

**Summary Report: Workshop on Children and Young  
People with a Disability and their Families, 06  
September 2022**

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## 1. Introduction

The Independent Review of Children’s Social Care Services in Northern Ireland was commissioned on 21<sup>st</sup> January 2022. Ray Jones, Emeritus Professor of Social Work at Kingston University and St George’s University of London, is engaged as the Independent Lead Reviewer. Since undertaking this task, Professor Jones has met with a wide range of stakeholders, and importantly, families and children with experience of Children’s Social Care services. Professor Jones is assisted by an Advisory Panel which includes:

- Professor Pat Dolan, UNESCO Chair in Children, Youth and Civic Engagement
- Marie Roulston O.B.E, Former Director of Social Work at the Northern HSC Trust
- Her Honour Judge Patricia Smyth, a Deputy High Court Judge who had previously served as an Advisory Panel member on the Gillen Review of Family and Civil Justice.

A key objective of the Review is to engage with and hear the views and experiences of stakeholders who are in contact with Children’s Social Care Services, to build a perspective on how services are delivered across Northern Ireland. One of the engagement processes to achieve this, is to run a series of themed workshops. The first workshop in the series was held at the Junction in Dungannon, on 6 September 2022 and focused on ‘Children and Young people with a disability and their families’.



*Round table discussions underway at the Workshop.*

## **1.1 Workshop Objectives**

- Highlight the key issues affecting children's social care services
- Listen and hear the experiences of people who are in contact with these services
- Provide an opportunity for service users and providers to engage, discuss and feedback on the main challenges and issues to help shape services for the future
- To help inform and improve delivery of services
- Explore and examine opportunities to develop robust and sustainable service models

## **1.2 Attendees**

A wide range of stakeholders that included service users, parents and carers, practitioners, policymakers, service managers, voluntary and statutory organisations were invited and attended the workshop. In total 85 people participated in the workshop. The Cedar Foundation facilitated the young people attending, and Children in Northern Ireland (CiNI) facilitated the parents and carers who attended.

## 2. Structure of the Workshop

The workshop was co-chaired by Padraic Farrell, a young person with a disability, and Marie Roulston, a member of the Review Advisory Panel.

The workshop was structured as follows:

- Professor Jones opened the workshop, welcomed everyone, and highlighted the aims of the workshop. The co-chairs, Padraic and Marie followed this by introducing the afternoon's programme.
- Attendees were asked to complete a survey questionnaire and to identify what they consider are the three main issues for Children's Disability Services.
- Four speakers each delivered a five-minute presentation on their experiences with Children's Disability Services and identified key issues from their perspective. Two young people spoke, followed by a parent and a social worker.
- Round table discussions followed. Each table had groups of 8-10 individuals based on their organizations/roles. The task was to have an engaging discussion to identify and record the main issues that they decided were most pressing.
- This information recorded by the scribes at each table was then collated and analysed along with the completed survey questionnaire responses. After a short hospitality break the findings were presented by Professor Dolan, a member of the Review Advisory Panel.
- A plenary discussion led by Professor Jones, gave the opportunity for attendees to reflect on the issues and themes that emerged.
- Lastly, attendees were asked to complete feedback forms to help inform future workshops.

### 2.1 Presentations

Four speakers each delivered five-minute presentations on the most crucial issues affecting Children's Disability Services, from their individual perspectives. Mary Kerr and Emmet O'Reilly spoke from the perspective of young service users, Marian Bradley spoke as a parent and Margaret Ann McKee spoke from the perspective of a social work practitioner.



Mary Kerr and Emmet O'Reilly spoke about their experiences with children's disability services.



