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## EVIDENCE INTO PRACTICE

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## PROJECT ADVISORY GROUP

The research team was assisted by a Project Advisory Group, which provided accountability, guidance and support. This group met physically on four occasions. The research team are grateful for the advice and facilitation provided by this group throughout the duration of the study. This group comprised:

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## REPORT FORMAT

The report has been written primarily with the practice community in mind. Each strand of data collection and synthesis – dataset reviews, interviews, stakeholder events, working groups, focus groups, and surveys – contains a box with key findings. **To preview this report, the researchers would recommend reading the key findings from each section followed by the final recommendations (Chapter 7 of the Part 1 report).**

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## **APPENDIX I: DATASETS REVIEW**

**It is not possible to include this section at this time, as Caldicott Guardian approval has not been received, in order to access NHS data. Once approval is received, this section will be completed and included within the report.**





## APPENDIX II: STAKEHOLDER EVENT AND WORKING GROUP SESSIONS

### Introduction

A Key Stakeholders Event was held at the front end of the research (6<sup>th</sup> May 2016) to gather views and themes for consideration during the main fieldwork phase of the project. From this Event the recruitment of a small working group took place (see **Appendix VII** for the full list of Working Group members). The Working Group met twice to consider the key messages that arose from the initial Stakeholder Event.

The purpose of these qualitative elements of the project was to find out:

- Views on current provision of adults' mental health services and support;
- Any gaps in current provision;
- Views in relation to the nature and extent of future requirements; and
- Assets (groups, networks, individuals, etc.) across West Lothian.

### Key Stakeholders Event (6<sup>th</sup> May 2016)

The first section of the Stakeholders Event involved small group discussions focused around the following six key areas of investigation:

1. WHAT WORKS WELL - What support and services currently work well for people with mental health problems across West Lothian?
2. GAPS - What are the main gaps and areas for improvement in support and service provision for people with mental health problems across West Lothian?
3. DUPLICATION - Are there any areas of duplication in support and service provision for people with mental health problems across West Lothian?
4. CAPACITY AND INEQUALITIES - Which groups/geographic areas are currently well served across West Lothian and which are not well served?
5. ACCESSIBILITY - What are the current facilitators of and barriers to support/service accessibility for people with mental health problems across West Lothian?
6. TRANSITION - What are the current strengths, weaknesses, opportunities and threats of transition arrangements for young people moving to adult support / services?

#### What works well?

- Day services are really good, respite also
- Staff at Newell and SAMH are doing a great job
- West Lothian is a small enough area and due to this the statutory and 3rd sector organisations are well connected. There are good relationships

- Distressed tolerance is a very effective project. It is group work, a 12 week course- this worked. This involved Peer group work, where people were meeting even out with the group setting
- Multi-agency working. Communications between agencies. (we all know one another's mobile numbers). Good relationships at all levels from referral right through. 'The West Lothian Way'
- There are good relationships between the social work and the police, however the Adult Protection Officer post is being removed and this be a huge loss for social work
- Prioritising MH for housing – OT new involved in this. Early for assessing outcomes but looking at mental health not just physical health
- Blue badge – mental health – OT team involved in this in West Lothian. How does cognitive, impairment feed into disability and people's right to a blue badge. Criteria with this pilot might mean some fall through the gaps for the BB
- Perinatal mental health unit at St John's working well. Reactive attachment bonding helping to reduce neglect, not many beds though
- Wards in St John's are better than 10 years ago in staff attitudes and service provided
- Social prescribing works well. Structured psychologically informed service not as available for these who don't need psychology and psychiatry from NHS.
- Outreach mental health for tenancy support to ensure tenancy is not lost, works well but can do more
- Service flexibility
- Good at conducting health assessments
- Good relationships between health and social care
- Advocacy service response
- Peer volunteers
- Yes, there are good services, but not enough
- Think all good. Group Living a good service, always people to have people around them and support them
- Had been concerned about people being supported in own homes. Works well but doesn't suit all. Some need group support and come to services that provide group support. Something about being comfort of being in group situations where don't need to explain themselves
- Links with advocacy really strong
- Links with Social Work very good/ responsive, try to sort out things. Helped people move on through SDS particularly option 1. Seems more solid than in other areas
- Some services from past not sustained
- Want to see outcomes approach in West Lothian validated
- Dual diagnoses
- We are seeing people with learning disabilities with mental health issues
- Substance misuse is the background of people we are seeing

- Good working relationship with different clinical services → good outcomes for patients (systems/organisation not as sensible)
- Good communication with third sector – opportunity to make it better (systems makes it take a long time to get thing done)
  - Willingness to get things done
- People under 65 diagnosed with dementia – challenging for them. Deterioration can happen very quickly – services can struggle to keep up.
- Quality of care deteriorating because of recent changes
- Once we get patients into system actually assess/treat well (good skill base within team) - matching them up with right treatment works well.
  - Transition easier
  - Signposting works well
- MOOD doing really well – social prescribing
  - Low level intervention
  - work as conduit to other community-based activities
  - offer lot of peer support / buddying
  - signposting
  - issue is people becoming aware of MOOD – limited capacity)
- Is a flexibility re age in some community services

### Gaps?

- There has to be more one to ones with a CPN.
- More education for GP's, as several do not understand mental health issues, also they are very time orientated.
- Distressed tolerance, a great initiative, but due to lack of funding there is a gap with this now as the service is not running. This was developed in West Lothian with lots of partners. The service kept people out of hospital and aided the recovery process.
- You have to be in the system to be referred.
- We found it hard to find free space where people could meet for a coffee and a blether.
- More supported accommodation, there is a gap there. There are many people in hops due to lack of supported accommodation. The accommodation available does not fit their needs. Young people with Early Onset Dementia, they lose out to older people with dementia.
- Housing is a really big issue, there used to be youth housing, but this has since disbanded.
- We should have a joint young person/mental health/substance use/ community based initiative. If we target young people we will not be working with them at 35.
- Supported accommodation model would be good so people are kept in the community.

- Eating Disorder Unit – few months away from national accredited. As these are hosted services for the region it shelves the budget line for folk in West Lothian. There is a significant loss in West Lothian for West Lothian residents. 156 adult mental health beds closed in West Lothian in last few years. Very little resource in community. Investment is currently short term with no exit strategies for clients in the community. Inpatient beds lost and no replacement to compensate in community services/outpatient
- Development in community has been around statutory not around general mental health. If you're subject to Mental Health Assessment you get a good service but not if you have a general mental health issue. Never meeting 18 week targets more like 18 months
- Caseloads for psychiatry is 2 to 3 times higher Edinburgh. Impact on clients is diagnosis deprivation which means other services are not available until patient has seen psychiatrists
- GP involved with self-management, every GP has access to CP. Current re-design as access to talking therapies not everything has to go through the GP but someone needs to direct the care. Employers helping support to those who work with ESA, counselling support
- Not enough to help those who can't self-manage "middle people not serviced" low level support can be offered under tenancy support and if the client has an alcohol drug problem, this feels/able driven.
- Services are not available until someone wants to engage, leads to crisis. Not turning up twice and discharged, then case helped by professional who isn't an expert and can't help. Not wanting people off as DNA's or sending letters, no opting in
- Not enough money in system, 3rd sector working at lower unit cost, can West Lothian meet capacity?
- Engagement model needs to change. Proactive approach, one to one intensive engagement could save money.
- Can ISB move money to early intervention? ISB has to be driven to do something differently.
- Needs of carers (e.g. respite/ provision generally)
- There are no information sharing systems between health and social work
- The police are only able to forwards information to social workers, people from health can't access information
- Incompatibility of IT systems is a big issue overall
- Don't have sufficient interim care
- Not enough accommodation available
- Not enough support available
- Limited resources – slows or blocks on discharges
- Unskilled workers working within the area
- Gatekeeping process delays things for people- more trust needs to be given to service and service delivery
- People are assessed to death

- Lack of GP services, people off for months have had to diagnosis
- There is a lack of young people services, we need to get one person to speak with young people once a month
- There are gaps in the workforce as well as some services, training/ awareness
- Limited rehab resources → difficult to move on from Ward 17
- Limited long-term care → bottle-neck in rehab services
- Housing / supported accommodation = big issue
  - Takes a long time / lots of red-tape
- Need to be more creative – not age-based service provision
  - community-based services getting better – Mindfulness services accept over 65s
- Timely post-diagnostic support (finance issue – not been confirmed)
- NHS doesn't necessarily know about third sector
- Very long waiting lists for things like psychology
- Not truly patient-centred – don't ask patients
  - Very quiet about some of the services for fear of over-subscription
  - People find it difficult to refer / services guard their resources very fiercely
- Stigma still there – doesn't help people access services they need
- Common information point / HUBS in local areas (people there to point them in the right direction – make referrals). People don't know about services that are available.
- Council / NHS and third sector all have different IT systems – if they could share info – save people time and effort. It's very disjointed.
- Managed Clinical Network should work better to sort out a directory
- Disconnect between management and staff on the floor – too much time spent away from 1:1 patient-care

#### Areas of duplication?

- During the referral process, there is a lot of paperwork duplication from a client's point of view. There is not one recording system where everyone could access.
- Given allocation of hours by commissioner. Sometimes deliver more than one service, need to be clear about who does what
- Framework agreement. Appears to be inequality about it as not getting same amount of hours
- Duplications and redesign need to be explored first before we decide there isn't enough resource
- Scatter gun approach
- Addiction services and mental health not sitting well together and often seeing the same client group
- Efficiencies can be achieved if merged together

### Capacity and inequalities?

- There are no care homes for young people across West Lothian, the Young Person's Unit is in Edinburgh
- The Green gym is closed. This was a good resource, and it empowered people to take responsibility to go along
- Some 17 years olds are accessing services where there are lots of 35 year olds and this is not fair
- Social care workers are having to rush people in their own homes, as they run over the time allocated. Sometimes they cannot leave one person but then the next client loses out. But... there is not time frame for interaction with someone who has a mental health issue
- When someone presents at A&E it is very impersonal, however the Distressed Tolerance project involved working with NHS staff to overcome this
- Public transport is a big issue- buses starting later and finishing early. Affecting people using the variable community groups. People from Linlithgow cannot go to certain services due to buses. This is disabling rather than enabling.
- We compartmentalise things (physical health) but when people do move on... such as after rehab, then the chances of them sliding back increases, and then there are many of these services in Edinburgh and not in West Lothian.
- Delayed discharge is an issue due to lack of available housing
- Inequality of provision with acquired or traumatic head injuries
- People are unable to access all services- outlying areas- the public transport is a problem
- You have to have a formal diagnosis better service
- PTSD- people have difficulty in accessing services-capacity issue
- NO ex-offenders/ travelling community for years. Put in same category as veterans
- Refugees
- Prevention and early intervention
- There is a gap in crisis work
- For respite, awareness has to be raised- not sure if there is a gap
- Under 65s with dementia – don't fit into day care or lots of other activities because they just cannot do them
- some also limited what they can access by themselves also
- Multi-diagnosis – no services in WL for those with MH and
  - Dual-diagnosis (drug and alcohol)
  - Behavioural
  - LD
- Those without MH issues but:
  - those in distress
  - those with social crisis

- addiction

### Accessibility?

- There are services which are Lothian health board but certain services cannot access these as they are based in West Lothian, however, this may change due to the integration agenda
- Several things happen in Glasgow or Edinburgh, and the smaller areas, such as West Lothian, are forgotten about. This is evident in SAMH
- There are lots of services based in Glasgow or Edinburgh and accessing them is difficult for clients
- HMP Addiewell are merging mental health and addiction together, this could happen in the community
- Performance monitoring framework in mental health – not here, should it be? Focused on heat targets and SW maybe in wider services
- Outcomes – are they properly assessed, specialised?
- Evidence base – how good is this? How closely are services following it?
- Edinburgh centric services easier for West Lothian residents living in the east of the country
- Vulnerable people are expected to travel
- Gap – Satellite – Services, professional networks.
- There is only access to health day care if a diagnosis of a severe and enduring mental is given
- People not being able to travel on their own- independent travel, fear of getting out the door
- Geographical barriers, time of travel and transport issues-lots of rural parts with small villages
- People with mental health problems do not know where to go for help
- People from years ago presenting to services most really not knowing what they need to say/ how to say they need help

### Transition?

- There is a disconnect between education and social work. The introduction of a transition board who can look at the needs of young people earlier, may overcome this
- Limited knowledge of West Lothian position
- Difficult area- be a lot easier if money followed person
- Social work transition time have been really good
- Got to be 18 before most services (around the table) can engage with people
- In social work services a person becomes an adult at 16, but the foundations do not match up as referrals at social work is 16, but it is 18 for health
- The Child and Adolescent Mental Health Services waiting list is long
- Continuity in place for progressing-deemed to be a strength

- Younger adults team (17-25) – very small team – need diagnosis. Trying to join with social enterprise at Strathbrock. Still people with severe and enduring who can access.
  - Limitation – many YP don't have the required diagnosis but have significant needs that should be served. 'How can you provide so much for so few, but so little for so many?'
- Work better with third sector? Pilot Mid-Lothian in GP surgery for mapping services etc.

During the second part of the stakeholders event, each of the five small groups discussed five key priority areas they believed should be taken forward for consideration by the proposed working group. The five key priority areas were discussed in depth. Once the five key areas were identified at each table, all stakeholders were then allowed to vote for their top four from all key priority areas identified from all table (25 key priority areas in total). The top five key areas/themes are shown below, with the number of votes received in parenthesis:

- Accessibility (18)
- Unscheduled care (13)
- Keep well services (11)
- Early intervention (10)
- The 'West Lothian Way' (it's positive uniqueness) (9)

Other priorities are as follows:

- Communication (8)
- Service directory (information HUBS) (7)
- Suicide and self-harm (6)
- Training qualifications of non-specialised staff (5)
- Prevention and early intervention (4)
- Young people (4)
- Capacity building in community for those without severe and enduring diagnosis (4)
- Step down step up services (3)
- Duplication (3)
- Resources (3)
- Smarter use of resources (3)
- Reducing delayed / failed discharges (3)
- Work development and staff volunteers (2)
- Access (2)
- Person-centred (1)
- Mapping the way mental health services are offered (1)
- Inequalities (1)
- Post diagnostic support (no votes)



## Working Group Session 1 (18<sup>th</sup> May 2016)

Are the key messages highlighted at the stakeholder event a fair reflection of the current position in West Lothian (as headline themes)?

- Attendees were not sure where or what the duplications are. One potential suggestion was WELDAS and the Drug and Alcohol Team.
- It was generally acknowledged that it is "necessary to define the terms; to be precise about what we mean e.g. accessibility is a problem in some areas; not in others."
- "Police can receive between 75-100 adult referrals a week in West Lothian and about 70-75% relate to Self-Harm/Attempted Suicide; it should have a higher priority. Early intervention is required."
- A worry was expressed about the so-called 'West Lothian way' – "sometimes the West Lothian officers don't cooperate with other areas (e.g. there is a feeling with NHS Lothian that there has been an over-centralising of funds to Edinburgh). It needs to be understood as a local responsiveness/connectiveness to client needs, but it shouldn't exclude working with and learning from other areas."

Are there any missing 'key' messages?

- "There is a lack of connectedness between drug and alcohol and mental health services – dual diagnosis."
- Transitions.
- Carers for those with mental health issues. There is no carers advocacy (VOCAL no longer do this).

Currently, is there sufficient provision of services and support to meet presenting needs? Are the needs and expectations of people with mental health problems currently being met in West Lothian?

- "There needs to be more."
- "The quality of provision is very good, there are just not enough of them."
- Generally, there is a good range and a good choice of service and support; although, "needs aren't always being met" and "medics and social work don't always necessarily know what is there".
- "There are lots of good services (e.g. the Garden centre), but sometimes there are long waiting lists."

Are there any gaps in service/support provision?

- "Service User / Carer Involvement is void – partly due to the new infrastructure with the IJB reorganisation." There used to be a Mental Health Forum and a Service User Forum.

- Residential support that is more than just housing support.
- There is no disposal point for those in distress / those under influence – this group is a problem for the police.
- For those in distress – medium term support; access to CPN / psychological therapies:
- “sometimes it’s a question of having the appropriate disposal routes”
- “we are perhaps a missing bit for the shorter/medium term stuff”
- “things are changing though – there are things like telephone contact etc. like they do in Edinburgh.”
- Something like the Crisis House in Edinburgh (Penumbra) – “This is a Lothian-wide support, but the practicalities of getting someone there who is in crisis may be insurmountable – maybe something like that in West Lothian would be good?”
- Supported accommodation:
- “SAMH – it’s all shared which means we need to find suitable cohabitants.”
- “There is no housing with care provision for those with dual diagnosis or for younger people with Early Onset Dementia (those under 55). We did have 21 beds; the 17 with Barony have been deregistered which means these people are not being appropriately cared for.”
- “Templar Rise is not suitable for people with severe and enduring mental health problems which leads to the inappropriate use of Ward 17 and Pentland Court. This can lead to bed blocking.”
- “There is a lack of housing with care for those with poly-substance misuse.”
- “*The referral process / access into services may not be fit for purpose.*” You either present to the GP or A&E – there is no middle option. Or you have to call the police.
- OPD5 do the assessment if the GP makes a referral

Are there any particular groups (including ‘hidden’ populations) of people with mental health problems that you feel are NOT well-catered for in West Lothian?

- Early Intervention – Crisis Prevention:
  - “There is no third sector intervention in this area like there is in North and South Valley; Lanarkshire; Forth Valley etc.”
- Transition:
  - CAMHS to adult.
  - Adult to older people’s service – 65 is no longer considered old; “Is the age that you are relevant at all? Should it be needs rather than age-led?” “Health are trying; social care are failing – e.g. the Ability Centre is age restricted 16-64.”
- Carers.
- BME – especially women. There is Shakti in Edinburgh.
- The homeless – CPNs from the ‘Moving into Health’ service were however seen to be good.

- “There are problems on discharge from SPS Addiewell – often there is no support network in place. There is usually a substance misuse issue and often they are in need of a script over the weekend which hasn’t been organised.”
- Those with a Dual Diagnosis:
  - Substance Misuse;
  - Autistic Spectrum Disorder; and/or
  - Learning Disabilities.
- Those in need of Employment Support.

