

Regional Event Report



Complex Needs Supports: 'Responding Together'

21st September 2010

**Marriott Hotel Dyce
Aberdeen**

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Participating Organisations

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

Aberdeen City Council
Aberdeenshire Council
Aberlour Child Care Trust
Allied Health Care
ARC Housing
Archway
Ark Housing
Beannachar Camphill Community
Carers
Cornerstone
Dundee CHP
Dundee City Council
Highland Council
Inspire: Partnership through life
Kingsmead Home
Moray CHCP
Moray Council
NAS Support Group
NHS Grampian
NHS Highland
NHS Tayside
Quendale House
Real Life Options
Sense Scotland
South East Highland CHP
Sue Ryder Care
The National Autistic Society Scotland
Turning Point Scotland
VSA Carers Centre

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.iitscotland.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.iitscotland.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

Dr. Martin Campbell, JIT Action Group Member – mc1@st-andrews.ac.uk

Mr. Michael McCue, JIT Action Group Member – 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	Mrs. Susan Carr - LD Service Manager N.H.S. Grampian
10.00 – 10.10	Welcome, Introduction and Scene setting Michael McCue - JIT Action Group
10.10 – 10.30	The Challenge of Service Transition Michael McCue- 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 <i>Opportunity for people to participate and contribute to their understanding of the key service challenges / issues relating to service transition.</i>
12.30 – 13.15	Lunch
13.15 – 14.15	Workshop Session focussed on services for people with PMLD. <i>Opportunity for people to participate and contribute to their understanding of the key service challenges / issues relating to people with P.M.L.D.</i>
14.15 – 14.30	Tea / Coffee Break
14.30 – 15.30	Workshop Discussions focussed on services for people with other Complex Needs <i>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.</i>
15.30	Close

Welcome, Introduction and Scene Setting

Mrs Susan Carr, Service Manager (Learning Disabilities) NHS Grampian, 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 is 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'

Mr. Michael McCue, J.I.T L.D. Action Group

Michael delivered this presentation on behalf of Dr. Sally Cheseldine, from the 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.

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

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

He 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

Michael condensed the 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 18 completed questionnaires from 6 areas targeted by the Aberdeen 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 Aberdeen event, identified ‘issues’ around questions 1,2,3,5,7,9,13,15 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 / Issues

- Different professional / organisational language hampers agreed definitions
- Standard definitions might better inform and direct accurate local data
- There is a lack of confidence in the accuracy of available information
- Service transitions in older life require to be developed also
- Shared financial responsibility between key services is paramount
- There may be such disparate support needs amongst users that much more innovative service responses may be required for some individuals
- Early intervention requires to be well planned and resourced
- Formality of transition ‘handover’ processes vary significantly
- Truly integrated processes involving key organisations – Health – Local Authority – Education – Housing are scarce
- Less resources in adult services stretched to meet needs of children in transition
- Needs assessment does not translate to service response
- There is a lack of strategic capacity planning for children
- Joint working systems and joint assessment must improve
- Need to identify prospective care providers as early as possible in transition process
- Early identification of a need for specialist services, housing and equipment is frequently lacking
- Supports don’t follow the child into adult services
- Adult general health services are insufficiently ‘joined up’
- New regulations affecting Independent Living Fund
- Financial planning does not appear to cross boundaries
- The needs of accommodated children are poorly responded to

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 :

- Utilise Self Directed Supports to better facilitate service transitions
- Use planned and agreed protocols and procedures around transition to realise 'flow' and 'seamlessness' between services – not a 'leap of faith'
- Potential for Specialist children's teams working alongside joint adult teams within shared service planning models
- Planning for service future demands informed by more accurate data around numbers and needs
- Have a form of Co-ordinated Support Planning system around service transitions – particularly for those with the most complex support needs
- Give Health Boards the responsibility for collecting and sharing data around service transitions
- Start transitions planning around an individual's 12th birthday – a co-ordinated / robust / effective process which starts planning with the service user, carers and family jointly with key service providers
- Develop clear transition pathways with joint funding and service planning agreements and visible co-ordination processes

