



# **Independent Advocacy**

## **Perth & Kinross**

### **Report on Local Service Provision 2015/16**

A report on a consultation funded through the Integrated Care Fund

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## About Independent Advocacy Perth & Kinross

**We and our volunteers stand alongside you to safeguard your rights, help you to understand your choices, and empower you to be heard**

To enable those people in Perth and Kinross experiencing mental health problems or learning disabilities (including children and young people), physical disabilities, dementia, frailty or age-related problems and people who are unpaid Carers, to have their voices heard by providing Independent Advocacy so that they are involved in decisions which affect their lives.

We work together with volunteers to create a stronger community where people are valued.

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# **Report on Local Service Provision**

Independent Advocacy Perth & Kinross

IAPK, 90 Tay Street, Perth, PH2 8NP

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## **Context & Background**

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The process of listening to peoples' experiences has been a very humbling one. The people whom I have spoken with have been so willing to share their lives with me, a stranger, which is really an honour. It has been interesting how they too found value in this process, with many of them saying that speaking about their experiences helped – just to have someone listening to them. In light of this, I considered it important to not go into the meetings armed with paperwork and too rigid a set of questions, but to be flexible to meet them where they were. I introduced my intentions – to find out their experiences of getting support from services - and we went from there.

I observed that people would seek support from services after some crisis occurred in their lives. This crisis could be a health issue, or it could be a change in role – to becoming an unpaid Carer, for example. In all cases, there had been a major shift in their situation, and they were placed under a lot of pressure and needed help and support to manage. I have also observed that people tended to focus on what was not helpful about the support they received, with a sense of injustice and frustration that had not been heard or resolved. I have used the term 'support' in this report to also encapsulate a lack thereof, for want of a better word.

This report is organised to include a summary of the findings across all the meetings I conducted as well as a snapshot of each meeting. These snapshots can be found in the 'Case Studies' section. People also spoke with me about their experiences with services other than NHS and PKC, and these comments can be found in the 'Additional Feedback' section. I considered it important to represent the whole story, so I gave time to listen at each meeting. This has resulted in a large amount of information being contained within this report. I have

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included links, to enable greater ease of navigation through this information (press left-click to follow a link), and so that you may dip in and out of case studies as you please.

A proportion of the people I spoke with had received support from Independent Advocacy Perth & Kinross (IAPK), and so I took the opportunity to gather their views on the service. I have also spoken with a handful of staff who work alongside advocates on their experiences of the provision of support from IAPK. Again, I have summarised this feedback as well as including it as two separate case studies.

As an Independent Advocacy (IA) organisation, we do not provide any other service besides IA. The views expressed here are not the views of IAPK, they are drawn directly from conversations with people. I have taken care to ensure that the stories as written are as true to how they were originally told as possible.

People who use IA services are considered to be partners of the service, rather than service users. In line with this, throughout this text '*partner*' will refer to a person being supported by services. As well, '*advocate*' will refer to a paid/voluntary advocate; and '*staff*' will refer to a paid/voluntary worker from a private, public or third sector service. A glossary of acronyms and definitions can be found towards the end of this report.

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## Summary of NHS & PKC experiences

In total, 81 partners shared their experiences (see [Case Studies](#) 1 – 31). They have lived within P&K for an average of 30 years each (**11%** aged  $\geq 65$ ; **4%** aged  $\leq 25$ ; **26%** female; **19%** male).

*The following challenges were identified by partners:*

Physical disability (**67%**), health (**63%**), mental health (**41%**), language (**32%**), housing (**30%**), employment (**22%**), financial (**20%**), abuse (**15%**), being an unpaid Carer (**12%**), addiction (**11%**), learning disability (**10%**), education (**9%**), children (**9%**), criminal justice (**7%**).

The percentages of similar feedback are shown with the relevant case studies identified in brackets.

	<b>NHS</b>
<b>Positive Feedback</b>	• Hospital care <b>16%</b> (2,18)
	• GP support <b>12%</b> (1,7,9,10,19)
	• OT assessments <b>2%</b> (4,20)
	• Physiotherapist and Psychologist support <b>2%</b> (11,20)
	• PRI interpreter <b>1%</b> (14)
	• CRHTT support <b>1%</b> (18)
	<b>PKC</b>
	• Sheltered housing wardens <b>22%</b> (2,5)
	• Social work support <b>12%</b> (7,10,12,15,19)
	• Support from workers with lived experiences <b>2%</b> (24)

Relating to: **Information Provision**

- Dialogue about what to expect: “Managing life after....” (incl. unpaid Carers) **49%** (2,4,8,16,17,21,22,26)
- Variation in spoken/written communication to suit partners’ needs **49%** (2,7,26,27)
- Open dialogue with health/care staff about needs (incl. unpaid Carers) **31%** (1,2,4,7,10,20,24,25)
- Knowledge of available support for unpaid Carers **22%** (1,2,19,21,22,24)
- Preventing repetition of ‘story’ to different staff **14%** (7,10,18,24,27)
- Improvement in communication from PKC Housing **12%** (3,6,27,28)
- Improvement in communication from Key Workers **9%** (1,6)
- Improvement in communication from surgery Receptionists **9%** (6,23)
- Provision of SDS training for employers **6%** (7)
- Hopeful approach for addiction recovery/MH **4%** (18,24)
- Clarity on care costs **1%** (17)

Relating to: **Service Provision**

- Tackling loneliness and isolation **25%** (1,2,3,4,13,14,19,21,29)
- Improvement in quality of paid Carers support **19%** (1,2,19,21)
- Improved access to disabled services **16%** (2,3)
- Individualised support – beyond the standardised ‘cut-off’ point **15%** (4,6,24,25,27,29)
- Faster resolution of PKC Housing issues **12%** (3,6,27,28)
- Alternative to / redevelopment of St Catherine’s Square **9%** (6,16)
- Practical support: transport, cutting grass, moving furniture, food shopping, etc. **9%** (1,4,17,19,25,27,29)
- Provision of out-of-hours / emergency support **7%** (10,19,24,27)
- Consistency of MH worker **7%** (10,18,24,27)
- GP appointment flexibility **7%** (6)
- Allocation of support prior to crisis point **5%** (19,21,24)
- Accountability for social work in formalised social work involvement, e.g. CP/ASP cases **4%** (8,9,15)
- Access to psychologist **4%** (28,31)
- Faster wheelchair modifications to home / pavements **2%** (4,28)
- Alternative to respite care **2%** (1,21)
- Increased numbers of hospital staff **2%** (18,19)
- Allocation of responsibility for BPD **2%** (10)
- Legal high misuser support (incl. unpaid Carers) **2%** (24,29)
- Redevelopment of Community Alarm **2%** (1,20)
- Intermediate unit for care between home / secure unit **2%** (10)
- Linking of adult services (in line with children’s’ services) **1%** (27)

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### Other

*Outside of the statutory services, support is also highlighted as coming from the following services; please see the [Additional Feedback](#) section of this report for comments relating to these services:*

Myself, CATH, Police Scotland, DWP, Richmond Fellowship, Key Worker, CILPK, PUSH, Church, Caledonia Housing Association, DCC, Healer, Legal Aid, Solicitor, Welfare Rights, PKAVS, Cleaner, Friends, RVS, Vision PK, RNIB, Crossroads, Community Group, Care Housing, CHSS, Family/Partner, IAPK, Stroke Association, P&K Disability Sport, Bannatynes, Perth Access Cars, Food Train, Transport, Private Housing, Chemists, Mindspace, Job Centre, MP, Positive Choices, Headway, Samaritans, SCAA, Barnardo's, P&K Young Stroke Group, Employer/Colleagues, PKAVS MEAD, Women's Aid, Crown Office, Perth College, Alzheimer's Scotland, Supermarket, CAB, Hairdressers, Conversation Cafe, EPICS, Tayside Deaf Hub, Scottish Fire & Rescue, North East Sensory Services, Deaf Action, Lip-Reading Group, Action on Hearing Loss, Amplifon, SAMH, Child Brain Injury Trust.

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## Summary of IAPK experiences

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In total, 19 partners shared their experiences along with 9 staff (see [Case Studies](#) 32 & 33). In the year 2015, out of the total numbers supported by IAPK: **12%** lived in Tulloch, Hillyland, Rattray and Letham; **7%** manage multimorbidity (*estimate*); **19%**  $\geq 65$ ; **12%**  $\leq 25$ .

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### Outcome 1: Improving health & wellbeing

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**68%** of partners of IAPK interviewed said IA support improved their *health*.

IA involvement is described as improving partners' confidence and expression, thereby improving their wellbeing and mental health. Advocates can support a partner through a challenging time in their lives and help to alleviate pressure and anxiety. This role for the advocate has also been supported by staff interviewed.

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### Outcome 2: Facilitating independent living

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**53%** of partners of IAPK interviewed said IA support improved their *freedom*.

Advocates support partners with housing issues and house moves. They also support with care packages and assisted living situations.

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### Outcome 3: Facilitating positive experience of services

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Both partners and staff interviewed described IA as facilitating partner engagement, involvement, and acknowledgement by improving the dialogue with partners and staff – in both directions. IA supports partners to work within the system, and to clarify as well as speed up processes. Advocates are also tasked with signposting partners to other avenues of support. Staff describe how the advocate is able to redress the imbalance of power, and how valuable it is for this support to be coming from someone who is independent from other services.

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### Outcome 4: Improving quality of life

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**63%** of partners of IAPK interviewed said IA support improved their *happiness*.

Both partners and staff interviewed highlighted how IA helps to resolve issues and facilitate a positive

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outcome in some instances. The advocate listens and supports the partner. Staff describe how the advocate can improve a partners' thought processes.

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### **Outcome 5: Reducing health inequalities**

Staff discussed how IA facilitates a stronger voice for those struggling to be heard, thereby enabling them to have a more equal opportunity for engagement with support.

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### **Outcome 6: Providing unpaid Carer's support**

**13%** of partners supported by IAPK in 2015 are unpaid Carers.

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### **Outcome 7: Keeping safe from harm**

**53%** of partners of IAPK interviewed said IA support improved their *safety*.

Advocates are in a position to identify partners experiencing, or at risk from, abuse. They support partners through the ASP process, as well as other situations where their rights are threatened. This role for the advocate has also been supported by staff interviewed.

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### **Outcome 8: Improving care provision**

Both partners and staff interviewed identified how IA involvement can improve feedback and staff interactions with partners. Advocates can help with complaints and the structuring of care around the individual needs of the partner.

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## Case Studies

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This section includes summaries of conversations held with partners and staff about their experiences of the provision of support from the NHS, PKC and IAPK. Where studies involve more than one person, the number involved is indicated in brackets.

- **Case studies 1 – 31** are the experiences of 81 partners on the provision of support from NHS and PKC. Their experiences outside of these services are contained within the [Additional Feedback](#) section. Partners were gathered from the following sources:

Source	Numbers
Deaf Community	24
IAPK	14
Community Groups/Events	13
CHSS	12
CATH	6
CILPK	5
Positive Choices	3
Word of mouth	2
SAMH	1
PKAVS	1

- **Case studies 32 - 33** are the experiences of 19 IA partners and 9 staff (who work alongside advocates) on the provision of support from IAPK.

Case studies are written from the first-person perspective and effort has been made to ensure they are as true to the stories as originally told.

