

## **Regional Event Report**



### **Complex Needs Supports: 'Responding Together'**

**7th September 2010**

**Beardmore Conference Centre  
Glasgow**

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## Participating Organisations

**A list of event attendees will be appended to this Report. However, the following Organisations were represented at the event**

Aberlour Child Care Trust  
A.D.S.W.  
Changed Days Independent Advocacy Project.  
Choices Care  
C.V.O. (East Ayrshire)  
Dumbarton Day Centre  
East Ayrshire Council  
East Renfrewshire CHCP  
East Renfrewshire Council  
Enable  
Glasgow City Council  
Glasgow West CHCP  
Glasgow South West CHCP  
Key Community Supports  
NHS Ayrshire and Arran  
NHS Dumfries and Galloway  
NHS Greater Glasgow and Clyde  
Partnership with people with profound learning disabilities and their carers  
Scottish Government  
The Mungo Foundation  
Turning Point Scotland  
West Lothian Council  
You First Advocacy

# Background and Context

## Background

'Delivering For Mental Health' (2006) informed the Scottish Government Mental Health Division's Mental Health Delivery Plan in its intention that, 'people with learning disability who have challenging behaviour and mental health needs require improved access to evidence based support and services'. Additionally, there was a commitment to develop both Local and Regional networks to share, inform and develop positive practice and responsive services. In light of these aims, the Mental Health Division established a working group in 2007, which was made up of appropriate representatives from NHS Boards, Local Authorities, Voluntary Organisations and Regulatory bodies.

The group, entitled the 'National Co-Morbidity Working Group', chaired by Professor Alex McMahon, initially focused on the use of In-Patient and related services for people with a learning disability with mental health needs, and convened a National Conference in February 2008, to consider responsive/effective service models and the required future service developments for this client group. What emerged from the outcomes of this Conference was a widening of the remit of the group to consider the scope of services for people with a learning disability with challenging and/or offending behaviours and/or autistic spectrum difficulties. A work plan, informed by the outcomes of the Conference, was developed, which included the aspiration to identify the most responsive models of service for this client group via a detailed analysis of existing International, National and local service models and from these identify key service model elements/characteristics.

The group produced an outline of 22 Key Service Model characteristics, which informed both the content and intended outcomes of a follow-up event entitled 'The Scottish Responses to Challenge and Complexity' ; a National Conference geared to address some of the service model questions and issues raised following the previous 2008 event. Feedback and developments from this event appeared to be very positive, and the predominantly theoretical service modelling work took on a greater practical/operational resonance with it informing the Joint Improvement Team's Learning Disabilities Partnership Support and Development Programmes.

Having determined that it had achieved what it set out to do, and that its original intentions were being continuously developed through other existing structures and fora, the Co-Morbidity group held its last formal meeting in January 2010. The Mental Health Division had made a commitment to run another National event in March 2010. However, it was agreed that a more appropriate way forward would be to hold 3 Regional events in the early Autumn of 2010, to present the final outcomes of the group's work, aligned with the related 'on the ground' developments of the J.I.T. partnership programmes and other related work streams.

## Context

### **The Joint Improvement Team Learning Disabilities Partnership Support and Development Programmes**

Since 2008, the Joint Improvement Team has been engaged in extensive work across a number of areas in conjunction with people with a learning disability, their carers and service providers, to establish a vision, direction and development in those services which seek to support people with a learning disability and their families. This programme of work has demanded that it be based upon, and informed by, up-to-date and comprehensive, evidence-based data regarding individual needs and future service demands, emergent populations, current resources, resource utilisation, and associated financial information. To date this work programme has been supported primarily by two J.I.T. developed documents; the 'Commissioning for Change Workbook' (2008),

see <http://www.jitscotland.org.uk/toolkits/capacity-to-change/learning-disabilities/>

and the toolkit entitled '7 Steps to outcomes based commissioning support and services for people with learning disabilities '

see <http://www.jitscotland.org.uk/toolkits/improving-outcomes-info/>

The latter document has undergone a recent revision, and a review of the former is in progress. The learning disability partnership support and development programmes have to date involved 6 N.H.S. Board areas and 13 of their Local Authority partners. All have undertaken joint service review and development by using the JIT Workbook to populate and refine data regarding current service access, resources and projected future demand. In terms of specific client group, and/or service specific focus, partners have been supported in the review and development of a number of determined priorities including the following;

- Definitions of complex support needs – people with profound and multiple disabilities, autism spectrum disorder, challenging and offending behaviours and mental health issues
- Service options appraisal and service modelling for the above client groups
- Day services review
- Service commissioning review
- Review of service providers
- Review of Out-of-Area placements and consideration of alternative local service models
- Review of utility of Telecare supports
- 'Pilot' of Integrated Resource Framework (I.R.F) for people with complex needs
- Service transitions – including a recent paper developed by Dr. Sally

Cheseldine for the JIT

See - <http://www.jitScotland.org.uk/action-areas/commissioning/>

The JIT learning disability partnership and development programmes are detailed in a work-plan which is reviewed and updated on a bi-monthly basis through the JIT Learning Disability Action Group. This group has membership from both within and out-with JIT in recognition of, and accordance with, related work-streams, organisations and agendas, including;

- Community care outcomes framework
- Integrated Resource Framework
- Delayed discharge, including 'complex' delays
- Telecare supports
- Managed Care Networks activity and Models of Care Project
- N.H.S. Quality Improvement Scotland
- The Same As You Implementation Group
- Mental Health / Adult Support and Protection Division
- Association of Directors of Social Work (A.D.S.W)
- N.H.S. Education for Scotland (N.E.S)
- Scottish Consortium for Learning Disability (S.C.L.D.)

For further information on the JIT Learning Disabilities Partnership Support and Development Programmes, contact;

Mr. Alex Davidson, JIT Associate – [alex.davidson6@btinternet.com](mailto:alex.davidson6@btinternet.com)

Dr. Martin Campbell, JIT Action Group Member – [mc1@st-andrews.ac.uk](mailto:mc1@st-andrews.ac.uk)

Mr. Michael McCue, JIT Action Group Member – [pittsburgh@sky.com](mailto:pittsburgh@sky.com)

# Event Organisation, Aims and Objectives

## Organisation

The 3 Regional events were organised and structured to allow the outcomes of the Co-Morbidity group service modelling work and related work streams around its original client group focus, to be utilised to develop service responses within a regionally specific geographical and operational context.