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 Aberdeen event, identified 'issues' around questions 4,5,11,15,16 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 :

- Clear protocols of engagement with other service 'tiers' such as Primary and Acute Healthcare services are not uniformly in place
- Crises situations are generally not well anticipated, planned for and handled well
- Not all services have resource flexibility to respond to crises

- Data on 'specialist' support needs and requirements under-developed
- The impact of resource pressures on service provision for this user group is considerable
- There does not appear to be an understanding that responding to the service requirements of people with P.M.L.D. is a wider responsibility than just Health and Social Care services
- Direct payments can sometimes lead people into non-regulated services and this may increase risk and vulnerability
- Workforce planning, training and deployment are major challenges
- Communication/information sharing amongst agencies/services is frequently compromised by professionalism and/or bureaucracy leading to increased risk and vulnerability
- Clear care pathways are significantly under-developed and seldom reviewed/evaluated as to their responsiveness
- Continuing Practice Development should focus on the needs of this user group
- Families should not be over-burdened with delivering and supporting care whilst the service user is in hospital
- Care management is critical in delivering services to this client group
- Sharing best practice between organisations and services requires to be more of a priority
- Visible leadership is lacking
- Risk management is not comprehensively effective enough and vulnerabilities remain, despite the publication of National Reports/Investigations etc
- There are considerable geographical challenges in responding to the healthcare needs of people with P.M.L.D
- Services remain insufficiently sensitive to recognising changes in health well-being and 'equilibrium'
- Access to and retention of specialist support equipment is a major issue
- 'Professionalism' and rigidity of role frequently compromises supportive/responsive interventions
- There is frequently a 'conflict' over who is responsible for providing care support to people with P.M.L.D. who are admitted to Hospital services

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 :

- Service re-design potential rather than new commissioning process in all cases
- Need to focus on qualitative outcomes – relationships, ‘talking points’, things to do and use these outcomes to drive service re-design and development
- There should be a local directory of opportunities and issues for people with P.M.L.D.
- More service user, carer and family involvement in the planning, delivery and evaluation of services for people with P.M.L.D.
- There should be more regulation to provide needs sensitive and accessible services, ‘fit for purpose’ environments
- Use legislative pressure to seek enforcement of accessible and needs responsive services
- Use more standardised procedures, protocols and policies to minimise ‘postcode’ lottery of service delivery
- Have more ‘joint’ service planning, resourcing and provision for this user group
- Carers should be more involved in multi-agency co-ordination of service responses
- Shared training and ‘pooled’ staffing between services can improve responsiveness
- Liaison nurse role should be developed and expanded
- Taking a corporate approach to responsibility and risk management
- Government should take responsibility for ensuring that inter agency/inter organisational good practice is shared and developed
- Carers and families have a role to play in both the preparation of and delivery of guidance on health interventions for people with P.M.L.D.
- There should be clear and standardised agreement regarding the resource responsibility to provide care supports to people with P.M.L.D. who use Hospital-based services

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 :

- Care staff recruitment and retention are major issues
- Leadership from the top down is lacking
- Residential environments for people with challenging support needs frequently not 'fit for purpose'
- Individual services should have been reviewed – single tenancies often not the most qualitatively responsive option
- Insufficient 'short break' services to minimise placement breakdown
- Crises responses particularly challenging in rural and remote areas
- Care plan adherence is often an issue of language and governance
- Staffing retention is frequently a challenge due to roles/expectations being insufficiently clear
- Corporate responsibility is not uniformly applied, often resulting in risk aversion
- People with challenges are too often inappropriately placed
- Service users and carers are still not involved enough in service planning, delivery and evaluation
- Related services – e.g. Housing not involved early enough in processes
- Advocacy services remain under used for this service user group
- There are few personalised and supported day opportunities for people with the most challenging needs, often resulting in further challenges to services
- There is often no 'whole systems' approach to service planning, management and review
- There are issues with transport accessibility for people with complex needs
- There is a significant service gap around services, particularly health services, for children with mental health issues
- The issue of 'void' costs needs to be looked at
- Activity opportunities should be more personalised and meaningful

