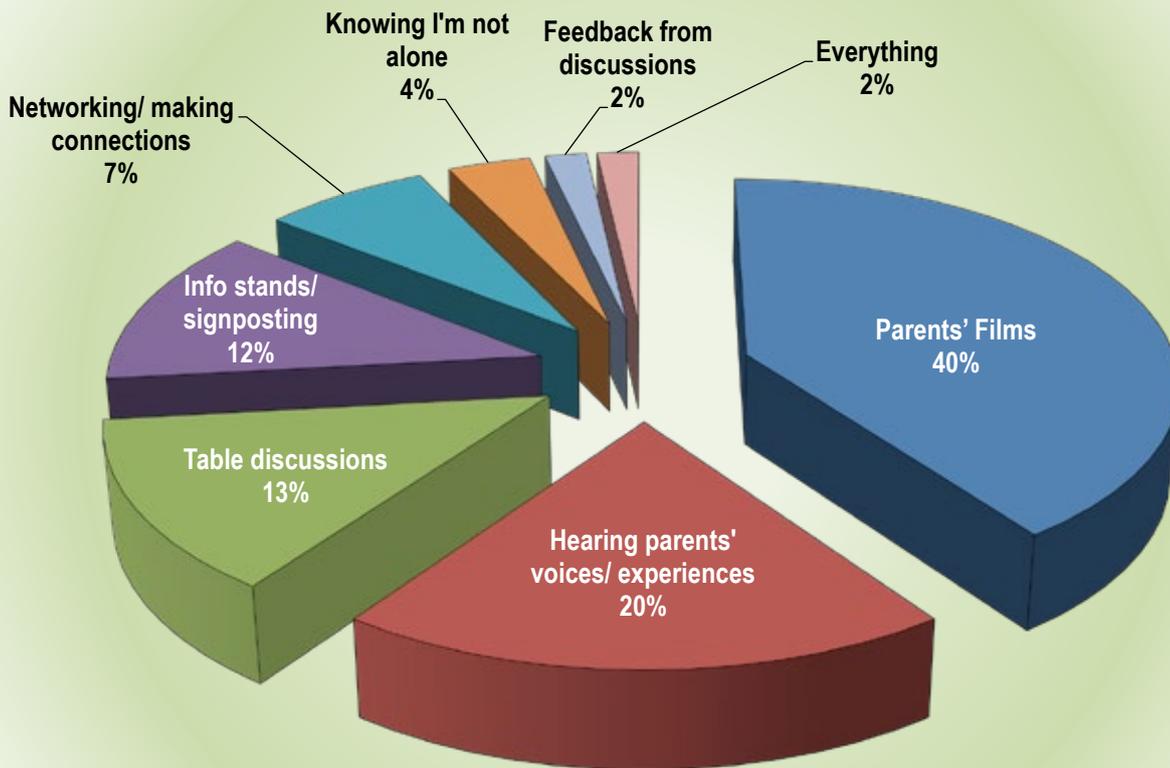
How useful did you find the parent's films when describing their journeys?



How beneficial were the table discussions?



## How well did we do it?



What was the highlight of the day in your opinion?

## Is anyone better off?



Some quotes from participants



Is anyone better off?

Comment...



Is anyone better off?

For services and organisations only - Make one change statement you can deliver on after today's event:



- More partnership working/sharing 7 replies
- Listen more to parents 6
- Communicate more with parents 5
- One point of contact/signposting 4
- Follow up meetings to today 2
- More co-production with parents & carers 2

“Making sure that I am the main point of contact for the pupils on my database”

“Education is helpful to change. This has been a door opener”

“Check in with clients/parents to help them access services they might need”

“To be more aware of parents needs that we assume they know about”

“Leaflet for new parents from our service”