It was intended to hold these events in 3 areas;

1. East of Scotland to accommodate service users, carers, NHS Boards and their partners from the Tayside, Forth Valley, Lothian, Borders and Stirling areas.
2. West of Scotland to accommodate Glasgow and Clyde, Dumfries and Galloway, Lanarkshire and Ayrshire.
3. North of Scotland to accommodate Grampian, Highland, Western Isles, Orkney and Shetland.

Whilst being aware of the inability to satisfy all prospective attendees in terms of the geographical location of the events, it was decided, (based on value for money and public transportation arrangements) to hold the East event in Dunfermline, the West event in Glasgow and the North event in Aberdeen.

Both the Glasgow and Aberdeen based events moved fairly quickly to full subscription, but in contrast, the Dunfermline event remained well under subscribed, even nearing its date, and it was decided, reluctantly but for reasons of cost efficiency, to cancel it and offer those individuals who had expressed an interest in attending, alternative places at either the Glasgow or Aberdeen event.

It was intended that the morning session would be replicated across the 3 areas, and would focus on a series of short but informative presentations around strategic, operational and service evaluative innovations and good practice in service responses to people with a learning disability who have complex support needs.

The afternoon sessions were planned to be workshop-based and intended to build as logically and seamlessly as possible from the outcomes of the 2009 National Conference in terms of regionally/locally relevant service challenges and solutions.

It was intended that the events would be both informed and directed by a process of prior consultation with key individuals from each area and a process of information gathering to ensure regional/local context and resonance.

In order to realise this objective, three separate questionnaires were developed around the key 'themes' of the presentations and workshops, namely ; service transitions (child to adult services), people with profound and multiple learning disabilities (P.M.L.D.), and other complex needs such as challenging behaviour and mental health issues.

The questionnaires were 'distilled' from key service model characteristics produced from research into service models relating to each key theme, and were designed to capture a general sense of the extent to which current service responses were meeting each key characteristic. Questionnaires were requested to be circulated widely across service user networks, carers and services within each partnership area and were designed to be returned anonymised. Copies of the original questionnaires are appended to this Report.

There was an ambition to ensure the desired 'width' of service user/carers, organisational and operational representation of attendees required to produce the service review, re-configuration and development intentions of the events. Detailed Workshop facilitation guidance and a statement of clear desired aims were prepared, to help generate as productive and developmental outcomes as possible. Additionally, the 80 delegates were divided by both organisation and/or geography, in order to realise the variation in role, remit and experience required to generate the desired 'balance' in outcomes of the workshop sessions.

## **Event Aims and Objectives**

The purpose of this event is to consider local and regional services and supports for people with a learning disability who have Complex Needs; including those with P.M.L.D., mental health difficulties, autism spectrum disorder and challenging/offending behaviour.

The event is intended for service users, carers, service planners, commissioners, providers and evaluators and aims to build logically and strategically upon previous events regarding National service responses to challenge and complexity held in 2008 and 2009.

The event will include presentations regarding developments in, and reflections on, educational, workforce and strategic planning; commissioning; operational delivery and evaluation of, services for people with a learning disability who have complex support needs.

Additionally, the event will include a series of interactive workshops focussed on the review of local and regional models/systems of service response, and on the development of these within the context of locally/regionally specific service requirements; effective service characteristics and a climate of challenging resources.

This event will be one of 3 Regional events intended to generate responsive local/regional service developments and subsequently inform an 'aggregated' National profile of service responses to the support requirements of people with a learning disability who have complex needs.

## Event Programme

- Chair for Day**     **Dr. Margaret Whoriskey, Executive Director, J.I.T.**
- 10.00 – 10.10**     Welcome, Introduction and Scene setting  
**Dr.Margaret Whoriskey/Michael McCue**
- 10.10 – 10.30**     The Challenge of Service Transition  
**Dr. Sally Cheseldine - J.I.T. Action Group**
- 10.30 – 10.55**     The Changing Demography of People with Learning Disabilities  
**Ms. Elaine Kwiatek - Project Manager LD M.C.N**
- 10.55 – 11.15**     The Workforce Challenges  
**Tommy Stevenson - NHS Education for Scotland**
- 11.15 – 11.30**     The Workshops : origin, intention and outcomes  
**Michael McCue - J.I.T. Action Group**
- 11.30 – 11.45**     **Tea / Coffee Break**
- 11.45 - 12.30**     **Workshop Session focussed on Service Transitions**  
*Opportunity for people to participate and contribute to their understanding of the key service challenges/issues relating to service transition.*
- 12.30 – 13.15**     **Lunch**
- 13.15 – 14.15**     **Workshop Session focussed on services for people with PMLD.**  
*Opportunity for people to participate and contribute to their understanding of the key service challenges/issues relating to people with P.M.L.D.*
- 14.15 – 14.30**     **Tea / Coffee Break**
- 14.30 – 15.30**     **Workshop Session focussed on services for people with other Complex Needs**  
*Opportunity for people to participate and contribute to their understanding of the key service challenges / issues relating to people with other complex needs ; including autism, challenging / offending behaviour and mental health needs.*
- 15.30**                 **Close**

## Welcome, Introduction and Scene Setting

Dr Margaret Whoriskey, Executive Director of the Joint Improvement Team, opened the day by presenting an introduction to the background, context and aims of the event. Mr Michael McCue, J.I.T Action Group, then briefly addressed the following key points (text with further information on these in the preceding 'Background and Context' section of this report);

- National Working Group on Complex Needs (2007-2010)
- Service Modelling Exercise
- Key Service Model Characteristics
- J.I.T. Learning Disability Capacity for Change Programmes
- Related work-streams

## Event Presentations ;

Since full copies of the event presentations have already been forwarded to delegates/attendees, it is not intended to provide a comprehensive account of these in this report. Rather, the key points of each presentation will be considered.

### Presentation - 'The Challenge of Service Transition'

**Dr. Sally Cheseldine - J.I.T L.D. Action Group**

Sally's presentation was based on a paper she prepared for the J.I.T. which has previously been referenced in this report.