### Service User Engagement

- “Service user engagement is falling apart in some ways in West Lothian. The integration agenda requires that you take the people with you – it’s not done very well.”
- “It should be about day to day activity. There should be the opportunity to do some collaboration – co-production.”
- The Garden Centre is not accessed by SAMH, Barony etc. but could be – there needs to be better systems in place in order to do this.

### What works particularly well for services and support for people with mental health problems in West Lothian?

Participants were asked to comment on what works well in mental health service provision across West Lothian by noting their thoughts on Post-It notes. These were the remarks made:

- Multi-agency working.
- Breakaway and Recovery.
- Addiction Services.
- Ward 17 is much better than before.
- Good relationships with SMU and CPNs (Joint Working).
- Interagency Working.
- Partnership working across different agencies/organisations.
- Joint working with police on ASP issues – good supportive links.
- Partnership working.

How effective are the identification, assessment and care management processes for people with mental health problems?

- “Self-Directed Support is not fully embedded – there is variation worker to worker about what is offered / what it is perceived to be able to do. The Council needs to audit that – it requires standardisation.”
- “It is really down to your social worker.”
- Mental Health is seen to have a smaller budget than Physical Disability - there is an inequality.
- “There are massive inequalities in levels of award”
- “Once a Service User gets an allocation there is a gap about what you do with it.”
- “Carers don’t know about SDS, but providers have come out to speak to carers / service users.”

How well do services and support integrate and work together?

- “Confidentiality issues get in the way of allowing working together.”
- The SDS Single Shared Assessment isn’t accessible to the NHS.
- West Lothian has a good history of integrating Health and Social Care. “There are certain instances of good working practices, but there is room for improvement. There are good relationships with the college; Adult Support and Protection; advocacy; carers.”
  - They are currently looking at two integrated community mental health teams; there may be opportunities for third sector?

**Working Group Session 2 (3<sup>rd</sup> June 2016)**

Is there a genuine choice of services and support available in relation to range, consistency and quality of provision?

- For Carers – Cares of West Lothian (COWL) is the only support for carers – they have a new service for carers of those with mental health problems
- Choice is given with initial assessment; in the goal setting
  - “There may be limitations if they don’t have the right funding in place”
- Self-Directed Support (SDS):
  - “Choice from an SDS perspective depends on who is doing the assessment. It depends whether the person doing the assessment offers it.”
  - “It might become confusing for the service user – some people just see a pot of money – they don’t necessarily see the limitations (i.e. that they have to get a train to Oban not take a taxi).”
  - “We’re trying to think outside the box a bit more – trying to drag people along with us – we’re still trying to find our feet.”

- “Lots of people are still saying ‘just get me whatever hen’”
- “Choice is a much wider thing – we need to think about: does a patient have a choice about their treatment/therapy? A Choice regarding coping strategy? Choice over whether they would be better in a ward or the community; choice regarding professional? Choice over psychiatrist/CPN/anyone at all?”
- “Are the service users at the centre of their care?”
- (MHAP) “There is a common request to change psychiatrists– but there are limited psychiatrists, which leads to long waits for appointments.”
- SAMH try to match clients with staff they ‘gel’ with
- ACAST – short term/crisis team – “it is a small team so we have to be clear with service users that the same member of staff can’t always visit”
- Ward 17 – patients have more control/choice over key nurse/worker
- Community Outreach Team (COT) – assign a key worker too
- Psychological interventions – often have to be delivered by specific professionals. *“There are not many options.”*
- For mild depression – Step out group / Nightingale groups / GPs refer to online support – *“lots of people are just looking for someone to speak to”*
  - GAP – counsellor to help through low mood / depression / anxiety – someone to help them through a low point. ‘A listening ear’
  - Need this low level support
  - “Doesn’t necessarily need to be delivered by highly trained mental health professionals – it doesn’t require intensive mental health input.”
  - “Lots fall into this category; but there is little support available out there”
  - ACAST can sometimes deliver something short term (assessment – needs mental health professional to do this; psycho-educational input/tools for anxiety / practical problem solving etc. – doesn’t need a mental health professional for this), but there is nothing for them to refer to.
  - “The distress tolerance programme has gone now (many people attending this service attended no other service – this was preventative – it stopped them becoming service users).”

#### How accessible are services and support for people with mental health problems?

- “There doesn’t seem to be any direct route for a person to self-refer to commissioned services [e.g. to LAMH]; people have to go through the assessment process because social work holds the purse strings. The problem could have deteriorated between referral and the assessment process.”
  - No low threshold support in West Lothian whilst they are waiting for assessment (Bathgate House used to offer this)

- Is a stress-control class
  - Cyrenians have a HUB
- Advocacy and COWL is self-refer
- Can self-refer to social work – all referrals are then screened
- NHS Mental Health Services are accessed via GP;
  - Out of hours - NHS 24 would make an out of hours GP appointment or set up an appointment with the duty psychiatrist for formal assessment. A&E in an emergency. ACAST is available up to midnight if you present at A&E. If you call the police with suicidal thoughts, they would also attend.
  - “Sometimes phoning out of hours or Breathing Space is the only way to get an out of hours’ psychiatry appointment.”
    - Sometimes it takes a long time to get an ambulance to take suicide attempts to hospital
- There is no crisis support for carers
- “Addictions services have a very good model – they have drop in centres which are self-referral / drop-ins”
- Transport – physical access to services is an issue:
  - If service users don’t have a budget for staff to travel too – service users can’t access these services
- In lots of ways things are better than 20 years ago – there wasn’t an ACAST service then
  - “Stigma went away when it [inpatient provision] went to St Johns”
  - The hospital is much more open to working with the third sector

#### How good is accessibility to and integration with mainstream health and social care services?

- Lots of supported college places – Bathgate
- “The vast majority of those on mental health wards have other medical problems and perhaps their physical conditions aren’t necessarily met. For example, if someone falls in Ward 17, they have to get medically trained staff from another ward to help lift as they don’t have manual handling training.”
  - It is getting better though
  - Addictions and mental health services work well together
- Xcite – good links with mental health services – offer gym memberships etc. to those with mental health problems
- Health Improvement Team – good links with mental health services; they help facilitate training/services etc.
- Criminal Justice – working in the Civic Centre makes a big difference; next to Police and Public Protection gives easy access

- Adult Protection
  - Having a point of contact does make a difference – but the post not being replaced upon retiral in September. *“This is a unique role in West Lothian – it will be missed.”*

What does/doesn't work particularly well in West Lothian, in relation to the transition of young people into adult MH services?

#### CAMHS to Adult Services/Supports

- Carers find it very difficult – the level of support is much lower in adult services than CAMHS.
  - COWL do not offer transitions courses for mental health carers in same way as they do for parents of children with learning disabilities.
- High proportion of young people (14-17) presenting at A&E with self-harm/suicidal ideation; there are fewer young person inpatients.
  - Response for young people is good – they will always be seen; after initial assessment (doctor and assessing nurse); they always have access to on-call CAMHS specialist
  - Police get involved – they will contact social work and talk to young people and parents/education etc.
  - An alarming number of young carers self-harm (COWL) – COWL offer quite a lot of 1:1 support for this; they have a waiting list which is growing
  - “Young people need lifeskills and tools to deal with distress.”
- There are link workers in schools – Guidance Teachers

#### Adults to Older People Services/Supports

- SAMH support people regardless of age
- MHAP could work with people over 65 – although contracted upto 65
- COWL work with those aged over 8
- Social work can work with people over 65 – *“it's about continuity of care”*
- In Health – “if they are receiving treatment they wouldn't automatically transfer at 65, we would wait for treatment to end.”
  - CPNs – still work to 65 – “it's not prescriptive though”
  - “There is a fair amount of discretion”
- “There is an Issue with Ward 3 (Psychiatry of Old Age) – largely a dementia ward. It can be quite violent – not necessarily the right place for older people with other psychiatric issues or young people with early onset dementia.”

#### Hospital to Community

- COWL work in St John's – often people are discharged at very short notice and rely on family carers
  - COWL sit on discharge planning meetings

- Hospital discharge was an add-on with the Carers Act
- There is still an issue about whether the ward will talk to your care provider about getting a care package
- It can be inconsistent – “social work isn’t always told when people are discharged”
- MHAP might get a referral but the patient may be discharged before they are seen and they leave with no forwarding address

Are there any defined and agreed ‘Integrated Care Pathways’ within the MH sector in West Lothian?

- Is a model the NHS tries to work to, but it is not consistent
- It does work with high tariff cases – referral to MAPPA (ICP merges into MAPPA)
- “It sounds like a big secret”
- “I think I’ve heard of it”

What are the key gaps or issues that need to be addressed pertaining to service provision for those with MH problems in West Lothian?

- “It is very difficult to deal with things in isolation – if you change something it has an effect on something else somewhere down the line.”

Where would you like to see future investment go? (Ranked in order of priority)

1. INCREASING THE CAPACITY of existing mental health services
2. EXPANDING THE RANGE of existing mental health services
3. ENHANCING THE QUALITY of existing mental health services
4. IMPROVING THE INTEGRATION of mental services and other services



## APPENDIX III: KEY STAKEHOLDER INTERVIEWS

### Introduction

A total of 33 people representing public and 3rd sector services directly or indirectly engaged in the provision of Mental Health services participated in interviews. The majority were conducted as one-to-one, face-to-face interviews; a small number were joint interviews and another small number were conducted by telephone.

Interviews were semi-structured in nature, primarily focusing on the following topics:

- The role and responsibilities of the interviewee and a description of the service in which they operated.
- Strategic priorities.
- Which groups are well served / less well served by current arrangements.
- Localities.
- Service strengths and weaknesses.
- Service user / Carer involvement.
- Well-being.
- Any other relevant observations.

### Strategic priorities

Commonly discussion of strategic priorities began with a review of the current Commissioning Priorities for Mental Health, as stated in West Lothian's IJB Strategic Plan 2016 / 26. However, this was not possible or appropriate in all cases; particularly where the interviewee was unlikely to have detailed knowledge of these priorities or how they had been arrived at.

Where interviewees were aware of the commissioning priorities stated in the strategic plan, there was often broad endorsement of these. But, importantly, thereafter interviewees would then offer a wide range of additional strategic priorities for consideration; sometimes these were explicitly stated as such, but more often they were inferred; by the weight of emphasis given by interviewees.

Where comments could be characterised as striking at the heart of how positive Mental Health and well-being could be delivered in the future, we have categorised these as a comment on strategic priorities.

The sheer range and diversity of priorities offered by interviewees was such that it is a challenge to represent them with clarity. Nonetheless, they can be broadly grouped under the following headings:

- Service configuration and service models.
- Management arrangements.
- Planning and resourcing.

- Prevention
- Health Inequalities and Access
- Assessment and SDS
- Service User and Carer involvement
- Well-being

#### Service configurations and service models

With regard to service configuration, a number of interviewees felt there was a need to address weaknesses in how services operated as a coherent whole.

#### Mental Health services and patient flow

Some suggested that whilst individual Mental Health services were working appropriately, linkages with complementary services were not always adequate to ensure effective treatment pathways and efficient patient flow through the system. Thus several people questioned whether the current configuration of Mental Health Acute in-patient, Rehab and support services in the community was fit for purpose.

More than one cause was suggested for issues with patient flow; slow progress through Rehab was cited as not only having negative consequences on the pace at which service users return to the community, but also on occupancy and availability of Acute in-patient beds; at worst preventing acute admissions and a reliance on treatment in the community through the Acute Care and Support Team. One said:

*'The Rehab facility is consistently full. Recently, 25% of patients in Acute have been waiting for a move into Rehab. This is a whole system 'flow' issue.'*

Another:

*'Some go straight home without appropriate access to Rehab.'*

Another said:

*'156 in-patient beds have been removed, however they have not been well served by the community support models that have been put in place.'*

In a similar vein, another said:

*'People are stuck in hospital because of a lack of appropriate supported accommodation.... The existing supported accommodation is appropriate for some, but not all. Some are being sent to supported accommodation out with the area.'*

#### Gaps in services

When discussing strategic priorities, many interviewees identified gaps in services. A common theme was the adequacy and configuration of services for those that might loosely be categorised as

'Distressed'. This was so commonly cited as an area of strategic concern that it's worth illustrating with a number of perspectives, each from a different interviewee. Thus one said:

*'There are huge numbers of people with mental distress and related social problems. It shows in A&E and is probably impacting on community services'*

Another said:

*'Those who need urgent unscheduled care are not well served; those with addictions, self-harm, in distress, with personality disorders, with dual diagnosis, and other conjoined medical and psychiatric problems. (Linked with this may be) social problems, homelessness, unemployment and loneliness'.*

Another:

*'We have a lot of Young People presenting at A&E with signs of distress. This is a challenge because we don't have CAMHS in-patient beds on our doorstep'.*

And another:

*'People in distress often present at the General Practitioner. But the GPs have nowhere to refer.'*

Discussion of those 'in distress' was often linked to discussion of the responsiveness and capacity of psychological therapies. Of those who commented, there was universal concern that the waiting list for Adult Psychology was approximately a year. One said:

*'There used to be a full-time Adult clinical psychologist for West Lothian, but they now serve West Lothian, Midlothian and East Lothian.... The post is stretched to unbearable limits and West Lothian has less consultant time. ... It's appalling that it's a stand-alone service.'*

Another said:

*'Psychology is struggling with access. There is a lot of room for improvement. It's letting a lot of people down.'*

Some argued the lengthy waiting lists were simply a function of inadequate capacity<sup>1</sup>; to which some ventured potential solutions.

*'There was previously training for particular therapies, but now because we don't have a certificate, we are not able to deliver. I would like us to go back to that way of working. Staff have been de-skilled and dismissed, but we would be able to build this back into our working practice.'*

One commented that psychological capacity was a Lothian wide issue:

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<sup>1</sup> At time of writing, we understand The Scottish Government has made additional finance available for psychology services in Lothian and that this will result in an additional 4.5 psychologists, five nurses and admin support available throughout the area. However, one estimate suggests Lothian would instead require an additional 13 psychological therapists, above the historic baseline, to provide a sustainable service.

*'(Compared to other Health Boards) NHS Lothian has the lowest number of psychologists and the lowest banding. If there was more investment, we may be able to change the model of care. We should have more nurses delivering psychological therapies'.*

For one, current arrangements were broken beyond repair:

*'Our current approach to psychotherapies will never deliver. We must change the system. We can't reward people for being inefficient in a daft system'.*

Referring to the lack of coherence, one observed that West Lothian lacked an adequate 'Matched Care model'; where psychological therapies could be delivered in a tiered manner, by a range of disciplines and including 3rd sector providers.

Other gaps / service weaknesses identified by more than one interview were 1/ for those with dual diagnosis (Substance Misuse and Mental Health problems) and 2/ those Young People who weren't sufficient priority to be treated by Children and Adolescent Mental Health Services (CAMHS).

### Service models for Mental Health / Mental health problems

One interviewee questioned whether an adequate distinction was made between those with Mental Illness and those with a Mental Health problems; implicit in this view was the suggestion that current services were not adequately recognising the need for different approaches to the treatment of, on the one hand, Severe and Enduring Mental Illness (Schizophrenia, Bipolar Disorder etc.) and, on the other, Mental Health problems; such as Anxiety, Depression, Substance Misuse and Trauma.

Several interviewees saw a necessity or opportunity to redesign models of care. One said:

*'Services are getting really quite stressed across all care groups; both by numbers and complexity. Local services have been designed for certain levels of need, but we need to revisit the service model and its relevance.... Our models of care are not going to be sustainable in the long term'.*

Another said:

*'We don't need more money, but the ability to transcend the models that cause us difficulty. We've mistaken guidance for tramways. We have become addicted to waiting lists to manage demand. But we should manage today's work today. We should look again at our pathways and co-produce with patients'.*

Another:

*'We want to stop working in silos. As a first step I would bring together psychologists and psychotherapists as part of a preferred model, leading in time to fuller a multidisciplinary team. There was a joint Mental Health team in the East which worked well. It comprised a Community Mental Health Team, an Intensive Home Treatment team and Psychological Therapies. Anything that involved Mental Health came through that team; the single referral point worked very well.'*

Another:

*'We must embed community-based care. Psychiatrists have historically worked to a sector role; i.e. assigned to 'random' GP practices. We need to ensure they are allocated more appropriately, perhaps along a localities model. We need to maximise GP capacity to deal with patients with Mental Health issues; approximately 1/3rd of appointments are Mental Health based.'*

Several felt consideration should be given to 'ageless' models. For example:

*'(In respect of transitions from Adult to Older Persons services) ... Some areas, e.g. psychology, could be ageless. At the very least Adult Older People's Mental Health teams should treat patients the same. Older People's teams are still very consultant led, whereas Adult services use a triage system.'*

Several commented favourably on a perceived increased emphasis on 'Recovery'. However, some felt the phrase was at times misapplied or misunderstood and also that the concept still had to gain traction in some areas.

*'I like the Commissioning Plan's emphasis on building social capital, of doing for yourself. This is a recovery model.'*

Another said:

*'Recovery has to be a focus.'*

Another said:

*'As a result of current supportive approaches, clients are talking about what they are going to do to advance their Recovery; using the strategies they have been taught.'*

But in contrast another said:

*'The Recovery model is not as developed in West Lothian, still a very medical model.'*

Another:

*'Recovery does not mean 'get better'. Recovery is a journey. The outcome statement 'More people with mental health problems will recover' demonstrates a lack of understanding. The statement is irrelevant.'*

And another:

*'Recovery is not relevant in the case of Alzheimer's; Enablement is a better word... Enablement is about potentially releasing people to have a more fulfilled life.'*

### Management / structural arrangements

Several interviewees were of the view that current management / structural arrangements for Mental Health services in West Lothian are not fit for purpose; being fractured and disjointed.

*'(On community services) The priority needs to be the integration of Mental Health services that are already in West Lothian. The structure holds us back. There are 2 Mental Health teams, an*

*MHO team, a Mental Health Assessment Team and the Community Outreach team. Services do not come together in a coherent form'.*

Another said:

*'I'm concerned that in West Lothian we have too many small teams; too many people fall between the stools. The structure is skewwhiff and does not make sense to me.'*

Another:

*'There is a lack of an appropriate governance structure'.*

A view articulated by some was that all services should be pulled together under a single Mental Health Manager.

### Resourcing and planning

Many interviewees considered that the combination of constrained resources and growing demand meant current approaches were unsustainable.