*Marian Bradley gave her experiences as a parent caring for a child with a disability.*



*Margaret Ann McKee, NHSCT spoke about the challenges faced by social workers on a daily basis.*

## **2.2 Round Table discussions**

Following the presentations, the attendees engaged in group discussions, with each table being asked to identify the three most pressing issues affecting children and young peoples' disability services. Attendees were placed at a table according to their respective organisation or role. This allowed the social workers, or young people facilitated by the Cedar Foundation for example, to discuss the issues which related directly to them at their respective tables. Each table was assigned a sheet of flipchart paper, with a scribe assigned to facilitate the discussion and record the issues the group had decided were most important.

## **2.3 Analysis of Issues by Professor Pat Dolan**

The information recorded during the group discussions, was then collected and analysed by Professor Pat Dolan and the members of the Review's Secretariat. This information was

compared with the survey questionnaires which had been completed earlier, to find common themes. Professor Dolan compiled his analysis into a PowerPoint and delivered a presentation on the key issues highlighted by these responses (Refer to pages 7 - 10 for a breakdown on the responses).

## **2.4 Plenary Discussion**

The workshop was brought to a close with a plenary discussion led by Professor Jones. Attendees were asked to contribute with an open floor style, providing their experiences with disability services for children and young people. Many were able to offer a personal example of how they were affected by the issues which had been discussed.

### **3. Themes and Issues Raised During the Workshop**

#### **3.1 Common Themes**

Several themes emerged across the surveys, presentations, and round table discussions. A recurrent issue was the need for more practical hands-on help for disabled children and young people and their families, both within their home, through activities and opportunities outside the home, and through short breaks and respite care.

There was also the recognition that children, young people, and parents through their experiences built up an expertise about how services were working and that there was a particular strength in the advice and support parents could and did give to each other.

Those who had experiences of services were often the best guides and navigators for others trying to find their way through the complexity of services, but it was also noted that there should be more social workers to help ensure families receive the support they need.

Transitioning from child to adult services was also often raised as an area which needs improvement; current provision in this regard was seen as disjointed, with a lack of support for young people once they reach adulthood. Overall, services were seen as overstretched, with too much pressure on families, social workers, other workers and on the system itself.

A lack of funding was seen as one of the main inhibitors of effective service delivery. A more inter-connected multi-agency approach, along with increased collaboration between different professionals and teams was as seen as a necessary step to alleviate pressures. Many attendees were also of the opinion that children and young people's disability services lack direction in Northern Ireland, with a regional strategy needed to amend this.

#### **3.2 Issues Raised During the Presentations**

##### **Mary Kerr and Emmet O'Reilly (Young people)**

- The turnover rate for social workers is too high which creates instability for young people.
- The young people highlighted the frustration of being taken out of school to attend medical appointments. This is especially pressing, considering time already lost during the pandemic.
- There should be more services and professionals supporting ages 16 - 30 years. Services should not end when a young person becomes 18- 19.
- Due to this gap, one of the young people described leaving services at age 19 as falling into a 'black hole'.
- Young people, particularly those with complex needs, need increased opportunities and support to socialise and feel included in social environments.
- There is the need for partnership working between disability services and youth workers in the community. Youth clubs often do not offer training in personal care to youth workers, which could be facilitated.



- To prevent isolation and mental health problems from developing or becoming aggravated, it is crucial that these needs are met.

### **Marion Bradley (Parent of a young person with a disability)**

- A major issue for parents of children and young people with disabilities is the transition from child to adult services.
- There is no support or training for young people post 18 years old.
- Parents are concerned about being left to cope on their own if their partner dies or worry about who will support their children after their lifetime.
- There is a lack of respite, or none at all for families.
- Early intervention should be more readily available and accessible.
- Social work should be seen as a 'vocation' not as a 'profession.'

### **Margaret Ann McKee, (Social Work Practitioner, NHSCT)**

- There is a lack of available and appropriate fostering placements for children with disabilities.
- A lack of planned short breaks for families.
- A lack of staff in teams.
- Specific early intervention for children with disabilities is also lacking.
- Too many pressures on parents.
- Too much pressure on the system means that users get a diluted, overstretched service, while social workers and others are also under pressure.