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Case Study	Challenges
<b>NHS/PKC</b>	
<a href="#">Study 1</a>	Being a Carer, Health, PD
<a href="#">Study 2</a>	Health, PD ( <b>x12</b> )
<a href="#">Study 3</a>	Employment, Health, Housing, MH
<a href="#">Study 4</a>	Financial, Health, MH, PD
<a href="#">Study 5</a>	Health, Housing ( <b>x6</b> )
<a href="#">Study 6</a>	Addiction, Employment, Financial, Health, Housing, MH ( <b>x6</b> )
<a href="#">Study 7</a>	Abuse, Education, Employment, Financial, Health, Housing, LD, MH, PD ( <b>x5</b> )
<a href="#">Study 8</a>	Ex-Carer, Financial, MH
<a href="#">Study 9</a>	Children, Health
<a href="#">Study 10</a>	Being a Carer, Criminal Justice, Employment, Health, MH ( <b>x2</b> )
<a href="#">Study 11</a>	Health, Housing
<a href="#">Study 12</a>	MH, PD
<a href="#">Study 13</a>	Children, Criminal Justice, Employment, Financial, MH
<a href="#">Study 14</a>	Abuse, Health, Language, MH, PD
<a href="#">Study 15</a>	Abuse, Children, LD, MH
<a href="#">Study 16</a>	LD, MH
<a href="#">Study 17</a>	Ex-Carer, Health, PD
<a href="#">Study 18</a>	MH
<a href="#">Study 19</a>	Being a Carer, Education, Health, Housing, LD, MH
<a href="#">Study 20</a>	Health, MH, PD
<a href="#">Study 21</a>	Being a Carer, Health, MH
<a href="#">Study 22</a>	Being a Carer, Health, MH, PD
<a href="#">Study 23</a>	Children, Employment, Financial, Health, Housing, Language, PD
<a href="#">Study 24</a>	Abuse, Addiction, Being a Carer, Criminal Justice, MH, PD ( <b>x2</b> )
<a href="#">Study 25</a>	Employment, Health, PD
<a href="#">Study 26</a>	PD, Language ( <b>x22</b> )
<a href="#">Study 27</a>	Abuse, Criminal Justice, Education, Financial, Health, Housing, MH
<a href="#">Study 28</a>	Abuse, Children, Health, Housing, MH, PD ( <b>x2</b> )

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<a href="#">Study 29</a>	Health, MH
<a href="#">Study 30</a>	Health, Language, PD (x2)
<a href="#">Study 31</a>	Addiction, Children, Employment, Health, MH
<b>IAPK</b>	
<a href="#">Study 32</a>	IA partners (x19)
<a href="#">Study 33</a>	Staff working alongside advocates (x9)

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

Study 1: Challenges Being a Carer, Health, PD	
<p>I am a female, aged 74 and I have lived within P&amp;K my whole life. I was the sole unpaid Carer for my husband who suffers from <a href="#">Parkinson's</a>. One morning, I woke up to have suddenly lost my sight. Up until this point, I had been managing his care needs well. Now, I can no longer drive, and I struggle to manage my own health alongside my caring role. I have no time for myself.</p>	
NHS	<ul style="list-style-type: none"> <li>• I have found my <i>GP</i>, <i>district nurse</i>, and <i>NHS 24</i> to be very helpful.</li> <li>• My husband has to travel to the <i>community Parkinson's nurse</i>; she is the only nurse available.</li> <li>• The <i>Parkinson's consultant</i> misprescribed once, which caused me some problems.</li> <li>• <i>Patient Transport</i> is not available for every appointment. It does not coincide with paid <i>Carers'</i> arrival. There is no set time for coming back, which is not helpful when I want to be out of the house for as little time as possible/need to plan care.</li> <li>• My husband was discharged from <i>PRI</i> before he was ready; the <i>Drs</i> had not spoken with the <i>nurses</i>.</li> </ul>
PKC	<ul style="list-style-type: none"> <li>• The paid <i>Carers</i> are all very nice; however, they only come for 45 minutes, which is not enough time for me to get anything else done. Sometimes they come quite late and then I will wash him without their help. The times at which they come was not discussed. On holiday periods they are short staffed – they should have a bank of paid <i>Carers</i> to use. The <i>tuck service</i> should be later as he has disrupted sleeping habits.</li> <li>• In a time of crisis, the <i>Community Alarm</i> directed me elsewhere; this was not helpful.</li> <li>• I have never met my <i>Key Worker</i>.</li> <li>• When I went into hospital, he was put into <i>respite care</i>. They did not speak to me about his needs and medication requirements. He went 10 days without medication and his health deteriorated rapidly as result. The care was good, but being there unsettled him a lot. He has never been the same since.</li> <li>• There are not enough <i>respite vouchers</i>.</li> <li>• <i>Social work</i> helped me with the voucher scheme and accessibility changes around the home.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• I have also received support from: PKAVS, NHS GP, Cleaner, Friends, RVS, Vision PK, RNIB, Crossroads, PKC Social, PKC Carers, NHS 24, NHS CMHT, NHS Community Nurse, Community Group, Care Housing. [See: <a href="#">Additional Feedback</a>]</li> </ul>

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

Study 2: Challenges Health, PD	
<p>Twelve members of Chest, Heart &amp; Stroke Scotland (CHSS) support group. Some have been in attendance for many years. Many of us suffer from <a href="#">aphasia</a>. We are all at different stages in our recoveries from a <a href="#">stroke</a>. It can be difficult for us to communicate and understand, especially over the telephone. Our families are such a source of support in providing unpaid care.</p>	
NHS	<ul style="list-style-type: none"> <li>• We have had positive experiences of our care in <i>hospital</i>.</li> <li>• Managing life after a stroke was never explained to us upon discharge from <i>hospital</i>.</li> </ul>
PKC	<ul style="list-style-type: none"> <li>• Paid <i>Carers</i> do not have enough time in 15-minute appointments to care. For some of us, the paid <i>Carers</i> visit is the only contact we have in a day and they often won't take time to chat. They don't organise the short time they have. It is not enough time to cook a meal that is in any way decent. Staff are always changing. Staff do not understand the specific care needs following a stroke.</li> <li>• In some <i>sheltered housing</i>, the warden support is great, along with <i>cleaner</i>. They explain what is written on the post despite supporting 40 people.</li> <li>• <i>Live Active</i> pool used to be closed to non-disabled users for certain times in the week, but this facility was withdrawn.</li> <li>• Some <i>PKC</i> staff will call us on the telephone, but this is very difficult for us.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• We have also received support from: CHSS, NHS GP, Cleaner, Family/Partner, RVS, IAPK, Stroke Association, P&amp;K Disability Sport, Bannatynes, Perth Access Cars, Food Train, RNIB, PKC Live Active, PKC Library, PKC Housing, PKC Carers, Transport, Community Group, Private Housing, Chemists. [See: <a href="#">Additional Feedback</a>]</li> </ul>

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

<b>Study 3: Challenges Employment, Health, Housing, MH</b>	
<p>I am a male, aged 49. I have lived within P&amp;K for 15 years. I moved back to Perth after difficulties with my life abroad. I was isolated and struggling with my MH. Since moving back, both my upstairs and downstairs neighbours undertook renovation work which left visible holes from my property into theirs'. This work has never been completed. This further impacted on my MH.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I spent some time in <i>Murray Royal</i>, but was not signposted to any other support services and proceeded to spend 4 years without support.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I have reported a derelict factory building, broken foundation for the Queens Bridge and a waste pipe that leaks human waste onto the street and nothing has been done about any of these by <i>housing/environmental services</i>. These are concerns for public health and fire safety.</li> <li>• It has been very difficult for me to get support for a private housing issue. <i>Housing</i> have amenity notices but they don't serve them - they seem reluctant to use the powers they have available. They manage the building warrant, but haven't been checking that the works have been finished.</li> <li>• The <i>disabled library</i> on West Street was accessible inside and out, it was also a social thing, but they shut it and spread the services to the other two libraries in Perth which are not accessible. This issue has been raised to no avail.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Vision PK, Mindspace, IAPK, Job Centre, PKC Live Active, PKC Library, PKC Housing, PKC Environmental, MP, NHS Murray Royal, NHS Psychiatrist. [See: <a href="#">Additional Feedback</a>]</li> </ul>

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

<b>Study 4: Challenges Financial, Health, MH, PD</b>	
<p>I am a male, aged 55. I have lived within P&amp;K for 23 years. I suffered a severe <a href="#">stroke</a> and was no longer able to work. Work had been a very important part of my life. Around the same time, my marriage broke down and I suffered a couple of close family member bereavements. My MH suffered. I get no support now.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I met with a woman from <i>Central Healthcare Team</i>, which was invaluable support.</li> <li>• The <i>OT</i> support at the hospital which assessed my needs was very helpful.</li> <li>• I had regular checks from the <i>Physiotherapist</i> for the first 6 weeks out in the community. These gave me hope, something to hold onto.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I was bombarded with information and handouts after the stroke, but I couldn't take it all in.</li> <li>• The support was given for a short period of time and then it stopped, its removal should be more gradual. It was a standard support 'package', which wasn't centred on my needs – it didn't take into account the severity of my stroke and my MH problems.</li> <li>• I was in hospital for 6 months, but it took 9 months for the kerb to be lowered. In the end, I contacted my counsellor and had the problem sorted.</li> <li>• I had to request support from <i>social work</i> to organise adaptations to the house.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I needed more support for day-to-day problems, like cutting the grass, moving furniture, food shopping. It felt like I was begging when having to ask for help.</li> <li>• I could have done with someone to teach me basic skills to make my life easier when back into the community.</li> <li>• I have also received support from: Positive Choices, CHSS, PKAVS, NHS GP, Family/Partner, Mindspace, Job Centre, Headway, Samaritans, SCAA, Barnardo's, PKC Social, NHS Physiotherapist, NHS OT, NHS PRI, P&amp;K Young Stroke Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

Study 5: Challenges Health, Housing	
<p>Six female members of Dalreoch Friendship Group, a member-led coffee morning for over 55's living in sheltered housing in Letham. There are no common challenges which bring us to this group, it serves a social function. We haven't sought support beyond the standard (GP, nurse) because we were brought up to "just get on with it". We do not attend groups, etc., in the community.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• At the chair exercise class with <i>Live Active</i> they had me doing exercises that were not advised by my therapist, so I stopped attending.</li> <li>• In <i>sheltered housing</i>, the <i>wardens</i> used to visit many different houses just to check that we were OK. This was an excellent service. <i>Wardens</i> are no longer provided.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• We remember a time when neighbours would check on you and care for you. This doesn't happen anymore.</li> <li>• We have also received support from: NHS GP, Friends, Family/Partner, Dalreoch Friendship Group, PKC Live Active, PKC Housing, Myself, Community Group.</li> </ul>

[See: [Glossary](#)] [See: [Case Studies Table of Contents](#)]

<b>Study 6: Challenges</b> Addiction, Employment, Financial, Health, Housing, MH	
<p>Four partners of Churches Action for the Homeless (CATH) day centre and two members of staff. As partners, we are experiencing homelessness and its associated issues. As staff, we have experienced year-on-year funding cuts; no other local services are taking on the responsibility for supporting the homeless and vulnerably housed.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• In many surgeries the receptionist is rude, which puts us off going (<i>partner</i>).</li> <li>• The service at <i>Drumhar Health Centre</i> as good as the staff there understand us (<i>partner</i>).</li> <li>• The <i>GP</i> has refused to see us as we have missed too many appointments. This is a common issue as we lead chaotic lives. There is no flexibility from the <i>GP</i> about it. It's always 3 strikes and you're out. Once I missed an appointment because I was in custody. I had no way of notifying the <i>surgey</i> - the <i>Police</i> wouldn't do it for me (<i>partner</i>).</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• We have been assigned a <i>Key Worker</i>, but have never met them. They only get in touch when we are due to move from temporary into permanent accommodation (<i>partner</i>).</li> <li>• We have been ignored by <i>housing</i> about moving out of <i>St Catherine's Square</i>. It is such a challenge to be in a space that is like a prison with other people living there who are drug dealers and paedophiles and straight out of prison. It is hard to keep yourself straight with all those types around. I want to make my mark on my home and pour some love into the place, but it's not mine and <i>housing</i> had said that I would only stay there for a year, but it's been much longer than that now. There is no support offered there (<i>partner</i>).</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• We (<i>partner</i>) need support beyond the point at which we find a place to live, and we (<i>staff</i>) need more funding if we are expected to be the only service that is providing this support.</li> <li>• We (<i>partner</i>) have also received support from: CATH, NHS GP, Job Centre, Police Scotland, PKC Social, PKC Housing, DWP, Richmond Fellowship, Key Worker. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 7: Challenges</b> Abuse, Education, Employment, Financial, Health, Housing, LD, MH, PD	
Five members of the Centre for Inclusive Living P&K (CILPK), a user-led disabled access organisation. We all have some form of PD, and various other personal challenges.	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• We have been well supported by our <i>GP</i>.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• There is a high turnover of paid <i>Carers</i>, and we have to explain our situation to each new staff member. Some do not communicate very well, and do not listen to us. Some we do not want to support us. Some don't know what they are doing and won't do the dishes. They have also positioned us incorrectly when they leave, which makes things very difficult. We have expressed these concerns without any remedial action having been taken.</li> <li>• We have to repeat information to individuals within the same department at <i>PKC</i>, and with a speech impediment this is especially difficult.</li> <li>• For <i>SDS</i>, there is no training and support as an employer.</li> <li>• We are happy with our <i>social work</i> support.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• Staff (including paid Carers) should be trained in communication aids such as <a href="#">Talking Mats</a>.</li> <li>• We have also received support from: CILPK, NHS GP, Friends, Family/Partner, IAPK, Crossroads, PKC Social, PKC Carers, PUSH, Church, Caledonia Housing Association. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 8: Challenges Ex-Carer, Financial, MH</b>	
<p>I am a female, aged 66. I have lived within P&amp;K for 2 years. I was the primary unpaid Carer for my mother, who suffers from <a href="#">dementia</a>. I became the focus of an adult support and protection (ASP) case; however, the criteria were not met. In this time, my mother’s health deteriorated and she has never returned to my care.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• It took several days for <i>PRI</i> to identify that my mother was suffering from a urinary infection.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I was not communicated about the content of the <i>ASP meetings</i> and was given very little warning about them. It was badly handled. There was no report provided for the initial meeting. Throughout, I felt criminalised.</li> <li>• <i>Dementia services</i> didn’t adequately explain to me as an unpaid Carer what happens as dementia progresses, but came down like a ton of bricks when things went bad. I can understand why families don’t want them involved.</li> <li>• I felt forced into a position by <i>social services</i> to accept that my mother wouldn’t relent in her antagonism towards me. My mother was then placed in a care home.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Friends, Family/Partner, IAPK, DCC, Police Scotland, PKC Social, NHS 24, Care Housing. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 9: Challenges Children, Health</b>	
<p>I am a male, aged 62. I have lived within P&amp;K for 8 years. My fiancé reported to social work that I had struck her children; it has become a child protection (CP) case. I went on to have a child with her, but have seen the time I can spend with my daughter constantly reduced and increasingly supervised. My daughter now lives in a situation I think unsafe, and I feel powerless to protect her. I am in limbo waiting to be given access to her and it is so painful to watch her grow older without me.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• My <i>GP</i> has been a rock. He is a great guy, who I completely trust.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• <i>Social work</i> have not listened to me. I originally approached them when my fiancé mistreated her children, and they said that there was nothing they could do. I think she has been able to manipulate the system to use it to get me - like she has done with her previous partners who also no longer have access to their children.</li> <li>• I feel criminalised by <i>social work</i>; my treatment from them is out of proportion to my actions. I reckon I am a good case for them to get their teeth into and they won't let it go. They pick apart everything that happens at meetings with my daughter to fit their version of the truth.</li> <li>• <i>Social work</i> have driven my daughter without a car seat, which is illegal.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• Social work should be accountable in their practice.</li> <li>• I have also received support from: NHS GP, Friends, Family/Partner, IAPK, PKC Social.</li> </ul>