*'There is a compelling case for change. We need to look at different models of care, whilst not underestimating the difficulty of choices. We need to look ahead to how we can provide good services; the way we are delivering just now won't be sustainable. That's a fact. There may not be cuts, there may be ways of doing things differently.'*

Some suggested areas of current inefficiency:

*'Some patients are being escalated unnecessarily and expensively ... If we don't understand demand and capacity, it causes problems elsewhere. It can create more unscheduled care demand, which is very expensive'.*

Another said:

*(Arguing that inappropriate services had been commissioned) 'The contracts team are not equipped for the job. There is a dreadfully amateurish approach to commissioning because they don't look at the evidence base; they are driven by a contract culture. They don't listen to professional voices and alternative proposals are ignored'.*

Another:

*(Regarding workforce issues) 'We need got to get the models right. We have to keep using Bank and Agency staff. Sickness absence is high (7 – 8%).'*

Others remarked on the impact of Locum consultant appointments, not only were they more expensive but the short periods of attachment meant that working relationships were undeveloped and joint working undermined.

One commented on the hidden costs of the Personalisation agenda.

*'Delivering a person centred approach is challenging for us to purchase effectively and efficiently. Individual purchase makes it harder to plan. Personalised care may not be able to benefit from group provision.'*

Some noted the current drive for savings could have adverse consequences for efficiency and quality in the long term, and impact on opportunities to redesign and develop services.

*'We can demonstrate the case for preventative action, but I'm concerned there maybe cuts in this area. ...Early intervention does stop things happening and is efficient'*

Another:

*'Our budget is almost 100% staff; so any savings come from staffing. We have twice the number of referrals, but staffing levels have eroded'*

Another:

*'I'm concerned at losing posts and trained staff being replaced by untrained. I'm not able to improve services and have to give up something to get something, but there's nothing to give. It feels like a vicious circle.'*

Another:

*'Funding uncertainty is stifling innovation.... We can't plan beyond next year'*

Another:

*(Commenting on the impact of resource constraint on well-being initiatives) it's frustrating that there is no funding that gives a strategic approach to developing work such as this. There are fantastic bits of work going on, but sustaining interventions is a problem. All funding for projects is short-term.'*

Interviewees had proposals for how resources might be better deployed.

*'Sometimes we have too many silos. We need to look at the interface of the professions. We need more generic services and less duplication.... We need to think about how the whole system fits together; it may need radical redesign'*

Another said:

*'Do less, but do it better'*

And, in a similar vein, others spoke of managing expectations:

*'There is a big gap in expectations regarding Mental Health. Expectations are much larger than Mental Health see the role. This disjunction is a problem and sets up conflict and disappointment.'*

There was often recognition that Health and Social Care integration offered opportunities but this was tempered by the knowledge that pursuit of change would be challenging.

*'It is clear that the IJB will have to come up with different approaches. The organisations will need a bit of time to get used to the IJB. Progress is being made... There may need to be a shift*

*in resources between the NHS and the Council. There are vested interests, and these may be difficult to break'.*

More than one commented on the political challenges, arising out of integration.

*'We need to redesign models of care. This will need political buy in and the right national messages.'*

Another:

*'Setting up the IJB has been difficult; very political'.*

And another:

*'It's politically very close between the SNP and Labour; (leading to) paralysis for about a year before election.'*

Some felt closer engagement with service users and carers offered opportunities in designing sustainable approaches.

*'We need to be more confident in our engagement with service users and others. (When reshaping services) Really listen to what people need. This might bring efficiencies. This is where social capital is important. The SDS agenda is set up to do this; what are the outcomes for individuals? We need to grow this side of how we do business... Co-production needs to be at the heart of our thinking'.*

Another saw opportunities for closer engagement leading to enhanced community capacity.

*'What can we do to promote community capacity building? It's about driving things from the bottom up'.*

## Prevention

Many commented on the value of prevention and early intervention, but this was often qualified by the recognition that it can be hard to invest in this when struggling under the weight of current and pressing demand.

*'Getting upstream is a good idea. For example, increasing the capacity of parents. Mental health services shouldn't be an island; they should have good links up and down, internally and externally; to education, social work, gyms etc., moving upstream to choke off demand.'*

Another said:

*'Strategic upstream intervention is required and the impact would be quantifiable. Why does someone have a drug and alcohol issue? Because of the environment in which they exist. It needs a bolder approach.'*

And another:

*'Prevention is crucial in terms of early years, Children and Families. (This could) drive future reductions in inequalities.'*



But one noted:

*'(Investment in) prevention and early intervention poses a challenge when there are restricted budgets. (Impact) is difficult to measure.'*

And another:

*'We've had 10 years of focus around prevention and early intervention and it's a difficult and challenging place to go. Individuals will often not seek help until there is a crisis. People may be offered something early on, but may not take it up. In general, the prevention rhetoric is overstated and aspirational. Attribution becomes more difficult the more upstream you go.'*

### Health Inequalities and Access

Whilst some commented on the importance of addressing health inequalities, others doubted whether significant change was being achieved.

*'(Tackling) Health Inequalities has to be a major driver.'*

Practitioners spoke of the impact of health inequalities on their day-to-day work.

*'Deprivation is a primary health inequality; we see it in our caseload... The impact of deprivation is a given; there's more unhappiness. I feel people from these communities feel like 'losers'... We are often fighting against wider issues.'*

As well as those in poverty, others identified homeless people, people with a dual diagnosis, and / or chaotic lives, as at particular risk of experiencing health inequalities. In this regard, some felt the contribution of wider services was not always recognised.

*'Not all of the NHS see anti-poverty work as a key part of Recovery and tackling health inequalities'.*

Indeed, some voiced concern the current commitment to tackling health inequalities was tokenistic.

*'Inequality will become an increasing problem. It's just picked up as an afterthought at the moment.'*

Access issues were identified by some as contributing to, or exacerbating, health inequalities. Interviewees identified more than one form of access issue; these could be broadly characterised as (1) practical impediments to access and (2) inappropriate or accidental restriction of service to those in need. In illustration of the former, several interviewees remarked that some people had to travel to access services using inadequate transport links. Thus one said:

*'Bus and transport services are a weakness. Current arrangements undermine access.'*

Another:

*'Semi-rural communities struggle to access services; for some villages the last bus back is 6 PM'.*

One combined a critique of geographic arrangements with comment on how those with Mental Health issues might be further affected by having to travel.

*'What is lacking in West Lothian is equity. We are a poor relation because of our setting. Some services are based in Edinburgh, but call themselves Lothian wide. But for some, crippled by anxiety etc., it's a massive step to get on the bus to travel to the services. Consequently, those services are not equitable.'*

Inadequate or poorly communicated pathways were seen as undermining access.

*'Lack of a pathway affects how work is done on the ground. There is a lack of clarity about roles and responsibilities; how it fits together. If we can't understand it, we can't communicate it to service users.'*

Another believed a lack of access to appropriate services could have profound consequences.

*'Those with Distress are least able to access but most likely to complete suicide.'*

But not everyone saw access as an issue in West Lothian:

*'I am not aware that access is an issue.'*

### SDS and assessment

Whilst often the principles of Self Directed Support were broadly supported, there was significant concern regarding how it is currently delivered and its impact on availability of support services. Some felt SDS had not yet 'grown the market' and could in fact be detrimental to the provision of valued services.

*'SDS is a serious problem for us. In principle fine, but could impact on the viability of services.'*

Another:

*'The reality is the market hasn't responded; it's not offering anything greater... The downside of SDS is not having firmed up budgets. It's difficult for small scale providers and undermines their viability.'*

And another:

*'It's hard to commission for small numbers. Even though SDS could theoretically address, it needs providers and (scarcity) is still reflected in the price.'*

Two interviewees remarked upon what they saw as the inequitable impact of SDS resource allocation. Thus one said:

*'There are inequalities in SDS; some with less need can access more than those with greater. Practice does not match the principles. Those people with the most severe illness are not getting the best out of it. People feel confused, including us.'*

Similarly, another was of the view that some care groups received disproportionately large SDS packages compared to their client group.

But others were more positive about what SDS could offer. For example, it could offer greater flexibility in the purchasing respite care:

*'SDS can be creative without you having to go to a (designated) 'place'; previously a Care Home was commissioned to provide respite, but having a building is inflexible and backward.'*

To a lesser degree, practical issues were identified by a small number as hampering the assessment process: such as the time taken to complete assessments and deliver care packages; the sheer volume of workload arising from entitlements to assessment; and GP assessments not being able to passport people direct into services, such as the Acute Care and Support Team.

In Young People's services The Mental Health Well-Being Screening Group was identified as making a positive contribution to assessment and effective placement in services. Its multidisciplinary approach was seen as a strength.

*'(The Screening Group) is a brilliant way of pulling sparse resources together into one meeting. It takes a lot of pressure off ... Any disagreements happen in an open way.'*

### Service User and Carer involvement

There were mixed views regarding the quality and extent of service user and carer involvement, but the prevailing view was that both these areas require strengthening and that co-production could be beneficial to service design delivery. It was clear, that for some, enhancing service user and carer engagement should be a strategic priority.

A range of views is reflected here. One said:

*'There isn't a way of doing service user and carer involvement; it's not an embedded way of working. If they improved that, it would be much more useful to them.'*

Another:

*'At a strategic level there is representation, but it could be better; there is a danger of tokenism. Health not particularly good at engagement at the planning service design level.... Historically service driven rather than person driven. This needs a cultural change.'*

Another:

*'The quality and extent of service user involvement varies. There is a high level of involvement in day services. Mental Health advocacy is accessible. There is a User's Forum and Collective Advocacy. I don't think primary health care is well served. General Adult Psychiatry is starting to look at getting feedback; driven by common complaints. It's a developing area of work and is a willingness and appetite to do it.'*

And another:

*'The quality and quantity of service user involvement is insufficient. We must be willing to hear even hear even if what we hear is unpleasant feedback we need to get a balanced view from everyone'*

## Well-being

The concept of Well-Being and the value of pursuing it divided some interviewees. One said:

*'(Regarding the concept of Well-Being) Scrap it! This is promoted by well-meaning people, but it's a waste of money. I don't understand why it's there and the level resources that are going in. It's a taboo subject to criticise well-being, so management won't. If we are serious about the well-being agenda, we need more practical help. It can be tokenistic.'*

Another:

*'Well-Being is such a broad term it is problematic. Need to be more focused about what we mean.'*

But another said:

*'Everything which comes out of the CPP is underpinned by Well-Being. There's an understanding that the strength of your local community enhances Well-Being. Building community capacity (offers the opportunity of) low investment high-impact. Communities get a real buzz out of this.'*

## **Which groups are well served**

Interviewees were asked to comment on which groups were well served and not well served by current arrangements. We would stress that comments were a matter of individual opinion and may not have been informed by systematic evaluation of service quality, therefore they should be treated with caution. Unless otherwise stated, this section only lists specific groups as well served if more than one interviewee commented to that effect. The same is also true of the following section, regarding less well served groups.

### People with Severe and Enduring Mental Illness

Some identified those who suffered from a Severe and Enduring Mental Illness as being relatively well served, with community services being praised. Thus said:

*'The Community Outreach Team is joined up and it works well. A lot of people are supported well by a good service with a good name.'*

### People with Dementia

Some were positive about services for people with dementia. But this was not a universal view, with some believing those with early onset dementia were less well served.

### The Affluent.

Two people remarked that the wealthy were well served.

## Which groups are not well served?

### People In Distress

As outlined earlier, many interviewees were of the view that those who suffered lower-level mental health problems and 'Distress' were not well served; due to a lack of services and clarity over referral pathways<sup>2</sup>. When discussing those 'In Distress' interviewees often listed a wide range of subgroups; commonly this included: people with addictions, who self-harmed, who suffered anxiety or depression, who had personality disorders, or had additional social problems such as homelessness.

For example, one said:

*'People with dual diagnosis are poorly served; they get shunted from pillar to post... (Also there should be more services) for those with low-grade anxiety / depression. GPs feel a lot is passed back to them; services are not persistent enough. If clients don't open the door they are referred back to the GP.'*

The duration of interviews did not allow for detailed discussion of the reasons why all the individual subgroups listed above were not well served, or what opportunities there might be for improvement. However, we would note that, given the potential numbers associated with these groups, the volume of people poorly served by current arrangements could be sizeable indeed.

### Carers, including those caring for people with dementia

Some concern was expressed that Carers, particularly those looking after people with dementia, were not always adequately supported.

Post Diagnostic Support was generally welcomed, but some commented on the timing and duration of this and also whether, given the high numbers diagnosed with dementia, support services to carers had sufficient capacity.

*'Support for carers should be given higher priority... Post-Diagnostic Support only lasts 12 months, but it's often much later that carers need help and support; at the aggressive stage, the wandering stage.'*

### Vulnerable Young People with a Mental Illness, particularly those transitioning into Adult services

More than one interviewee believed that Children and Young People, particularly vulnerable groups such as those who had been Looked After, were not always well served.

*'Children and Young People should be a strategic priority. Traditionally they have separation and loss issues and may be traumatised. From 16 years upwards young people are less likely to*

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<sup>2</sup> It is noteworthy that a Distress Tolerance Group has recently been discontinued. There was a clear difference of opinion between some interviewees as to whether this group had been effective value for money. One begged the question, 'where do we refer them to now?'

*engage voluntarily. But the group are more likely to figure in Mental Health Services and have been less well served in the past.'*

The same interviewee said:

*'We don't have a Mental Health Team for Children and Young people, but by default have created a team through the Children and Young People team, but they are not trained in mental health. There are generic Support Workers morphed into servicing that group. This is not a strategic choice. It's a bit of a scary place for those workers; with people being referred in with self-harm / suicidal ideation... Some are sent back into (statutory) residential settings. Some young people have committed suicide over the years.'*

It was commented that handovers of young people transitioning from CAMHS into Adult MH services often did not happen and that there was a significant difference in the working styles and arrangements of CAMHS and Adult services. This meant that:

*'... Some families feel a bit out of it. It's a bit of a sharp jump off.'*

Another said:

*'The CAMHS is things GPs most complained about. There is a lack of clarity for GPs as to who is and isn't an appropriate referral. Transitions are also problematic. There is a sense that many are discharged at 17/18 without a plan because of their age; some should probably have been referred to Adult services.'*

### People with Autistic Spectrum Disorder (ASD).

Some interviewees commented on a lack of local services and a clear referral pathway for those diagnosed with ASD. Services for them were based in Edinburgh, and limited in capacity by being consultant led.

### Others.

One interviewee thought people with brain injury were not well served. As a single voice, this view would require additional corroboration before being given weight.

## **Localities**

Interviewees were asked their views on the current Localities arrangements of the Health and Social Care Partnership; the Partnership has two localities - East and West.

Many interviewees did not have strong views on the division into East and West. However, a few noted that this division ran counter to other divisional arrangements already operated by The Council and that a single standardised approach would be more helpful.

*'Most work The Council does is in Ward areas; in some services we have three areas. We keep splitting West Lothian up into different areas, depending on service.... A commonality of areas would be good. Artificial lines are drawn'.*

It was noted that one potential consequence of not being consistent in the way in which West Lothian is divided is that datasets may not be easily comparable.

As discussed already, transport arrangements were seen as a significant issue regarding access to local and Lothian wide services.

Some interviewees commented that differences in wealth across localities, coupled with the combination of rural and urban communities, could make commissioning and service delivery a challenge. For example, one said:

*'It can be difficult to get support in the more outlying areas; there can be labour force issues'.*

Some saw opportunities for closer links between Mental Health services and emergent GP clusters. But others were less optimistic, asserting that GP practices would not work together.

### **Strengths of current services and arrangements.**

Interviewees were asked to identify the strengths and weaknesses of Mental Health services. Many diverse strengths were remarked upon but, to avoid overemphasising a single viewpoint, unless otherwise stated this section will focus on those strengths identified by more than source.

Some of the strengths are referred to in other sections and therefore will not be re-examined in depth.

#### Joint Working

Whilst some gave examples of where joint working was perceived as a weakness, many identified this as an area of strength and commented on the positive benefits this brought. For example, one said:

*'A strength of local services is joint working across disciplines. It feels like an Open Door policy. You generally know someone who will help you; going the extra mile is really evident in West Lothian'.*

Some remarked positively on what they described as 'The West Lothian Way'; although the nature of this was never fully articulated, by implication this was a unifying, locally derived, ethos and commitment.

The Community Planning Partnership was identified as a positive force by some; 'it's one of the better ones'.

The Mental Health Well-Being Screening Group was cited by more than one as a good example of joint working.

*'(The group) is a multi-agency forum of Health, Local Authority and Voluntary organisations. It includes Child and Adolescent Mental Health services and Psychology. The purpose of the group is to offer a single referral route; matching services to people, rather than them sitting on a waiting-list... The single route stops multiple referrals and stronger joint working.'*

Some commented on the positive relationships between statutory services and the third sector.

*'There's some good work looking at where and when interventions can be made. They are prepared to work in partnership with ourselves and the third sector.... For example, with Ward X and also Addiwell Prison.'*

Examples of positive joint working between community services were given.

*'Having CPNs based in GP practices seems to be really good; allowing closer relationships'.*

### The commitment and quality of staff.

Several people identified staff across in-patient Mental Health, community Mental Health and supporting third sector services as positive assets. Thus one said:

*'There is a definite will of staff to deliver the best services they can'.*

Another:

*'(Regarding community MH services) we have the basics of a fantastic service based on really good staff and relationships with each other. There is a willingness to work differently.'*

Another:

*'Staff are highly motivated to do the best they can for their clients. There is a high standard of work going on in the community.'*

### Acute services

Some made positive comment not only about staff in acute, but also service arrangements. For example:

*'We have some fantastic specialist services; Mother and Baby, Eating Disorders etc. The wards are good; deeply therapeutic. Acute Psychiatry is full of fantastic caring nurses. The Crisis Team is good.'*

Another said:

*'There are very good reports about the work of the Acute Care and Support Team. They are vital in preventing emissions.'*



## Community services

Interviewees remarked upon positive and productive relationships between community teams, including third sector services. The relationship between The Community Outreach Team and the Mental Health Assessment team was described as good.

The Dementia cafes operated by Alzheimer's Scotland were recognised as making an important contribution. Some already use the dementia cafes to contact clients of mutual interest and others remarked that they might be a useful platform upon which other outreach activities could be built.