## **3.3 Issues Raised in the Survey Responses and Round Table Discussions**

### **Issues identified by Policy Makers**

- How Children's Disability Services are structured needs to be examined. These services should be needs led, with a whole family approach taken. Children and their carers need to be involved in producing services, to ensure policies stay in touch with their needs.
- In terms of transition care planning, more integrated working should also be facilitated between Health & Education. There is the need for greater resources, staff and effective governance to ensure positive outcomes in this area. Without these measures, transitions are not seamless.
- In terms of workforce development, there is the need for greater skills mix across teams, safe staffing and retaining experienced staff.
- Early intervention measures including pre-diagnosis support is needed.
- It is difficult for people to get the support they need due to high thresholds and they often do not get help in time. Supply is also much greater than demand as people are

not seen in time. This leads to crisis-driven commissioning and practice in response. Early intervention measures would help to prevent this.

- Parents and practitioners should be enabled to manage risks better and make informed decisions.
- Greater support is also needed for residential care.
- Efficient case allocation is needed.
- Isolation and a lack of community integration for those struggling with disabilities is also an issue. Primarily, this is due to continuing social stigma.
- This is exacerbated by inadequate infrastructure and transport links for disabled persons, along with poor physical and social spaces. In rural regions this is especially the case, or areas with high levels of social deprivation. There is also the need for proper therapeutic and sensory services to help combat this.
- The role of social workers also needs to be reevaluated. It isn't necessary for social workers to always be the primary contact. Currently, there is a heavy emphasis on social workers to meet and identify all needs.
- Lack of funding is a major issue. This has created constantly struggling 'Cinderella services' that lag 10 years behind mental health services. A common strategy exists for child and adolescent mental health and a similar approach should be taken for disability services. Will and strategic leadership would be required to deliver an agenda for children with disabilities. Political awareness is absent and instead, elected representatives need to promote disability as an issue.
- In terms of what is working well, policy makers identified cross-departmental co-operation, family support hubs and the registered intermediary scheme.

### **Issues identified by Service Managers**

- A clear, strategic direction is absent.
- Commissioning and contracting are not working.
- Continued flexibility and support is also required from RQIA.
- There is a current lack of domiciliary support for children with disabilities.
- Overall, regional inconsistencies are an issue as they create a 'postcode lottery' for families regarding the availability and quality of services.

### **Issues identified by Social Workers/Practitioners**

- A regional strategy for long-term placements, in particular, across each Trust is missing.
- There should also be a focused effort to restore short breaks and planning for those requiring long-term out of home placements. There is little in the way of respite and summertime supports.
- There is a lack of appropriate placements and no specialist placements in NI.
- The social workers felt the frequent turnover of staff is due to high levels of pressure, as they are, "expected to do everything."
- Anxiety, sleep and behavioural issues were highlighted as areas which need pre-emptive action.

- There should be the development of more after-school clubs involving the voluntary and community sector.
- Bureaucracy and red tape leads to families not being seen in time.
- Long waiting lists are also a major issue.
- Retention of staff and regional recruitment, with more admin support required in particular.
- There is the need for a regional facility for emergency and long-term placements.
- Therapeutic intervention was also mentioned as an area which needs improved.
- Social workers also noted the need to move away from 'silo mentalities' towards increased collaboration between teams.

### **Issues identified by Parents & Carers.**

- The parents and carers strongly felt that there are not enough social workers to meet their needs. They suggested that peer support networks could be one way to bridge this gap, at least in terms of first contact and at the time of diagnosis.
- Families need wraparound support, especially outside office hours. Services need to be flexible therefore, to meet the needs of families. This support has to be practical in its approach and could be given by family liaison workers to take the pressure off social workers.
- The direct payments system also needs increased support.
- The expertise of families must be utilised to advise service development. The parents/carers think that it should be possible for them to go through training to help provide services.
- Increased effort needs to be put into social opportunities for young people with a disability as, "the children with the most complex needs have the least provision."
- All aspects of a child's life (Education, Health, and Care) should be addressed in one plan, with one trust to deliver this strategy.
- Parents also mentioned that currently, many would have to give up work to care for their child when their support ends at 18.
- They also recognised that for parents of children with disabilities, the cost of living crisis will pose an even greater economic challenge.

