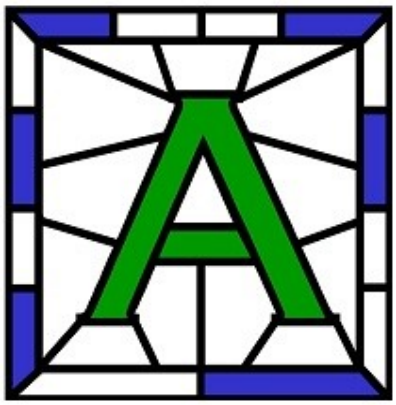


Voice of Experience

Lomond & Argyll Advocacy Service

Long Term Conditions Project

2016 - 2019

This project was supported by the Transforming Self Management in Scotland Fund provided by the Scottish Government, administered by Health and Social Care Alliance Scotland.

Who we are:
Our Long Term Conditions Advocate team

Left to Right:: Scott Rorison (Service Manager), Anne Timmins, Sarah McFadzean, Simon Richardson, Arlyn Bolton, Ailsa McCrae (Team Leader Argyll & Bute)

Introduction:

Lomond and Argyll Advocacy Service wish to thank the Health and Social Care Alliance for having chosen to fund our Long Term Conditions (LTC) Project during 2016 to 2019. We have had a remarkable opportunity to demonstrate the significant benefits and value that advocacy can make to someone living with a Long Term Condition in improving their quality of life.

We were delighted to have received the news we had secured this funding, as we were eager to ensure that people living with long term health conditions had fair access to support and an independent voice when they were struggling to be heard.

LAAS were often contacted by people who had experienced significant difficulties with accessing services and support regarding their care and treatment, yet we were unable to assist them under the funding arrangements we had in place. We asked ourselves if this was acceptable and how could we support change to ensure equality of access to our Service for individuals in Argyll?

We gathered significant considerable evidence from a range of sources and demonstrated there was a need for people with LTCs to have advocacy support. We wanted to ensure the playing field was levelled, and people with LTCs were able to have the same access to advocacy as an individual living with another health condition, such as a mental disorder.

LAAS was eager to work towards supporting the self management strategies of the Scottish Government. This new project ensured people felt in control of their lives through the decisions and the choices that they wanted to make. We focussed on enabling people to develop their own self management skills whilst being supported by an advocate.

The project commenced in January 2017, with a team induction and development week. We then began promoting and building awareness of the project across the challenging geography of Argyll & Bute. The referrals steadily came in, and by April 2017 our advocacy workers were working to full capacity. We were advocating alongside individuals with a LTC to ensure they were being heard, respected and included, and that they were treated with fairness, dignity and respect on matters that directly affected or impacted upon them.

LAAS believes that people should not have to be labelled or fit into a particular box in order to access Independent Advocacy, especially when they are in crisis or struggling with an issue that is impacting on their ability to live an independent life. Access to advocacy should be based on need with an assessment of exploring whether an individual is being treated fairly and their rights respected.