**Study 10: Challenges Being a Carer, Criminal Justice, Employment, Health, MH**

A female, aged 27 (*daughter*) and her father, aged 66 (*father*). Both have lived within P&K for 12 years. I (*daughter*) was moved into care after my parents struggled with my [borderline personality disorder](#) (BPD) and chronic self-harming. I also suffer from anxiety and depression. I now live at home with my parents.

NHS

- I have seen 3 or 4 different *psychiatrists* in a year. It's difficult for me to have to explain my story each time. (*daughter*)
- The new protocol for my self-harming stipulates that my injuries are to be dealt with at home. I was not consulted about this, and only found out as it was in process. (*daughter*)
- Some *health professionals* are rude and unpleasant to me and manhandle my wounds. My MH gets worse if I am treated poorly. There is no point in telling me I have done wrong, as I know that already. I want to be taken seriously and to be, at least, checked out by a *Dr* when I self-harm. Otherwise I think, "What's the use in caring for myself, if they don't care for me?" Stuff like being given gas and air, removing bandages slowly, simple things that make a big difference. (*daughter*)
- Most *ambulance staff* are ok, some don't treat me well. The two *paramedics* who regularly support me have become better since they embarked on BPD training. Now they show care. (*daughter*)
- My *GP* has stayed the same, and it works well now. (*daughter*)
- She has been pushed between MH services and physical health services, and between psychiatry and psychology. (*father*)
- She is either in a secure unit or at home - there is no intermediate. (*father*)
- They are not providing her with stitches. (*father*)
- The support is generally good from the *CMHT*; however, it is in a constant state of flux. The *CPN* is leaving, and there is no replacement for her. She provides good support for her, so this loss is distressing. When you call up the *CMHT* (the on-call 9-5 worker/out-of-hours worker), it can feel like they are having you answer a checklist, and then they just say, "Use your DBT tactics". When she is in that place, nothing else matters - it's too late for the tactics. Sometimes the *CMHT* tell her to have a bath - but it's in the bathroom that she does most of her self-harming. Some staff that regularly deal with her aren't aware of her history and a lot of time is wasted explaining it. What she needs is as simple as a conversation; she needs to talk it through. (*father*)
- At *Murray Royal* they often refuse her admission. She is left until the morning when the local surgery opens. (*father*)

## REPORT ON LOCAL SERVICE PROVISION

	<ul style="list-style-type: none"> <li>• There is no surgical team after 6pm at <i>PRI</i>, which makes it very difficult if she self-harms. <i>(father)</i></li> <li>• They have to call <i>NHS24</i> when out-of-hours, and there is this whole procedure they have to go through just to get in touch with the crisis team at <i>Murray Royal</i>. It's a waste of time. <i>(father)</i></li> <li>• Once a <i>CPN</i> made a comment on her notes about the potential for her to use pain medication incorrectly, just a feeling they had not from evidence, and that account has stuck so that she now won't be given pain relief. There has been trouble too with her medication boxes, they are concerned that she has substances with her other than those which are regulated and that she will abuse them; this has resulted in one occasion when she had to ask 10 times for her medication. <i>(father)</i></li> <li>• It is a long way to <i>Ninewells</i>, and the <i>A&amp;E department</i> have been especially unpleasant. Sometimes I have been left with stuff inside me <i>(daughter)</i>. The nurses often make snide comments, which she can overhear; once they said, "Well what the hell do you expect us to do about it?!" It's not very professional. Sometimes she gives them attitude, I'm not sure who started it, but they are the professionals and they shouldn't be giving attitude back. There seems to be a lot of ignorance about her condition. Once they left the knife she had used on the table beside her! <i>(father)</i></li> <li>• Support is needed at different times, not often in the day. There is often only one out of hours <i>GP/Police/ambulance</i>, and there are not enough <i>psychiatrists</i>. <i>(father)</i></li> </ul>
<p style="text-align: center;"><b>PKC</b></p>	<ul style="list-style-type: none"> <li>• <i>Social work</i> has helped me to get on the housing list. <i>(daughter)</i></li> <li>• <i>PKC</i> got things moving, pushing for better communication. They organised it so that she had contact time while in <i>Murray Royal</i> to allow time for her wounds to heal. They looked into creating a halfway house, a safe space, where people could go when they are in crisis - between a locked ward in <i>Murray Royal</i> and home. <i>(father)</i></li> </ul>
<p style="text-align: center;"><b>Other</b></p>	<ul style="list-style-type: none"> <li>• More preventative measures, so that it doesn't always reach crisis before someone intervenes. <i>(father)</i></li> <li>• Service provision needs to be more localised. <i>(father)</i></li> <li>• We have also received support from: NHS GP, Family/Partner, IAPK, Police Scotland, PKC Social, PKC Housing, NHS 24, NHS CMHT, NHS Murray Royal, NHS Perth Royal Infirmary, NHS Paramedics, NHS Ninewells, NHS Psychiatrist, NHS Psychologist, Friends, Healer, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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Study 11: Challenges Health, Housing	
<p>I am a female, aged 35. I have lived within P&amp;K for 19 years. I suffer problems with my foot and with <a href="#">somatoform</a>. I am living in hospital, where I have been for the last 2 years. I am ready to leave, and no longer receive the support I did when I originally arrived. There are no suitable council homes for me to move into and this is a great frustration. I don't see myself as having a MH issue. Originally it was just me and my mum, but now I have a network of support.</p>	
NHS	<ul style="list-style-type: none"> <li>• <i>Strathmartine</i> has given me my life back. As much as I hate it there and don't agree with all of the practices. It has very much helped me to get better to where I am today.</li> <li>• The support from my <i>Physiotherapist</i> has been excellent, and he has got me moving again.</li> <li>• The support of my <i>Psychologist</i> has also been excellent.</li> <li>• I will be able to continue seeing them (<i>Physiotherapist/Psychiatrist</i>) when I am back in the community, which is great. The contact from them is very regular, which is very beneficial.</li> </ul>
PKC	<ul style="list-style-type: none"> <li>• I have now been waiting over 3 months to move out of hospital into a ground floor flat, and there is not one available. There is not enough <i>social housing</i>, and I am bed blocking at the hospital.</li> <li>• <i>Social work</i> has not been particularly helpful for me in achieving my aims.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Family/Partner, IAPK, PKC Social, PKC Housing, NHS Physiotherapist, NHS Psychiatrist, NHS Strathmartine, NHS Psychologist, Private Housing. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 12: Challenges MH, PD</b>	
<p>I am a male, aged 53. I used to drink socially, and heavily, which led to me being diagnosed with <a href="#">Korsakoff's syndrome</a>. My memory is severely impaired and I have set my kitchen on fire, twice. The brain damage I have suffered leaves me vulnerable.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• It was because of <i>social services</i> that I was diagnosed with Korsakoff's syndrome.</li> <li>• My previous <i>social worker</i> said that any change in my housing had to go through them, which was not true. Since I have changed <i>social worker</i>, things have been great and I get on fine with my new <i>social worker</i>.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Friends, Family/Partner, IAPK, PKC Social, PKC Housing, PKC Carers.</li> </ul>

<b>Study 13: Challenges Children, Criminal Justice, Employment, Financial, MH</b>	
<p>I am a male, aged 60. I have lived within P&amp;K my whole life. Around five years ago I had a psychotic episode, during which I suffered from delusions of poverty and gave away my business and belongings. This took me from being a millionaire to being left with only my house. I am very isolated and living the life of a hermit. I am involved in a legal battle to get my belongings back. I feel frozen in time. Legal Aid are repeatedly denying me support.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I have always been listened to by the <i>NHS</i>.</li> <li>• I rarely see anyone; the only people I see are my <i>health workers</i>. It can be a fortnight between appointments.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I do not feel listened to by the <i>government</i>.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Family/Partner, IAPK, Legal Aid, Solicitor, MP, Welfare Rights, NHS Move Ahead, Employer/Colleagues, NHS Psychiatrist, NHS Psychologist, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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**Study 14: Challenges Abuse, Health, Language, MH, PD**

I am a female, aged 56. I have lived within P&K for 11 years. I was a victim of domestic abuse, and ended up in hospital as a result. I was supported by Women's Aid to move into a new council home. I was getting on with my life, when one day - 3 years later - my ex-husband was picking my lock with a knife. I was terrified, and contacted the Police who said there was nothing they can do as only I witnessed it. I now live in fear. I am attempting to divorce him, but he is making accusations that I am not who I say I am, and I cannot afford a translator to support me in court (I don't speak English well). Legal Aid is repeatedly denying me support. I am also suffering from [arthritis](#) and anxiety.

<b>NHS</b>	<ul style="list-style-type: none"> <li>• <i>Ninewells</i> and <i>PRI</i> have provided me with a very good interpreter.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I was living in <i>Fairfield Housing Association</i>, there was no extra support given after the attempted break-in. I have had to personally set up cameras by my door as I am so afraid.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: PKAVS MEAD, NHS GP, Friends, Mindspace, IAPK, Police Scotland, PKC Housing, Legal Aid, Solicitor, Women's Aid, MP, Crown Office. [See: <a href="#">Additional Feedback</a>]</li> </ul>

**Study 15: Challenges Abuse, Children, LD, MH**

I am a female, aged 23. I have lived in P&K for 9 years. I have a LD and I was sexually abused as a child. I had a child and was drinking heavily, and I sought the support of social work because I didn't want my daughter to grow up without her mum. Social work became my guardians. I have now turned my life around but they are still involved, and this brings me much anxiety. I want to move on without them being involved.