### **Issues identified by Children & Young People**

- The children and young people reiterated that a lack of social opportunities for those living with disabilities is a major issue. This absence of social opportunities also becomes most evident when a young person is transitioning towards adult services.
- The young people would like to receive more guidance and training when it comes to being independent and transitioning to adulthood.
- There should be increased guidance for parents.
- Youth workers could be included within social work teams.
- Better, more constructive relationships could be built between families and social workers.

- More time needs to be given for young people to get to know their social worker. Many young people can't build a relationship due to high turnover rates.

### **Issues identified by the Voluntary & Community Sector**

- The voluntary and community sector representatives stated that they are doing the work of statutory services and not receiving the same pay or funding.
- They also argued that social workers face disempowerment at every level, from practitioner to director.
- Waiting lists were again raised as an issue, especially for ASD and ADHD assessments.
- There is a lack of advocacy services, and a lack of childcare provision for children with disabilities.
- Social workers could develop their knowledge of local services further.
- Another important issue raised by the voluntary sector is that often, families remain unaware of support which is actually available to them, such as direct payments and family fund grants, as these services aren't promoted enough.

### **3.4 Plenary Discussion**

Professor Jones started the plenary discussion by highlighting some of his reflections from what he had heard and seen since he commenced the Review in February 2022. He does not see an integrated health and social care service in Northern Ireland; when you scratch the surface, he sees people working in their own groups. He hasn't met many administrative workers working with social workers, nor many social work assistants or family support workers, and he sees this as a resource which is being missed. He recognised the positive strength of professional identity in Northern Ireland but also saw social workers performing duties that could and should be performed by for example social work assistants or admin staff. He highlighted that he had struggled to find the services to provide the practical support that many families need. He proposed the idea of navigators to guide service users through the system and an advocate for when it's not working and wondered whether a regional children's social care service would provide a greater focus and consistency in services for disabled children and their families.

Other points made by attendees during the discussion included:

- The need for policy and funding to go hand in hand with education and health.
- The need for a recognition that families do not always want the intrusion of social workers.
- The way our health system plans, commission, provides and delivers services five times over for each HSC Trust. It was felt that it would be more sensible to only plan how services should operate once and implement these strategies equally across the region.
- Experts (i.e., children, young people, parents, and carers) in local areas should be recognised.

- Social workers should be present and have the capacity to listen, absorb emotional pain and be beside parents to support them at periods of difficulty. There should be a good balance between acting on urgent cases and being supportive and protective.
- Social workers should do 3 key things – 1) offer practical help, 2) be navigators, 3) provide one front door to integrated teams.
- Transition planning should start when the young person is age 14 and carry on after age 18 where appropriate.
- The importance of having familiar team support while young people and families are in contact with services.
- Social workers would benefit from having locally based behavioural support workers to help progress faster more responsive support where appropriate for a young person, rather than them being referred on a waiting list for a service e.g., CAMHS.
- The Voluntary and Community Sector could if funded, offer more support to families and to statutory services.

Some examples of health and education demonstrating good practice by working together were highlighted such as a school, which has an onsite nursery, occupational therapist, physiotherapist, and speech therapists. Professionals are also brought into the school for appointments so that pupils don't miss too much time away from lessons. Another example is that of a college which promotes working in partnership with parents and therapists.

#### **4. Conclusion**

The workshop concluded with Professor Jones and the co-chairs thanking everyone who attended, and for contributing with their experiences and views on how to improve social care services for children and young people.