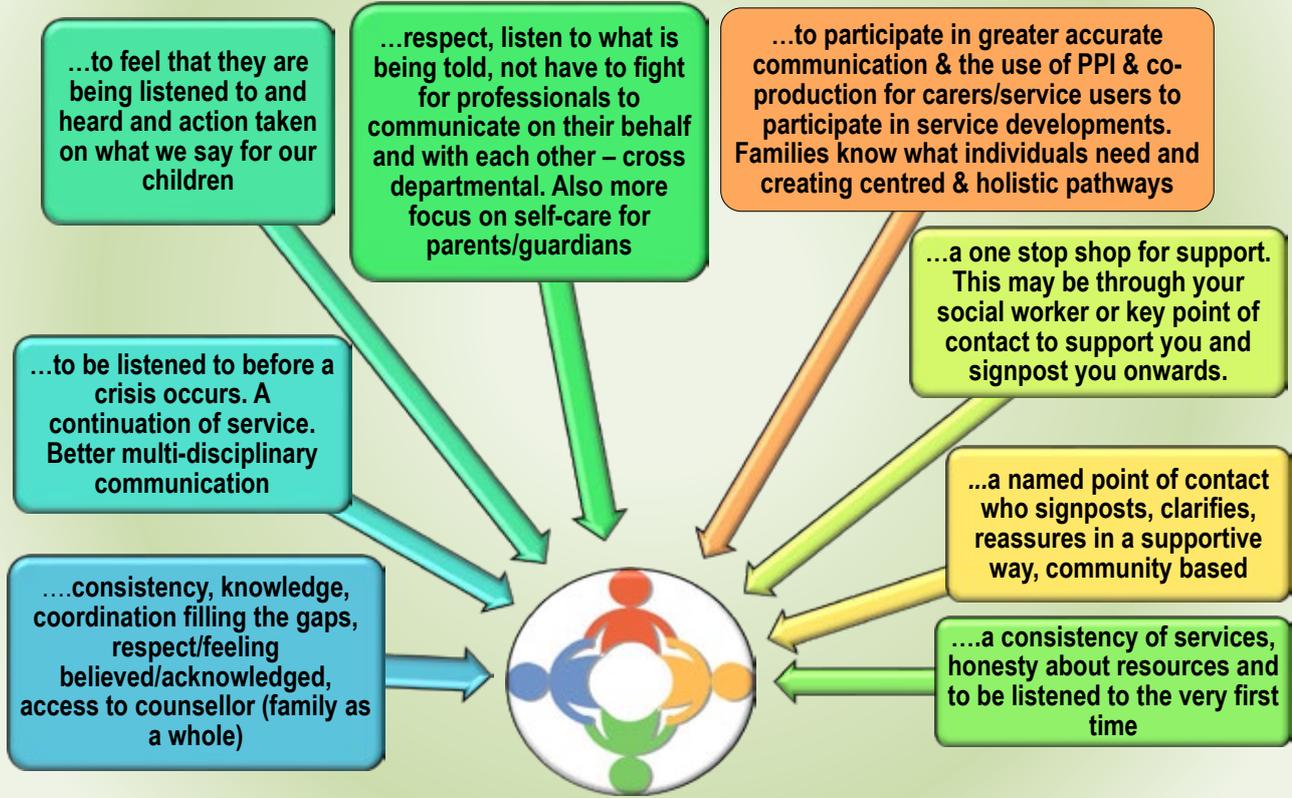
“Champion disability within our organisation and with Locality Planning”

“Care enough to really listen and take action”

## Is anyone better off?

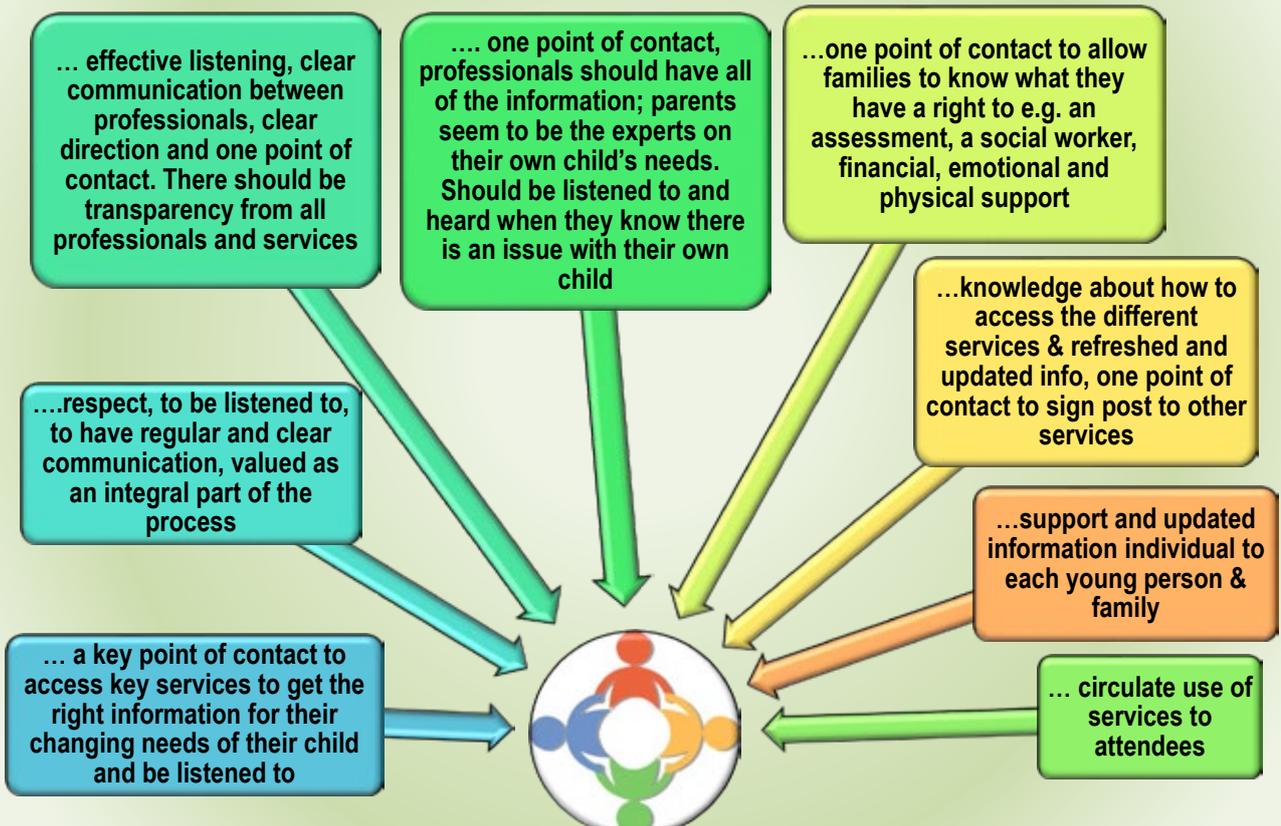
At the end of the table discussions, each table fed back one thing each family should expect from services in the area...