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 :

- Resources need to be integrated for this service user group

- Develop care staff training passports for movement between organisations and services
- There should be multi-disciplinary/multi-organisational (with users / carers) Risk Management/Advisory groups to support services
- Services should look at options to 'pool' resources, particularly out of hours/crises responses
- There should be a formalised and explicitly structured framework for sharing good practice and learning between services
- There should be greater use of co-ordinated service frameworks such as the Care Programme Approach for individuals with the most challenging service support needs
- There should be both National and local service model planning and evaluation groups ; involving users/carers and all relevant service providers/services
- Involve service users and carers more in care staff recruitment
- There should be more service 'partnership' approaches to staff training which might facilitate care staff working responsively across organisational boundaries
- There needs to be a formal and explicit structure to encourage and support
- There needs to be greater flexibility regarding the ways in which service providers deliver the desired and required outcomes for people with challenging needs
- In care staff recruitment processes, there should be a greater focus on pre-employment 'screening', induction evaluation and continuous support practices

'Aggregated' 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

- **Use of professional language hampers communication**
- **No formal processes / protocols**
- **Lack of joint working systems / whole systems approach**
- **Geographical challenges**
- **Workforce challenges**
- **Lack of user / carer / family involvement**

Solutions

- **Nationally / locally agreed processes and procedures**
- **Joint planning, delivery and evaluation**
- **Develop clear operational service pathways**

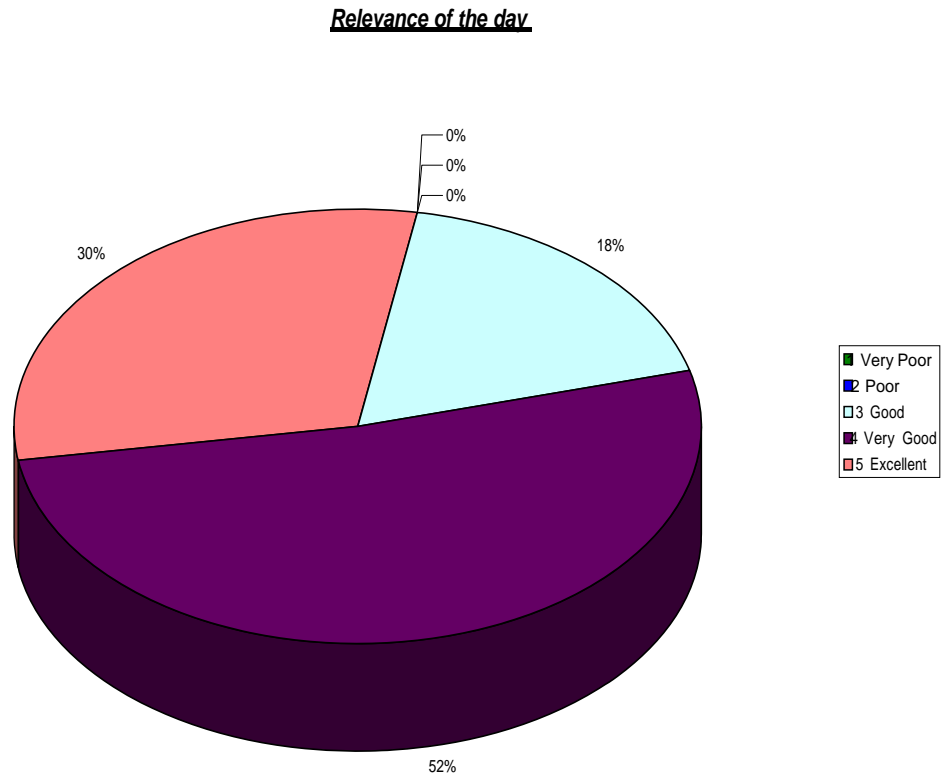
List of Participants / Attendees- Aberdeen