Sally began her presentation by re-iterating a question posed by Professor Peter Mittler, in 2007 ;

***' Why is it so difficult to put ( good transitions ) into practice ? '***

Sally then addressed her key issues as follows ;

**WHO** are we talking about

**WHAT** does a good transitions process look like ?

**WHAT** range of services are required ?

**WHO** pays for this ?

EVALUATION and REVIEW

Sally condensed her key considerations to the following points;

There **must be** a clear pathway for service transitions

There **must be** clarity over funding

There **must be** adequate and accessible information for families

There **must be** service user involvement

There **must be** engagement from Adult services

## **Presentation - ‘The Changing Demography of people with learning disabilities ’**

**Elaine Kwiatek, Project Manager, Learning Disability M.C.N.**

**N.B.** Elaine’s presentation was jointly prepared with Dr. Michael Brown, Lecturer and Nurse Consultant, Edinburgh Napier University.

Elaine began by outlining the aims of the presentation;

Overview of demographic issues

Overview of health needs evidence

Workforce issues (also relating to Tommy Stevenson’s presentation)

Future challenges and opportunities

Elaine continued by considering the wider determinants of health and well being, including poverty, before focussing upon the main issues regarding the changing demographics of the learning disability population, including ;

A projected 11% increase over the next 10 years

An ageing learning disability subpopulation

An increasing number of people with complex support needs

The major health support needs of people with a learning disability

The presentation moved on to consider the UK Nursing workforce issues in terms of supporting people with a learning disability, particularly those with complex needs. Elaine discussed the retracting, and ageing LD nursing workforce, and the importance of recruitment, retention and workforce planning within a context of an increased demand for services and specialist skills. Elaine continued by discussing the Centre for Disability Research at Lancaster University and their findings regarding the changing demands for services and care supports. Elaine’s presentation concluded with a reflection upon the current situation;

Increase in co-morbid health issues for people with a learning disability

Increasing demand on mainstream healthcare services

Increased demand on specialist services

Increased demand challenged by limited resources

..before closing with a consideration of the future direction of services.

## **Presentation - 'Developing the workforce in learning disability services'**

**Mr Tommy Stevenson, Educational Project Manager, NES**

Tommy opened his presentation by outlining the aims of the project he is currently managing at NHS Education for Scotland;

To analyse data on the educational needs of the current workforce linked to models of care

To work with partners to identify existing educational provision and identify short medium and long term gaps

To produce a report for the consideration of partners, on the future direction of learning disability health services and workforce needs

To commission appropriate educational resources

Tommy went on to discuss the strategic drivers behind the project as well as the principal care groups it was intended to address. The initial stages of the project were considered against the current backdrop of ongoing and related work streams. Tommy continued by reflecting upon prospective factors for success, consultation with the workforce in terms of the outcomes of the project 'task and finish groups' and inter connected activity. There followed a consideration of related issues and care groups, including;

General healthcare

Voluntary and private providers of services

The needs of children and younger people

Complex support and complex healthcare support needs

Educational and service investment and pro-activity

Effective management of information

Lessons from other services / initiatives / experiences

Tommy concluded his presentation by reinforcing the requirements of maximising workforce capability and ensuring visible and robust workforce leadership.

## **Introduction / Bridging to the Workshops - ‘ Origin, Intention and Outcomes’**

**Mr Michael McCue - JIT LD Action Group**

Michael gave a brief overview of the origin of the event workshops, which largely related to the subject matter contained in the 'Background' and 'Context' section of this report. Additionally, Michael emphasised the 3 major themes of the workshops;

- Service Transitions
- People with who have profound and multiple disabilities
- People with other complex support needs

The main intentions of the workshops were to;

- Present and consider local and national perspectives on the 3 'themes'
- Generate and agree on key service challenges / issues
- Generate potential service developments / 'solutions'

The main outcomes of the workshops aspired to be;

- To inform the work of the Joint Improvement Team and other related work streams
- To produce brief regional event reports
- To promote positive local and regional 'networking'

To inform each of the workshop sessions, short questionnaires were prepared in relation to each of the workshop 'themes'. These questionnaires were based on a number of key service model characteristics developed from service review and modelling work conducted around the three workshop 'themes' of service transition, people with profound and multiple learning disabilities and people with a learning disability with other complex support needs (copies of these questionnaires are appended to this report). The set of 3 questionnaires was distributed to health board areas and their key partners in advance of the regional events, alongside a request that these be distributed as widely as possible across their services. Whilst the response returns were not comprehensive - a total of 15 completed questionnaires from 4 areas targeted by the Glasgow regional event - there were, nonetheless, sufficient returns received to usefully inform the workshop discussions and outcomes.

## Workshop Session - 'Service Transitions'

*Opportunity for people to participate and contribute to their understanding of the key service challenges/issues relating to service transition.*

Questionnaire returns relating to the 'service transition' theme for the Glasgow event, identified 'issues' around questions 7,10,16 and 20 in the questionnaire. Workshop discussions around these questions and additional service issues / challenges produced the following key points (each workshop group (of 5 groups) was requested to identify a minimum of 3 major service issues / challenges relating to the workshop theme) ;

### **Main Challenges/Service Issues :**

- Need for even stronger consultation with service users and carers
- Service vision needs to be 'shared' at all levels
- National variance in service response creating 'postcode lottery'
- Need for better definitions around transitions to facilitate better service planning
- Need to start transitions planning around age 14 years
- Named persons responsible for transitions planning and co-ordination
- Transparency around service commissioning process is critical
- Services accessed as a child should 'bridge' into adulthood where required
- Evaluation of services should be more focussed on outcomes for users of services
- Risk aversion impacts on individuals with more complex support needs – are their needs 'the same as you ?'
- Use of different professional / organisational language and service access age criteria are major hindrances to effective service responses
- Support and service needs actually increase for many children as they get older
- Services should not be divided between children and adult services – they should be continuous
- Given the importance of effective data/information sharing, there are too many apparent organisational/procedural barriers in place
- Parents and other family carers can play an important role in the training of service care staff
- Out of area placements can be challenging to carers in terms of their responsiveness once individuals return to the home or 'within area' again – this in itself is a transition
- Variation in school leaving ages hampers transition processes
- Include service users and carers in joint planning and joint working processes
- Improve interface between adult services and education
- Educational 'outreach' services should be better resourced and developed
- Service users, carers and families should be more 'in control'

- Some criteria around service transitions can be ‘incompatible’
- More ‘active’ processes should be utilised to support transitions – co-ordination and services around the child approaches
- The longer term benefits of ‘getting it right’ / prospective costs of ‘getting it wrong’ at service transition stage should be made more explicit

Additionally, workshop groups were requested to identify at least one and no more than three, service/organisational/strategic responses which might address those challenges/issues identified.