<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• <i>Social work</i> supported me through a difficult time.</li> <li>• <i>Social work</i> tells me what to do, which is not helpful. I am ready to move on, the guardianship has been removed. However, I still have to attend meetings. I get very anxious about these, as I feel like the things that I say can be used against me - they are looking at my life so closely, and I can't do anything without them commenting. It's funny because I sought their help, but now I can't get rid of them. I want an end date to their involvement.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: Family/Partner, IAPK, PKC Social, PKC Carers, Perth College.</li> </ul>

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<b>Study 16: Challenges LD, MH</b>	
<p>I am a female, aged 33. I have lived in P&amp;K my whole life. I spent a large part of my youth in care after being sexually abused as a child. I have lived in various different accommodations with mixed experiences.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• Some services provide you with information some services don't. <i>Housing</i> in some areas listens to you. I've had mixed experiences of <i>supported accommodation</i>. My experience at one place was very good because they had things well organised – rules of the house and responsibilities for the people living there.</li> <li>• My experience at <i>St Catherine's Square</i> was terrible. There is such a bad mix of people there - paedophiles along with young girls. I complained about it. It was only when I got really upset and cried that they agreed to do something about it. All the windows are facing one another; it's not a good environment.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• An education in basic skills when you are living in care as a child is missing. When you leave, you are not prepared for managing your money/doing your washing/cooking etc. These are essential skills. Without a proper education in them, you can fall back into bad times due to finding life a challenge and struggle with no-one to support you.</li> <li>• I have also received support from: CATH, Family/Partner, IAPK, PKC Housing, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 17: Challenges Ex-Carer, Health, PD</b>	
<p>I am a male, aged 91. I have lived within P&amp;K for 52 years. I lost my wife to <a href="#">dementia</a> in 2013. I was her primary unpaid Carer. I began needing the support of services a couple of years prior to her passing. I didn't ask for help when perhaps I could have.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• At <i>Ashdean</i> they would write about her weekly visit in a book, this really helped me. They also picked her up in a car; however, when she got more ill she couldn't get in the car anymore and had to go back to <i>Parkdale</i>.</li> <li>• I received a bill for her care from <i>Ashdean</i>, and it gave no break down details of the cost. I called and asked about it, but no-one responded. Once, the district nurse removed her catheter without informing me - and I had to get it refitted.</li> <li>• The <i>community MH nurse</i> didn't explain the groups and support available to me and my wife clearly.</li> <li>• She wasn't happy at <i>Parkdale</i>, but it was the only place she could get the right kind of transport to.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• There is no communal area where I live, and the local village hall doesn't have enough community groups that you don't need to be a member of some group to go to.</li> <li>• I have also received support from: NHS GP, Friends, Family/Partner, Alzheimer's Scotland, PKC Social, PKC Carers, DWP, NHS 24, Community Group, Care Housing. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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**Study 18: Challenges MH**

I am a female, aged 54. I have lived within P&K for 19 years. I suffer from [bipolar disorder](#) and am frequently in hospital for treatment. I have been receiving treatment for the last 20 years. There must be hope. When you are diagnosed you get this removal of freedom, and it's like living life in a cage. It takes years of support and counselling to gain confidence, otherwise you just end up coming back in again and again.

<b>NHS</b>	<ul style="list-style-type: none"> <li>•The services in <i>Murray Royal</i> are always understaffed resulting in decreased ability for the nurses to achieve success and results in staff burn out. My report from the <i>hospital</i> was horrific. This place is a prime example of having management issues; it's not about more money but about the correct allocation of funds. You need the distinction between care and management/finance. Managers need to be good at managing people; otherwise you get burnt out staff. In <i>Moredun Ward</i>, the nurses are amazing, but they are constantly in crisis because they are not well managed. You need high staff morale, so they can work well as a team.</li> <li>•The <i>CRHTT</i> works really well, because they go into the home with the person. They connect person by person with the patient. It's thorough. They link with support services at home. They know about the legal rights and they gain the patients' trust.</li> <li>•I went through 3 different <i>charge nurses</i> and 6 <i>psychiatrists</i> in 5 months.</li> <li>•There is no <i>IPCU</i> at <i>Murray Royal</i>. The only choice is to be locked into your room, it's like solitary confinement.</li> <li>•At <i>Carseview</i>, despite this being an acute unit, they check where you are going to next and whether it is suitable emotionally and socially for your recovery. In <i>Carseview (Ward 2)</i> it is cold and although designed to be 'state of the art', but it's like prison cells. It's the small things, like at dinner the door shutting so you can get a second helping, the heating is difficult to operate as is the grill over the window - it takes your control away. There is no quiet room provided. And no interview room.</li> <li>•At <i>MHTS</i> meetings now you have a panel of professionals, it's like an interview. Once I walked out. They are all talking in professional jargon; it's intimidating and doesn't help with your anxiety.</li> <li>•It's good that you are offered Yoga, Thai Chi, walks, and physiotherapy. It was only 8 years ago that you would be put in a strait jacket and stuffed full of medication.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>•Nothing was raised.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>•I have also received support from: NHS GP, Family/Partner, IAPK, Police Scotland, Solicitor, NHS Murray Royal, NHS CRHTT, NHS Ninewells, NHS Psychiatrist, NHS Psychologist.</li> </ul> <p>[See: <a href="#">Additional Feedback</a>]</p>

**Study 19: Challenges Being a Carer, Education, Health, Housing, LD, MH**

I am a female, aged 68 years. I have lived within P&K for 40 years. I have been caring for my husband for 20+ years. For better or for worse, you just get on with it. It is only in the last 4 years that I have been given support with unpaid care, since suffering from a [stroke](#), which has impacted on my mobility. I think my [stroke](#) maybe came about as a result of the pressure of caring. Until I was 60, I had kept very well and kept fit. I am only just beginning to get my identity back after 20 years. I have felt very isolated.

<b>NHS</b>	<ul style="list-style-type: none"> <li>• At the weekend, I have to <i>call 111</i> but not in the week. There is no difference to the care and support needed. It's not fit for purpose, and they have you answering questions like “Is he breathing?”, when all I need is the usual help to get him moved. He always takes unwell at night, when the services aren’t available.</li> <li>• It was one time when I went mad at the <i>ambulance staff</i> that the support of paid <i>Carers</i> arrived. I was just at the end of my tether.</li> <li>• The <i>GP</i> recommends I take an <i>ambulance</i>, but they are not offered easily. I get quizzed on the phone when I call. I can only be away from him for an hour. They ask why I need one, but I have more than just one problem - it's not as simple as that. It is difficult to get to <i>hospital</i> you need someone with a car. I am frightened of <i>buses</i> in case I take a funny turn.</li> <li>• I get on with my <i>GP</i> really well, he organised a <i>Chiropodist</i> to come to my home and he understands the situation and knows my husband.</li> <li>• The <i>Chiropodist</i> didn’t think they needed to come to my home. They didn’t understand.</li> <li>• The <i>Community Nurse</i> comes to the home, but I am responsible for ordering everything.</li> <li>• The <i>hospital staff</i> are too busy and the food is not so good.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• The care from paid <i>Carers</i> is mostly good, and they will help by bringing bread and milk over. Some days they are clearly in a rush. <i>Social work</i> changed it from 30-45 minutes to help with this. They are on zero-hour contracts, and some come from Kinross or Dundee. I was getting the support of private care, they were always on time and you never had to call to check where they were, but this was taken away when he came out of hospital. It was about 2 years ago. Now there is no consistency, and I don’t know when I will be getting new staff - they just turn up at my door and in 6 months’ time old ones might reappear.</li> <li>• <i>Parkdale</i> forgot to send back his night bags and they only have single beds.</li> <li>• <i>Social work</i> sorted out respite for me, which was the first time in 20 years.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I find it easier to get out at night, but there's nothing on.</li> <li>• I have also received support from: NHS GP, Friends, Family/Partner, PKC Social, PKC Carers, Supermarket, NHS 24, NHS Perth Royal Infirmary, NHS Paramedics, NHS Chiropodist, Community Group, Care Housing, Chemists. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 20: Challenges Health, MH, PD</b>	
<p>I am a male, aged 68 years. I have lived within P&amp;K for 45 years. I had a bowel operation 12 years ago, which left me with a <a href="#">stoma</a>. I never had the follow-up operation. My MH has been affected by my physical problems and it is getting progressively worse as the pain worsens. My wife has <a href="#">fibromyalgia</a>, and I rely on her for parts of my care - it is never clear when she will take a turn for the worst.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I do not feel listened to by the <i>NHS</i>.</li> <li>• The <i>Community Alarm</i> rings your named person; this is not helpful as I could do this myself.</li> <li>• At <i>Ninewells Pain Unit</i> I have been getting pain injections (<i>lidocain</i>) for 12 years now. They used to give me injections every week, now it is down to once every 10 weeks. It no longer helps. The pain is getting worse. I have written to my <i>Consultant Anaesthetist</i> about this, but he just dismisses it saying there is no clinical evidence. He talks down to me. There are other forms of pain medication out there, and he has said that he will propose I am offered these but nothing has come of it. The treatment I get is not individualised, it is as though my condition doesn't warrant help.</li> <li>• There are a few people who have these injections, we all feel the same. The seats at <i>Ninewells</i> they make us sit in as we wait for the injection are so uncomfortable, and they have us all coming for appointments at the same time, it's not well organised.</li> <li>• An <i>OT</i> came and assessed my needs, which was helpful, but these have changed and no-one has come back since.</li> <li>• I have been given a <i>Physiotherapist</i>, who is such a big support for me. But I am afraid that they are going to stop our sessions, which is causing me great anxiety as nothing is in place to replace her.</li> <li>• I got the support of a <i>Psychologist</i> for a couple of years after the operation, she was very good.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: CAB, Positive Choices, NHS GP, Cleaner, Friends, Family/Partner, IAPK, PKC Live Active, PKC Social, DWP, NHS Physiotherapist, NHS Occupational Therapist, NHS Ninewells, NHS Psychologist, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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Study 21: Challenges Being a Carer, Health, MH	
<p>I am a female, aged 80. I have lived within P&amp;K my whole life. I am the primary unpaid Carer for my husband, who was diagnosed with <a href="#">dementia</a> 6 years ago. My MH has been adversely affected as a result of my caring role and I am on medication for depression. No-one asks me if I am ok and what help I need. I don't know what support is available to me.</p>	
NHS	<ul style="list-style-type: none"> <li>• When my husband was given the diagnosis that was it. There was no explanation of what this would mean and of where I could turn to for support. I wasn't given the information I needed to understand the implications of the diagnosis.</li> <li>• When I came back out of <i>hospital</i> for my own health problems, they just left me to it, no-one supported me. I went from all the care to no care. It was such a shock for me and my MH suffered. I feel so isolated at home.</li> </ul>
PKC	<ul style="list-style-type: none"> <li>• The <i>ambulance staff</i> helped to organise paid Carers support after I lost my rag at them one time.</li> <li>• The paid <i>Carers</i> timing is terrible, and I have had to call to ask where they are sometimes. They have been an hour and a half late, so I end up doing it myself. They cook a microwave meal, but I don't think that's the way to eat so I just cook myself.</li> <li>• I have been told to keep a higher level of care in place, even though he doesn't need it yet, because it is difficult to change it when you need more in the future.</li> <li>• I wouldn't want him to go back to <i>respite care</i>. Since he came back from his first visit he has changed and although he has regained some of his former self, I don't think he will ever be the same as before he went. It's so confusing for him and it disrupted him badly. There was no other choice, as I was in <i>hospital</i>.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• I have also received support from: Positive Choices, NHS GP, Friends, Family/Partner, RNIB, PKC Social, PKC Carers, Church, NHS Perth Royal Infirmary, Hairdressers, Community Group, Care Housing. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 22: Challenges</b> Being a Carer, Health, MH, PD	
<p>One male attendee from Perth Carers' Café. My wife suffers from <a href="#">dementia</a> and I am her primary unpaid Carer. My MH has been negatively impacted as a result of my caring role.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I wasn't told what to expect. I have found the emotional impact the most difficult to deal with and there has been a lack of support given to help me with this.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• I have been offered paid <i>Carers</i>, but it is not what she would have wanted. So, for now, I have said no to this.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I have also received support from: NHS GP, Friends, Family/Partner, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

<b>Study 23: Challenges</b> Children, Employment, Financial, Health, Housing, Language, PD	
<p>I am a female, aged 38. I have lived within P&amp;K for 12 years. I have been paralysed since birth in my left leg. Twelve years ago, I moved to Scotland from the Philippines. My initial time here was very traumatic and I received no support. I was isolated and became depressed. I received a lot of racial / disability abuse, which still happens now. Since moving to the UK, I have developed <a href="#">arthritis</a>, swelling, back pain, and I am now in near-constant pain. I would like to earn my own money, but standing and sitting for too long is difficult.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• At the <i>Yellow Practice</i> the receptionist was very rude to me.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• My home has been specially built to accommodate for my disability. Although, it is still a challenge for me to do things inside the house.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• I need help, but I try my best to do it my way.</li> <li>• I have also received support from: CAB, PKAVS, NHS GP, Friends, Family/Partner, PKC Housing, DWP, Church. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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**Study 24: Challenges Abuse, Addiction, Being a Carer, Criminal Justice, MH, PD**

Two mothers who act as unpaid Carers for their children. One has a *daughter*, the other a *son*. Along with our husbands, we care for our adult children who are at different stages in their recovery from addiction to heroin. We have very little support from services in our caring role and are caring ourselves stressed. There is a feeling that our children are second class. It pervades society. It's so negative, there is no hope. People need to acknowledge that their addiction is an illness. They are not in their right minds to help themselves.