#### **5. Feedback on the event**

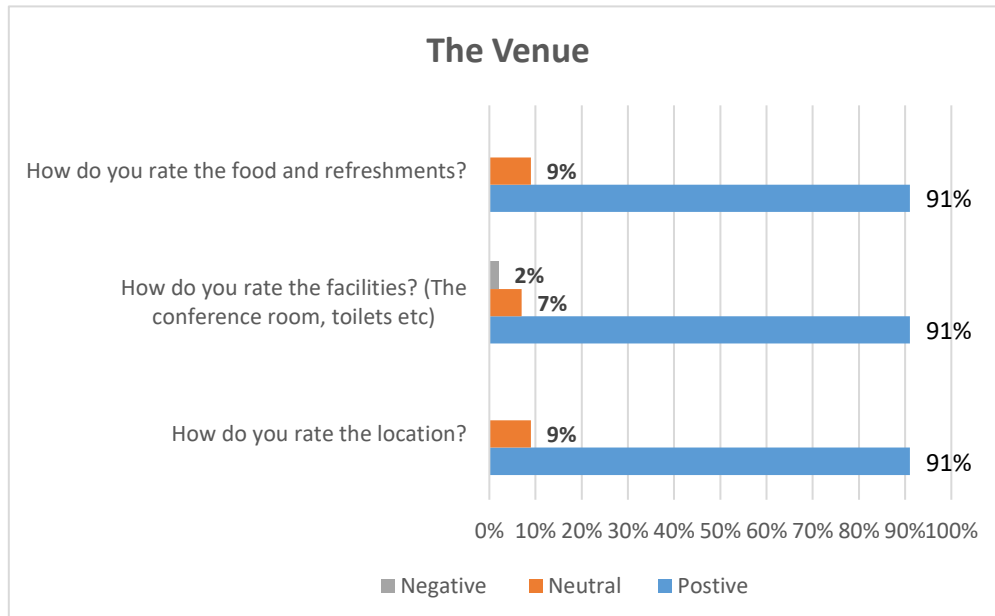
Feedback questionnaires were completed by 64% of participants and overall were very positive with 91% saying that they found the workshop to be useful in informing the Review with comments such as "*Engaging and interactive workshop. I just hope this Review will challenge and shape social care delivery in NI*"; 79% felt it was the right length and 88% of participants rating the content of the workshop positively. More detail is included at in the Appendix.

## Appendix

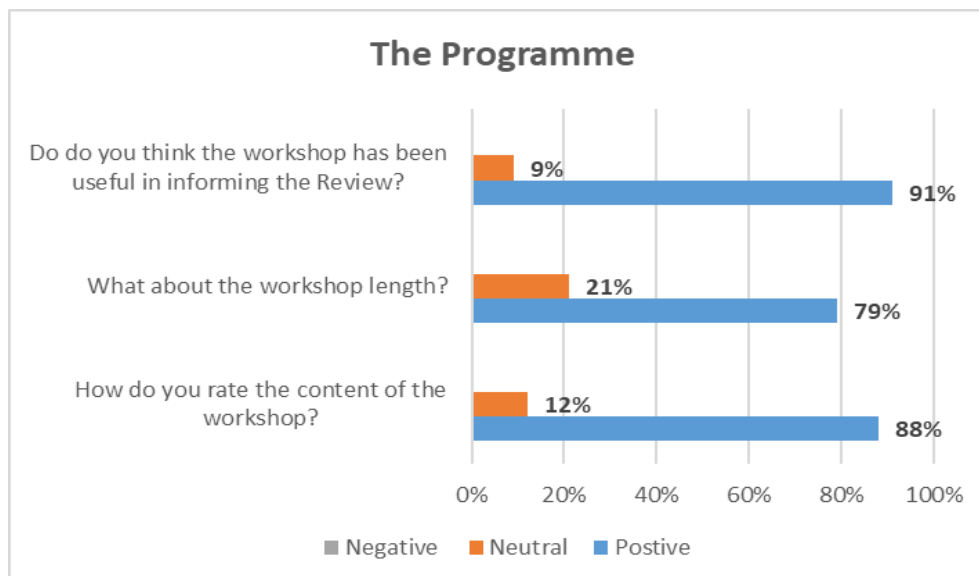
### Workshop for Children and Young People with Disabilities and their Families - Summary of Delegate Feedback

Feedback is based on collated findings provided by 64% of delegates.