Name	Organisation
Linda Alves	Aberdeen City Council
Sue Barnard	VSA Careers Centre
Xacquelina Bello	Cornerstone
Lesley Burnett	Dundee CHP
June Brown	
Susan Carr	NHS Grampian
Shellie Connor	NHS Tayside
Jim Cook	Cornerstone
Peter Collins	Talisman Energy
Val Culley	Inspire : partnership through life
Alex Davidson	JIT
Jacquelyn Durward	NHS Tayside
Fiona Fettes	Sue Ryder Care
Andrew Findlay	Ark Housing Association Ltd
Sharon Furey	NHS Tayside
Linda Forman	
Karen Glass	Cornerstone
Ian Gordon	Moray CHCP
Carolyn Griffiths	Orkney Council
Tom Hammond	NHS Forth Valley
Christopher Hatton	Kingsmead Home
Mike Hebenton	Aberdeenshire Council
Anne Hodges	Moray CHCP
Rachel Hubber	NHS Highland
Karen Jackson	NHS Grampian
Alan Jones	NHS Highland
Cath Keenan	Dundee City
Philip Kelly	Turning Point Scotland
Elaine Kwiatek	NHS Forth Valley
Yvonne Leathley	Aberdeenshire Council
Fenella Lewthwaite	Community Learning Disability Team
Lorraine Low	Sense Scotland
Kate MacDonald	Cornerstone
Donald Mackintosh	
Pamela MacKenzie	Sue Ryder Care
Catriona Manby	Sense Scotland
Michael McCue	JIT Action Group
George McCulloch	Inspire : partnership through life
Sarah McGregor	The National Austic Society Scotland
George McHattie	Real Life Options - Aberdeen City
Gail McKeitch	NAS Support Group
Rona Membury	Carer
Alastair Minty	Inspire : partnership through life

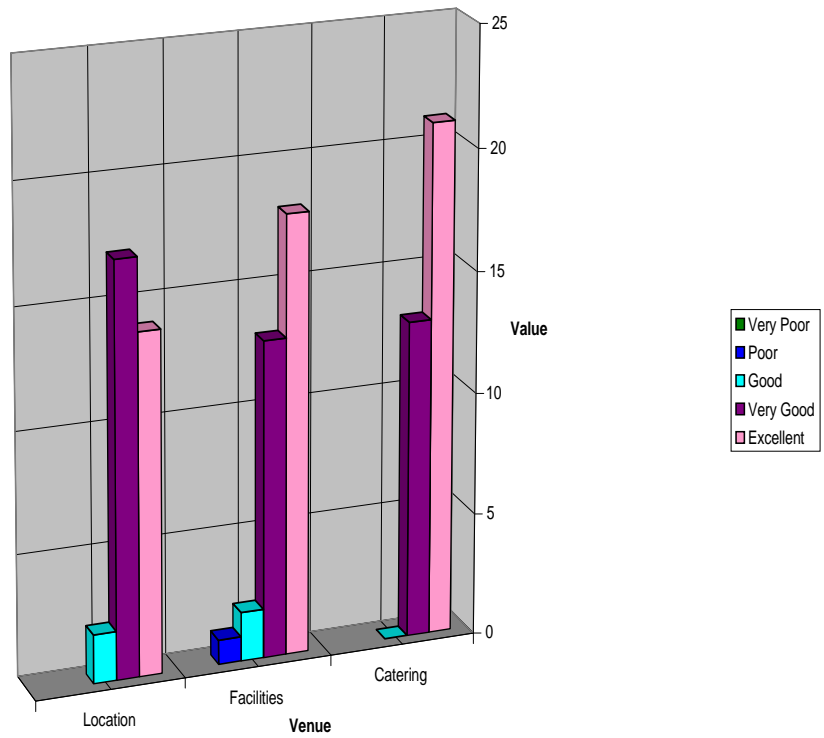
Thelma Morgan	Carer
Lynda Murdoch	
Jim Murphy	Carer
Margaret Park	NHS Highland
Keith Park	Sense Scotland
Elizabeth Phethean	Beannachar Camphill Community
Terry Pickard	Aberdeenshire Council
Linda Reid	Aberdeenshire Council
Philippa Roberts	Sense Scotland
Claire Scott	Aberdeenshire Council
Clare Scott	Quendale House
Wendy Scott	Dundee City
Emma Sharpe	NHS Grampian
Fiona Shearer	Aberlour Child Care Trust
Anne Slee	Moray CHCP
Forbes Sutherland	Ark Housing Association Ltd
Anne Swash	Aberdeen City Council
Tommy Stevenson	NES
Jackie Taylor	ARC Scotland
Laura Thom	Aberdeenshire Council
Jenny Whinnett	PAMIS
Tamsin Williams	
Faith Wilson	South East Highland CHP
Judith Wishart	