Ailsa McCrae, Argyll and Bute Team Leader, LAAS

We have assisted 380 clients during the lifetime of the project

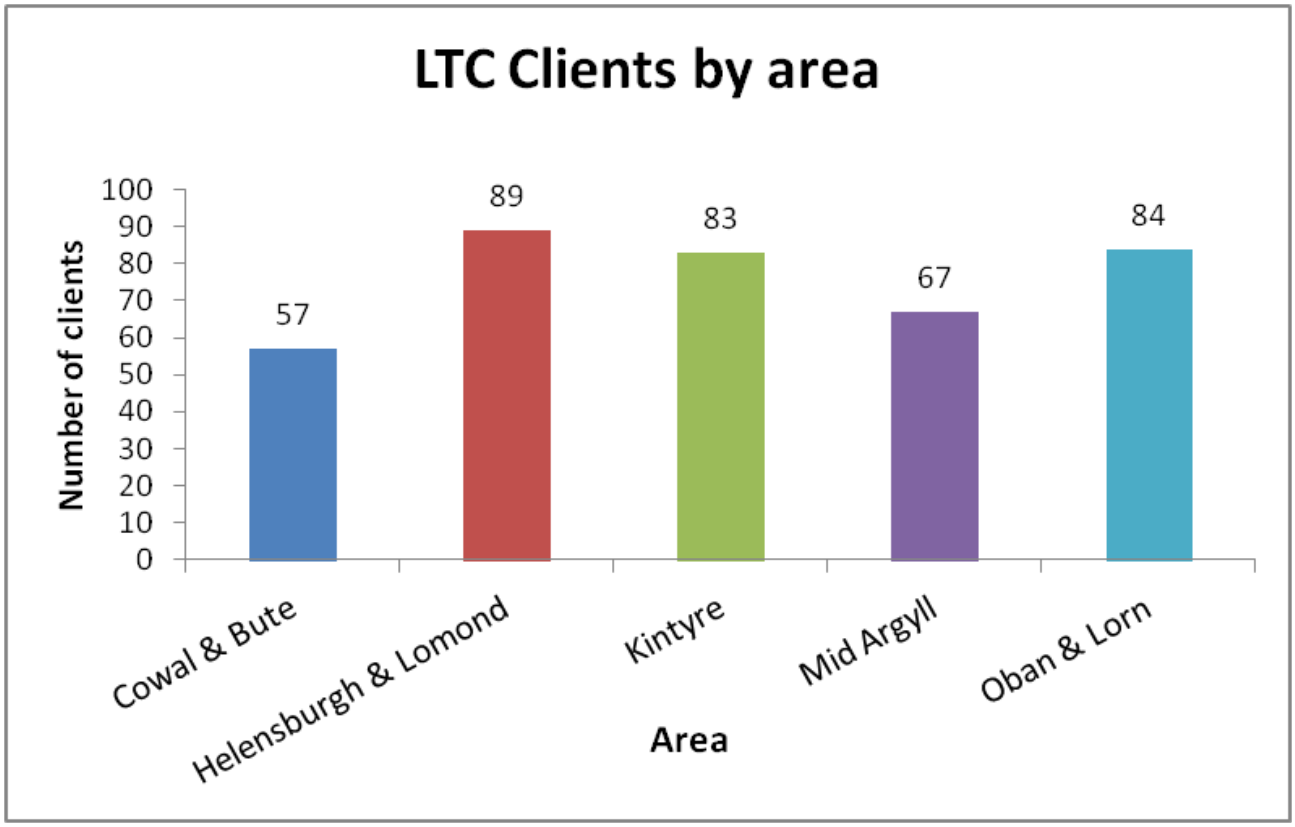


Figure 1: Number of Long Term Conditions Clients per area

We have assisted with **1320 issues**

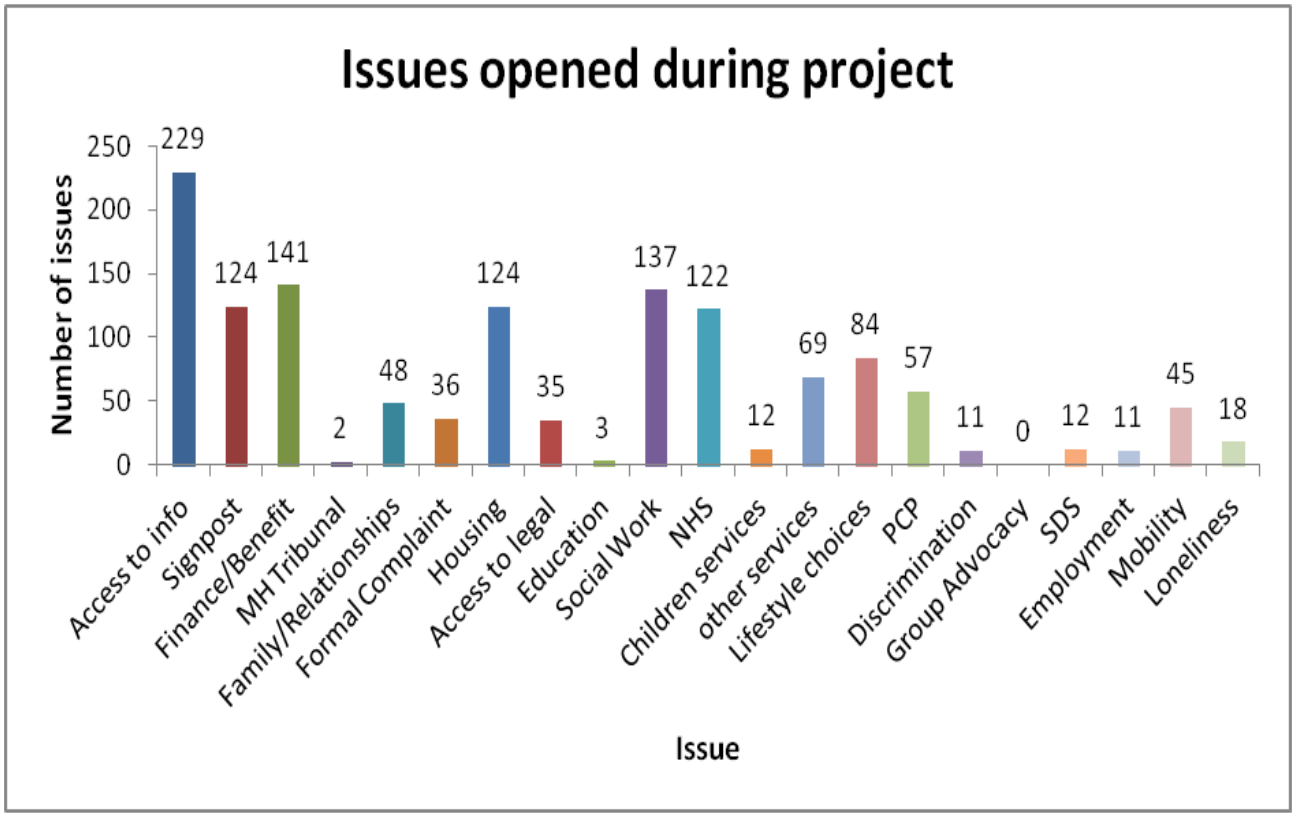


Figure 2: Number of issues opened during the project

Activities and places visited

Our promotions map showing referrals across Argyll & Bute and promotional activities that took place.

across Argyll and Bute from Tiree to Southend

Argyll & Bute Focus Event
Health Fair
Gala Days
Multi - disciplinary team meetings
Information days
Drop in sessions at local organisations
Care teams
GP surgeries

Gaining a Voice:

The individual was referred to the Service by an extended family member that recognised the person required a voice and support to make decisions about future housing needs. The individual had been having falls at home; they were isolated from the community and reported they felt slightly depressed.

The advocate met with the individual, the person was unclear about what help was required and felt nothing could be done to assist them. The advocate met with them a few times to gather their views and thoughts on what help they would like. It started with gathering small amounts of information. The individual began to talk more to the advocate and advised them they were struggling with their physical condition and a recent appointment with the specialist did not go well. The consultant had advised the client that they had provided all the surgery they could and would not be able to offer any further help with their degenerative condition at this stage. The individual advised that they felt a sense of loss and were struggling more than ever as they now felt that any hope of recovery had gone.

The advocate spent time getting to know the person, things they had enjoyed before, their past interest and listening to what was important to them in the future. This was difficult as the person said they felt they had no future and felt life was a daily struggle. The person expressed feelings of depression and how they didn’t want to go out, they told the advocate they had always been an upbeat person before and found they were a prisoner to their condition.

After gaining the trust in the advocate and the individual started to discuss matters, talk more about their future housing needs and asked the advocate to support them to explore options and choices that may be available to them. We did this along with the housing provider, GP and nurse.