Those produced were;

### **Potential Solutions :**

- Joint strategic planning and resources based on thoroughly assessed needs
- Begin transition planning process at 14 years at the latest
- Have named persons responsible for transition planning and co-ordination processes
- Start financial planning for transitions at or around age 14 years
- More formal research/analysis of good practice and service innovation
- Involve all prospective service providers in transition planning
- Involve service users and family throughout the transition process and beyond

### **Workshop Session - ‘ People with P.M.L.D.’**

*Opportunity for people to participate and contribute to their understanding of the key service challenges issues relating to people with P.M.L.D.*

Questionnaire returns relating to the ‘People with profound and multiple learning disabilities’ theme for the Glasgow event, identified ‘issues’ around questions 3, 9, 11, 12, 15 and 18 in the questionnaire. Workshop discussions around these questions and additional service issues / challenges produced the following key points (each workshop group (of 5 groups) was requested to identify a minimum of 3 major service issues/challenges relating to the workshop theme);

### **Main Challenges / Service Issues :**

- Access to community services still compromised by insufficient sensitivity to needs
- Liaison nurses should be based in hospitals rather than the community
- Interface with acute services still under-developed and insufficiently responsive
- Need for more independent advocacy services for people with P.M.L.D
- Need for engagement of Housing to realise more suitable planning and

provision

- Need to consider cost/benefits of individual accommodation versus shared living arrangements
- Still a lack of access to meaningful activities / opportunities to access services for people with P.M.L.D
- There is a role for good care management
- Some families do not necessarily wish integration in services due to concerns regarding support and management of risk
- There is considerable 'inequity' in service quality, provision and access across the country and within localities
- Acute care services should take more operational and financial responsibility for care supports relating to periods of ill health
- Professionalism and the reluctance to perform key support skills a major issue
- Self-directed supports could be used more widely, effectively and equitably
- Services are insufficiently orientated towards 'enabling' service users to maximise independence and reduce overall dependency where able
- Choices for people with P.M.L.D. are much more restricted than for other service user groups
- Care providers still appear 'under-developed' in terms of skills and competencies required to support people with P.M.L.D. safely and effectively
- There should be a form of complex needs 'register' with community based services to identify needs, vulnerabilities and ensure responsive communications between services
- There are real workforce challenges across the board in terms of supporting people with P.M.L.D
- There is a lack of specialist expertise in medical/health services for people with P.M.L.D
- There remains a significant lack of a 'values' base to service planning and delivery for people with P.M.L.D

Again, workshop groups were requested to identify at least one and no more than three, service/organisational/strategic responses which might address those challenges/issues identified.

Those produced were;

### **Potential Solutions :**

- Involve service users, carers and families in care staff training
- Use personal communication passports and other individually sensitive 'media' to realise effective supports and access to services
- The positive outcomes of Self Directed Supports should be made more evident and available to service users and families
- Establish systems / networks for the distribution / sharing of good practice
- All services and facilities should recognise their responsibilities to

- 'accommodate' people with P.M.L.D and be held accountable for demonstrating these
- Use more independent advocacy services to put forward service user voice

## **Workshop Session - ' People with other complex needs'**

*Opportunity for people to participate and contribute to their understanding of the key service challenges issues relating to people with other complex needs; including autism, challenging/offending behaviour and mental health needs.*

Questionnaire returns relating to the 'people with other complex needs' theme for the Glasgow event, identified 'issues' around questions 1,2,5,6,8 and 9 in the questionnaire. Workshop discussions around these questions and additional service issues/challenges produced the following key points (each workshop group (of 5 groups) was requested to identify a minimum of 3 major service issues/challenges relating to the workshop theme)

### **Main Challenges / Service Issues :**

- Issue of adherence to care plan is vital, if challenging
- Practice leadership essential
- Environments must be compatible with service users support needs and 'fit for purpose'
- Staff recruitment, training and retention is a major service challenge
- Effective communications systems often compromised by professional/organisational protocols and/or boundaries
- Continuous review of responsiveness of care package essential
- Services require to be flexible enough to respond to crises/escalation in challenges
- Local service responsiveness requires to be developed
- Values need to be explicit, shared and supportive of service responses
- Crises need to be anticipated and planned for
- Personalisation in services for people with challenging and complex needs may be particularly difficult to realise without considerable focus
- Rural areas have distinct and amplified service challenges which need to be recognised and responded to
- Resource flexibility is a major challenge but valuable service response
- Services for this user group need to be part of a continuum, with agreed eligibility criteria and protocols for access / egress
- Service user involvement remains under developed for this user group
- Workforce and succession planning are crucial to the sustainability and planning of services
- Incentives for staff retention and professional / personal development are under invested in
- Need to consider culturally sensitive service responses for this user group

- Housing – availability and suitability is crucial and there is a need for involvement at very early stages in planning and throughout service delivery
- Risk management strategies must be supported by multi-agency agreement and based on individual support needs
- Care staff competence and skills demand continuous audit, planning and investment
- Supports to access occupational, employment and recreational activities are crucial to the sustainability of the overall service package

Yet again, workshop groups were requested to identify at least one and no more than three, service/organisational/strategic responses which might address those challenges/issues identified.

Those produced were;

### **Potential Solutions :**

- Develop ‘systemic’ strategies to address service and workforce challenges
- Maximise the role of service users, carers and families in care staff training
- Develop shared learning and shared training opportunities across services and organisations
- Involve Housing services throughout service planning and development given the importance of ‘fit for purpose’ environments and location
- Develop national and local mechanisms for joint organisational planning and delivery of services for this user group
- Some services may be ‘shared’ in terms of resourcing and delivery, for example, crises responses
- The challenges faced by rural and remote services demand particular focus and innovation
- Good practice needs focused research and sharing between services
- Services should consider outreach / in-reach responses to ensure appropriate access to and egress from specialist facilities

### **‘Aggregated’ service challenges / issues / solutions**

The following represent those challenges / issues and solutions common to all three workshop ‘themes’ of service transitions, people with P.M.L.D and those with other complex needs ;

#### **Challenges / issues**

- **Professional/Organisational barriers to information sharing**
- **Lack of workforce skills and competencies**
- **Lack of joint working systems/whole systems approach**
- **Geographical variance in quality of service provision/response**

- **Lack of user/carer/family involvement**

### **Solutions**

- **Nationally/locally agreed processes and procedures**
- **More shared research and service innovation**
- **Joint strategic planning, service delivery and evaluation**