Feedback from evaluation questionnaires ;

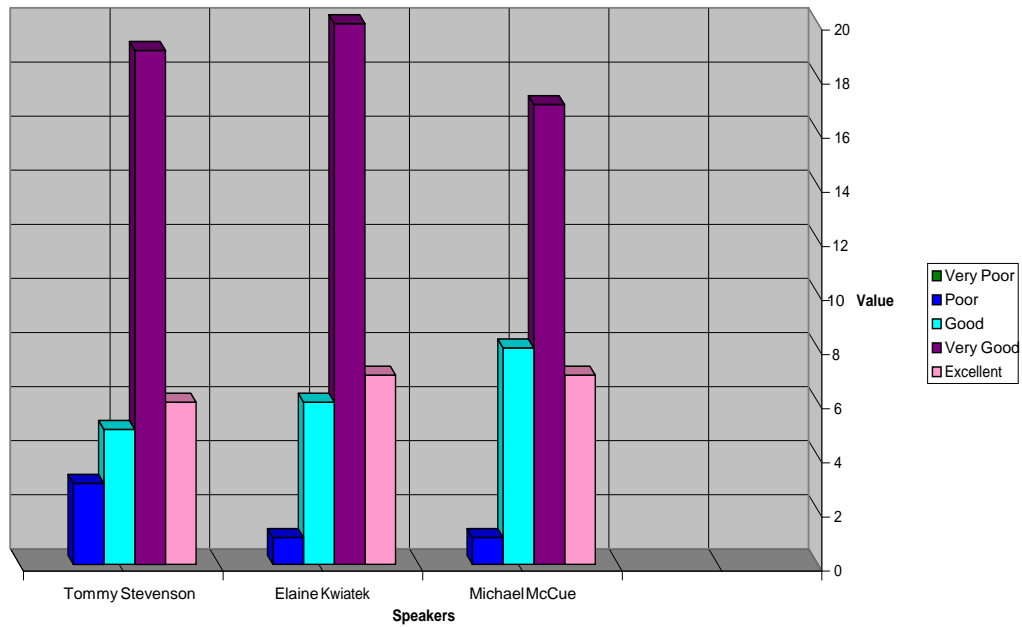
Event evaluation questionnaires were distributed towards the close of the event. There was a very reasonable return, with a total of forty questionnaires completed .Those returned, either at the end of the event or at a later date produced the following feedback ;