**NHS** • *PRI* kick them out of hospital at 3am, it's asking for trouble.

**PKC** • At *Highland House* we keep being told to back off, which is so frustrating. If we don't support them, then no-one else will. We don't understand how you can be expected not to care when you are their mother. We want to be treated as equals. As unpaid Carers, we are treated like second class, bottom of the pile. Someone needs to care for our children. We are not given the support to do so. Our views are not listened to. You have to break down and lose your temper for someone to listen to you. There is no forum for bringing problems forward, so that the service provision can be 'family-orientated'. Recovery requires hope and services working together with the family. It's not just that services are not supporting, it's that they are doing the opposite - they are creating problems. They are making things worse by not consulting with unpaid Carers – about appointments, etc. Once they are outside that building that's when everything changes, that's when families are there. What do they want - people to just drop like flies? We don't understand what they want. Negative encounters with people can make all the difference to their mood and resolve. They are left alone at home, they don't have friends. All the people they used to spend time with they no longer see because they are trying to leave that lifestyle behind.

• When my husband was really sick, and I thought he was on his death bed, *Highland House* caused a 12-hour delay in her (*daughter*) being able to see him. It was also the anniversary of her bairn's death. I admit she has done wrong, but I don't think that the punishment should pervade all parts of her life; this treatment was inhuman. A worker said to her, "You and your mother can complain all you want, but nothing will be changed". They are supposed to take decisions together, so she is involved in the process. This is not giving her a choice. She is judged on her past all the time, and all parts of her life are treated the same. There is a general opinion that it pervades everything that they (*recovering substance misusers*) do and that brush tarnishes everything. They are talked to so patronisingly and dictated to, and they are afraid to speak up. I understand a lack of money, but care and compassion costs nothing.

## REPORT ON LOCAL SERVICE PROVISION

	<ul style="list-style-type: none"> <li>• After she (<i>daughter</i>) had been sentenced to assault, they stopped her collecting from <i>Asda</i> on account of the fact that she might attack the girl again - who are they to conclude such a thing, she has served her time! They are being judge and jury; it was not in her court order. It's ridiculous as you can go in for other bits, just not your prescription.</li> <li>• Some of the workers at <i>Highland House</i> are great, especially those who have lived experiences.</li> <li>• The paid Carer's support worker at <i>Highland House</i> doesn't have the powers to do anything and they are not there 24-7. You need someone to call when you are in a crisis.</li> <li>• <i>Conversation Café</i> is good, there is one you can attend every day of the week now. However, they are all on at different times and locations, and it's hard enough to keep up with that when you are not using.</li> <li>• At <i>SMART Recovery</i> you have to tell your story over and over again in a group setting. It's not the right thing for everyone.</li> <li>• It is the same whenever they (<i>recovering substance misusers</i>) travel somewhere. There is such a delay in getting the methadone. It's very limiting. It's the same when leaving prison, getting methadone should be 'stress-free'. There is a 4-week delay for methadone, when it should be the same day. And they have to prove that they are still using, keeping records in a diary. When they make a request to put the methadone up, they ask: "Are you still using?" If not, then they won't help.</li> <li>• They have to keep going over their story with the <i>workers</i>, "Would you like to tell me your story, I haven't had time to read your notes?" It is a new person who hasn't read the notes, they are not engaging properly with them.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• There is no after care, no therapy or talking things through – they (<i>recovering substance misusers</i>) are pretty much left to their own devices. There could be something in their care plan – an hour a week, something to get them into the community. They say, "They have been seen doing something for themselves" – they can be given guidance for this.</li> <li>• At EPICS, we are joining in with the legal high group. More people have come to us about legal highs - it's already a big problem, and there is nothing in place to support people- it's like it doesn't exist.</li> <li>• We have also received support from: Family/Partner, Conversation Cafe, IAPK, NHS Perth Royal Infirmary, EPICS, Community Group, Police Scotland, Crown Office, PKC Highland House, NHS Tayside Substance Misuse Service, PKC Alcohol &amp; Drug Partnership, PKC SMART Recovery, Chemists. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 25: Challenges Employment, Health, PD</b>	
<p>I am a female, aged 46. I have lived within P&amp;K for 31 years. I have recently been diagnosed with <a href="#">multiple sclerosis</a> (MS) and suffered a family bereavement also at this time. I am now able to enjoy the journey I am on, assisting others with worse disabilities.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• It was very impersonal. I was given blood tests, but not with an explanation to take away. I had to complete a 'fatigue calendar', which was not helpful for me at that time (although it may have been for the <i>NHS</i>). They are trying to make you fit symptoms and it's too general. It affects different people differently.</li> <li>• The way the <i>Neurologist</i> spoke to me and the language he used was too high-flouting.</li> <li>• I was given an <i>OT</i> assessment after 9 months, but I could have done with this in the first 3 months. So it's not especially helpful.</li> <li>• When I burst into tears in front of my <i>Physiotherapist</i> - that's when I was signposted to a <i>neurologist</i>.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• More practical help would be welcome.</li> <li>• I have also received support from: Positive Choices, NHS GP, Family/Partner, Mindspace, IAPK, NHS Physiotherapist, NHS Occupational Therapist, NHS Neurologist, NHS MS Nurse, Community Group. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 26: Challenges PD, Language</b>	
<p>Twenty-two members of lip-reading classes in Blairgowrie and Perth (<i>students</i>), and their tutor (<i>tutor</i>). We all suffer from some form of hearing impairment, although ranging in ages and in the level of hearing loss and its cause. We have received very little support and signposting up until joining this group. It's a hidden disability, and there needs to be more public awareness about it. We used to struggle to speak up about the fact that we were experiencing issues with our hearing. It is a confidence issue, especially at the beginning. Staff do not reach out to meet you when you are needing support.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• <i>NHS Audiology</i> didn't refer us to other services, the appointments are short and there is no support with understanding the diagnosis. There are no posters up for other services. You are given your hearing aids and that's it. (<i>students</i>)</li> <li>• I was told that in 3 years my hearing aids would be changed, but there is no follow-up. There can be a lot of deterioration in that time. (<i>students</i>)</li> <li>• I am in the process of getting my cones changed to the older version moulds. It has taken 2 years for them to agree to this. Now they are changing them back for everybody. (<i>students</i>)</li> <li>• A quarter of people suffer from hearing loss, and their first port of call is their <i>GP</i>. They get a referral to <i>Audiology</i>, but then nothing else. There is much more to living with a hearing loss than just a hearing aid. (<i>tutor</i>)</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• There is too much emphasis on IT, it comes from the government, but so many older people don't want to learn IT skills and so they will just be missing out. (<i>students</i>)</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• We are often contacted by staff by the telephone, not acknowledging that this is difficult for us due to our hearing loss. (<i>students</i>)</li> <li>• You need help with how to clean them. It's a very tricky process, it's very delicate. You should get a package and an explanation on how to clean it - you are not shown. (<i>students</i>)</li> <li>• We would like access to work. To be able to enjoy and participate. There needs to be greater knowledge in the workplace. (<i>students</i>)</li> <li>• I am the only qualified lip-reading tutor in P&amp;K and I have to turn people away. The funding is soon stopping. It would be good if there were classes for relatives too. (<i>tutor</i>)</li> <li>• We have also received support from: NHS GP, Family/Partner, Vision PK, IAPK, Tayside Deaf Hub, Myself, Community Group, Scottish Fire &amp; Rescue, NHS Audiology, North East Sensory Services, Deaf Action, Lip-Reading Group, Action on Hearing Loss, Amplifon. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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**Study 27: Challenges Abuse, Criminal Justice, Education, Financial, Health, Housing, MH**

I am a male, aged 25. I have lived within P&K for 13 years. I have suffered from [obsessive-compulsive disorder](#) (OCD) since the age of 15 and I also deal with anxiety and depression, which can make me aggressive. My mum left and I faced threats of eviction from my home. I wasn't receiving benefits and was thrown out into homeless accommodation with no consideration for my MH and my vulnerability. I am not comfortable with the numbers of different support workers I can be in contact with, and currently I don't welcome any support. I don't realise when I am unwell, it just seems like I am me.

<b>NHS</b>	<ul style="list-style-type: none"> <li>• A <i>CPN</i> would pay me house visits. She taught me some breathing exercises to help with my MH. She didn't persist with her support - she didn't show enough patience.</li> <li>• At a <i>Psychologist</i> appointment, I was showing some erratic behaviour and it turned out that I hadn't been taking my medication - I hadn't realised. They stopped the sessions after I pushed for it. They should have persevered, instead they acted defensively. They were pushing the expectation for me to get better. I was given the wrong exercises, they were not appropriate as they were for rehabilitation. I don't know why there was this confusion as the workers are in the same service. These kinds of mistakes have a big effect on my MH, maybe they don't realise.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• The <i>housing</i> staff are always changing and I felt like I was being passed about. It's like they forget that I have different communication needs and punish me for not communicating in the 'normal' way, rather than changing the way that they interact with me. When I am in the throes of my OCD and I am cleaning, I don't answer the phone.</li> <li>• I was moving around friend's houses, sofa-surfing and getting some company. Because I wasn't in the property, <i>housing</i> emptied it. They said I hadn't been reading the letters for 6 months, but they never made any phone calls and they hadn't contacted my advocate despite her having contacted them. I had two meetings with a <i>housing officer</i> and I really had to fight to get my property back. All my stuff had been removed and I was concerned about stuff having been damaged, but they were not addressing my concerns. Lots of my belongings were damaged or missing. The suggestion was that I was up to no good, and living somewhere else by choice.</li> <li>• It took such a long time for <i>housing</i> to replace the boiler, even though it was deemed dangerous. It had such an impact on my MH, I was afraid and I felt trapped. They kept shifting the responsibility.</li> <li>• They sent me a strongly worded letter - 'RENT ARREARS!!', but it was only for garden maintenance and it was only a couple of quid. At one point there were two letters a day.</li> </ul>

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<b>Other</b>	<ul style="list-style-type: none"><li>• It's like you're coming up against a blank space. There shouldn't be so much support, like in child services - all the services should be joined together. I used to get a lot of support from many different services, but I have cut ties as there were too many of them. In the adult services, no-one has a clue. The number of people is overwhelming and demanding.</li><li>• I need help with stuff like cooking, shopping and getting outside for things. I need a network of care and help to establish connections. Sometimes I won't leave the house for up to 3 weeks.</li><li>• Services will quickly lose contact or cut off the communication - you are expected to chase them. They don't help you when you no longer 'meet their requirements'. It takes me a long time to build a relationship with a member of staff and when I get passed on, they don't keep in touch. People don't take responsibility; they help you only within their remit. I struggle to meet new men, especially, but there was an expectation that I could just switch worker - but it takes me time. If I miss an appointment, they should give me a phone call.</li><li>• There should be something to recognise the person they are contacting. They need to know who they are talking to.</li><li>• I need emergency support.</li><li>• I have also received support from: NHS GP, Friends, Family/Partner, IAPK, PKC Social, PKC Housing, Crown Office, NHS Community MH Team, NHS Central Healthcare Team, NHS Psychiatrist, NHS Psychologist, SAMH. [See: <a href="#">Additional Feedback</a>]</li></ul>
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Study 28: Challenges Abuse, Children, Health, Housing, MH, PD	
<p>A 22 year-old female, who has lived within P&amp;K her whole life, and her mother. I (<i>daughter</i>) experienced swelling on the brain as a child and died, only to be brought back to life and to then relearn how to walk again aged 6. I now live alone and the first and only support for I have received for myself now comes from IAPK. I (<i>mother</i>) have many different physical conditions – <a href="#">myalgic encephalomyelitis</a> (ME), <a href="#">fibromyalgia</a>, <a href="#">spondylitis</a>, <a href="#">diabetes</a>. It was difficult to raise a child with a brain injury alongside 4 other children. I have recently sought psychological help. When I (<i>daughter</i>) was growing up, my mum had to figure it out herself. They never helped make it easier for us. There were no ramps put in place to get the wheelchair into and out of the house.</p>	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• My previous <i>GP</i> never helped, he gave me the wrong medication and he would say that it was only one thing per appointment. He didn't help me with my anger issues. I want someone honest, who cares about how I have issues with my anger - I can't calm down. (<i>daughter</i>)</li> <li>• I was seen by a <i>Psychiatrist</i> once. He sent me away, with no follow up to assess the problem. There is just the assumption that I am getting support elsewhere. (<i>mother</i>)</li> <li>• I have not been allowed to see a <i>Psychologist</i>. (<i>mother</i>)</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• My stress at the moment is my <i>housing</i> - my neighbours give me the fear. I struggle to wake up in the mornings and I don't go out - I have no friends, they have all left. One woman made a mistake about my address which meant I had to start my application from scratch. She called me a liar. The place I am in now is freezing, and I keep falling on the stairs. It is stressing me to the max. Issues with heating and work needing done in the kitchen just take ages. (<i>daughter</i>)</li> <li>• I moved from one <i>PKC</i> property to another, and a lot of my belongings were lost, even though I was assured by <i>housing</i> they would be moved to the new house. There was no help given to me to put the mirror up and plumb the washing machines and those kinds of jobs. (<i>mother</i>)</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• There was no support for children with brain injuries in Perth, and I had to travel to Glasgow. (<i>daughter</i>)</li> <li>• We have also received support from: CATH, NHS GP, Family/Partner, Headway, PKC Housing, NHS Psychiatrist, NHS Psychologist, Child Brain Injury Trust, IAPK, PKC Social. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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Study 29: Challenges Health, MH	
<p>I am a male, aged 53. I have lived within P&amp;K for 15 years. Fifteen years ago I was admitted to Murray Royal hospital and was given the diagnosis of <a href="#">bipolar disorder</a>. I received a lot of care and was well supported; however, no-one supports me now with my MH. It is difficult to know when you are unwell, you still feel like yourself.</p>	
NHS	<ul style="list-style-type: none"> <li>• One day the <i>Community Nurse</i> just stopped coming. It wasn't like they tapered the ending of the support; it just went straight to nothing.</li> <li>• I see my <i>GP/Nurse</i> every 3 months for blood tests and to check on my <a href="#">diabetes</a>. The support I get for my physical health is good.</li> <li>• At <i>PRI</i>, they are not doing anything for MH. And the staff are changing all the time, I am not keen on going there when I need help.</li> <li>• My <i>Psychiatrist</i> had good intentions, but she wanted to keep me in <i>Murray Royal</i> for longer than was necessary.</li> </ul>
PKC	<ul style="list-style-type: none"> <li>• I had a <i>Housing Officer</i>, but once my benefits were sorted they closed the file. I still needed them - I needed help to get outside, appointments and food supplies. But nobody was there to help.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• I need practical support and help with benefits, it's very stressful and uncertain for a lot of people and they don't know where to turn for support.</li> <li>• I am very lonely and need some company. Often I won't leave the house for days. It would be nice to have someone to talk to.</li> <li>• At the time of crisis with my illness, I received a lot of involvement from services, but no-one is supporting me with my MH now and will likely only do so when another crisis arises.</li> <li>• Dundee and Glasgow have outlawed legal highs, but Perth hasn't. I've seen some horror stories, especially with kids so young.</li> <li>• I have also received support from: CAB, NHS GP, Friends, IAPK, Job Centre, DWP, Welfare Rights, NHS Community MH Team, NHS Community Nurse, NHS Murray Royal, NHS Perth Royal Infirmary, NHS Psychiatrist. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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<b>Study 30: Challenges Health, Language, PD</b>	
Two females aged 68 and 66. One has lived within P&K her whole life, the other for 34 years. We are both deaf.	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• <i>Social work for deaf</i> never listen to us and think they know best. They are controlling and patronising and old-fashioned.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• Other services are not deaf aware and can't communicate effectively with us.</li> <li>• We have also received support from: Tayside Deaf Hub, Support Worker. [See: <a href="#">Additional Feedback</a>]</li> </ul>