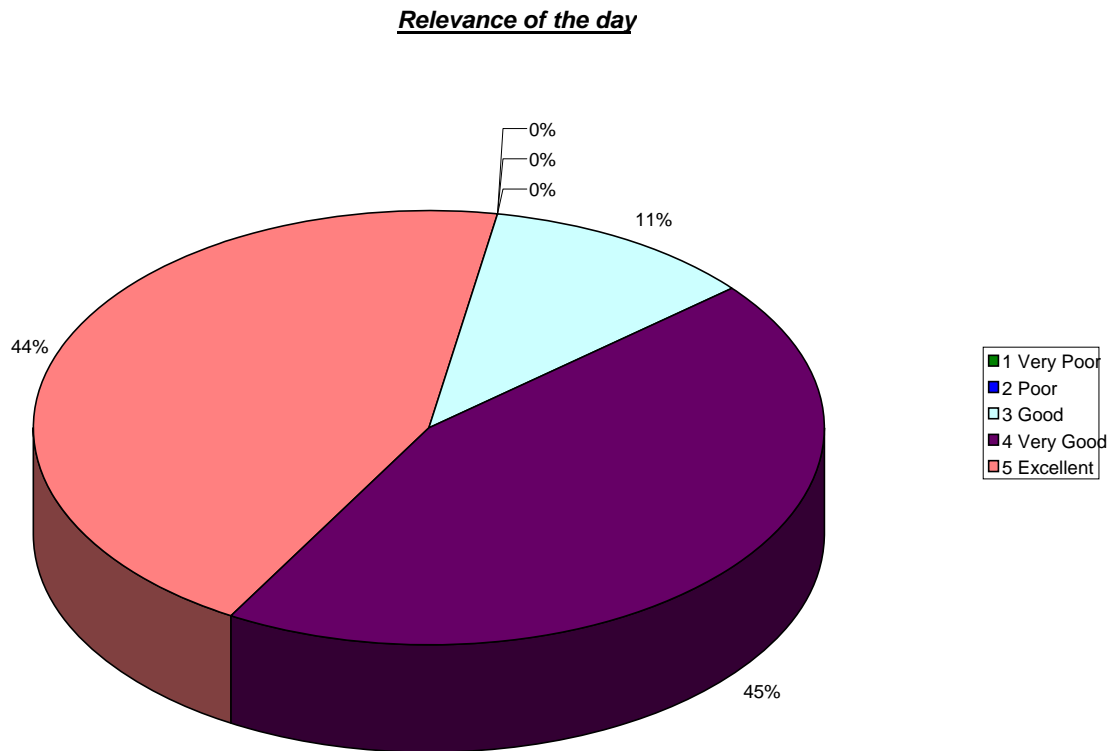
## List of Participants / Attendees – Glasgow Event

Name	Organisation
Anne Barton	
Susan Bigger	South West CHCP, Pollock
Margaret Brenan	Renfrewshire Council
Fiona Brown	Renfrewshire Council
Jayne Buchanan	The Mungo Foundation
Margaret Caldwell	Cosgrove Care
Claire Carswell	CVO (EA) Ltd
Charlie Coggrave	GCC
Bernadette Collins	Renfrewshire Council
Stephanie Crawford	NHS
Maureen Dale	GCC
Alex Davidson	JIT
Gillian Duffy	Choices Care
Margaret Elby	You First Advocacy
Joe Fagan	CVO (EA) Ltd
Laura Farquhar	CVO (EA) Ltd
Joan Fraser	Changed Days Independent Advocacy Project
Frances Fullarton	North Ayrshire Adult Services
Arthur Fulton	West Lothian Council
Linzi Galbraith	CVO (EA) Ltd
Mark Gallagher	NHS GCC
Margaret-Anne Gilbert	Scottish Government
Irene Hackett	Aberlour Child Care Trust
Tom Hammond	NHS Forth Valley
Nicola Hanssen	East Renfrewshire Council
Katriona Hendry	Renfrewshire Council
Suzi Ives	South West CHCP, Pollock
Nicky Jenkins	North West Kilmarnock Area Centre
Peter Jung	Turning Point Scotland (charity)
Lorraine Kane	GCC
Ronald Kane	Turning Point Scotland (charity)
Eugene Kelly	South West CHCP, Pollock
Elaine Kwiatek	NHS Forth Valley
Mary Kennedy	East Ayrshire Council
Valerie Kerr	GCC
Steven Leighton	Renfrewshire Council
Linda Lightbody	Renfrewshire Council
Carol Lindsay	Fife Council

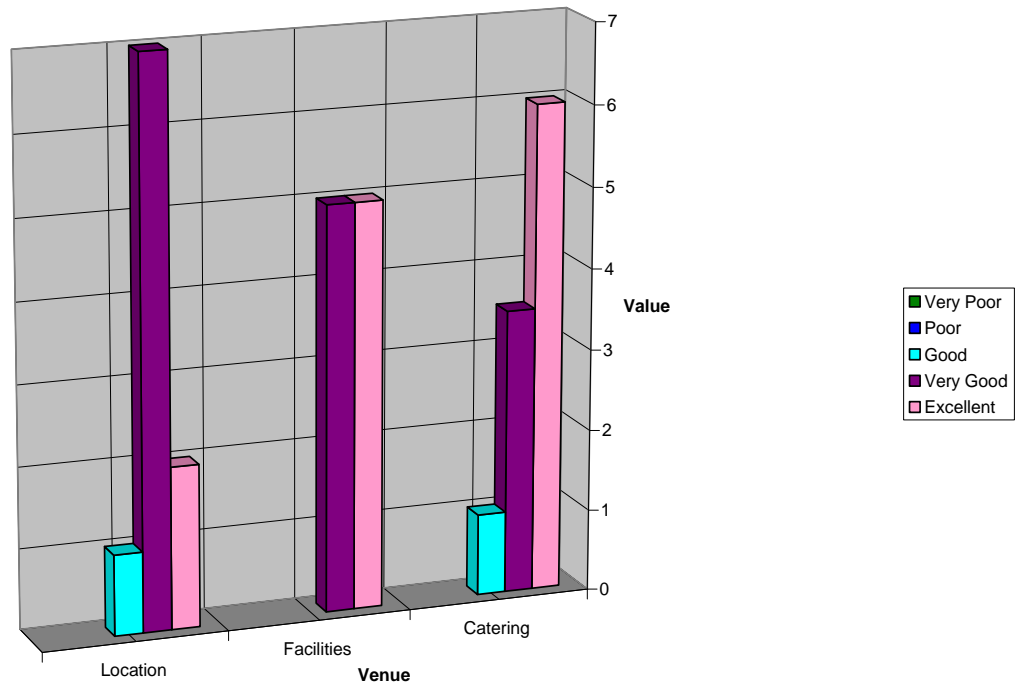
Claire Logue	The Mungo Foundation
Maree Love	East Renfrewshire Council
Sharon Lowe	Renfrewshire Council
Paul MacArthur	Key Community Supports
Kirsty MacKenzie	Enable
Rhoda MacLeod	Glasgow Council
Faye Masterman	Renfrewshire Council
Elizabeth Matheson	Complex Needs Supports Team, Glasgow
Marion McArdle	Parent
Michael McCue	JIT Action Group
Peter McCulloch	Renfrewshire Council
Beth McGeehan	Ayrshire Central Hospital
Dr Robin McGilp	Berryknowes Resource Centre
Paul McKenna	Renfrewshire Council
Yvonne McLeave	You First Advocacy
Tracy Morris	Turning Point Scotland (charity)
Paul Nolan	Crichton Hall
Jim O'Rourke	North Ayrshire Adult Services
Amy Phillips	JIT
Liz Platt	PAMIS
Kate Quinn	Dumbarton Day Centre
Ann Rafferty	Renfrewshire Council
Sharon Reilly	The Mungo Foundation
Margaret Rhodan	Renfrewshire Council
Jane Rolling	Changed Days Independent Advocacy
Neill Simpson	NHS GCC
Jim Smith	NHS Ayrshire and Arran
Tommy Stevenson	NES
Amanda Taylor	West CHCP LD Service
James Thomson	GCC
Cindy Wallis	East Renfrewshire CHCP
Ian Williams	Just Connections, Partners for Inclusion
Margaret Whoriskey	JIT