The Mental Health and Well-Being Screening Group was advocated as both educating referrers and connecting users to a broadened range of community services.

*'Quite often referrers don't know what is available, is needed or required.... The Group takes an increasing number of referrals from GPs; re self-harming / counselling.... More options are provided than previously; the range of services has strengthened and broadened.... CAMHS now divert a number of people through the Screening Group, so they get picked up and matched a lot quicker.'*

There was positive endorsement of the work of The Mental Health Advocacy Project, although there was a recognition that it may be most in contact with those suffering Severe and Enduring Mental Health issues.

*'The Mental Health Advocacy service is very well-run and responsive.'*

Some interviewees were positive about the contribution of social housing providers, particularly at a strategic level, but this was not a universal. One said:

*'There is a very well established approach to linking housing with people social care need.'*

Another:

*'There is a strategic role across West Lothian Council and its partners to reduce health inequalities through Housing / Planning etc.; there's a strong focus on tackling poverty, using community development approaches.'*

## **Weaknesses of current services and arrangements**

Previous and following sections, such as those on strategic priorities, refer to many of the key weaknesses identified by interviewees, therefore, we will largely avoid reiteration of these. Unless otherwise stated, to avoid overemphasis of a single individual's view, this section will concentrate on weaknesses identified by more than one interviewee.

Once again, we would stress that the following is based upon the opinions and experience of interviewees and their views are not necessarily founded on separate and substantial evidence.

### Poor Joint working

Unfortunately, while some reported positive joint working, this was far from universal experience. For example, one said:

*'Joint working is a big problem. There are not effective links regarding Dual Diagnosis.'*

Another:

*'(Our service has a problem with) Adult Psychiatry. There is a lack of willingness of Adult Psychiatry to work with us and communicate. (Staff) are not respected in the role..... don't return calls or emails.'*

Another spoke of their frustration at not engagement from psychiatry:

*'It needs a simple point of referral plus a Panel to allocate appropriately into the right services. This was tried, but psychiatry didn't come.'*

Another identified the weakness weaknesses of joint working where it relied on relationships rather than systematic following procedures and process.

*'West Lothian has had a well-developed integrated model. But this has made people quite tribal. It works on relationships, not systems.'*

Whilst some viewed 'The West Lothian Way' positively, not everyone agreed; implying that it undermined shared approaches..

*'West Lothian constantly refers to the West Lothian culture, it needs to stop doing that. It sees itself out with Lothian'.*

### Poor communication

Poor communication was a separate issue, but one that also appeared to be impacting on the effectiveness of joint working. Some interviewees spoke of a lack of awareness of referral pathways, tensions arising from misunderstandings of the role of particular services and unrealistic expectations fuelled by lack of knowledge. Thus one said:

*'There can be communication problems between in-patient NHS staff and community services. A tension, and there can be over expectations of what can be provided in the community, including safely.'*

Another said:

*'(Regarding those with Dementia) Poor communication can lead to a breakdown between individuals and services. Information is not given in a clear way. People don't get a diagnosis in writing; therefore, may fail to retain.'*

### Staffing issues

Several staffing issues were identified that were undermining current service delivery and the fostering of long-term productive relationships. As referred to earlier, there were concerns regarding vacancies / high turnover in psychiatry; not only were there high costs arising from locums but they're transient nature undermined joint working.

Sickness absence was reported as high (7-8%) in some in-patient wards and some interviewees also felt there was low staff morale.

*'We have to keep using bank and agency staff. Sickness absence is high.'*

### Evaluation of the impact

Some were of the view that there was insufficient effort made to evaluate impacts. One said:

*'Historically (The Council) have not been good at encouraging our commissioned services to measure impact; we need to get better that.'*

Another:

*'It's very difficult to get managers involved in impact assessment.'*

### Inadequate physical health monitoring and interventions

Some voiced concerns, that whilst there might have been improvements, the physical health needs of people with mental health problems (particularly those with Learning Disability) were not always being systematically and adequately addressed.

*'Physical health checks should be done and an evidential trail provided.'*

### Lack of access to appropriate drug and alcohol services

As touched upon earlier, there was concern regarding the treatment of those with Dual Diagnosis and difficulties accessing appropriate services for this group. One said:

*'There is a massive growth of substance misuse amongst those with Mental Health problems / Mental Illness. This is the biggest growth area. But we don't have enough internal access to specialist services. Better alignment is required.'*

Another believed that a failure to address the needs of those with drug and alcohol problems had wider consequences.

*'Drug and alcohol is a massive problem. A growing area. The Police refer far more than before. Those with drug and alcohol problems clog up the system and put a huge strain on stretched resources.'*

### Demand and capacity in CAMHS

Some expressed concern that there was a lack of capacity in the CAMHS. They argued this showed itself in waiting lists, referrals back into lower order services and only limited sessional work with some clients before discharge from CAMHS.

### Ethos

Some interviewees felt the ethos of services was biased towards a medical model. Some advocated more social /empowerment based model.

*'At the IJB level there is still the difference of thinking styles; the medical model, the social model and the empowerment model (which is more radical). There is still a dominance of the medical model, but we are dealing with people not an illness.'*

### Risk aversion

Some suggested that risk aversion, especially with regard to threatened suicide, could lead to inappropriate service responses; such as overtreatment or referral into services that were unable to respond timeously. Thus one said:

*'We are becoming very risk averse. Clinicians are worried about being sued. Using the S word (suicidal) opens many doors. Some patients may have already had similar presentations.'*

### Lack of support for carers

Some felt there was a lack of support for carers of people with mental health problems. Some suggested that because the needs of such carers may be less obvious this resulted in a lack of prioritisation. Whilst it was noted that carers of West Lothian had a group for carers of people with mental health problems, some felt they were more focused on supporting carers of people with physical disabilities.

### **Service user engagement**

Taking the sweep of interviews as a whole, the evidence was that engagement with, and empowerment of, service users was variable. There were examples offered of positive engagement with service users. One said:

*'(Through weekly meetings etc.) I'm confident that where we can we seek patient and carer involvement. We are keen to get feedback. (But we're) not always good at showcasing and working through improvement.'*

Another:

*'The quality and extent of service user involvement varies. There is a high level of involvement in day services. Advocacy is accessible. There is a User's Forum. There is collective advocacy.'*

But others cited a lack of opportunity and commitment to co-production, limited efforts to build community capacity and lack of joint governance arrangements as indicative of an unwillingness to offer real influence. One said.

*'There is very little opportunity for people to come together as a united voice. Feels like people are being kept apart deliberately... People don't hear back from consultation exercises.'*

Another:

*'We are probably weakest in this area. We do the basic stuff; survey people. We have a good sense from a small number of people, but don't have participation in the design of services.'*

Another:

*'We used to have a Reference Group, including members who were service users and carers. This gave major stakeholders a say in commissioning of services. It means there's nowhere to take complaints regarding the process of commissioning.'*

Again, the evidence in respect of engagement with individual service users was also variable. One said:

*'Everything we do is totally agreed with the service user.'*

But another:

*'I don't think staff are in a mind-set of empowerment. Empowerment would be more than just business as usual engagement.... When you look at what that (Empowerment) means you get more resistance.'*

One articulated the benefits of service user involvement as:

*'If we really listen to what people need, could reshape services. This might bring efficiencies. This is where Social Capital is important.'*

Finally, a number felt insufficient effort was made to reach out to, listen and respond to the needs and wishes of minority groups. A number of reasons for this was suggested, including: the level of effort involved, cultural challenges, an unwillingness to look for problems, practical communication difficulties and the prejudices and biases of individual members of staff.

## **Carer engagement and support**

Many saw benefits engaging with carers, but agreed that the quality and extent of this was variable. Thus one said:

*'We need to work with carers. Every patient with a carer costs less. We shouldn't treat them as an unwanted extra.'*

Another:

*'There isn't a way of doing service user and carer involvement; it's not an embedded way of working. If they improved that, it would be much more useful to them.'*

However, some were positive about their work in this area:

*'We do this very well. Engage widely with carers and other (important parties). We provide a bit of a conduit; hospitals and psychiatry can be a bit of a mystery. We help to give people an understanding of what's going on.'*

## APPENDIX IV: SURVEY RESULTS (STAFF, DENTISTS, OPTOMETRISTS AND PHARMACISTS)

### Staff Survey

In order to capture the views of staff working in adult mental health services across West Lothian, an online survey was created using the Survey Monkey tool and the link disseminated to all local services. The distribution list was agreed in advance with commissioners. Staff were asked for their opinions on current service provision and to identify any gaps or areas which could be developed going forwards.

In total, 115 individuals began the survey, but some questions attracted fewer than 40 responses. Key themes and issues are presented in the appendix below.

The vast majority of respondents were female (88%; n=97) and 40% (n=44) were aged between 46 and 55.

Staff who responded (n=109) came from a variety of health, social care and third sector agencies – the full breakdown is shown in the table below:

Organisation	Frequency of Response	As a % of Total Responses (n=109)
Commissioned Provider	31	28.4%
Adult Mental Health – General	13	11.9%
Social Policy	9	8.3%
Third Sector	9	8.3%
NHS	6	5.5%
Old Age Psychiatry - General	6	5.5%
Adult Mental Health - Community	5	4.6%
Allied Health Professionals (AHPs)	4	3.7%
Adult Mental Health – Inpatient	4	3.7%
Psychiatry	4	3.7%
Adult Mental Health – MH Nursing	3	2.8%
Old Age Psychiatry – Community	3	2.8%
Other (including H&SCP; Police; SPS; CAMHs)	12	11.0%

Respondents were asked which areas their services cover; Livingston was most comprehensively served (n=82; 75%); Linlithgow, West Calder and Whitburn were least comprehensively served (n=c22%).

In order to further contextualise the subsequent answers given, it is important to note the roles respondents carry out on a daily basis. The full list of roles is shown in the table below, but it is clear the majority have at least some direct operational experience:

Job Role	Frequency of Response	As a % of Total Responses (n=109)
Support Worker	29	26.6%
Nurse / Clinician	26	23.9%
Senior/Service Manager	19	17.4%
Team Leader	14	12.8%
Allied Health Professional (AHP)	6	5.5%
Occupational Therapist	5	4.6%
Counsellor	4	3.7%
Admin/Finance/HR	2	1.8%
Social Worker	2	1.8%
Other (Police/PO)	2	1.8%

### Service Evaluation

Staff were asked to evaluate their service against a variety of criteria. Their responses are shown in the Figure below:

Statement	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree	Nil Responses
Our service works effectively with people who have mental health problems.	40.0% (n=46)	29.6% (n=34)	3.5% (n=4)	5.2% (n=6)	0	21.7% (n=25)
Our staff are knowledgeable about how to respond appropriately to presenting mental health problems.	40.9% (n=47)	32.2% (n=37)	2.6% (n=3)	5.2% (n=6)	0	21.7% (n=25)
Our service undertakes comprehensive assessments.	40.0% (n=46)	27.0% (n=31)	5.2% (n=6)	2.6% (n=3)	1.7% (n=2)	24.3% (n=28)



Our service uses a validated or common assessment tool to identify individual risks and needs.	<b>36.5%</b> <b>(n=42)</b>	25.2% (n=29)	7.8% (n=9)	4.3% (n=5)	1.7% (n=2)	24.3% (n=28)
Our service has established referral routes with other mental health services.	<b>38.3%</b> <b>(n=44)</b>	29.6% (n=34)	7.0% (n=8)	1.7% (n=2)	0.9% (n=1)	22.6% (n=26)
There are defined criteria for classification of mental health risks (low, medium, and high); as well as referral to specific types of mental health services.	22.6% (n=26)	<b>34.8%</b> <b>(n=40)</b>	9.6% (n=11)	7.8% (n=9)	1.7% (n=2)	23.5% (n=27)
Our service is easily accessible to service users from across the whole of West Lothian.	<b>30.4%</b> <b>(n=35)</b>	29.6% (n=34)	7.0% (n=8)	10.4% (n=12)	0.9% (n=1)	21.7% (n=25)
There are effective pathways into older people services that promote joint working.	16.5% (n=19)	<b>35.7%</b> <b>(n=41)</b>	9.6% (n=11)	12.2% (n=14)	1.7% (n=2)	24.3% (n=28)
There is a defined written pathway(s) for people with co-occurring alcohol / drug and mental health problems.	8.7% (n=10)	<b>27.8%</b> <b>(n=32)</b>	25.2% (n=29)	13.0% (n=15)	1.7% (n=2)	23.5% (n=27)
Our service communicates effectively with other mental health services.	27.8% (n=32)	<b>37.4%</b> <b>(n=43)</b>	5.2% (n=6)	6.1% (n=7)	0.9% (n=1)	22.6% (n=26)
Our service has effective working relationships with other mental health services.	26.1% (n=30)	<b>39.1%</b> <b>(n=45)</b>	5.2% (n=6)	5.2% (n=6)	1.7% (n=2)	22.6% (n=26)
Our service communicates effectively with a wide range of other non-specialist mental health services.	21.7% (n=25)	<b>43.5%</b> <b>(n=50)</b>	7.8% (n=9)	5.2% (n=6)	0	21.7% (n=25)
Our service has effective working relationships with a wide range of other non- specialist mental health services.	20.9% (n=24)	<b>40.9%</b> <b>(n=47)</b>	7.8% (n=9)	6.1% (n=7)	0.9% (n=1)	23.5% (n=27)
Our service provides good information about mental health problems, including other sources of help available.	27.0% (n=31)	<b>42.6%</b> <b>(n=49)</b>	6.1% (n=7)	1.7% (n=2)	0.9% (n=1)	21.7% (n=25)
I am confident working with people with mental health problems, including those in crisis.	<b>44.3%</b> <b>(n=51)</b>	25.2% (n=29)	3.5% (n=4)	2.6% (n=3)	0.9% (n=1)	23.5% (n=27)
I am competent working with people with mental health problems, including those in crisis.	<b>47.8%</b> <b>(n=55)</b>	25.2% (n=29)	3.5% (n=4)	1.7% (n=2)	0	21.7% (n=25)
<b>Total responses: 115</b>						

Around 70% of respondents appear to believe their service works effectively with people with mental health problems and provides good information and that staff are knowledgeable and know how to respond appropriately to presenting mental health problems. As individuals, a similar number of respondents reported feeling both confident and competent working with people with mental health problems, including those in crisis.

Respondents were then asked what they think their service does particularly well. Sixty-nine responses were received and a range of comments were provided. Key themes are highlighted in the Figure below:

Key Theme	Frequency of Response	As % of Total Responses (n=69)	Example comments
<b>Person Centred Care</b>	21	30.4%	<p>"Supporting individual interests and skills, focussing on the person rather than their diagnosis or condition."</p> <p>"Respecting individual's differing needs."</p> <p>"I think we work with a person centred approach at all times and treat everyone as individuals regardless of their background and support them to achieve their goals."</p> <p>"We have been developing a person centred outcome approach and not service led."</p>
<b>Joint Working</b>	17	24.6%	<p>"We work effectively with other agencies in providing the best possible care for all our service users."</p> <p>"I believe that we have a very good relationship with other agencies. I would say this helps us to work very effectively and efficiently which ultimately is going to benefit the client."</p> <p>"Liaise well with other multi disciplinary teams."</p>
<b>Service User / Carer Involvement</b>	16	23.2%	<p>"Involves patients and carers in all aspects of the treatment."</p> <p>"Forming good working, therapeutic relationship with clients. Working in partnership with clients to meet their identified goals and needs. Working together with clients and any appropriate services to help the individual live as independently as possible within the community."</p> <p>"Works with younger people with dementia and their families and supports them to live their lives and achieve their outcomes. Supports carers to continue with their caring role."</p>
<b>Empowerment / Supporting Independence</b>	11	15.9%	<p>"Empowering people to make informed choices, responding quickly and effectively to changes in circumstances in people's lives and providing appropriate support."</p>

			<p>"We particularly help people we support to be more independent, and give them the skills to help them every day."</p> <p>"Listens to individuals needs and gives service users the tools to participate in their care plan, work well with other agencies."</p>
<b>Crisis Care / Inpatient Support</b>	9	13.0%	<p>"Working in acute inpatients I believe we respond well to those in crisis. The inpatient experience offers something creative and different from other acute inpatient units in that we offer a therapeutic programme that assists our clients to tackle their issues in many different settings..."</p> <p>"Flexible and very friendly service that helps to fill service gaps people need in a crisis."</p> <p>"Responds effectively to support individuals in crisis."</p>
<b>Keeping People at Home / Early Intervention</b>	7	10.1%	<p>"Maintaining people with mental disorders in the community."</p> <p>"Meeting the needs of the patients in an holistic approach within their own homes."</p>
<b>Promotes Recovery</b>	6	8.7%	<p>"We work in a recovery focused way, and we are person centred focused."</p> <p>"We use a Recovery based approach to our care and include all areas of Mental Health Services in statutory and voluntary in providing the best possible service to our service users."</p>
<b>Signposting / Sourcing Information</b>	6	8.7%	<p>"Provides a holistic assessment to identify needs &amp; signposts to the appropriate service/resource."</p> <p>"Respecting individual's differing needs signposting to other services where appropriate."</p> <p>"We are good at finding out about support services for people in West Lothian."</p>
<b>Community Engagement / Reducing Isolation</b>	5	7.2%	<p>"Helps people to feel less lonely and allows them to get back out in the community. Participating in groups, doing things they once did before, making new friends."</p> <p>"We ensure all service users have access to all facilities within their community and provide one to one support in this area if need be."</p>
<b>Good staff team / Communication</b>	5	7.2%	<p>"Communication within the team and with other services."</p> <p>"Staff commitment and enthusiasm."</p> <p>"Work well as a team, communicate effectively."</p>
<b>Working with Dual Diagnosis</b>	3	4.3%	<p>"Treating clients with co-existing mental health and substance dependency."</p> <p>"Harm reduction and support for substance misuse."</p>
<b>Misc.</b>	11	15.9%	<p>"Being creative in approaches."</p> <p>"Supporting women fleeing domestic abuse."</p>

"Most of all caring."  
"Consistency of care."