The advocate supported the individual to gather evidence of their needs changing to support the application, then helped them to make calls and supported the individual to send emails and complete necessary forms. This person was offered a new more suitable accommodation promptly afterwards.

The advocate continued to support the person with a range of health and social care issues during this period and gradually the person started to focus more on self management and addressing matters themselves. They said they felt security in having a new home and were living in an area where they could more readily access services. The person started also to think about a hobby they could pursue at home that they could manage with limited assistance. The individual also started up their physiotherapy exercises again and started looking at what they can do now and looking at ways of maintaining their condition, health and movement.

The advocate built the trust of the individual and ensured the person felt listened to and worked with them at the pace that was right for them. The advocate researched what may be available to the person in their area, provided leaflets and information. The advocate encouraged the person to make decisions and choices and ensured the needs of the person were addressed to the appropriate services.

Helensburgh & Lomond Region

Project Worker:
Arlyn Bolton

Since the project started Arlyn has assisted and supported 95 clients in the area. Each client has had an individual service, the worker would arrange to meet with them at their home or in a place in the community that was comfortable to both. Depending in their presenting issue, Arlyn would support them to explore the difficulties and look at options and choices to assist the person to overcome the address the concerns and reduce the barriers they faced.

Each client has a person centred approach with no set amount of appointments. Our work is as long as it takes. Our work is as long as it takes to ensure the person felt supported, valued listened too and that options and choices were fully explored to help them resolve the issues. Not all the time could all of the issues have the outcome the people were looking for, but people reported feeling more in control and supported, simply because they felt supported to have their voice heard.