## Feedback from evaluation questionnaires ;

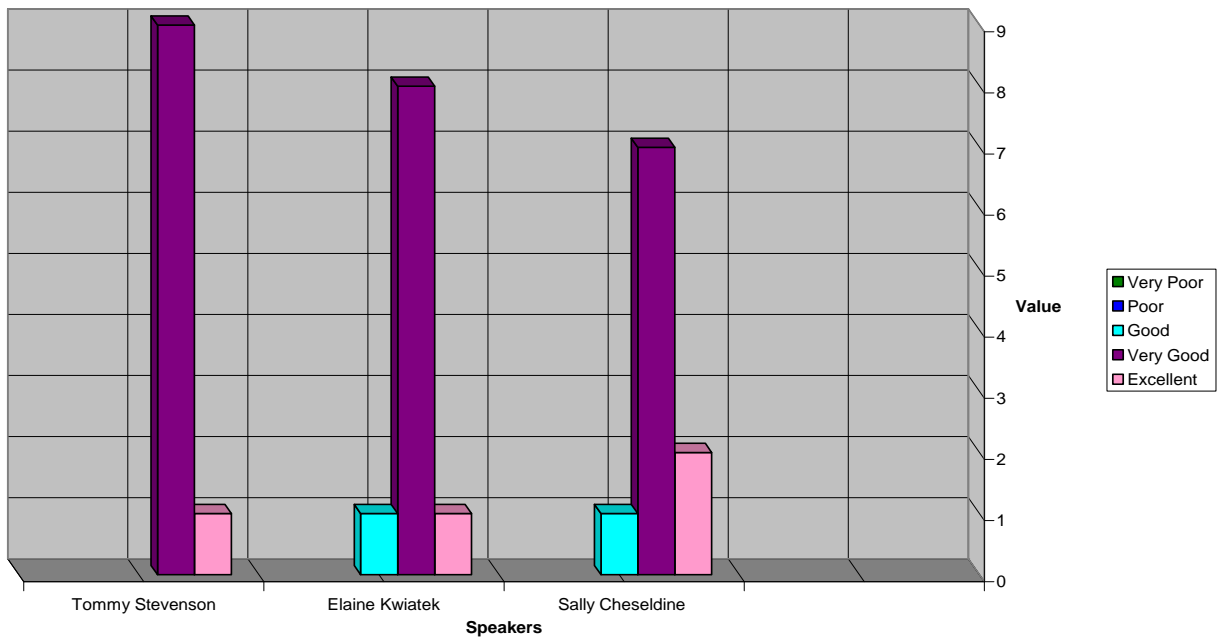
Event evaluation questionnaires were distributed towards the close of the event. Unfortunately, only ten questionnaires were completed .Those returned, either at the end of the event or at a later date produced the following feedback;



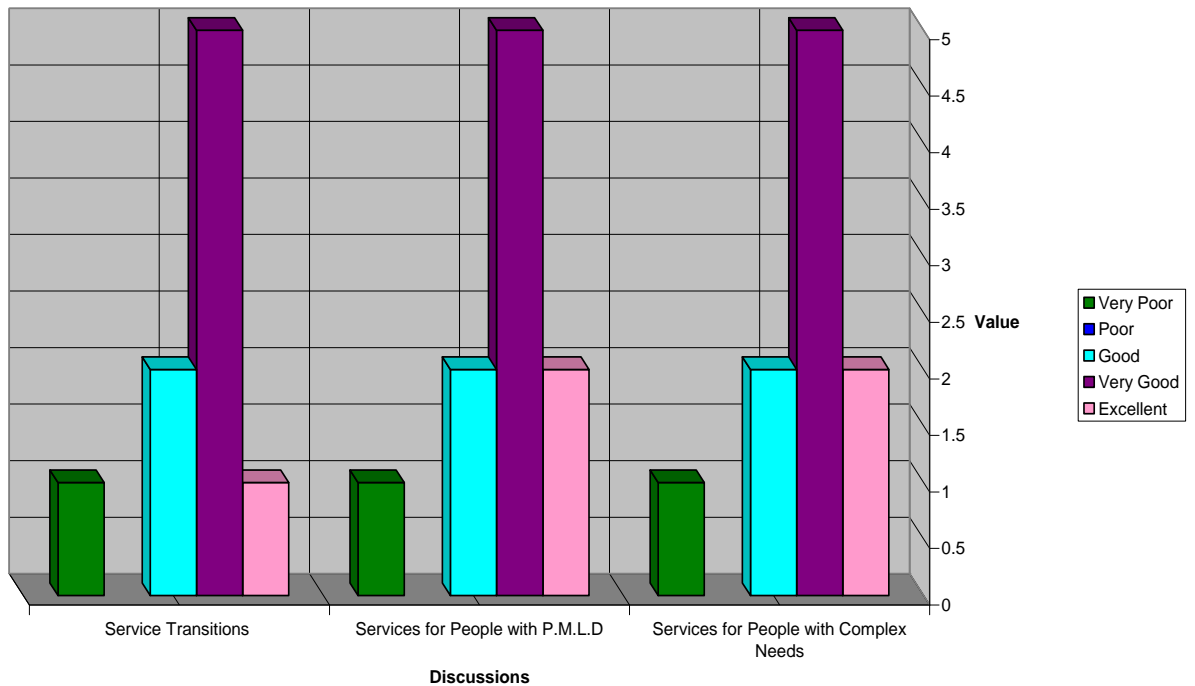
### What did you think of the Venue?