They were then asked how they thought their service could be improved. Sixty-five responses were received and a range of comments were provided. Key themes are highlighted in the Figure below:

Key Theme	Frequency of Response	As % of Total Responses (n=65)	Example comments
<b>More Resources</b>	21	32.3%	<p>"Without wanting to sound simplistic, our greatest challenge is one of resourcing. I understand budgetary constraints affect all public and voluntary sector agencies, but resources are becoming ever scarcer and this has many effects on our ability to provide the high calibre of service we aim to."</p> <p>"More resources to cope with increasing referrals."</p> <p>"Improved therapeutic environments could be achieved with smaller units and higher nurse-patient ratios."</p>
<b>Staff Recruitment / Retention</b>	17	26.2%	<p>"Recruitment and retention of staff is affected by our inability to reward staff with the salary they merit. There are many jobs our staff could do which provide better wages and demand much less commitment, skill and are much less difficult in terms of the behaviour they are expected to tolerate in the performance of their role."</p> <p>"Staff recruitment difficult at the moment due to low rates of pay offered to care staff, paying staff higher wages will ensure adequately trained and experienced staff working in these important positions."</p>
<b>Better Joint Working</b>	13	20.0%	<p>"We view further collaboration and increased resourcing as essential in developing a better and more consistent service."</p> <p>"Better links with referrers and partner agencies."</p> <p>"More coordinated responses from joint working between NHS elements and WL Council so that there is no duplication of efforts and resources are streamlined to be more efficient."</p>
<b>Work Force Development</b>	7	10.8%	<p>"Staff training in mental health awareness."</p> <p>"More specific training in CBT, and other specific approaches."</p> <p>"I think all staff should have access to Assist (suicide intervention training) Also mental health first aid."</p> <p>"Better training for officers out on the street but this is resource intensive."</p>

<b>Better Communication</b>	6	9.2%	<p>"They could improve communications with in the team."</p> <p>"I feel there is always room to improve communication, no matter how conscientious we are there can always be something missed."</p>
<b>Reduced Waiting List</b>	5	7.7%	<p>"There is a increasing waiting list for post diagnostic services and it would helpful to have at least one more dedicated dementia link worker to help reduce this. People are currently having to wait up to 5-6 months for this service."</p> <p>"Better mental health services for adults and children with faster response times."</p>
<b>Better Advertising</b>	4	6.2%	<p>"Better communication/advertising."</p> <p>"Ensuring that professionals from statutory community mental health and addiction services are aware of the service we provide."</p>
<b>Less Paperwork</b>	4	6.2%	<p>"Keyworkers have more and more paperwork re: Service User participation that has to be completed and reviewed regularly, when asked, the people I am keyworker to will immediately refuse to look through these things, to offer any opinion or to sign them. Keyworkers then have to document every time this happens, all of which is very time consuming and keeping staff from being hands on and working one to one with the people we are there to support. I think Service Users should have the right to opt out of certain paper exercises that really have nothing to do with their support needs."</p> <p>"Less doubling up of paperwork/administration/computer work etc..."</p> <p>"Less paperwork."</p>
<b>Clearly Referral Pathways</b>	4	6.2%	<p>"More specialist awareness of mental health issues and referral options."</p> <p>"By further developing the pathways into the service and looking at a more robust joint working with our partners in social care to prevent lengthy waits for people into other services."</p>
<b>Clarity on Roles</b>	3	4.6%	<p>"Very little clarity on who does what for ex there is a lot of reluctance from CPN's to accept referrals as their roles have changed more recently and they feel they are forced to play second fiddle to psychologists..."</p> <p>"Joint working between the CPNs and Social Workers could be improved to better understand each other's roles within the team."</p>
<b>Misc.</b>	10	15.4%	<p>"More community based service."</p> <p>"More interaction with service users."</p> <p>"Prisoners complain regularly that they do not get the support they need from NHS in prison. Their opinion is that</p>

			<p>it takes too long to get any assistance from the point of referral. More mental health workers in the prison could help to reduce the delay."</p> <p>"Influence more about early prevention work rather than crisis management."</p> <p>"Rehab remains a problem - moving people on and stopping the "revolving door" culture."</p> <p>"Offering support in evenings / weekends not referrals as yet."</p> <p>"I think being able to provide alternative services within housing support such as employment and benefit advise, more a one stop shop."</p>
<b>Answer Not Relevant</b>	4	6.2%	

Next, respondents were asked what forms of support their service provides post-discharge. Sixty-eight people answered and a range of comments were provided. Key themes are highlighted in the Figure below:

Key Theme	Frequency of Response	As % of Total Responses (n=68)	Example comments
<b>Onward Referral / Signposting / Information Provision / Advice</b>	38	55.9%	<p>"Looking into other agencies to continue working with the service user on their road to recovery."</p> <p>"Issued with helpline phone numbers and addresses if required."</p> <p>"When service is discharged the individual is given list of contact numbers i.e. suicidal prevention, if they feel they need further assistance to adjust."</p> <p>"We identify appropriate services to provide ongoing support."</p>
<b>Discharge to a Specialist</b>	10	14.7%	<p>"Discharge is usually to a Nursing Home or an NHS Palliative Care unit where all needs are met without our ward having to provide support."</p> <p>"The unique type of treatment we offer usually means that the person is followed up by their consultant."</p> <p>"Significant amounts of required via a nurse or Consultant. Medication management is provided as well as symptom management."</p>
<b>Peer Support</b>	7	10.3%	<p>"SMART recovery meetings/Specific support groups - e.g. anxiety/depression."</p> <p>"Peer support employment."</p> <p>"Groups - fellowships, recovery cafes, employability, aftercare."</p>

<b>Voluntary Placements</b>	5	7.4%	"Voluntary Placements."
<b>Isn't Any</b>	5	7.4%	
<b>Outpatient Support / Support at Home</b>	5	7.4%	"Access to out patient treatment ie Anxiety Management; Confidence Building; Assertion Skills; working towards personal goals; structuring time and working towards employment." "Home visits, medication monitoring."
<b>Misc.</b>	11	16.2%	"With some clients we offer a provision whereby they can be placed on our passive caseloads for a period of three months, which means they can contact us within that 3 month period should they require further help or advice - if we do not hear from them in that period they are then discharged from our caseload." "Equipment & adaptations." "We make people aware that they can come back to our service if any issues arise in the future. We're also happy to speak to people on the phone until we can take them from the waiting list. We will also direct people to other services if they're having to wait for ours." "Up to 4 weeks telephone support."
<b>Nil or N/A</b>	13	19.1%	

As a follow-up question, respondents were then asked what more could be done to support service users post-discharge. Sixty-three responses were received, although many were not relevant and there was not any overwhelming agreement. Some of the key themes are highlighted in the Figure below:

<b>Key Theme</b>	<b>Frequency of Response</b>	<b>As % of Total Responses (n=63)</b>	<b>Example comments</b>
<b>Growth of Supports in the Community</b>	5	7.9%	"Increase amount of external support options, especially for younger people with cognitive impairment." "More access to recovery based services, more things for service users to engage in post discharge to support the work of the community team."
<b>Peer Support</b>	5	7.9%	"User lead peer support after discharge from outpatient service." "To be able to have a moving on group where there are people who have been through support and have managed without it so that it doesn't seem so daunting for the person."

<b>Better Transition</b>	4	6.3%	<p>"I think the important issue for us is to advocate for an appropriate transition period prior to the ending of the service."</p> <p>"Introduce them to the perinatal CPN before discharge and perhaps an escorted home visit so its familiar to both patient, their families and the CPN."</p>
<b>Follow-Up Meetings/ Care</b>	4	6.3%	<p>"A follow up meeting possibly six months after leaving service."</p> <p>"Some kind of contact system that will engage clients at specific times."</p> <p>"Dedicated community service with definite date of follow up within 7-10 days of discharge from inpatient services."</p>
<b>More Support Workers</b>	3	4.8%	<p>"Increasing the number of Mental health workers in the prison."</p> <p>"Increase community nurses."</p>
<b>Wider Range of Resources</b>	3	4.8%	<p>"Wider range of resources."</p> <p>"More services to be moved onto."</p>
<b>Drop-Ins</b>	3	4.8%	<p>"More drop-in services so clients can receive immediate support when required."</p> <p>"Think some form of drop in / befriending service would be helpful."</p>
<b>Misc.</b>	14	22.2%	<p>"Transport to get to appointments."</p> <p>"Assure them they will receive the same level of support to help them on the road to recovery."</p> <p>"A point of contact should they require reassurance."</p> <p>"Possibly rehab treatment to support CPNs and Outreach Mental Health OT (SJH)."</p> <p>"Care in the community."</p> <p>"I think we should be asking the services users what they require."</p> <p>"Tenancy support or more increased general support services to help people deal with the issues listed above to promote sustained recovery."</p> <p>"Increased availability for day care to allow more than once weekly attendance in some cases."</p>
<b>Nil or N/A or Don't Know</b>	26	41.3%	

Respondents were then asked to rate the level of service user and carer engagement and involvement in their service and the community (Rating scale: 1=Very Poor, 2=Poor, 3=Adequate, 4=Good, 5=Very Good, 6=Excellent).

Between 66 and 68 responses were received to these questions, and the average ratings were thus:



- The level of service user engagement in your service: 4.44 (i.e. between Good and Very Good)
- The level of service user involvement in your service: 4.28 (i.e. between Good and Very Good)
- The level of involvement/ integration service users have in their community: 3.45 (i.e. between Adequate and Good)
- The level of carer/family involvement in your service: 3.92 (i.e. between Adequate and Good)

Respondents were also asked to use the same scale to rate the overall quality of their service. Thirty responses were received, and the average rating was 4.79 (i.e. between Good and Very Good).

### Gaps in Current Service Provision

Respondents were asked whether they thought there are any gaps in adult mental health services in West Lothian. Seventy people answered this question, and around 80% (n=57) thought there were. A range of comments were provided. Key themes are highlighted in the Figure below:

Key Theme	Frequency of Response	As % of Total Responses (n=70)	Example comments
<b>Early Intervention / Prevention</b>	8	11.4%	<p>"Most people's mental health has deteriorated immensely before they get referred to mental health services, I believe if a service is available to them at the start of their mental health deteriorating, it would make it easier to help them on the road to recovery before it gets out of hand."</p> <p>"Crisis prevention/intervention to prevent hospital presentation/admission delivered by staff that are known to the people."</p> <p>"Early intervention - feedback from people we work with is it is difficult to get support early on and often you are dismissed if not seen to be in acute crisis."</p>
<b>Waiting Lists</b>	6	8.6%	<p>"Even when people become very acutely unwell there is a long wait to be seen by a psychiatrist."</p> <p>"Impression I have is that there are long waiting lists for out-patient appointments too."</p> <p>"Waiting lists too long and therefore gaps emerge."</p>
<b>Youth Services</b>	5	7.1%	<p>"There are also gaps for young people who are transitioning from adolescent to adult services."</p> <p>"Not enough services working directly with young people and families, some services now only offer consultation in schools."</p> <p>"More preventative services aimed at young people."</p>

<b>Appropriate Housing / Tenancy Support</b>	5	7.1%	<p>"Single supported accommodations funding."</p> <p>"Real issues regarding limited access to longer term beds/placements for people who can't live at home alone."</p> <p>"Types of housing support / supported accommodation."</p> <p>"Shortage of supported accommodation (with support 24/7) or cluster with 24/7 on call who could come out if need be."</p>
<b>Rehabilitation</b>	5	7.1%	<p>"...patients only receive a rehab type service if they are in the inpatient rehab unit (Pentland Court). There would be great benefits from having a service that would work with people in their own home."</p> <p>"Limited rehabilitation services."</p> <p>"Rehab need to be clarified/improved."</p>
<b>Crisis Support</b>	4	5.7%	<p>"A crisis help line for carers who are supporting someone who is in a crisis and is not able or willing to get to their doctor or A&amp;E."</p> <p>"I feel there's a gap in mental health services when service users become unwell and their consultant is unable to see them for some time."</p> <p>"Individuals in crisis can be turned away from hospital. Leaving them nowhere to go."</p>
<b>Dementia Support (including EOD)</b>	4	5.7%	<p>"Need more support for people with dementia especially younger people with dementia."</p> <p>"People with Dementia require contact throughout their journey and this is not always possible which makes it harder to be re-referred and continuity for the PWD is fragmented."</p>
<b>Dual Diagnosis</b>	3	4.3%	<p>"No service for adolescents with mental health and substance misuse problems."</p> <p>"[No service] supporting individuals with dual diagnosis (such as drug and alcohol) or for those on the learning disability spectrum (adults who weren't diagnosed earlier with Asperger's)."</p>
<b>Mental Health Education</b>	3	4.3%	<p>"Educating people in mental health issues and early intervention."</p> <p>"Support for under 18's/ education about mental health."</p>
<b>Misc.</b>	18	25.7%	<p>"There is also a gap in providing exercise opportunities for people with severe and enduring illness who, as a side effect of their medications, are at greater risk of developing physical complications such as obesity and diabetes."</p>

		<p>"Very little for people with fatigue; anger management; vocational rehab; services for younger people; accessibility of services often Edinburgh based."</p> <p>"A more comprehensive and better resourced approach to day services appears to be essential."</p> <p>"There is a lack of provision for people whose behaviour has become very challenging but are not assessed as requiring hospital admission."</p> <p>"Particular gap for befriending for those with mental health issues."</p> <p>"No service for anxiety spectrum illness not reaching chronic and enduring status. Poor service for chronic and enduring affective disorders."</p> <p>"Whilst not specific to mental health, there are problems with the implementation of Self Directed Support."</p> <p>"Weekend and out of hours' services for people in crisis/distress."</p> <p>"Self Harm Counselling for mental health but not psychiatry- the likes of life coaching/mentoring/etc."</p>
<b>N/A / Nil Response</b>	<b>10</b>	<b>14.3%</b>

### Areas of Duplication and Overprovision

Respondents were then asked whether they thought there were any areas of duplication or overprovision in mental health services in West Lothian.

Sixty-nine people answered these questions. Over 70% (n=50) did not think there were any areas of duplication. Of the 19 who did, the following pertinent comments were made:

- "People can be referred into various services and results in too many people trying to do the same thing."
- "Double work e.g. assessments on paper and on computer."
- "Within community mental health teams."
- "Quite often, we duplicate services if people are having to wait a while for various things to happen."
- "More than one service involved can duplicate work if not communicated effectively."
- One respondents did however note, "There is some overlap, but I think this is necessary."

Similarly, over 90% of respondents (n=63) were unable to identify any areas of overprovision. The six respondents who believed there were areas of overprovision, made the following pertinent comments:

- "COT as above."
- "Eating disorders and peri-natal care."
- "Lack of psychological therapies is an issue ACROSS Scotland. Biological psychiatry dominates."

### On Resourcing

Respondents were asked for their comments about the resourcing of services for adults with mental health problems. Forty-two individuals answered this question and a range of comments were provided. The key theme which came through was that mental health services were not adequately funded (n=10; 23.8%):

- "In our view mental health services in West Lothian are under-resourced."
- "I think all public and voluntary sector services are under resourced at this time, but mental health services are not always viewed with the same sympathy, by the public, as some other areas, and this may impact on how resources are allocated."
- "Historically, funding has been thought to be poor for Mental Health services."
- "Mental ill health is one of the leading causes of sick leave from employment, therefore by providing better funding to mental health services this would not only help individuals but also help the economy as a whole. Young people's services are especially important to fund, as the better support and treatment children and young people receive with their mental health the less likely they are to require intense support from mental health services as adults."

One respondent did however note, "There is poor understanding of the demand and capacity that exists in WL which means no one has a clue about adequacy of resourcing."

A range of other comments were also provided as illustrated in the table below:

Key Theme	Frequency of Response	As % of Total Responses (n=42)	Example comments
<b>Poor Referral Process / Difficult to Access Available Services</b>	6	14.3%	<p>"I feel that the services that are available are difficult to access without a social work or psychiatrist's referral."</p> <p>"We have to go through GP's before being referred to either A&amp;E or psychiatrist, it feels like we are not recognised as being able to assess individual whom we work with on a daily basis and have a good awareness of them and any changes in their presentation."</p> <p>"It can be very difficult to access services to support people with mental health issues."</p>

<b>Long Waiting Lists</b>	5	11.9%	<p>"Usually people with mental health problems have to be placed on a waiting list before they are referred to mental health services."</p> <p>"Waiting times far too long for people to be seen."</p> <p>"Patients requiring rehabilitation services are often kept waiting due to the limited resources of rehab beds in West Lothian."</p> <p>"With self-directed support, there is generally a large waiting list and people require to wait a long time on the implementation of support."</p>
<b>Staffing Issues</b>	5	11.9%	<p>"Staffing levels are always a problem."</p> <p>"There is an increased demand for mental health services but staffing levels have not reflected this. If staffing levels were increased this would result in savings longer-term (currently money is wasted through delayed hospital discharges and guardianship assessments)."</p> <p>"For a number of years now we have been resourced by Locum Consultant Psychiatrists within the acute inpatient unit. clearly the cost of this is not sustainable. It also does not represent value for money... my view is that there is limited "buy in" from Locums to invest in making the service "fit for purpose" and again there can be a pretty narrow view as far as beds/flow is concerned."</p>
<b>Misc.</b>	23	54.8%	<p>"I think in some areas there is more of a focus on doing things for people rather than working with them to enable them to do things themselves."</p> <p>"Better partnership working with psychology/psychiatry - more communication from psychology/psychiatry."</p> <p>"Most of our prisoners suffer from metal health and addiction problems. I think there should be more interaction with prisoners and the NHS mental health providers within the prison to reduce the 'take a pill' attitude."</p> <p>"More specialist services required for children."</p> <p>"I have great concerns regarding the commissioning of services for provision of accommodation for individuals with mental health problems..."</p> <p>"Funding for the type of support some clients would benefit from i.e. befriending and social outlets/activities as they may not have the confidence or ability to manage to access mainstream outlets /activities such as these."</p>

### Groups Not Well Served

Respondents were asked whether, in their opinion, there any particular groups with mental health problems that are not well-catered for in West Lothian. Fifty-one individuals answered this question, and the following key groups were mentioned as being poorly served:

- Those aged over 65 who did not have dementia (n=9)
  - "Depression/other mental health issues in older people does not attract funding. Perception is that it is normal aging almost."
  - "Insufficient experienced/skilled staff."
- Younger adults (n=9)
  - "Services are aimed at the general adult population and there is poorer engagement with younger clients due to lack of knowledge/skills of this client group."
- Minority Ethnic Groups (n=7)
  - "Poor understanding of health care needs of this population."
- Carers (n=4)
  - "There is a range of support available for individuals who have a mental health condition, however those who support the person with the condition are often overlooked. The issues surrounding patient confidentiality, human rights etc can leave a carer feeling powerless, excluded and isolated."
- Those with a Dual Diagnosis – Substance Misuse (n=3)
  - "They are seen as being troublesome and addicts."
- Those with a Dual Diagnosis – Learning Difficulty/ASD (n=3)
  - "In my experience a service user with dual diagnosis can only access services for the most recognised diagnosis."
- Those aged between 50 and 65 (n=3)
- Those with Early Onset Dementia (n=3)
  - "Most of the traditional services are not appropriate and this group have very specific needs in terms of partner's potentially still working, financial implications, dependent children,
- Those with Dementia (n=2)
- Offenders (n=2)
- Those with a physical disability (n=2)
- The transgender community (n=2)
- Women (n=2)
- Individual respondents also mentioned the following groups:
  - Those with literacy issues
  - Those needed with a psychological intervention / counselling
  - Those living in outlying aread

- Those with personality disorders
- Men
- Children and Young People – especially LAAC
- Women experiencing domestic abuse
- Those with depression / anxiety
- Those exhibiting challenging behaviour
- Those with ARBD

### Asset Mapping

Respondents were asked what other assets, resources, groups, individuals, and/or opportunities are available across West Lothian to support mainstream services in meeting the needs of adults with mental health problems. Thirty-nine individuals provided an answer to this question and a range of comments were provided. Key assets mentioned included:

- **Third sector provisions (n=15)** e.g. West Lothian Family Support Group; CRUSE; One Parent Families Scotland; Sure Start; LBGT Youth Scotland; Penumbra; West Lothian Youth Project; Domestic Abuse Helpline; Edinburgh Women's Rape and Sexual Abuse Centre; Men Against Sexual Abuse (MASA); Men's Centre; Open Secret; Skylight; Survivor Support; Women's Aid West Lothian; Victim Support; Alzheimer's Scotland; Answer Project; Contact The Elderly; Older Men Under Stress (OMUS) Carers of West Lothian Carers Scotland; Depression Alliance Scotland; Mental Health Advocacy Project (MHAP); Postnatal Depression Project; Breathing Space; Samaritans; Food Train; MOOD; SHEDS; Cyrenians;
- **Mental Health Clinicians (n=11)** e.g. CPNs; GPs; Mental Health Workers; Psychiatrists; ACAST; St John's; COT; Pentland Court (Rehab); CAMHs
- Day Care Services (n=4) e.g. Bathgate House
- Peer Support / Self Help Groups (n=4) e.g. Step Out; AA
- Volunteer Gateway (n=4)
- Counselling / Helpline (n=4)
- Supported Education / Employment Support (n=4)
- Social Work (n=3)
- **Misc. (n=8)** e.g. Hospital chaplain at St John's; 50+ Groups; Moving into Health; Advice Shop; Libraries etc.

### Recovery

Respondents were asked to what extent the principles and values of recovery are embedded in their personal practice, the service they work for, and more widely across provision in West Lothian. The following rating scale was provided: 1= Not at all, 2 = A little, 3= Partially, 4= Mainly, 5= Fully.

Between 65 and 68 individuals answered these questions, and the average ratings for each statement is shown below:

- Extent to which recovery is embedded in personal practice – Average Rating: 4.57 (i.e. between Mainly and Fully)
- Extent to which recovery is embedded within the practice of their service – Average Rating: 4.45 (i.e. between Mainly and Fully)
- Extent to which recovery is embedded within the practice of mental health services across West Lothian – Average Rating: 4.04 (i.e. between Mainly and Fully)
- Extent to which recovery is embedded within the local West Lothian mental health strategy – Average Rating: 4.11 (i.e. between Mainly and Fully)

Staff therefore believe recovery is more fully embedded within their personal practice than within services more generally and the wider mental health strategy.

### Future Priorities

Integration, capacity and quality have emerged as common issues from similar research studies conducted by Figure 8. Accordingly, respondents were asked to rate the following four statements in order of importance: (Rating Scale = 1= Most Important, 4= Least Important). Between 64 and 67 staff responded, and the average ratings and relative ranking of the statements is shown below:

- Improving integration of mental health services and other services – Average Rating: 2.20
- Expanding the range of mental health services – Average Rating: 2.34
- Increasing the capacity of mental health services – Average Rating: 2.75
- Enhancing the quality of mental health services – Average Rating: 2.87

Staff therefore ranked improving the integration of mental health services and other services most highly as a future priority.

### Any Other Points

Finally, respondents were asked whether they had any additional comments to make. There were few common themes so all points made are noted below:

- “Self-stigma and discrimination that is commonly associated with being a mental health carer or service user is a barrier to many who wish information, advice and support. Being able to support carers in overcoming self-stigma would hopefully help them in accessing support as soon as possible, both for them self and the person they support.”
- “Due to poor motivation, the people I support have little interest in many of the paper exercises and Service User participation activities expected of them. But when staff are working one to one and hands on with them daily, they engage fully with support.”



- “Just to reiterate need for services to be more than responding to crisis situations and to look at early intervention and prevention. Appreciate budget constraints however only ever mopping up if just respond to crisis situations.”
- “I feel we have a fractured, disconnected service. communication, particularly between acute and Rehab services is poor and my view is that this is based on poor relationships with each other and a rather negative view of each other's role. this is historical and is not new... people are very quick to criticise without knowing the whole facts and due to a lack of understanding of the service that is provided.”
- “Staff are demoralised because of staffing issues, top down changes, reliance on tick-boxes rather than trained professionalism. Lack of time to care. Bureaucracy. Revalidation, Appraisal. and endless HIS “improvements”. Staff are fearful of speaking up. The CULTURE is wrong. We are also overmedicalising too much. (Realistic medicine) the net result is that we cannot meet the needs of those who most need it.”
- “Our services provide stability for individuals with Psychotic illness. Investment in these areas need to be made to ensure that we can offer a continued and improving service to our service users, without causing further pressure and stress on the current workforce.”
- “Waiting lists impact upon ability to deliver high quality services.”
- “I think that there needs to be an acknowledgement of the range of difficulties that people can exist in terms of mental health - I have concerns when phrases including mental health needs / mental health difficulties are used as this covers people who may have anxiety such that it affects certain areas of their lives to a person with severe and enduring mental illness whose everyday life has been disrupted as a result of this.”

## Pharmacy Survey

Since Community Pharmacists are increasingly important front-line healthcare providers in the modern NHS and are taking on more of the clinical roles that have traditionally been undertaken by doctors, it was decided to survey this demographic for their views on service provision for adults with mental health problems across West Lothian.

The survey was devised by Figure 8 and signed off by key members of the Steering Group. The link was then disseminated to all community pharmacists across West Lothian (n=x) by Carol Bebbington (Senior Manager Primary Care and Business Support).

Unfortunately, only three pharmacists started the survey and one did not complete all of the questions posed. As such, few generalisations can be made, therefore instead of a systematic review of the whole survey, a few key points are instead noted.

## Role of Pharmacists

Respondents were asked what they, as pharmacists, are currently doing to support adults with mental health problems. Answers suggest respondents both provide services directly to this demographic and signpost them on to other relevant organisations:

- Services provided:
  - "Provide trays for patients struggling with medication. Contact GPs where we feel there are compliance issues."
  - "We dispense instalment scripts as requested by GPs to help organise those needing this. Dosettes also provided for complicated regimes/where needed if confused easily by meds."
- Agencies signposted to: GPs; Support for Carers; and online resources on anxiety, depression.

When asked whether they were happy with the level of information they have received about services in West Lothian for adults with mental health problems, the following comments were made:

- "Aware can access services through GP's but not sure other than CAMHs what these are, also the chill out zone in Bathgate, these are just one's I know of for young people but again a directory for all age brackets would be very helpful."
- "More leaflets and info please."

#### Barriers Preventing Adults with Mental Health Problems Accessing Services

Pharmacists were then asked whether they believed there were any barriers preventing adults with mental health problems from accessing services/provisions from which they might benefit. Both of the respondents who answered this question believed 'Distance to Service', 'Availability of Public Transport' and 'Stigma' were barriers.

#### Services Which Work Well / Not So Well for Adults with Mental Health Problems

Respondents made the following comments when asked which services work well for adults with mental health problems in West Lothian:

- "CAMHs appears to work well if individuals are agreeable to access. Chill out Zone works well for others but not everyone..."
- "Memory clinic and REACT."

And they made the following comments when asked what the main gaps and areas for improvement are in support and service provision for adults with mental health problems:

- "Keeping support and services local, having a directory for all health care professionals to access, directory for families of older people or mental health problems to access."
- "Better signposting and self-referral process maybe."

## Dentistry and Optometry Survey

Since both dentists and optometrists also have a key role to play in keeping people healthy and in the community they too were surveyed for their opinions on service provision for adults with mental health problems across West Lothian.

The survey was devised by Figure 8 and signed off by key members of the Steering Group. The link was then disseminated to all community dentists and optometrists across West Lothian (n=x) by Carol Bebbington (Senior Manager Primary Care and Business Support).

Unfortunately, only one dentist and five optometrists started the survey and two of the latter did not complete all of the questions posed. As such, few generalisations can be made, therefore instead of a systematic review of the whole survey, a few key points are instead noted.

### Dentistry

The one dentist who responded indicated that they were *"totally unaware of support services"* available for adults with mental health problems in West Lothian, and concluded by noting, *"As we are not NHS employees we receive virtually no information regarding support services and are consistently forgotten in local health planning."*

### Role of Optometrists

Respondents were asked what they, as optometrists, are currently doing to support adults with mental health problems. Answers suggest respondents do not currently do as much as they would like to support this demographic:

- "GP referral or communicating with carers only."
- "We do not have much support to offer patients relating to their mental health issues and would be keen to have materials which could help."

None of the respondents were happy with the amount of information they have received about services in West Lothian for adults with mental health problems. One made the following comment:

- "Would appreciate further advice and support to give to patients."

### Barriers to Accessing Local Optometrist Services

When asked whether there were any barriers preventing adults with mental health problems accessing local optometrist services, one respondent made the following comment:

- "Patients concerned with being judged, stressed or anxious about giving the "wrong answers" or being told they have severe eye or general health problems. Some patients are also worried that we cannot help them, i.e. if they are non-verbal."

None of the respondents were able to answer questions pertaining to good services for those with mental health problems or on any areas of over-provision / duplication.

## APPENDIX V: FOCUS GROUPS

### Introduction

In order to capture the views and opinions of adults with mental health problems and carers themselves, as part of the fieldwork staff at Figure 8 facilitated a series of four qualitative focus groups and a range of 1:1 semi-structured interviews.

Groups were hosted in a variety of venues across West Lothian and representatives of the following groups were spoken to:

- Adults with Severe and Enduring Mental Health Problems (n=12)
- Young People with Mental Health Problems (n=6)
- Family Carers of Adults with Mental Health Problems (n=10)
- Adults with Early-Onset Dementia and their Carers (via an Alzheimer's Scotland facilitated Dementia Café) (n=10)

Following discussion with Senior Charge Nurses it was agreed that the most effective way to capture the views of adults with mental health problems who were currently in-patients on Wards One, 17 and in Pentland Court, a series of one-to-one interviews with this demographic were also conducted:

- In-patients on Ward One (IPCU) (n=3)
- In-patients on Ward 17 (n=2)
- Residents of Pentland Court (n=3)

Discussion encompassed a range of topics including what services and community supports work well and not so well locally for adults with mental health problems; whether there are any areas of duplication; whether there are any particular inequalities in service and support provision; and whether these supports and services can be easily accessed by those who would benefit from them. These discussions have been combined with data from the service user's and carer's surveys and are summarised in SWOT analysis form in **Chapter VI** of the Main Report.

### What Works Well?

Participants were asked what services and community supports currently work well for adults with mental health problems across West Lothian. Those so affected and their carers provided several examples of services and supports they thought work well. Common themes included:

- Day-care Services such as Bathgate House; the '81 Club; Answer House
  - The activities that were facilitated in these services were mentioned by many who use them as being of particular value such as: history group, walking group, music group, art group etc. Similarly, the young people polled said they would appreciate supported learning (courses like photography and film studies) when they transition into adult

services. The opportunity for social drop-ins in day-care services were also appreciated by the adults.

- "You can bring your official letters in to your key worker at Bathgate House"
- "You can't quantify how much we get out of this group." [Early Onset Dementia Café]
- In-patient Services at St John's:
  - "The vast majority of staff are great" – (Carer)
  - On Ward 17:
    - "The staff are nice - they are very approachable; they smile"; "Staff are brilliant; really nice"
    - "It's not like a hospital – it's nice and relaxing"
    - "The food is great!"
    - "The activities are good, but they aren't on at the weekend"; "I like the gym, the meditation and the walking group."
  - On IPCU:
    - Staff - "the job they do is absolutely fantastic"; "they deal with really trying situations very well and still have time for me who's never been in a panic situation." "I have never been cared for as well; not even by my mother and father."
    - "It's better than the IPCU in Edinburgh because there you only get out once a day; here you can get out as many times as you want up to 10 or 11 o'clock at night."
    - "IPCU is good because it's more relaxed."
  - Links with other services:
    - "I'm getting my own house through the hospital."
    - "I've got three social workers and there is a good link up between substance misuse and mental health services."

All interviewees did however note that they did not like the smoking ban in place for in-patients in St John's. Comments made pertaining to this included:

- "I was in here three years ago when you could smoke and I never witnessed any restraints; this time, I've witnessed five and I think it's because people can't smoke to calm down."

One interviewee also noted activities did not always cater sufficiently for women:

*"Some of the OT activities organised on the ward are too male orientated. There are only two women on the ward at the moment so they don't do many female activities."*

- Pentland Court:
  - "Pentland Court is a good service for my 20-year-old child" (Carer)
  - "Pentland Court is better than Ward 17 – have more freedom here."
  - "I like the trips."

There were also some negative comments made about this service. These included the feeling that physical health issues were not dealt with adequately and that the staff do not always give patients sufficient information:

*"You don't get enough notice about reviews and meetings. I only found out on Sunday afternoon that I had a review meeting on the Monday."*

*"No one tells you anything here [PC] – there are real communication problems."*

- Independent Advocacy – MHAP:
  - "Helps you to have a voice, like with the doctors"
  - "MHAP is an excellent intermediary; it helps to get opinions of service users heard with the Council / NHS etc."
- GPs:
  - "My GP surgery is fantastic [Practice in Armadale]"
  - "My GP was fantastic – she really listened to me"
- Other services mentioned:
  - Therapeutic Gardens
  - Strathbrock Centre – Woodwork; Gardens
  - "The Police are very good, but it is not their job to manage a mental health crisis" (Carer)
  - The young people polled valued the opportunity to manage their anger through sport and activities like karate / dancing: "It gives you something to channel your anger into – it helps you learn how to release your anger in an appropriate way and it also reduces anxiety."
  - One-Year Post Diagnostic Support for (Early-Onset) Dementia - *"PDS has worked well for me"; "I've got nothing but praise for her [PDS worker]"*.

Some carers also mentioned the positive role of the wider community and the support they gained from friends: *"50% of the help I get [is from] my neighbour..."* (Carer for adult with early-onset dementia).

## Gaps?

Participants were then asked whether there were any gaps, or services/provisions which were not working well for adults with mental health problems in West Lothian. Those so affected and their carers provided various examples of services and supports they thought were missing or not working as well as they might. Common themes included:

- Psychiatric Services:
  - "You see a different [psychiatric] consultant at hospital every time"
  - "There aren't enough ward rounds [inpatient] – you only see the psychiatrist one a week."
  - "It's really difficult to change psychiatrists because there aren't many of them."

- "I haven't seen a psychiatrist since I got here [3 months ago] ...I feel like I've just been dumped here [Pentland Court]."
- "I had my Tribunal today [on STDO], but the hearing had to be postponed to next Tuesday because the doctor who attended wasn't Section 22 Approved."
- "ACAST operate until 12 midnight; but not after that"
- "Staff need to be appropriately trained and know how to talk to younger people / people with speech impediments – sometimes we feel patronised."
- Psychological Services:
  - "There's not enough psychology"
  - "There's a lack of trained practitioners for CBT"
  - "There's a really long waiting list for counselling – we had to access private counselling for our son." (Carer)
- In-patient Capacity:
  - "There aren't enough beds in Ward 17 – I've been waiting since last Thursday to be transferred [from IPCU; now Wednesday] and another lady was only transferred today and she was waiting since last Thursday too."
- Appropriate Housing Support / Options:
  - "Tenancy support doesn't always provide the right type of support – e.g. they don't always open the post if it's not in my care plan."
  - "I'm still here [Pentland Court] because the social worker said there's nowhere for me to go."
- Pathways into services:
  - "Access into services if your loved one deteriorates is really poor: the GP is the first point of call. Out of hours you have to either take them to A&E if they'll go or call the police – this isn't good though because they can end up with a criminal record. There is no crisis team; someone to call who would visit immediately." (Carer)
- Services for those with Depression / Anxiety:
  - "There're massive waiting lists for CPNs/counselling for those with depression – but we don't want services taken from psychiatry to psychological services."
- Low Level Preventative Services:
  - "There are few mental health services available if you work; things like the Ability Centre should be open in the evenings and offer wellbeing classes." (Carer)
  - "It has to get to crisis point before anything is done." (Carer)
  - "There's a lack of groups [in the community]. I would like to attend things like book clubs and writing clubs for people like me who suffer with lack of concentration."
- Support for Carers:
  - It was noted that there is no advocacy service for carers and this was seen, by carers, to be a gap in provisions. *"Carers are not being heard."* (Carer)



- It was also noted that families / carers are often unaware of legal procedures like appointeeship / guardianship etc. Carers of West Lothian are, apparently, trying to increase awareness about this.
- "Carers are not seen as of value until they want the carers involved – then they have to jump through hoops." (Carer)
- "There is no one for carers to phone when they are at their lowest point" (Carer)
- Loneliness can be an issue for carers (Carer of someone with early-onset dementia)
- Support for those with early-onset dementia/their carers:
  - Respite care:
    - One participant reported her frustration at having to wait months to be told whether she would be receiving respite for a holiday she had booked. She did not want to take on the role, through SDS, of organising respite and dealing with money.
    - Another spoke of using a local residential facility for respite but how it had been a bad experience and they hadn't used respite since.
  - Appropriate information / practical support:
    - Information and support regarding incontinence / female personal care/hygiene were important but not always available.
    - Training in managing difficult behaviour appears to be lacking.
- Self-Directed Support:
  - Many participants (including those with severe and enduring mental health problems) had not heard of SDS
    - "SDS is not explained"
    - "No one told us how to access the allocated budget"
- Knowledge/Awareness re what is available:
  - "You don't know what you don't know."
  - Websites are not always helpful - *"I wanted someone to talk to give me a simple yes or no."* It was also noted that a reliance on online information could exclude some without Internet access.
  - People are unaware of services – "there's not the community spirit any more."
  - "You have to find out everything for yourself"
- Other gaps identified included:
  - Some reported that they had to wait in excess of 6 months for assessment and services.
  - A number of carers mentioned it was difficult to get an initial diagnosis – especially with young people/teenagers.
  - Carer's mentioned the potential for financial exploitation when loved ones are in Ward 17 etc. – unless the person is under guardianship / has an appointee, families/carers cannot stop them spending money when they are manic.