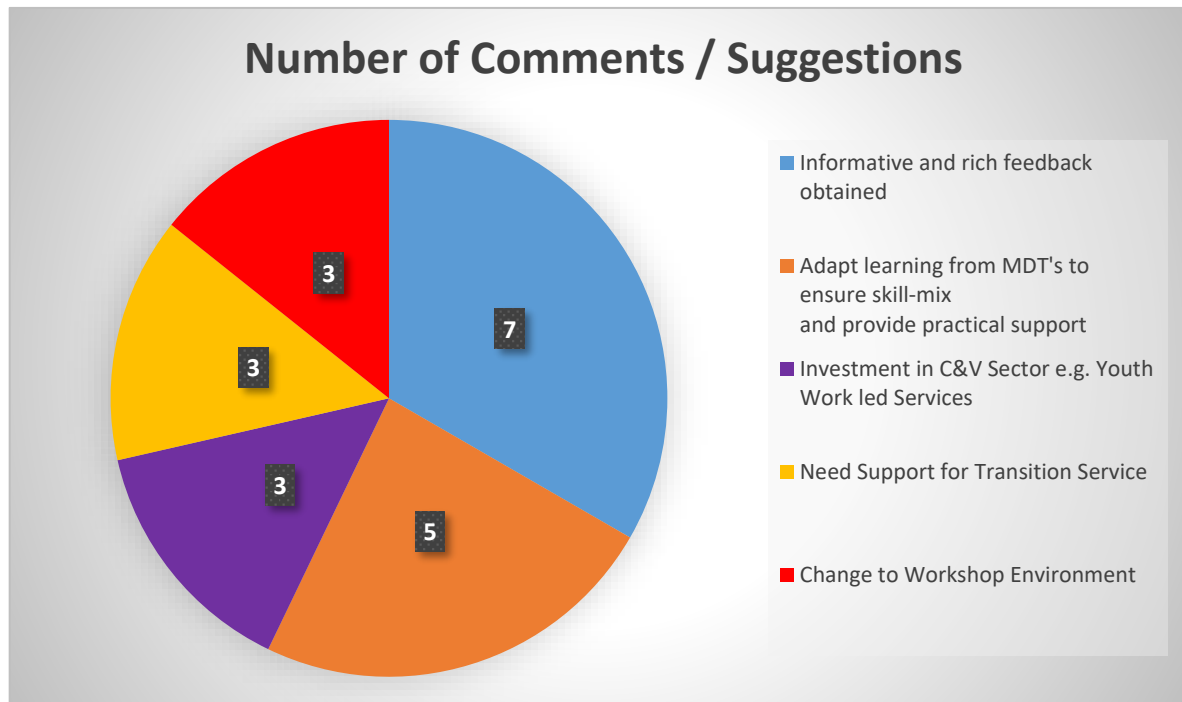
#### (i) The Venue



#### (ii) The Programme



(iii) Comment / Suggestions Analysis



(iv) Comments and Suggestions

*The richness of the voices of YP and parents/carers and sw staff would be valuable to disseminate sooner, rather than later. I'd like to share with my students – Lecturer in Social Work*

*Engaging and interactive workshop. I just hope this Review will challenge and shape social care delivery in NI – Employment Officer*