<b>Study 31: Challenges Addiction, Children, Employment, Health, MH</b>	
I am a female, aged 54. I have lived within P&K for 30 years. I have lived with what I suspect is <a href="#">Asperger syndrome</a> for many years. I also deal with anxiety and depression. No-one tells you, It's ok to be different. It would be better for them to help you to accept where you are and to learn how to deal with it. It is not as accepted to be different in Scotland.	
<b>NHS</b>	<ul style="list-style-type: none"> <li>• I am frustrated by the <i>psychological</i> help I have been offered, as it has only been CBT and I don't believe I need to learn how to 'think correctly' – I need help to learn how to work with who I am, how to live with my acute social phobia, rather than trying to change my feelings towards socialising to fit what society thinks is the 'correct' way of being – this just makes it worse when I go out. In CBT, I have been told that it is because I am not trying hard enough.</li> <li>• I haven't known my <i>GP</i> very long. They don't know what to do either. When I collapsed, they assumed depression/anxiety but it was a heart condition. They don't listen, and there is an assumption without a re-evaluation of the situation</li> </ul>
<b>PKC</b>	<ul style="list-style-type: none"> <li>• Nothing was raised.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• There needs to be greater awareness of adults living with <a href="#">Asperger syndrome</a>. You are not likely to be diagnosed with the condition as an adult, the support for a teenager is much better. It hasn't been easy to find out what support is available.</li> <li>• I have also received support from: NHS GP, Friends, Family/Partner, NHS Psychiatrist, SAMH. [See: <a href="#">Additional Feedback</a>]</li> </ul>

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### Study 32: Partners

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- Consolidated experiences from 19 IAPK partners who were asked: “**How did IA help you?**”
- **47%** found IA support *extremely helpful*, **37%** found IA support *very helpful*.
- See: [study 3](#), [study 7](#), [study 8](#), [study 9](#), [study 10](#), [study 11](#), [study 12](#), [study 13](#), [study 14](#), [study 15](#), [study 16](#), [study 18](#), [study 27](#), and [study 28](#).

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### Outcome 1: Improving health & wellbeing

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- **68%** said IA support improved their *health*.
- “They listened and understood and saw my perspective. They stand beside you and let you be heard. You have no idea how powerful that is.” (3)
- “Someone listening to me. Being with me in and out of meetings. Knowing someone cares to help me with my problems I worry about to do with me and my daughter.” (9)
- “They gave me support through a difficult time. They are knowledgeable.” (7)
- “Someone who listens to you. No judgement. My advocate has helped me feel more confident when speaking with other services and helps to reduce my anxiety.” (15)
- “My advocate is a very nice, kind lady. She listened to me. She has been very helpful and patient and has helped me with the ESA form.” (14)
- “For nine years my advocate and the staff have been 100% supportive with every concern and mental health issue. They have been attentive and very kind at all times.” (18)
- “Even if she doesn't have time to speak on the phone, she is always working away on something for me.” (28)

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### Outcome 2: Facilitating independent living

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- **53%** said IA support improved their *freedom*.
- “They helped and are helping me to resolve major issues with my flat working with PKC and building standards.” (3)
- “My advocate helped me to get this house; she says stuff I wouldn't be able to say.” (27)
- “My advocate helped me to move house, I am thankful that she got me away from my mum.” (28)

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### Outcome 3: Facilitating positive experience of services

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- “They helped me to communicate effectively in meetings - to know when to speak and importantly

when not to speak. It was a very emotional experience for me and it was challenging not to get angry.” (8)

- “I was treated with much more respect after IAPK became involved. In meetings, I used to be ignored but now social work acknowledges me and listens to me more.” (9)
- “PKC building standards are now listening to me and hopefully being more pro-active.” (3)
- “Felt I was listened to and recognised.” (7)
- “IAPK has helped me and continues to help me more than words can say. When at meetings alone I was treated in a disgusting ‘not there’ way. IA being there I am treated with respect.” (9)
- “They got the ball moving with surgery and gave me good support in communicating with my GP. They helped me to explore other paths I could go down when I was stuck.” (10)
- “My advocate was a great help to me trying to find avenues to explore and try and get me some kind of justice from the predicament I find myself in at this time. I am a bit of a dinosaur, but she was able to use her internet access to send and receive answers to some of the questions I raised. She was also a good listener and would listen to my ramblings; she also seemed a genuine and caring person and always had time for me.” (13)
- “IA helped me to know what type of help and support is available even on a legal basis and assisted me going to various meetings.” (16)
- “She helped me a lot. She told me about Arc Brae. She helped me to move here. She picked me up and talked to me. She helped me with a lot of things. Meetings and living at the place. I enjoy the group meetings - I like to hear what's going on.” (case study not included)
- “She has helped me with the legal stuff, acting like a solicitor and finding information out.” (13)

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### **Outcome 4: Improving quality of life**

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- **63%** said IA support improved their *happiness*.
- “They listen and help me with any issues coming in. They always speak up for you; she knows how to communicate with me.” (7)
- “They listen more to my advocate. I don't know all these fancy words and what to do and say. She's the best help I've ever had - the first help for me. I don't know where I'd be without my advocate - she's top notch!” (28)

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### **Outcome 6: Providing Carer's support**

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- “They were great and provided with support at the Case Conferences and in-between. I value the trust and the friendly attitude of all people who listened to my story. IAPK did their best in the circumstances and I'll never forget that help. Thank goodness for their existence.” (unpaid carer; 8)
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**Outcome 7: Keeping safe from harm**

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- **53%** said IA support improved their *safety*.
- “Helped me with my care package, and helped get money for PA's and work out what was needed. I know these services know me and have my best interests in mind and can point me in the right direction for support.” (7)
- “They helped with a contract I had taken out. I would have been charged a large amount of money and my advocate helped by speaking to the company and explaining my condition and that they should not have signed this contract with me as a result of my mental health – she helped me to get out of paying it.” (12)

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**Outcome 8: Improving care provision**

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- “Whenever they were involved, social services picked up their act. Social service and Dementia Services didn't get it all their own way. The feedback came through more frequently.” (8)
  - “They have supported me with complaints re nursing staff and other staff involved in care. They have given me access to a mental health solicitor. They helped contact all persons concerned and resolve issues, or take them as far as possible.” (18)
-

### Study 33: Staff

- Consolidated experiences from 9 staff with a working relationship with IAPK were asked about their perceptions of: **“The role of IA.”**
- Staff interviewed included: Review Officer (Children’s Panel), Solicitor (MH and AWI), Solicitor (Education), Community Staff Nurse (Older Person’s MH), MH Nurse (Prison), Solicitor (MH) & MHTS Convenor, Social Worker & MHO, Family Contact Officer (Prison), Subject Leader (ASN).

#### Outcome 1: Improving health & wellbeing

- “Partners feel valued; they are more involved in the process, more engaged in the process.”
- “IA has a wider remit than I do, than the teachers do. The advocate couldn't persuade or dissuade them, but it did help. It was an opportunity to talk through it - to reduce the anxiety. To move them along a little bit.”
- “It’s about finding that balance, and sometimes IA helps to bring a level of balance to partners because they will have an opportunity to have that conversation with you guys if that’s a burning thing they have to get off their chest to then be able to move forward.”
- “It’s the little things – the things we don’t have time to manage in here because these guys, the majority are stressed. They don’t have money always to phone their solicitor, they can’t get through to them but the advocate does it, he gets through to them and then feeds back to them and the advocate uses email and everything in here; he uses that and then informs the partner and takes away that stress which makes our job easier because if partners are getting stressed out about why their solicitor has not been in contact, that causes massive problems but the advocate just emails.”
- “The advocate goes way beyond what I would imagine normal roles are. They will try their best to get that partner’s problems sorted for them – which is massive in here. Things which may seem insignificant to us.”
- “I see that the partner becomes chattier, more confident. The help is not just 'localised' to the issue - the partner becomes calmer and more able to concentrate - it removes that big worry in the background. I've seen this with a number of them - it takes the weight off their shoulders, they are happier.”

#### Outcome 3: Facilitating positive experience of services

- “I welcome IA involvement. It helps the partner as often they are in combat with social work and the advocate is someone on their side.”

## REPORT ON LOCAL SERVICE PROVISION

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- “If you have a situation with a partner that’s actually bolstered by the fact that they have someone sitting with them and they are happy to speak up, then often the advocate will say - I don’t have anything to add, he has said it all. But it’s useful having them there, some partners won’t have a good memory, they will have a chat with the advocate beforehand and have a list of things they want to say, but it can be stressful sitting through a tribunal, as you go through that it can be easy to forget specific points you want to raise and it’s good that an advocate has a note there.”
- “We are supporting the partner and the advocate is extending that support by being another staff that can dedicate time. And they can go out and make contact with outside agencies – the advocate does a lot of contact with solicitors and things like that which is stuff that we just would not have the time to do or be able to do and they can advocate on their behalf, from a legal perspective.”
- “To make sure they are being listened to and included in the process.”
- “One partner has problems articulating himself in certain situations – I think it’s a problem with the health services wherever he’s been out in the community, so an advocate got involved with him and now he feels more comfortable with his advocate present in any health situation which is good.”
- “It means that someone else might be explaining it from a different point of view, not a different point of view, it’s a different influence, because a lot of partners think that as a social worker you represent the establishment and everything else, and I think it’s important that partners get the same sort of explanation of what the order is about and why we are asking for it into language that they will perhaps be more readily to understand. And accept that is from somebody independent.”
- “I think you are there to be a voice for someone in meetings, even if it’s a CPA meeting/guardianship application meeting. So I think you are there to support partners at meetings so that their voice is heard. And I think that’s important, because if you are faced with a panel of social workers, Dr, senior social workers, it can be very intimidating. They may see it as them versus the rest of the world, and the staff that are making decisions. So I think it’s good.”
- “They will meet the parent before a meeting and go to the meeting with them. Helping them to understand reports by going through them with them and bringing clarity. They will steer the person towards the appropriate staff member to contact.”
- “And those kinds of meetings, having somebody there with you who isn’t your mum telling you - you just have to do what the doctors are telling you - or isn't somebody else saying well I'm telling you this is what's happening. Somebody who is genuinely on their side, supporting them, metaphorically holding their hand through the process. Not feeling swamped by a case conference with 12 staff, who all 'know best'. And then between them, arguing it out, while they're sat there at the end of the table going, "Huh?!" Having an advocate there to say, "We are here", or sat with them saying "It's alright, I am with you". It must make a phenomenal difference, it just must. And it’s not always possible for staff like me to be in that position.”
- “It’s an extra support network, especially for partners with MH problems who can be very

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distrusting of anything associated with the NHS, partners that have been detained think that everything is a bit of a conspiracy and it's just good to know that it's someone independent that has nothing to do with the health board.”