### Presentations



Thoughts on Group Discussions



## Some specific comments ;

Were the workshops useful ;

*‘ Yes, however I was expecting to be informed of good practice and share good practice with colleagues It wasn’t clear to me that the event was a consultative event - however this was a useful and valuable process to be included in.’*

*‘ Yes, however it would have been even more helpful to have looked at some of the financial challenges and care options ’*

*‘ Very useful good discussion and relevance to practice’*

*‘ The workshops were a perfect opportunity to discuss/debate current and future issues around transitions and was also helpful to exchange ideas and experiences ’*

*‘ I found the workshops useful but felt that we lacked time to do the topics justice ’*

*‘ Well scaled event, attempting to tackle a very serious issue. Good networking opportunities, and plenty of learning at workshops’*

*‘ Interesting to hear service users’ perspectives and ideas ’*

**What was the least useful part of the event ;**

*‘ None really, too short a day possibly ’*

*‘ The morning presentations were informative, but appeared to overlap on some areas and entirely miss any discussion on the potential impact the Personalisation agenda will have both now and in 5-10 years time ’*

*‘ Some of the intro could have been reduced without losing the scene factor ’*

*‘ What to do with information, I think we need more concrete action points ’*

**Any other comments ;**

*‘ Overall impressed with the focus on regional issues ’*

*‘ An enjoyable day but felt that the workshops could have produced more if time had not been limited ’*

*‘ Colleagues share the same disillusionment with the silo’ed working groups and the unrealistic expectations that are being created. It is time to have a whole systems look at what we need to do to ensure that resources are targeted in a way that will have a maximum impact in line with the SOA ’*

*‘ While I can appreciate the central location and the necessity to ensure ensure staff feel valued I think the venue was quite extravagant, good conference facilities, lunch could have been pared back, i.e. cold buffet, soup and sandwiches ’*

*‘ Thanks for an excellent event - hopefully will lead to seriously needed improvements in transition services ’*

## **Conclusion and next steps ;**

By way of brief conclusion to this report, it may be useful to address a few of the specific feedback comments, Firstly, it is important to point out that;

**The Joint Improvement Team has a protocol in place for the booking of event venues and facilities, which takes due cognisance of the requirement for cost efficiency and value for money. The selection of the venue for this event was consistent with this protocol.**

It is intended to take forward the outcomes of this event through both the operational engagement the J.I.T currently has through its Learning Disabilities partnership support and development programmes, and its strategic interface with other related work streams such as the N.E.S. workforce solutions project, the Same As You Implementation Group and the Managed Care Network Models of Care project. The J.I.T. Learning Disability Action Group, which has membership representation from the aforementioned plus individuals engaged in other related areas of work and interest, meets bi-monthly, to take forward this agenda. Additionally, the J.I.T. web-site will be updated to reflect and provide information on, the Learning Disabilities work in which the Joint Improvement Team is engaged.



## Learning Disability Regional Events

### Transitions Questionnaire

The following service characteristics were 'distilled' from a number of key service elements relating to service transitions produced as part of a service modelling exercise conducted by Dr. Sally Cheseldine on behalf of the Joint Improvement Team.

We would like you to self evaluate your services against these characteristics in terms of these being FULLY / PARTIALLY / NOT developed. Additionally, We would like you to identify if these characteristics would be useful to services where they have been rated as NOT DEVELOPED !

**Please circle the appropriate answer and give feedback on questions.**

**Thank you**

Q1: There are locally agreed definitions of 'learning disability' and 'complex needs' between families/carers, Education, Health and Social Care services ?

Fully	Partial ly	<i>Not Developed</i>	<i>Would be useful</i>
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Q2: There is accurate local data on young service users with a learning disability ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q3: There is accurate local data on young service users with complex needs ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q4: There are strong, agreed and reliable systems of information sharing between families/carers, Education, Health and Social Care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q5: The Health Board takes responsibility for collecting regional data on service users across all of its Local Authority partners ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q6: The process of transition planning begins around the service user's 14<sup>th</sup> birthday ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q7: There is engagement with adult services in Health and Social Care around the service user's 14<sup>th</sup> birthday ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q8: There is engagement with adult services in Health and Social Care around the service user's 14<sup>th</sup> birthday ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q9: There is a named person appointed to co-ordinate the preparation for change and the transition process itself ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q10: Within Health-care services, there is a formal 'hand-over' meeting with the service user, family/carers and the relevant medical/health personnel from child and adult Health-care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q11: There is a named contact from children's services to liaise with adult Health and Social Care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q12: A transitions/future services planning group is arranged between children's and adult services, to co-ordinate transition planning ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q13: There are clear lines of communication agreed between service user/family/carers and adult services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q14: There is a system in place for adult services in Health and Social Care to anticipate the budgets/funding required to meet the service user's assessed support requirements ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q15: There is a clear, and agreed, service transition pathway between the service user/family/carers and Education, Health and Social Care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q16: There is accessible, reliable and clear information available for service users and their family/carers regarding service transitions, and this is readily available through Education services and partner agencies ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q17: Service users in transition have continuous access to the support services they need ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q18: Support services are provided by a responsive, appropriately trained and skilled workforce ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q19: Throughout the process of transition, service users maintain access to the supports they require in terms of equipment, funding and direct care ?