*When services are reviewed, intervention should involve people with disabilities before being recommended so that harmful or deficit focused services are not used. e.g. Autistic Community do not recommend ABA as it has caused PTSD and is around teaching children to comply. Anecdotal evidence from people with disabilities needs listened to rather than dismissed in favour of ABA Practitioners – Service Manager*



*Mixed tables would have been preferred instead of each 'category' being seated together. I think I would have been more productive. I also would have liked more young people and parents to have spoken. Parental contribution from Marian Bradley was the most important to hear regarding improving services – Service Manager*

*Youth work led respite services would provide a break for parents focusing on young people's development, achievement and opportunities to develop peer relationships to reduce social isolation – Service Manager*

*A very informative day. Great to hear the voices of young people, parents and carers given such careful consideration. Great to get an update on the direction of the Review Team – CiNI Facilitator*

*It was good to see Ray, he adapted common sense to complex issues. Practical help and development of specialist services e.g. transitioning are extremely important – Parent*

*Hoisting and changing bench facilities need to be added to this excellent venue. Give more money to support community and voluntary services and less to statutory services. Ray your outline is excellent. You are on the perfect, right track. Thank you, I'm delighted I felt heard – Parent*

*Loop system not working. It doesn't appear to be connected to any microphone or speaker facilities - Researcher*

*2 points to consider:*

*MDT's in primary care, have social workers and health visitors on the team. They work a lot with families who have children with disabilities that are struggling.*

*Learn from multi-professional teams in Adult Services. In reality they become nursing and social work teams as psychology, medicine. AHP's demand professional line management – Policy Maker*

*I think more thought needs to be given to the Community and Voluntary Sector. Youth Centre's need to be fit for purpose with up skilled staff and changing facilities. Less stress on targets and more effective work – Service Practitioner*

*Really useful to hear initial thoughts how service provision can be delivered. The changes suggested target the particular need for ensuring that families and children can access the right door at the right time. Service delivery is targeted at provision of support so child protection services can be ring fenced for children in need of protection. Really useful afternoon, thank you – Inspector*

*I believe staffing levels across all bands and retention of staff needs to be a focus – especially staff who know and want to work with disability. There is a need for more resources e.g. an emergency regional unit for the most complex and in crisis children to ensure early intervention – Service Practitioner*

*Brilliant to hear from the young people who spoke and also an interesting insight into the day of a social worker – Parent / Carer*

*As a social worker, I agree with Ray's comments. Social workers would all prefer to be working alongside families providing practical support. Radical change is required in order to reduce bureaucracy - Service Manager*

*Excellent workshop, more of these are needed. Communication needs improved between social workers in different Trusts to reduce inconsistencies in practice. Integrated teams sharing a good skill-mix between different health and social care professionals is the way forward, to be more responsive and proactive in providing practical support to parents, children and families.*

*Reduce 5 Trusts to 1! There used to be 17/18 Trusts. Time to provide more practical support to families – Service Manager*

*A thought-provoking workshop – Service Manager*

*Good balance between parental view and social work view. Southern Trust had a 14 years – 25 years Transition Team until 6 years ago. This worked well until Adult Services developed an Adult Transition Team that took over from 18 years. This led to silo mentality and budgets. Need for Adult Services to get serious about working across traditional boundaries for better outcomes for people. Needs to be based on research evidence and best practice – Service Manager*

*Important to learn the lessons of multi-disciplinary line management from adult services – both positive and negative experiences – Policy Maker*

*Great workshop, good opportunity to meet others in different Trusts and hear from other perspectives. Very insightful! Looking forward to reading the Review. Southern Trust – massive issues with Transition Team and no support being offered – massive impact on families. Early intervention and behaviour support is required. All my families are at breaking point due to challenging behaviours beyond parental control. If we had specialist supports, we could access this which could significantly impact families. Only behaviour we can access is CAMHS which has long waiting lists. No social work assistants on team – 1 family support worker – more needed! - Service Practitioner*