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### **Outcome 4: Improving quality of life**

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- “I have seen that because partners engage better in the process, their understanding and knowledge of the process improves their thought processes.”
- “They support the person to be involved in the decision-making process.”
- “Better outcomes involve negotiation and support and I think that IA helps achieve that and, therefore, in the long run, although others may say it's an expensive service, I think it's a small price to pay for the benefit that would come from it.”
- “Advocates are able to attend at meetings that partners would normally be terrified of attending. I think that they are able to support them before those meetings so that they are empowered to express a view, either directly through their advocate or for themselves - feeling supported by their advocate. Which then, in my view, has the potential to improve care plans for partners, and if somebody is engaged in that process that is about them, the chances of success of that plan improve exponentially. We can all have lots of great ideas of what we would like to do in relation to other people and their lives and we think that that is all terribly fabulous, but if you don't engage the person in that process then that all disappears like water down the plughole, because they haven't been involved in the process because it's human nature to say "You're telling me what to do" and "Who are you to tell me what to do", even if they are subject to detention.”
- “It helps because it supports partners. It supports them to resolve issues.”

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### **Outcome 5: Reducing health inequalities**

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- “It facilitates a stronger voice.”
- “Sometimes because of their MH they find it difficult to get their point across – that's why I would refer them because mentally they were struggling and they would need a voice for them at that time.”

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### **Outcome 8: Improving care provision**

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- “The impact it has on the other staff - as parents they are taken more seriously, their concerns are taken more seriously. It has an impact on how other staff interact.”
- “We need to get better at individualising care and listening to the partners – they need to be at the centre – I'm all for that – you have to work in partnership – there's no point in you putting a plan in place because it's them that have to do it.”

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## Additional Feedback

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## REPORT ON LOCAL SERVICE PROVISION

### **Alzheimer's Scotland** [See: [Additional Feedback Table of Contents](#)]

- I called their helpline when my wife was initially diagnosed. They sent me a whole bunch of leaflets and information in the post; it was too much to take in. (17)

### **Action on Hearing Loss**

- They took my hearing aid, and cleaned it and replaced the batteries; you don't get help with this anywhere else. However, this service is only available once a month, it's not enough. (26)
- They did an open day at Kings Cross, it was very helpful. They showed you the different pieces of kit available. (26)

### **Amplifon**

- This is a private scheme. I hadn't thought of going anywhere else. It's a really good service; I have never had any problems. It's great; they give you a regular 6-monthly test. (26)

### **Balhouses Care Group** [See: [Additional Feedback Table of Contents](#)]

- The residents enjoy living at *The Grange* and said the staff are good - they are helpful and nice and they listen. The food is also good, and they enjoy taking part in helping out with chores. The residency has an activity room, drama and a barber who visits. They often take day trips out, which they really enjoy. One resident loves to create art and the staff have put some of his work up on the walls in the building which gives him a great sense of pride. They like living in the country and taking walks outside (case study not included).

### **Barnardos**

- I have used this service for moving furniture. They are the only place in town that will deliver it to where you need it in the house. (4)

### **Centre for Inclusive Living P&K (CILPK)**

- They always speak up for you. I can ask them for advice; they are knowledgeable. It is good to know that I have this support to turn to. When I have had questions or issues this service has helped to ease my mind and worries and to solve the issue. I had issues to report, knew they'd be resolved. I liked that I would have a voice and be part of decision making. I know this service knows me and has my best interests in mind and can point me in the right direction for support (7).
- They have offered me lots of support (case study not included).

### **Citizen's Advice Bureau (CAB)** [See: [Additional Feedback Table of Contents](#)]

## REPORT ON LOCAL SERVICE PROVISION

- There was one man there who was really rude. He said, 'why do you bother reapplying? Why are you applying anyway?' (23)
- They have offered advice, and helped me to fill out forms and keep a record of the dates that they were sent as confirmation. It helps a lot with my panicking. They have also given me help with the benefits and when I had to attend the district court - the legal side of things. They help with phone calls, as you can use their phones free of charge - mobile phoning costs a lot! (29)

### **Chemists**

- This is a helpful service as they deliver medicine to your home. (2)
- They are helpful, you can phone them and they will sort out your prescription. (19)
- People get served before those collecting methadone in the chemist - they are sent to the back of the line. She will often wait for 40 minutes. (24)

### **Chest, Heart & Stroke Scotland (CHSS)**

- I was frequently recommended this group by the NHS. I did attend, but it had too many older people. (4)

### **Child Brain Injury Trust** [See: [Additional Feedback Table of Contents](#)]

- When I was younger, they used to be very helpful and send me lots of stuff. They would come and explain the effects of my brain injury to staff that worked with me. Now, they invite me to stuff, but I am shy around new people so I prefer not to go. (28)

### **Church**

- I made some good friends at church, they welcomed me. (23)

### **Churches Action for the Homeless (CATH)**

- The Day Centre has been excellent (*partners' comments*) (6)
- The staff interviewed commented how funding is cut year on year, yet they are picking up the work that no-one else is doing - no-one else is supporting these guys. And the support does not just end the moment they find a place to live, as the council would like to think. The guys keep coming back for help. (6)
- They helped me to get a grant to pay for my electric bill. (28)

### **Cleaner** [See: [Additional Feedback Table of Contents](#)]

- A lady comes over once a week to clean, which is something I wouldn't be able to do myself. (1)

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### Community Group

- The local *Parkinson's group* offered little support, and my husband didn't want to go (1).
- They bring in speakers and discuss legislation, I go once a month when possible. It's a tailored support group for *Carers of those with MH issues*. The community Police office told me about the group. (10)
- I have attended a *creative writing group* in the past. There are times when I like to write and would one day like to write a story. When I first started attending, I wouldn't speak at all for weeks. I enjoy it now, one day it just started to flow. (13)
- I attend a church group called *The Well*. It is good to talk to other people who have lived similar experiences. (16)
- I go weekly to the *Carers group in Crieff*, but it shuts down in winter which is often when you need it the most. It's a good place to find out information, especially about sources of support. His Carers told me about it. (19)
- I try and go once a week, it's more of a social thing. I value having someone to talk to who has the same lived experience (*Perth Carer's café*). (22)
- There is a problem with talking groups [*recovery groups*] and that is going over your story again, the group is made up of the same people you are trying to get away from. (24)
- I attended a *MS support group* in Crieff, but there were people there with much worse symptoms than me and I didn't go back - I didn't identify with them and it was too upsetting. (25)
- I go to a *stroke group* once a week; I find it enjoyable. (case study not included)
- I don't go to any support groups. Just because you are all suffering from the same thing, you are also all different. And where would you meet them, as you are all socially phobic! (31)

### Crossroads

- They take my husband out to socialise one afternoon a week. This afternoon can be used to collect a weekly food shop and also gives him the opportunity to get out of the house. Respite vouchers are accepted by Crossroads. This is so helpful for me. (1)

### Crown Office [See: [Additional Feedback Table of Contents](#)]

- The court is not a place to be when you are already struggling with your MH. (3)
- I am in need of an interpreter in court, and cannot afford one. Just because I have passed my Life in the UK test does not mean I can defend myself fairly in court. (14)
- I had a *probation worker* who had concerns for me being out in the community, but didn't want to raise alarms. People won't take responsibility. (27)

## REPORT ON LOCAL SERVICE PROVISION

### **Deaf Action**

- They did an open day at Kings Cross, it was very helpful. They showed you the different pieces of kit available. (26)

### **Driver & Vehicle Licencing Agency (DVLA)**

- Every single person she has met in hospital has had their confidence severely knocked at one time or other in their lives. They carry around the belief that they are useless and incompetent, and they really believe it. There must be hope, you get this removal of freedom, like with the DVLA taking away your licence, and it's like living life in a cage. (18)

### **Department for Work & Pensions (DWP) [See: [Additional Feedback Table of Contents](#)]**

- As a Polish immigrant, my work fell through and I am now sleeping in a tent. There is no financial support for me due to my having only recently arrived here. (6)
- Attendance allowance cancels out Carer's allowance! One of the ladies from the day centre explained the financial situation to me, I wasn't getting the right amount but I didn't realise. (17)
- I was refused DLA 3 times; people came to my home to assess me and had me walking a set distance whilst timing me. They are suspicious of you first. There is one man on my street who I know is faking it, but I have to put up with so much to prove that my disability is real. It makes me not want to bother, but my friends push me to do it. I had an assessment 3 years ago to decide if I was eligible for my disability payments. They stuck pins in my legs and I came home covered in blood. There were several people in the room, and the Dr was a man and I was very uncomfortable being undressed in front of him. I don't think any man apart from my husband should see me like this. I was treated like I have done wrong. I felt so small, like I am like a criminal. I am not comfortable, but I don't have a choice. Yes, they will help me, but this torture first before they would help me. In order to be given access to benefit payments I was criminalised by the DWP and I felt attacked. It makes you scared to claim benefits - they leave you feeling like a criminal. Smaller than an ant (23).
- The communication has no context and is not clear. They notify you of a change in benefits but withhold a lot of information, which leaves you guessing and feeling uncertain. Maybe to remind you who is in charge of the money. (29)

### **Dundee Carer's Centre (DCC)**

- They showed me trust, and had friendly attitudes, when they listened to my story. They did their best in the circumstances and I'll never forget that help. Thank goodness for their existence. They were wonderful, and understood what I was experiencing. The counselling was tailored to the experience of

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a Carer. Unfortunately, there is no equivalent service provided in Perth. (8)

### **Encouraging Positive Involvement Carers Support (EPICS)**

•This group was set up to support people who care for someone who is abusing substances. We don't turn anyone away, and have seen a big increase in people caring for people who have used legal highs. Usually, it is just to talk to moan and get things off your chest. Our numbers are low - people won't admit that they have a problem in the family. I know a lot of the wealthy families have problems, which they would never admit. It's so hard to do it on your own. (24)

### **Family/Partner** [See: [Additional Feedback Table of Contents](#)]

- A very common source of support. Especially emotional support, conversation. (2)
- My three sons have been a big support - they have given up their lives for me. Their support has been amazing. When my son has a kid - where do you turn? You feel like an imposition on the family. (4)
- They know how to communicate and understand my views as I use an AAC device and Talking Mats. (7)
- My daughter was a power of strength. (8)
- Originally it was just me and my mum, but now I have a network of support. (11)
- I rarely see them; they live so far away. (13)
- My wife, despite having health problems herself, supports me with day-to-day life. I wouldn't be able to manage without her support. (20)
- Now my children are older, they provide me with support. I raised my two children with a disability, and it was really hard. They were a big challenge for me at this time. It's different now. (23)
- My husband and I have different opinions on how to care for our son, it is often the case that there is division within the family and that can be very hard when it is the only place you are getting support. (24)

### **Friends**

- For the times when I have overnight appointments, a friend will come to look after my husband. I have some friends in the village but the neighbourhood is not friendly really. I haven't spoken to our neighbours. Many friends don't know how to respond to you and so many of my friends have 'disappeared'. It can feel like you are begging when you ask for help. (1)
- The neighbours like to keep independent. People who have similar experiences come out of the closet when you tell them about your situation. (10)
- I have a family friend who drives me everywhere. I cannot go places on my own for fear. This

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person has been such a support for me for the last 2 years. (14)

- The neighbours are friendly just to say hello, although they have offered support. (19)
- When you get the diagnosis, people seem to disappear. You are left alone. (21)
- My friends will let me know if I start acting off again, you can't see it in yourself - it's just you, and you are used to it. They get me out the house sometimes. (29)

### Headway

- I was recommended this by the NHS, but there were too many older people and it was not doing me any good. (4)
- They wouldn't offer support for young people, and so I had to travel to Glasgow to get the support of a different service. (28)

### Legal Aid

- This has been denied to me on account of my not having taken out insurance against potential MH issues, which I did not have prior to my 'breakdown'. (13)
- I have been denied their support countless times, for 6 years now. They have written letters that are very accusatory. They have changed me from the victim into the criminal. (14)