- “There are not many wellbeing services for men”
- Self-help / peer support groups

### **Areas of Duplication / Potential for Disinvestment?**

Participants were asked to identify any areas of duplication in service or support provision or any areas from where funds could usefully be re-diverted for adults with mental health problems in West Lothian. Neither those with mental health issues nor carers could identify any significant issues in this area.

### **Inequalities?**

Participants were then asked whether there are any groups of adults with mental health problems (men/women/those with certain conditions) which are currently not well served in West Lothian. A range of comments were made under this point, but there was little consensus. Individuals noted specific issues such as:

- “Support for younger adults isn’t right”
- It appears that those with anxiety and depression do not get a good service.
- “Consultant services are no longer going to come out into communities – in the past they would have come out into health centres. Now they are just operating from St Johns, and lots of people [with mental health problems] can’t do public transport which mean they miss appointments which means they will be discharged.”
- “There are few mental health services available if you work.”
- “There are a lack of options for those with sensory issues and mental health problems.”

Subsequently addressed were the geographic areas currently well served across West Lothian and those which are not so well served. Many comments made following this question referred back to the limitations of public transport. It was repeatedly noted that if you live in outlying areas / remote villages, access to services via public transport is problematic – *“If you don’t drive, it’s difficult to get to services.”*

### **Accessibility?**

Adults with mental health problems and carers were then asked whether they can get to the supports/services they want, when they want them. Comments made pertaining to this question encompassed a range of themes:

- Out-of-hours provision
  - “There is no support after hours – ACAST stops at night”
  - “Bathgate House only opens one evening a week (Tues 4-6)”
- Waiting lists / Capacity

- “There are long waiting list for psychiatrist; psychology and CPNs”

## **Transitions?**

Participants were asked for their views on the various transitions in mental health services in West Lothian. A range of comments were made for each transition, but it was evident there was less experience of the transition from CAMHs to Adult Services.

### Child and Adolescent Services to Adult Services

- “It is often stable because they have a lot of support, but they often don’t have a psychiatric referral to adult services. BUT sometimes COT does get a referral from CAMHs – it can work!”

### From Acute / Inpatient Services back to the Community

- “Transitions from hospital to community [are] not terribly smooth.”
- There is no support for loved ones to get the benefits those they care for are entitled to – “sorting out benefits was a nightmare – it was down to us [carer] to get it all sorted out and support x in the meantime.” (Carer)
- “I’m worried about my transition back into the community – I don’t want to come back [to Ward 17]. At my discharge meeting I want contact details for groups/services to access”
- “Transition support services from hospital to home ‘does not exist’ and there’s no one to contact. I was given one hours’ notice to prepare for my daughter’s hospital discharge.” (Carer)

### From Adult Mental Health Services to Older People’s Services

- “COT don’t immediately transfer at 65 – it’s a nice way of working – person-centred.”

## **Priorities?**

Finally, adults with mental health problems and carers were asked for their list of future commissioning priorities. In order to get a comprehensive picture, all those mentioned are noted below in no particular order:

- Publicise a simple pathway into services
- Awareness raising amongst communities / Dementia Friendly Communities
- Improve physical access for those less mobile; not just wheelchair access
- Mental health should be on a par with physical health – there should be parity
- Support on discharge from hospital
- “There shouldn’t be so much of a stigma.”

- “There should be drop-in centres for mental health manned by psychologists and psychiatrists where you could talk to people and take time out to get your head straight.”
- SDS implementation for those who may not understand the implications
- Services like the Brock that encourages people to keep well – wellbeing / community engagement type activities
- We should be informed more
- Physical health should be dealt with better
- Key workers should be better
- Suitable housing solutions – “I’d like somewhere with my own bedroom, little kitchen and bathroom and a shared/communal living room, with help on hand if you need it. Somewhere with help on hand and privacy.”
- Education to reduce the stigma around MH issues – *“kids still “laugh at the loonies”*
- “More support groups like bereavement counselling; and support for mums with mental health issues so that you don’t always have to have your children taken away if you have a mental health condition.”
- Change in the way people are diagnosed – “I’ve had multiple diagnoses over the last 25 years, but you’re never told enough. If you don’t understand what you’ve got, it’s more difficult to recognise the symptoms for yourself.”
- “Extend ACAST so more people can be treated at home.”
- “There should be more people for us [people with MH issues] to talk to.” / “More opportunities for 1:1 support – it’s good to have someone to talk to you”
- “There should be more activities on the ward [Ward 17]”
- “More Ward 17-type things in the community across West Lothian.”
- Support for carers and Carers Advocacy Service
- Community Outreach

## APPENDIX VI: SURVEY RESULTS (SERVICE USERS AND FAMILIES/CARERS)

### Introduction

The purpose of this element of the research was to seek the views from a broad audience of service users and carers on the current provision of specialist mental health services across West Lothian. Specifically, service users and carers were asked to provide their views on the quality of services, key issues, gaps and areas for improvements.

### Service user survey - response rates

There were **73** responses received to the service user survey, of which **70** were completed sufficiently to enable use within the research.

### Service user survey – key themes

#### Survey respondents - demographics

There was a fairly even gender split of respondents, with a slight majority (53%) being male; whilst the vast majority of respondents (81%) were aged between 36 and 65 and of Scottish descent (94%). Respondents were asked what kind of mental health issue/condition they have. The full breakdown of results is shown in the table below:

Mental health issue/condition	Frequency of Response	As a % of Total Responses (n=132)
Anxiety	41	31.1%
Depression	32	24.2%
Schizophrenia	25	18.9%
Personality Disorder	7	5.3%
Bipolar Disorder	6	4.5%
Early Onset Dementia	6	4.5%
Obsessive Compulsive Disorder	4	3.0%
Post-Traumatic Stress Disorder	4	3.0%
Autistic Spectrum Disorder (including Asperger's)	3	2.3%
Korsakoff Syndrome	2	1.5%
Huntingdon's Disease	1	0.8%
Self-harm	1	0.8%

The vast majority of respondents (91%, n= 62) reported that they have received a formal diagnosis from a medical professional (e.g. GP, Community Psychiatric Nurse) in relation to their mental health condition.

#### Service and/or support provisions

Respondents were asked to note all services and/or support provisions that they are currently accessing or have recently accessed. The full range of services and/or support provisions noted are presented in the table below:

<b>Service/support provision name</b>	<b>Frequency of Response</b>	<b>As a % of Total Responses (n=131)</b>
<b>Day Care Centre</b>	20	15.3%
<b>Advocacy MHAP</b>	11	8.4%
<b>SAMH</b>	11	8.4%
<b>GP</b>	9	6.9%
<b>Housing Support</b>	9	6.9%
<b>CPN</b>	8	6.1%
<b>Barony Housing</b>	7	5.3%
<b>Penumbra</b>	7	5.3%
<b>Psychiatry</b>	6	4.6%
<b>LAMH</b>	5	3.8%
<b>St John's</b>	5	3.8%
<b>Alzheimer's Scotland</b>	3	2.3%
<b>Autism Initiatives</b>	3	2.3%
<b>Carewatch</b>	3	2.3%
<b>Duty Social Work</b>	3	2.3%
<b>Social Inclusion</b>	3	2.3%
<b>Art Link</b>	2	1.5%
<b>COT</b>	2	1.5%
<b>Lifeskills Support</b>	2	1.5%
<b>Peer Support</b>	2	1.5%
<b>Addiction service</b>	1	0.8%
<b>Cyrenians</b>	1	0.8%

<b>DASAT</b>	1	0.8%
<b>DBT course</b>	1	0.8%
<b>Dementia advisor</b>	1	0.8%
<b>Distress tolerance</b>	1	0.8%
<b>Green gym</b>	1	0.8%
<b>Mental health outreach</b>	1	0.8%
<b>Reablement</b>	1	0.8%
<b>West Lothian Living Service</b>	1	0.8%

Respondents were then asked to name the service/support provision that they are choosing to answer the survey questions about and the type of service/support they are/have been receiving. The breakdown of responses is provided in the two tables below:

<b>Service/support provision name</b>	<b>Frequency of Response</b>	<b>As a % of Total Responses (n=68)</b>
<b>SAMH</b>	18	26.5%
<b>Bathgate House (DS)</b>	12	17.6%
<b>LAMH</b>	10	14.7%
<b>Penumbra</b>	7	10.3%
<b>Barony</b>	6	8.8%
<b>MHAP</b>	5	7.4%
<b>CPN</b>	3	4.4%
<b>Art Link</b>	2	2.9%
<b>Advice shop</b>	1	1.5%
<b>Carewatch</b>	1	1.5%
<b>COT</b>	1	1.5%
<b>Housing/tenancy support</b>	1	1.5%
<b>Social work</b>	1	1.5%

Type of service/support received	Frequency of Response	As a % of Total Responses (n=107)
Lifeskills	43	40.2%
Emotional support	12	11.2%
Help with attending appointments	12	11.2%
Social inclusion	10	9.3%
Help with accessing services	9	8.4%
Help with housing/accommodation	6	5.6%
Talking therapy	5	4.7%
Benefits check	3	2.8%
Vocational classes	3	2.8%
DBT	2	1.9%
Company	1	0.9%
'Very little help'	1	0.9%

### Service Evaluation

Respondents were asked to evaluate the service/support they were reporting on against a variety of criteria. Their responses are shown in the table below:

Statement	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree	Nil Responses
The information I was given about this service/ support provision helped me decide whether to come along.	40.0% (n=28)	<b>47.1%</b> <b>(n=33)</b>	5.7% (n=4)	1.4% (n=1)	0	5.7% (n=4)
My referral to the service/support provision was straightforward and dealt with quickly.	<b>51.4%</b> <b>(n=36)</b>	38.6% (n=27)	0	4.3% (n=3)	2.9% (n=2)	2.9% (n=2)
I find it easy and convenient to get to the service/support provision.	<b>50.0%</b> <b>(n=35)</b>	40.0% (n=28)	2.9% (n=2)	2.9% (n=2)	0	4.3% (n=3)
I feel safe and comfortable when I attend the service/support provision.	<b>62.9%</b> <b>(n=44)</b>	34.3% (n=24)	1.4% (n=1)	0	0	1.4% (n=1)
The service/support provision is available at the times I need it.	<b>54.3%</b> <b>(n=38)</b>	35.7% (n=25)	1.4% (n=1)	2.9% (n=2)	2.9% (n=2)	2.9% (n=2)



The assessment/ initial discussion I was given helped me to work out my needs; and how they can best be met.	44.3% (n=31)	<b>48.6%</b> <b>(n=34)</b>	1.4% (n=1)	0	1.4% (n=1)	4.3% (n=3)
I have been actively involved in putting my care plan together and I am in agreement with it.	<b>51.4%</b> <b>(n=36)</b>	35.7% (n=25)	1.4% (n=1)	2.9% (n=2)	0	8.6% (n=6)
Other services/support provisions have been involved in my assessment and care plan.	<b>38.6%</b> <b>(n=27)</b>	31.4% (n=22)	12.9% (n=9)	5.7% (n=4)	2.9% (n=2)	8.6% (n=6)
My family/partner/carer are allowed to contribute to my assessment and care plan.	<b>37.1%</b> <b>(n=26)</b>	35.7% (n=25)	8.6% (n=6)	4.3% (n=3)	2.9% (n=2)	11.4% (n=8)
The service/support provision I attend encourages and supports me to talk honestly about my mental health needs.	<b>54.3%</b> <b>(n=38)</b>	41.4% (n=29)	1.4% (n=1)	1.4% (n=1)	0	1.4% (n=1)
The service/support provision I attend encourages and supports me to talk honestly about my general wellbeing.	<b>57.1%</b> <b>(n=40)</b>	37.1% (n=26)	2.9% (n=2)	1.4% (n=1)	0	1.4% (n=1)
The service/support provision I attend encourages and supports me to seek help from other services.	41.4% (n=29)	<b>50.0%</b> <b>(n=35)</b>	4.3% (n=3)	1.4% (n=1)	0	2.9% (n=2)
The service/support provision I attend has assisted me to get involved with my community.	38.6% (n=27)	<b>40.0%</b> <b>(n=28)</b>	11.4% (n=8)	4.3% (n=3)	0	5.7% (n=4)
I have a direct say in how the service/support provision is run and developed.	31.4% (n=22)	<b>42.9%</b> <b>(n=30)</b>	11.4% (n=8)	8.6% (n=6)	1.4% (n=1)	4.3% (n=3)
The service/support provision is good at working together with other services that I need and use.	35.7% (n=25)	<b>47.1%</b> <b>(n=33)</b>	10.0% (n=7)	1.4% (n=1)	1.4% (n=1)	4.3% (n=3)
The service/support provision focuses on my recovery.	<b>50.0%</b> <b>(n=35)</b>	34.3% (n=24)	8.6% (n=6)	4.3% (n=3)	0	2.9% (n=2)
The service/support provision meets my needs and helps me achieve my desired outcomes.	<b>47.1%</b> <b>(n=33)</b>	41.4% (n=29)	7.1% (n=5)	2.9% (n=2)	0	1.4% (n=1)
<b>Total responses: 70</b>						

At least 70% of respondents agreed with all the statements above. Levels of agreement with the given statements ranged from a minimum of 70% up to a maximum of 97.2% of respondents.

Respondents were then asked what they particularly liked about the service/support they are receiving. Sixty-four responses were received, which ranged across the following eleven key themes:

Key Theme	Frequency of Response	As % of Total Responses (n=64)	Example comments
<b>Good staff</b>	34	53.1%	<p>"Friendly professional staff. Knowledgeable as to update position re assistance available, very helpful."</p> <p>"The staff are good with confidentiality and helped make a good care plan for me."</p> <p>"Professional staff - flexible approach."</p> <p>"The friendliness of support staff, the assurance of being there when needed."</p>
<b>Enabling</b>	11	17.2%	<p>"It saved my life, it keeps me well, gives me the opportunity to develop new skills."</p> <p>"Allows me to live independently, help to complete household tasks."</p> <p>"My workers try to motivate me to go out in the community."</p>
<b>Easy to Access</b>	8	12.5%	<p>"Help is always available when I need it."</p> <p>"The assurance of being there when needed."</p>
<b>Peer Support</b>	8	12.5%	<p>"Mixing with others like myself."</p> <p>"Other service users help."</p>
<b>Person centred</b>	6	9.4%	<p>"Focuses on me. I am treated as an individual."</p> <p>"They are friendly and discuss my needs regularly, making changes as needed."</p>
<b>Good service ethos</b>	4	6.2%	<p>"Accepting, inclusive and non-judgmental."</p> <p>"Treating me with dignity and respect."</p> <p>"Feel as if i can speak to support workers without being judged, get plenty of encouragement."</p>
<b>Consistency of staff</b>	2	3.1%	<p>"Having the same worker so I don't have to explain what I need."</p> <p>The same worker all visits and someone else you know if your worker is on holiday."</p>
<b>Ensures wellbeing</b>	2	3.1%	<p>"The service looks after me well. The service ensures I am as well as I can be."</p>
<b>Feel secure</b>	2	3.1%	<p>"I feel secure."</p> <p>"I like the support, the support is structured."</p>
<b>Builds confidence</b>	1	1.6%	<p>"Helped my confidence and to gain valuable work experience which is really enjoyable. It allows me to put my skills from school to good use. Help is always available when I need it."</p>
<b>Nothing</b>	1	1.6%	<p>"There is nothing about .... that I like."</p>
<b>Supports individual decision-making</b>	1	1.6%	<p>"It helps me to carry out my decisions eg to make funeral plans, shopping."</p>

Respondents were then asked whether there was anything they disliked about the service/support they are receiving. Fifty-four responses were received, which ranged across the following ten key themes:

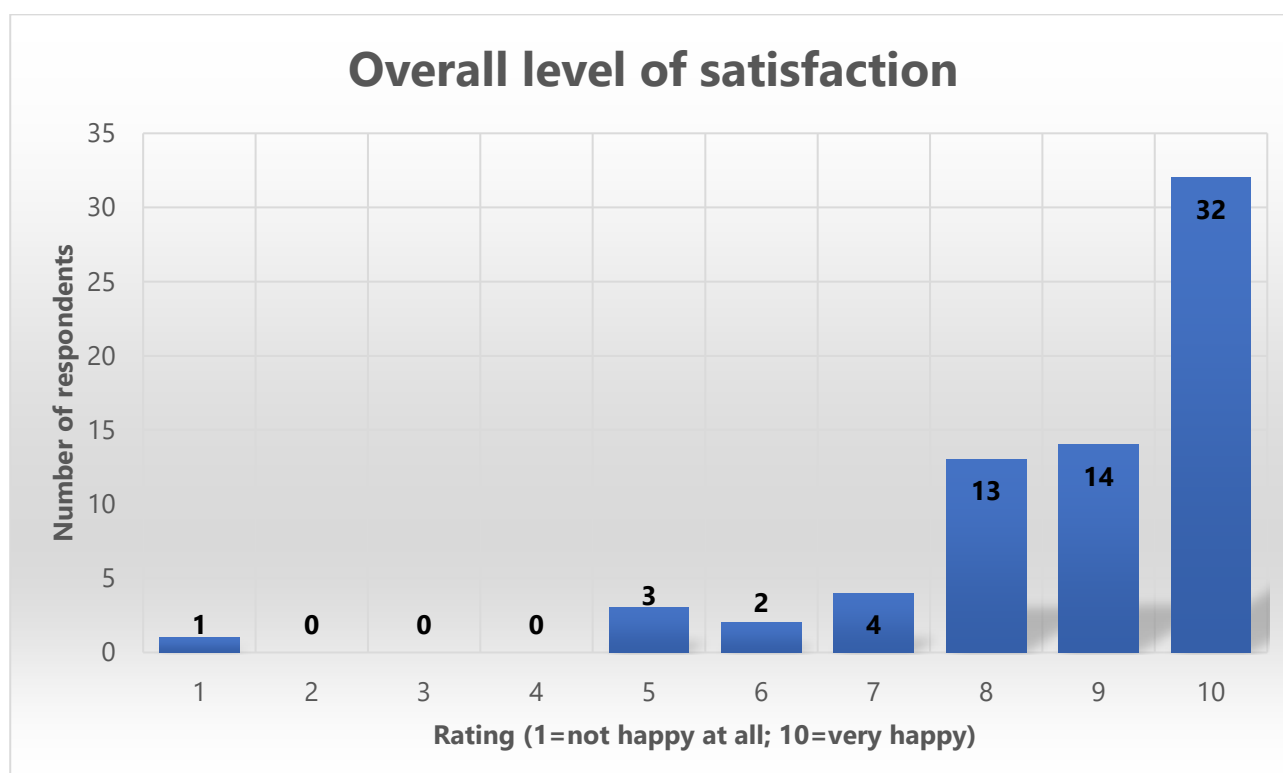
Key Theme	Frequency of Response	As % of Total Responses (n=54)	Example comments
<b>Nothing</b>	38	70.4%	"Nothing I dislike."
<b>Lack of peer support</b>	2	3.7%	"Would like more groups, chats, meet others like me."
<b>Lack of time with staff</b>	2	3.7%	"The time allocated to each session is limited." "Don't have enough time with staff."
<b>Poor level of psychiatric support</b>	2	3.7%	"Been too many cuts lately. Very disappointed at times, haven't seen a psychiatrist for years. I am on no medication and unless you are on medication, you are left to it."
<b>Support times</b>	2	3.7%	"I dislike my current support times." "When support worker appears at door with no notice."
<b>Lack of night staff</b>	1	1.9%	"Lack of staff during nights means not enough 1-1 time if staff are busy."
<b>Paying for transport</b>	1	1.9%	"Do not like paying for transport."
<b>Poor service</b>	1	1.9%	"Inconsistent, unreliable, incompetent, disorganised and not providing care needed."
<b>Review system</b>	1	1.9%	"Would like more people at the annual reviews ie perhaps a family member or advocacy."
<b>Change of staff</b>	1	1.9%	"Changing social workers."

Respondents were then asked what improvements they would like to see in service/support provision. Fifty responses were received, which ranged across the following ten twelve themes:

Key Theme	Frequency of Response	As % of Total Responses (n=50)	Example comments
<b>None</b>	24	48%	"No improvements needed."
<b>Trips out</b>	6	12%	"More staff, more groups outings for social interaction and well-being." "More social trips with service users."
<b>More social support</b>	5	10%	"More social support." "More social trips with service users, service user BBQ's."

<b>More staff/resources</b>	5	10%	"Additional staff and more resources."
<b>More groups</b>	4	8%	"More groups, more for me to do."
<b>Better communication</b>	3	6%	"Communications could be better."
<b>Less paperwork</b>	2	4%	" Less paperwork, I struggle with this."
<b>Staff consistency</b>	2	4%	"Try to maintain the key worker but I know I have to change with my worker is on holiday."
<b>Alter support time</b>	1	2%	"Adjustment to my support times."
<b>Dementia testing</b>	1	2%	"Testing for dementia."
<b>Free transport</b>	1	2%	"Allow some free transport if I need to pop out somewhere if the need arises, I can't really afford to pay."
<b>Service reliability</b>	1	2%	"Vast improvement in reliability is needed, and be more consistent. The company needs to improve in staff/time management and must provide care needed."

Finally, respondents were then asked to rate their overall level of satisfaction with the level of help and service they have received. (Rating scale: 1=not happy at all and 10=very happy). The sixty-nine responses received are presented in the table below:



## Carer survey - response rates

There were only **23** responses received to the carer/family survey, of which **20** were completed sufficiently to enable use within the research.

## Carer survey – key themes

### Demographic information

Survey respondents (carers/family members) were asked to provide some demographic information about the person(s) that they care for.

There was a fairly even gender split of the persons cared for, with a slight majority (55%) being male; with a fairly even split across age groups from 16-66+.

Respondents were asked what kind of mental health issue(s)/condition(s) the person(s) they care for has/have. The full breakdown of results is shown in the table below:

Mental health issue/condition	Frequency of Response	As a % of Total Responses (n=41)
Depression	8	19.5%
Anxiety	7	17.1%
Autistic Spectrum Disorder (including Asperger's)	6	14.6%
Early Onset Dementia	4	9.8%
Bipolar Disorder	3	7.3%
Obsessive Compulsive Disorder	3	7.3%
Personality Disorder	3	7.3%
Schizophrenia	2	4.9%
Self-harm	2	4.9%
Acquired Brain Injury	1	2.4%
Learning Difficulties	1	2.4%
Post-Traumatic Stress Disorder	1	2.4%

\* NOTE: The above categories are what respondents noted and not a prescribed set of mental health conditions (e.g. learning difficulties are not classed as a Mental Health condition).

The vast majority of respondents (95%, n= 19) reported that the person(s) they care for has/have received a formal diagnosis from a medical professional (e.g. GP, Community Psychiatric Nurse) in relation to their mental health condition.

#### Service and/or support provisions

Respondents were asked to note all services and/or support provisions that they have been in contact with in their role as a carer/family member over the last two years. The full range of services and/or support provisions noted are presented in the table below:

Service/support provision name	Frequency of Response	As a % of Total Responses (n=27)
<b>CAMHS</b>	4	14.8%
<b>SAMH</b>	4	14.8%
<b>Autism Initiative</b>	3	11.1%
<b>CPN</b>	2	7.4%
<b>Maple Villa</b>	2	7.4%
<b>Art Link</b>	1	3.7%
<b>Bathgate (daycare)</b>	1	3.7%
<b>COT</b>	1	3.7%
<b>Craigs Hill</b>	1	3.7%
<b>GP</b>	1	3.7%
<b>Penumbra</b>	1	3.7%
<b>Places for People</b>	1	3.7%
<b>Psychology Specialist Care Facility</b>	1	3.7%
<b>St Johns</b>	1	3.7%
<b>Social Work</b>	1	3.7%
<b>Ward 3</b>	1	3.7%
<b>None</b>	1	3.7%

Respondents were then asked to name the service/support provision that they are choosing to answer the survey questions about. The breakdown of responses is provided in the table below:

Service/support provision name	Frequency of Response	As a % of Total Responses (n= 11)
<b>SAMH</b>	4	36.4%
<b>Art Link</b>	1	9.1%
<b>Bathgate House</b>	1	9.1%
<b>Dementia Team</b>	1	9.1%
<b>Dialectic Behaviour Therapy</b>	1	9.1%
<b>Maple Villa</b>	1	9.1%
<b>Psychology Specialist Care Facility</b>	1	9.1%
<b>Social Work Assessment</b>	1	9.1%

### Service Evaluation

Respondents were asked whether the service/support they were reporting on as a carer/family member involves them directly in a number of different processes (Assessment; Care Delivery; Care Planning; Review of Care; Service Redesign/Development/Evaluation). The combined responses are shown in the table below:

Does the service/ support provision involve you directly as a carer/ family member in the following processes?	Yes	No
<b>Assessment</b>	<b>53.3%</b> <b>(n=8)</b>	46.7% (n=7)
<b>Care Delivery</b>	46.7% (n=7)	<b>53.3%</b> <b>(n=8)</b>
<b>Care Planning</b>	46.7% (n=7)	<b>53.3%</b> <b>(n=8)</b>
<b>Review of Care</b>	<b>64.7%</b> <b>(n=11)</b>	35.3% (n=6)
<b>Service Redesign/Development/Evaluation</b>	0.00% (n=0)	<b>100.0%</b> <b>(n=11)</b>

Respondents were asked whether they had had any contact with a family/carers support group/service within the past two years. A slight majority of those who responded (53%, n=10)

reported that they had. Those who had received support were then invited to describe the support they have received. The themed responses are presented below:

Description of support received as a Carer	Frequency of Response	As a % of Total Responses (n= 11)
Peer Support	3	33.3%
Courses	2	22.2%
Guidance	1	11.1%
Professional Support	1	11.1%
Respite	1	11.1%
Sharing caring responsibilities	1	11.1%

Respondents were also asked to note any 'other' sources of information and/or support they had received as a family member/carers of someone with a mental health problem. The responses given are presented in the table below:

Description of 'other' sources of information and/or support received as a Carer	Frequency of Response	As a % of Total Responses (n= 19)
COWL	5	26.3%
Social Work	3	15.8%
Autism Initiative	2	10.5%
Internet	2	10.5%
SAMH	2	10.5%
Ability Centre	1	5.3%
British Heart Foundation	1	5.3%
Diabetic Clinic	1	5.3%
GP	1	5.3%
Peer Support	1	5.3%

Respondents were asked if any of the following list of potential 'barriers' prevented them from seeking support in their role as a Carer:



Potential barriers to seeking support as a Carer	Frequency of Response	As a % of Total Responses (n=47)
I am unaware of support available.	7	14.9%
Lack of specialist facilities.	7	14.9%
Mental health-related support for carers is under-resourced.	6	12.8%
Stigma associated with a mental health problem.	5	10.6%
Mental health-related support for carers is not a priority.	5	10.6%
I am unaware of how to access support.	4	8.5%
My needs are not understood.	3	6.4%
Difficulty in getting to services.	3	6.4%
I do not need support.	2	4.3%
Confidentiality issues prevent me seeking personal support.	2	4.3%
My views are not listened to.	1	2.1%
The person I care for does not want me to seek support for myself.	1	2.1%
Delays or other difficulties in getting the help I need.	1	2.1%
A significant other does not want me to seek support for myself.	0	
Confidentiality issues prevent me getting involved in decisions about care or services.	0	



## APPENDIX VII: STAKEHOLDER LIST

In total, through the variety of methods used in this study, **XX** individuals were consulted as part of this needs assessment project. Names, titles and organisations for those professionals involved in the research are noted in the tables below. All users of services, peer mentors and carers are anonymised.

### List of Interviewed Stakeholders

	Name	Designation	Organisation
1	<b>Dr H Aditya</b>	Clinical Director, WL Mental Health Services	NHS Lothian
2	<b>Maggie Archibald</b>	HR Advisor, Equality and Diversity	West Lothian Council
3	<b>Marion Barton</b>	Head of Health	West Lothian HSCP
4	<b>Tommy Blue</b>	Team Co-ordinator, CAMHS	NHS Lothian
4	<b>Emma Boothroyd</b>	Team Manager, MH Assessment Team	West Lothian Council
5	<b>Morag Cameron</b>	Lead Occupational Therapist for MH	NHS Lothian
7	<b>Duncan Charles</b>	Manager, Adults With Incapacity & Mental Health Officer Team	West Lothian Council
8	<b>Aileen Eland, Alan Mciver and Helen Hay (Group interview)</b>		Alzheimer's Scotland
9	<b>Patricia Graham</b>	Head of Adult Psychology	NHS Lothian
10	<b>Belinda Hacking</b>	Head of Applied Psychology for Older Adults	NHS Lothian
11	<b>Kathy Hamilton</b>	Project Co-ordinator	Mental Health, Advocacy Project (MHAP)
12	<b>Lynne Henderson</b>	Clinical Nurse Manager (Acute Services)	NHS Lothian
13	<b>Dr Deborah Innes</b>	Clinical Lead, Scottish MH Service for Deaf People	NHS Lothian
14	<b>Jane Kellock</b>	Head of Social Policy / Chief Social Worker	West Lothian Council

15	<b>Len McCaffer</b>	Arts Officer - Wellbeing	West Lothian Council
16	<b>John McLean</b>	Outreach and Day Services Manager	West Lothian Council
17	<b>Elaine Nisbet</b>	Welfare Advice and Adult Basic Education Manager (Acting)	West Lothian Council
18	<b>Margaret Robertson</b>	Advisor, Dementia and Older Persons Tea, WL Advice Shop	
19	<b>Sarah Summers</b>	Group Manager, Looked After Children Services	West Lothian Council
20	<b>Patrick Welsh</b>	IJB Finance Officer	West Lothian Council

### List of Participants at Key Stakeholder Event (6<sup>th</sup> May 2016)

	<b>Name</b>	<b>Designation</b>	<b>Organisation</b>
1	<b>Dr H Aditya</b>	Mental Health Team	NHS Lothian
2	<b>Melanie Agnew</b>	Mental Health Nurse	NHS Lothian
3	<b>June Boothroyd</b>		West Lothian Council
4	<b>Ian Buchanan</b>	Chairman	West Lothian Public Partnership
5	<b>Gwen Burt</b>		Barony Housing
6	<b>Elizabeth Butters</b>	Alcohol and Drug Partnership	NHS Lothian
7	<b>Evelyn Cook</b>	Project Worker	Mental Health Advocacy Project
8	<b>Caroline Donaldson</b>	Project Leader	Mood
9	<b>Jillian Dougall</b>	Service Development Officer	West Lothian Council
10	<b>Aileen Eland</b>	Service Manager	Alzheimer Scotland
11	<b>Gillian Fairbairn</b>		Advice Shop
12	<b>Louise Finch</b>	Support Worker	Scottish Association for Mental Health
13	<b>Lesley Goldie</b>	Social Worker	West Lothian Council
14	<b>Lynn Gunn</b>		NHS Lothian
15	<b>Dianne Hayley</b>		NHS Lothian
16	<b>Gillian Henderson</b>	CPN Team Manager	NHS Lothian
17	<b>Ruth Kelly</b>	Regional Manager	Lanarkshire Association for Mental Health

18	<b>Wendy Kelly</b>		Richmond Fellowship
19	<b>Sheena Lowrie</b>	Health Promotion Specialist	NHS Lothian
20	<b>Lesley Mains</b>	Community Psychiatric Nurse	NHS Lothian
21	<b>Jamie McDonald</b>		NHS Lothian
22	<b>Dyo McKay</b>		NHS Lothian
23	<b>John McLean</b>		West Lothian Health and Social Care Partnership
24	<b>Kathleen McWhir</b>	Support Manager	Penumbra
25	<b>Carole Middleton</b>	Team Leader	NHS Lothian
26	<b>Lynda Mitchell</b>	Team Leader	Scottish Association for Mental Health
27	<b>David Murray</b>	Service Development Officer	West Lothian Council
28	<b>Tracey Mutch</b>		NHS Lothian
29	<b>Louise Ramsay</b>	Service Manager	Places for People Scotland Care and Support
30	<b>Rosemary Rennie</b>	Pentland Court	NHS Lothian
31	<b>Karen Spence</b>	Community Psychiatric Nurse	NHS Lothian
32	<b>Shirley Stanley</b>		NHS Lothian
33	<b>Lorna Stevenson</b>	Team Leader	Bathgate House
34	<b>Ailsa Sutherland</b>		West Lothian Council
35	<b>Fiona Tall</b>	Area Manager	Penumbra

### List of Participants at 1<sup>st</sup> Working Group Session (18<sup>th</sup> May 2016)

	<b>Name</b>	<b>Designation</b>	<b>Organisation</b>
1	<b>Jos Anderson</b>		Police
2	<b>Ian Buchanan</b>	Chairman	West Lothian Public Partnership
4	<b>Lynne Gunn</b>		NHS Lothian
5	<b>Kathy Hamilton</b>		Mental Health Advocacy Project
6	<b>Lesley Mains</b>	Community Psychiatric Nurse	NHS Lothian
7	<b>Mary-Denise McKernan</b>	Manager	Carers of West Lothian

8	<b>John McLean</b>		West Lothian Health and Social Care Partnership
9	<b>Lynda Mitchell</b>	Team Leader	Scottish Association for Mental Health
10	<b>Thomas Oswald</b>		West Lothian Drug & Alcohol Service

### List of Participants at 2<sup>nd</sup> Working Group Session (3<sup>rd</sup> June 2016)

	<b>Name</b>	<b>Designation</b>	<b>Organisation</b>
1	<b>Jos Anderson</b>		Police
2	<b>Ian Buchanan</b>	Chairman	West Lothian Public Partnership
3	<b>Evelyn Cook</b>	Project Worker	Mental Health Advocacy Project
4	<b>Lynne Gunn</b>		NHS Lothian
6	<b>Lesley Mains</b>	Community Psychiatric Nurse	
7	<b>Mary-Denise McKernan</b>	Manager	Carers of West Lothian
8	<b>John McLean</b>		West Lothian Health and Social Care Partnership
9	<b>Lynda Mitchell</b>	Team Leader	Scottish Association for Mental Health

### Focus Group Participants

Groups were hosted in a variety of venues across West Lothian and representatives of the following groups were spoken to:

- Adults with Severe and Enduring Mental Health Problems (n=12) – Friday 20<sup>th</sup> May 1pm-3pm
- Young People with Mental Health Problems (n=6) – Monday 30<sup>th</sup> May 1pm-3pm
- Family Carers of Adults with Mental Health Problems (n=10) – Monday 9<sup>th</sup> May 6-8pm
- Adults with Early-Onset Dementia and their Carers (via an Alzheimer's Scotland facilitated Dementia Café) (n=10) – Monday 20<sup>th</sup> June, 10am

Following discussion with Senior Charge Nurses it was agreed that the most effective way to capture the views of adults with mental health problems who were currently in-patients on Wards One, 17 and in Pentland Court, a series of one-to one interviews with this demographic were also conducted:

- In-patients on Ward One (IPCU) (n=3) – Weds 25<sup>th</sup> May 6-8pm
- In-patients on Ward 17 (n=2) – Monday 16<sup>th</sup> May 6-8pm
- Residents of Pentland Court (n=3) – Weds 8<sup>th</sup> June 2-4pm