### Families should expect...



## Is anyone better off?

### Families should expect (Continued)...



## Is anyone better off?

As a result of their involvement with this project,  
Parents on the Planning Group reported...

Increased knowledge of services and confidence to speak publically about their family's experiences with services

Increased self worth as a result of the process and event

Increased voluntary involvement with disability-based community groups

Increased awareness of services available to families with a child with a disability

Increased awareness of what families are entitled to with regards to disability

Obtaining positive feedback from families and friends after videos were released

Confidence that co-production works & is most effective when people work in partnership

Speaking with other parents to seek help for their own good mental health & wellbeing

Determination to take the outcomes of the event forward to help other families

## Is anyone better off?

The Planning Group has forged links with the NI CYP Strategy & Autism Strategy: meeting with policy makers to progress the results of findings

Contacts details of all 39 services & organisations will be shared among all attendees & members of the Newry LPG

The Planning Group is keen to link in with existing parent's forums in order to improve services & experiences for families with a child with a disability



Learning & feedback from the event and process to be shared with CYPSP, Southern Outcomes Group, Community Planning & Newry LPG members

Report due to be completed on the day, including all discussion themes, recommendations & information available on the day





**Films:**

**Video of the event:** [www.youtube.com/watch?v=hX0GCTwJGQYY](http://www.youtube.com/watch?v=hX0GCTwJGQYY)

**Parents' Video's:**

Ashling's Story: [www.youtube.com/watch?v=e9JlrVkjoc](http://www.youtube.com/watch?v=e9JlrVkjoc)

Sheila's Story: [www.youtube.com/watch?v=SdXCYh-17pg](http://www.youtube.com/watch?v=SdXCYh-17pg)

Martina's Story: [www.youtube.com/watch?v=IJWrcdCqDdg](http://www.youtube.com/watch?v=IJWrcdCqDdg)

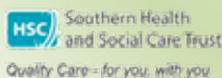
Emma's Story: [www.youtube.com/watch?v=20XBbwI0qM0](http://www.youtube.com/watch?v=20XBbwI0qM0)

Jim's Story: [www.youtube.com/watch?v=thpmP-WqTLE](http://www.youtube.com/watch?v=thpmP-WqTLE)

Joan's Story: [www.youtube.com/watch?v=okccLK0-dUA](http://www.youtube.com/watch?v=okccLK0-dUA)



Members of the Planning Team with June Wilkinson, Dept of Ed and Cllr Mark Murnin, Chair of Newry, Mourne & Down District Council







If you would like to join your local  
Locality Planning Group or if you  
would like more information please  
contact the Locality Development  
Officer for the Southern Area:

**T:** 028 9536 3966

**M:** 077 2523 2566

**E:** [localityplanning@ci-ni.org.uk](mailto:localityplanning@ci-ni.org.uk)

**W:** [www.cypsp.hscni.net](http://www.cypsp.hscni.net)

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