### Lip-Reading Class [See: [Additional Feedback Table of Contents](#)]

- The *lip-reading group* told us about gadgets available; if we didn't come to this class, we wouldn't know about them. To be a member of a class like this helps tremendously because you can share and compare information. I didn't know about any of the support until I came to this class, it linked it all together for me. When I first saw it advertised, I thought 'I'll never be able to do that'. It was advertised in Courier, libraries, shops. It has given me confidence in conversation, and to have the confidence to say I don't hear well. There is not enough funding for these lip-reading class from PKC adult education, for now the NHS are covering costs - but come June, there will be no classes left. (26)

### Member of Parliament (MP)

- I wrote to my MP detailing my story, but never received a reply. If the case is not of current relevance, then they are not interested in you. (13)
- The Life in the UK test is very easy. My abusive husband contacted his MP to report me as not being who I said I was. I received a letter from this MP accusing me of this falsehood. It is a defamation allegation. I am treated like a criminal. (14)

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### **Mindspace**

- They act as a catalyst for recovery, they are enabling. They help you to take control. Especially helpful are the group discussions. Peer-led group therapy. It is different learning mindfulness in a group to with a therapist - I was more honest about my experience and sharing ideas. It's also better, as with a therapist they are in a position of power. (3)
- This was the best thing I have ever done, they identified the problem. (4)
- I had a brilliant experience here. There was no judgement and it is individualised. There is a variety of people with MH issues and there is open communication about it, the group is very supportive. The people who work there are very enthusiastic. (25)

### **Minority Communities Hub (MEAD) [See: [Additional Feedback Table of Contents](#)]**

- One member of staff was very supportive but they left. They used to support me; I got on really well with one of their workers. She understood me and took time to listen. I won't use their service anymore, as one member of staff once spoke with other members of the community about my personal experience. I cannot forgive her for this, and will not trust the service again. They have said that they are too busy to help. (14)

### **North East Sensory Services (NESS)**

- They have provided us with 5 pieces of equipment each. (26)

### **P&K Young Stroke Group**

- I left, as I didn't like the direction it was moving in and the way it was managed. They wanted to just be doing the same thing every week, but you want to be moving forward. I created this group, because I wanted something different from the services already on offer. I wanted to get out and be doing stuff. The group still runs. (4)

### **P&K Association of Voluntary Service (PKAVS) [See: [Additional Feedback Table of Contents](#)]**

- I spoke to them to help me find a volunteering opportunity. They pointed me in the direction of stuff that didn't suit me/means nothing. (4)
- I have volunteered at the *day centre* doing arts and crafts. One day, I had run out of battery on my electric scooter and asked to charge it. The maintenance man was at reception, and he said 'we are not going to help you'. I feel safe there, it's my group. He was being racist and accusatory. When I got home, I hit myself... If it wasn't for my disability, I wouldn't be asking for help. Anyway, I have filed a complaint and I will be facing him. That experience put me off working for young Carers. The manager said, 'I know him, he wouldn't do that to you'. (23)

## REPORT ON LOCAL SERVICE PROVISION

### Police Scotland

- That evening I was interviewed by Police and next day my Mum's Care Manager. The Police said there was no case to answer. Social work felt differently. (8)
- The support from the Police has been very good (*father's comment*). (10)
- Some Police officers are nice, but some officers are not so nice and treat you like scum. They are expected to turn up for self-harming even though I would never hurt anyone other than myself (*daughter's comment*). (10)
- They said there was nothing they could do about the attempted break in as in law a thing must be witnessed by two people. They contacted my council housing office. I was then left to fend for myself. (14)
- The Police are very good now, and they have been schooled well on the difference between drug addicts, the abused, and the mentally unwell. They are responsible for putting people into psychiatric institutions whereas in the past they would all have been put into prison. (18)

### Positive Choices

- The self-management course was very useful. Leanne made me feel so welcome. I attended a peer support group. I like meeting with different people and hearing their different stories. But it was short, and there was no follow-up. You need something to come after it. (4)

### Richmond Fellowship [See: [Additional Feedback Table of Contents](#)]

- They visit once a week, I'm not sure how useful it is, I get more support here (CATH) most of the work gets done by them. (6)

### Royal Voluntary Service (RVS)

- They provide transport, but they only offer local support and not outside of area. (1)
- You need to register before you can access. (2)

### Salvation Army

- When I was first out in the community, they helped me so much. They got me my first flat; it was one of their own. It was just a bedsit, but it was a move - a move forward. They also offered help with literacy and numbers, but I didn't really need this. They just looked after you. (29)

### Samaritans [See: [Additional Feedback Table of Contents](#)]

- It was someone to listen to you; they can signpost you to other services. But it's almost like you don't know what to do, so it can be better to talk face-to-face. (4)

## REPORT ON LOCAL SERVICE PROVISION

### **Scooter (*transport*)**

•I bought my electric scooter 4 years ago with savings. Now I can go out every day. It has given me freedom. (23)

### **Scottish Charity Air Ambulance (SCAA)**

•I have always valued the work that they do. I volunteered with them doing street fundraising. The staff/volunteers were all really friendly. There was no judgement, and it gave me a sense of belonging to something that means something. The street volunteering was not good in the winter, so I didn't continue. (4)

### **Scottish Association for MH (SAMH) [See: [Additional Feedback Table of Contents](#)]**

•They just "fell off" when I didn't answer their calls, but when I am in the throes of my OCD and cleaning - I don't even hear the phone. I was expected to bring their attention back to me, rather than it being their responsibility to reach out to me. It's like there is a rule from management - no calling if you haven't been in office for a while. (27)

•I go here for emotional support, they come to visit, to advise me to open letters and to go with me on trips to Perth. It is very laid back, and sometimes it would seem that they have no plan. Sometimes, I end up counselling them. (31)

### **Scottish Fire & Rescue**

•They provide aids for the hard of hearing. One woman had an experience, where more than one person came to her house at once which made her feel very unsettled due to her hearing impediment. (26)

### **Solicitor**

•This is a very expensive service. (13)

•He uses big language. He expected me to understand what he was saying and questioned why I had brought a translator with me to meetings. He said that as I had passed the "Life in the UK" test, he didn't understand the need for a translator. I have not felt comfortable bringing a translator since. (14)

### **Stroke Association [See: [Additional Feedback Table of Contents](#)]**

•A lot of us use their *Speakability* service, which we find very positive. It is a very useful service and very appropriate it is as a support. (2)

## REPORT ON LOCAL SERVICE PROVISION

### **Supermarket**

- They will bring the bags into the house and help me put the food away in the cupboards. (1)
- Online shopping is very helpful, especially in the winter. (19)
- I'd like a job at ASDA, but the lunch breaks are too short. It takes me too long to move from one place to the other, and by the time I made it to their lunch room it would be end of lunch! Things are too high to reach on some shelves. (23)

### **Tayside Deaf Hub**

- Deaf Links advocate for me in various situations, e.g. health, council, bank. All staff can communicate in BSL. Other services are not deaf aware and can't communicate. Advocacy empowers me to make choices, have my voice heard and be independent. Have my rights to interpreter respected. (30)
- I need more help from Deaf Links. They are great but council should fund. (30)

### **Vision PK** [See: [Additional Feedback Table of Contents](#)]

- They do not have a driver. (1)

### **Women's Aid**

- They supported me a lot. They have been very helpful and very nice. They helped me get new housing and signposted me to IA. They went with me to the Police and they still support me with my solicitor. However, they are not available in the evenings. (14)

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## Glossary

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<b>ADHD</b>	Attention deficit hyperactivity disorder ( <i>MH disorder</i> )
<b>Aphasia</b>	A condition that affects the brain, which leads to problems with language
<b>Arthritis</b>	A condition that causes pain and inflammation in a joint
<b>ASD</b>	Autism-spectrum disorder
<b>ASN</b>	Additional support needs
<b>ASP</b>	Adult support & protection
<b>Asperger syndrome</b>	A form of autism, marked by difficulty with social relationships and communicating
<b>AWI</b>	Adults with incapacity
<b>Bipolar disorder</b>	A mental condition marked by alternating periods of elation and depression ( <i>MH disorder</i> )
<b>BPD</b>	Borderline personality disorder ( <i>MH disorder</i> )
<b>Borderline personality disorder</b>	A mental condition marked by unstable moods, behaviour and relationships ( <i>MH disorder</i> )
<b>BSL</b>	British Sign Language
<b>CAB</b>	Citizens' Advice Bureau
<b>CATH</b>	Churches Action for the Homeless
<b>CAMHS</b>	Child & Adolescent MH Service
<b>CBT</b>	Cognitive behavioural therapy
<b>CHSS</b>	Chest, Heart & Stroke Scotland
<b>CILPK</b>	Centre for Inclusive Living P&K
<b>CMHT</b>	Community MH Team
<b>CP</b>	Child protection
<b>CPA</b>	Care programme approach
<b>CPN</b>	Community Psychiatric Nurse
<b>CRHTT</b>	Crisis Resolution Home Treatment Team
<b>CTO</b>	Compulsory treatment order
<b>CYP</b>	Children & young people

## REPORT ON LOCAL SERVICE PROVISION

<b>DBT</b>	Dialectical behaviour therapy
<b>DCC</b>	Dundee Carer's Centre
<b>Dementia</b>	A set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language ( <i>MH disorder</i> )
<b>Diabetes</b>	A condition causing a person's blood sugar level to become too high
<b>DLA</b>	Disability living allowance
<b>DVLA</b>	Driver & Vehicle Licensing Agency
<b>DWP</b>	Department for Work & Pensions
<b>EPICS</b>	Encouraging Positive Involvement Carers Support ( <i>support group</i> )
<b>ESA</b>	Employment & support allowance
<b>Fibromyalgia</b>	A condition marked by chronic widespread pain
<b>GP</b>	General Practitioner
<b>IA</b>	Independent Advocacy
<b>IAPK</b>	Independent Advocacy P&K
<b>IPCU</b>	Intensive Psychiatric Care Unit
<b>Korsakoff's syndrome</b>	A condition marked by acute onset of severe memory impairment without intellectual dysfunction
<b>LD</b>	Learning disability
<b>MEAD</b>	Minority Communities Hub (PKAVS)
<b>MDT</b>	Multi-disciplinary team
<b>ME</b>	Myalgic encephalomyelitis
<b>Myalgic encephalomyelitis</b>	A condition marked by a range of neurological symptoms
<b>MH</b>	Mental health
<b>MHO</b>	MH Officer
<b>MHTS</b>	MH Tribunal Scotland
<b>MP</b>	Member of Parliament
<b>MS</b>	Multiple sclerosis
<b>Multiple sclerosis</b>	A condition that affects the central nervous system
<b>NHS</b>	National Health Service
<b>OCD</b>	Obsessive-compulsive disorder ( <i>MH disorder</i> )

## REPORT ON LOCAL SERVICE PROVISION

<b>Obsessive-compulsive disorder</b>	A mental condition where a person has obsessive thoughts and compulsive activity ( <i>MH disorder</i> )
<b>OT</b>	Occupational Therapist
<b>PA</b>	Personal Assistant
<b>Parkinson's disease</b>	A progressive disease of the nervous system
<b>PD</b>	Physical disability
<b>P&amp;K</b>	Perth & Kinross
<b>PKAVS</b>	P&K Association of Voluntary Service
<b>PKC</b>	P&K Council
<b>PoA</b>	Power of Attorney
<b>PRI</b>	Perth Royal Infirmary
<b>PUSH</b>	A charity pushing for inclusion for those with a LD
<b>RMO</b>	Responsible Medical Officer
<b>RNIB</b>	Royal National Institute of Blind People
<b>RVS</b>	Royal Voluntary Society
<b>SAMH</b>	Scottish Association for MH
<b>SCAA</b>	Scottish Charity Air Ambulance
<b>SDS</b>	Self-Directed Support
<b>Somatoform</b>	A mental condition that causes bodily symptoms ( <i>MH disorder</i> )
<b>Spondylitis</b>	Inflammation of the joints of the backbone
<b>SPS</b>	Scottish Prison Service
<b>Stoma</b>	Opening on the front of the abdomen, made using surgery
<b>Stroke</b>	A condition that occurs when the blood supply to part of the brain is cut off
<b>Talking Mats</b>	A communication symbols tool ( <a href="http://www.talkingmats.com/">http://www.talkingmats.com/</a> )

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## **Declaration of Interests**

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Siân Dawkins is an Independent Advocacy Worker (Health & Social Care Integration) at IAPK and receives a salary from IAPK which has been funded by PKC and NHS Tayside through the Integrated Care Fund. She has no financial or other conflicts of interest.

IAPK is an IA organisation receiving some of its funding from PKC and NHS Tayside. IAPK is completely independent from these statutory bodies and any other service provider.

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**END OF REPORT**