Fully	Partiall y	<i>Not Developed</i>	<i>Would be useful</i>
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Q20: The required funding, specialist equipment, services and expertise is available at a local service level, to avoid/minimise 'Out-of-Area' placements during transition ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q21: Protocols, systems and services for younger people and their family/carers experiencing transitions, are regularly and robustly evaluated and reported upon by Education, Health and Social Care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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## Learning Disability Regional Events

### PMLD Questionnaire

The following service characteristics were 'distilled' from key service elements produced as part of a service modelling exercise relating to people with Profound and Multiple Learning Disability being conducted by Mr Michael McCue on behalf of the Joint Improvement Team. We would like you to self evaluate your services against these characteristics in terms of these being FULLY / PARTIALLY / NOT developed. Additionally, we would like you to identify if these characteristics would be useful to services where they have been rated as NOT DEVELOPED !

**Please circle the appropriate answer and give feedback on questions.**

**Thank you**

Q1: The service has accurate and reliable information/data on service users who have Profound and Multiple Learning Disability ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q2: The service has a clear transition pathway from children's to adult services for people with P.M.L.D. ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q3: The planning and commissioning of services for people with P.M.L.D. involves joint / partnership working with service users / family / carers and Education, Health and Social Care services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q4: The service has clear protocols of engagement with other service 'tiers' such as Primary Care / Acute healthcare services ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q5: There are clear care pathways in place for people with P.M.L.D. ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q6: Services for people with P.M.L.D. are planned, commissioned and provided in light of safe / person-centred / evidence-based supports.

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q7: Services for people with P.M.L.D are provided locally, and within the principles of least restrictiveness ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q8: People with P.M.L.D. have access to services which provide total communication environments ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q9: Services for people with P.M.L.D. are well integrated into local communities to provide responsive Educational, Social and Recreational opportunities ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q10: Staff working in services for people with P.M.L.D. have access to continuous / ongoing specialist training and supports ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q11: Service users / family / carers are involved in direct care staff training initiatives ?

Fully	Partially	Not Developed	Would be useful
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Q12: People with P.M.L.D. have access to self-directed supports where desired ?

Fully	Partially	Not Developed	Would be useful
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Q13: Service users with P.M.L.D. have access to the required multi-disciplinary and multi-professional specialist supports ?

Fully	Partially	Not Developed	Would be useful
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Q14: Service users with P.M.L.D. have access to the required specialist technology / support equipment ?

Fully	Partially	Not Developed	Would be useful
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Q15: The service has developed T.A.C. ( Team Around the Child ) approaches to service delivery ?

Fully    Partially    *Not Developed*    *Would be useful*

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Q16: The service has developed individual protocols regarding crises supports / interventions for people with P.M.L.D. ?

Fully    Partially    *Not Developed*    *Would be useful*

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Q17: The service has sufficient access to support needs appropriate / barrier –free accommodation for people with P.M.L.D. ?

Fully    Partially    *Not Developed*    *Would be useful*

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Q18: Services for people with P.M.L.D. are strategically located to ensure responsive access to required health supports ?

Fully    Partially    *Not Developed*    *Would be useful*

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Q19: The service is sufficiently 'sensitive' to changes in the health and well-being of people with P.M.L.D. ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q20: The service has developed clear protocols regarding supportive and/or invasive interventions / procedures for people with P.M.L.D. ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q21: People with P.M.L.D. and their family/carers have access to well-trained, experienced and individually 'compatible' support / care staff ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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Q22: The service has named 'service liaison' individuals to facilitate people with P.M.L.D. accessing other related services and supports ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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## Learning Disability Regional Events

### Service Model Questionnaire

The following service characteristics were 'distilled' from 22 key service elements produced as part of a service modelling exercise relating to people with a learning disability with complex support needs. As part of a Workshop exercise at a National Conference held in March 2009, these represent the service characteristics deemed by Workshop participants to be the most crucially relevant / pivotal in the support of people with complex needs.

We would like you to self evaluate your services against these characteristics in terms of these being FULLY / PARTIALLY / NOT developed. Additionally, we would like you to identify if these characteristics would be useful to services where they have been rated as NOT DEVELOPED!

**Please circle the appropriate answer and give feedback on questions.**

**Thank you**

**Q1: CARE PLAN FIDELITY** - *Care plans are capable of being followed through robustly and have continuous evaluation across services and service locations / environments. This frequently involves the training of care staff across these services in order to help ensure that the care plan is applied consistently in the best interests of the service user.*

Fully    Partially    Not Developed    Would be useful

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**Q2: CARE STAFF RECRUITMENT, RETENTION AND ONGOING TRAINING** - *Care staff are appropriately skilled and qualified to address the support requirements of service users. This involves the robust investment in care staff training audit and activity to ensure that they are able to respond to changing service user needs. Issues of care staff age and gender are considered in applying personal and/or physical interventions as part of an individuals' supportive care plan.*

Fully    Partially    Not Developed    Would be useful

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**Q3: COMMUNICATIONS SYSTEMS** - *Continuous and effective systems of communication are considered pivotal to the support of individuals with complex support needs. There is a 24/7 approach to care provision and care co-ordination, as well as clearly defined protocols regarding information reporting and information sharing mechanisms.*

Fully	Partially	Not Developed	Would be useful
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**Q4: CONSISTENT MANAGEMENT** - *The service system requires the appropriate structures to ensure its management is consistent in support of its service user client group. The requirement for care co-ordination is considered paramount, and this is delivered via the required operational protocols and/or named personnel.*

Fully	Partially	Not Developed	Would be useful
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**Q5: CORPORATE RESPONSIBILITY** - *A corporate approach to responsibility of care, including any risk and/or restrictive practice elements related to care supports is made explicit and agreed upon.*

Fully	Partially	Not Developed useful	Would be
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**Q6: 'FIT for PURPOSE' ENVIRONMENTS** - *The service system provides an environment which is sensitive and responsive to user support requirements and facilitates therapeutic interventions and safe care practices.*

Fully	Partially	Not Developed	Would be useful
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**Q7: INDIVIDUALLY SENSITIVE SERVICES** - *The service system strives to meet service users individual needs as far as possible, and provide supports which are user needs sensitive. The service provides meaningful user specific activities.*

Fully	Partially	Not Developed	Would be useful
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**Q8: RESOURCE MOTILITY** - *At service planning and commissioning stage, services incorporate a resource flexibility and motility which helps them adapt to changes in service user support requirements and effectively manage periods of crises and increased service user support requirements.*

Fully	Partially	Not Developed	Would be useful
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**Q9: SERVICE USER INVOLVEMENT** – *Service users and their carers are fully involved in all stages of service planning, delivery and evaluation.*

Fully	Partially	Not Developed	Would be useful
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