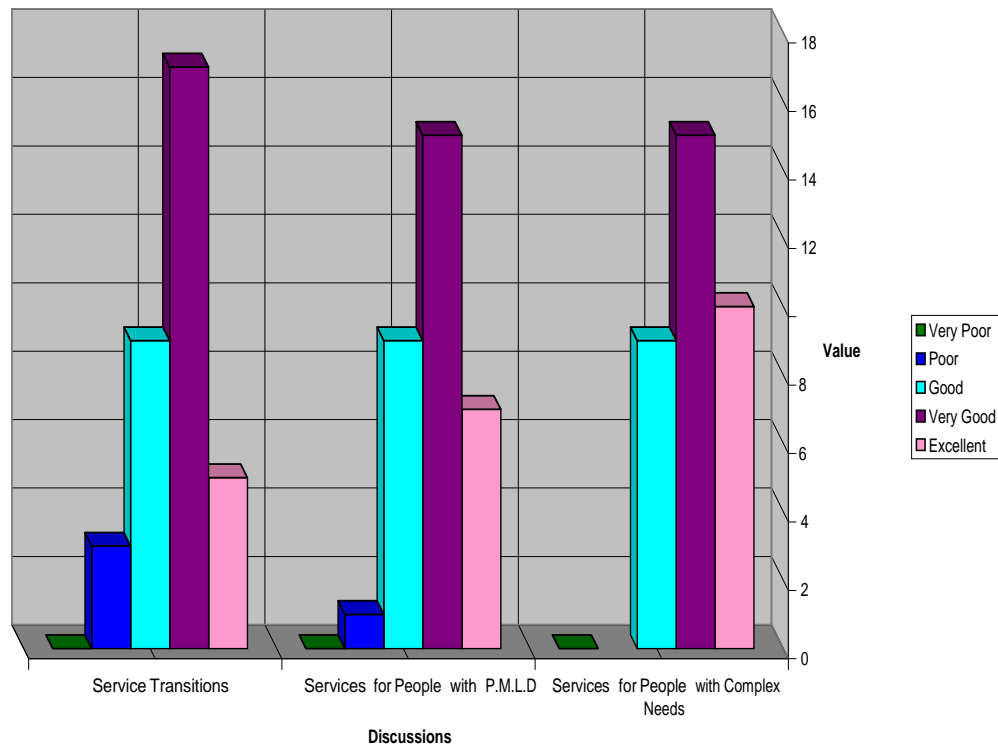
What did you think of the Venue?



Presentations



Thoughts on Group Discussions



Some specific comments ;

Were the workshops useful ? ;

‘ Interesting - similarities of issues and hearing the different views ’

‘ The focus of the workshops and the day as a whole was children and young adults. My area of work is with older people and over 65's. Whilst the day was interesting I would have liked to have seen some focus on transitions into long stay units for older people with LD and PMLD ’

‘ Yes - because they brought everyone's point of view together and acted as a catalyst for action ’

‘ Very good to hear the views of others and good discussion around what needs to be put in place ’

‘ Not really as turned into a moaning session and health v sw ect. Children vs adults. Not very productive ’

‘ Yes in that it highlighted issues but did not answer any of them. Good to hear what approaches are being used in other areas ’

‘ Yes, but where to now? Lots of relevant discussions ’

What did you like about the event ? ;

' Good venue, well organised, opportunities to meet people and network, good information '

' Acted as a spring board to pursue specific ideas on my return to job. Networking and hearing viewpoints '

' As a mother and carer it was very enlightening and showed how complex the problems of today are and that there is no easy answer '

' Yes, but it's as if we haven't really moved on - still talk about the same issues. Good to hear different areas of good practice, pity that different regions don't join up to have universal working/systems '

' Discussion groups '

' Interesting Presentations '

' Good team gelling and respect for different opinions - well facilitated '

What was the least useful part of the event ? ;

' Wanted more answers - more sharing and models being used '

' No real outcome '

' Speed on presentations '

' At times the venue was quite cold '

' That all the workshops sort of merged into one same outcome almost '

' Need to formulate actions and plans about what we can do '

' A bit hurried, as ever not enough time '

Any other comments ? ;

' Very relaxed atmosphere '

' 2 key note speakers unable to attend? '

' Catering was good but could have been less expensive given we are trying to save public money '

' Will look forward to seeing the outcome '

‘ Without extra resources it will be increasingly difficult to maintain current provision, let alone develop ’

‘ What comes of the event is what counts - will it convert into appropriate actions ? ’

‘ Well worthwhile event ’

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 14th 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 14th birthday ?

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

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

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

Fully	Partially	Not Developed	Would be useful
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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	Not Developed	Would be useful
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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	Not Developed	Would be useful
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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	<i>Not Developed</i>	<i>Would be useful</i>
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Q16: The service has developed individual protocols regarding crises supports / interventions for people with P.M.L.D. ?

Fully	Partially	<i>Not Developed</i>	<i>Would be useful</i>
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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	<i>Not Developed</i>	<i>Would be useful</i>
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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	<i>Not Developed</i>	<i>Would be useful</i>
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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 useful
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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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