Following the induction week, the early role was all about building connections, agency work, meeting partner agents, third sector organisations and members of the community and public groups and advising them of the new unique branch of advocacy we could now offer. Talks and presentations across the Helensburgh area were fundamental to ensuring the message of the project reached as wide an audience as possible. We made use of Social Media to connect with services, particularly groups and forums that in the past we had no contact.

Some of the services involved in the progression and success of this service in this area have been; Social Work, ACHA, Homeless team, Speech and Language, Citizens Advice and Welfare Rights, Education establishments and GP services. These services have been pivotal in ensuring the rights and needs of the client have been met through advocacy. The staff in the mentioned services have welcomed Advocacy and ensured that each client has been supported to have their voice heard.

This has had a huge impact on our client base, they have felt valued, empowered and listened to.

Some of the issues that clients have presented with have included.

Help to engage with GP and NHS services
Speaking with housing teams
Putting views forward to social work
Lodging formal complaints
Being aware of rights
Signposting to other agencies

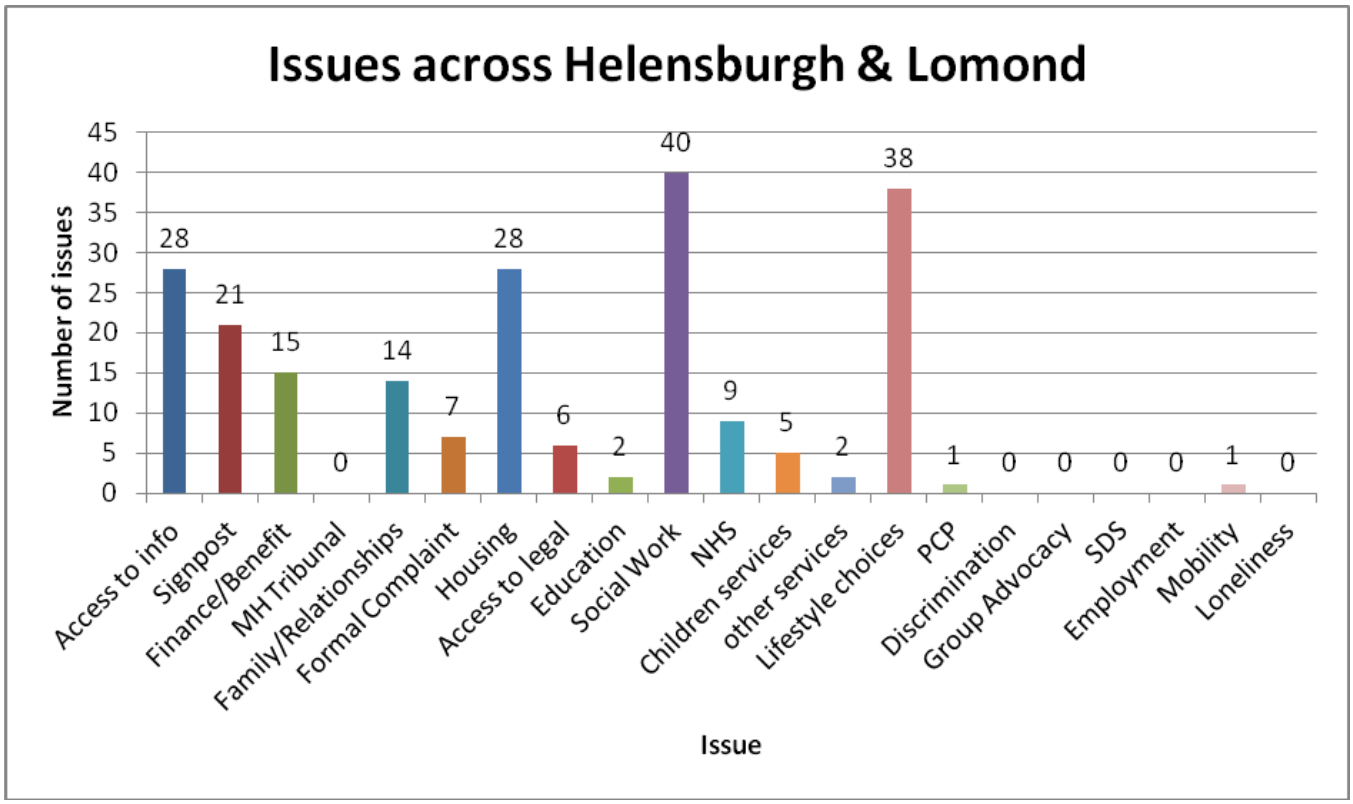


Figure 3: Issues opened in Helensburgh and Lomond during the project

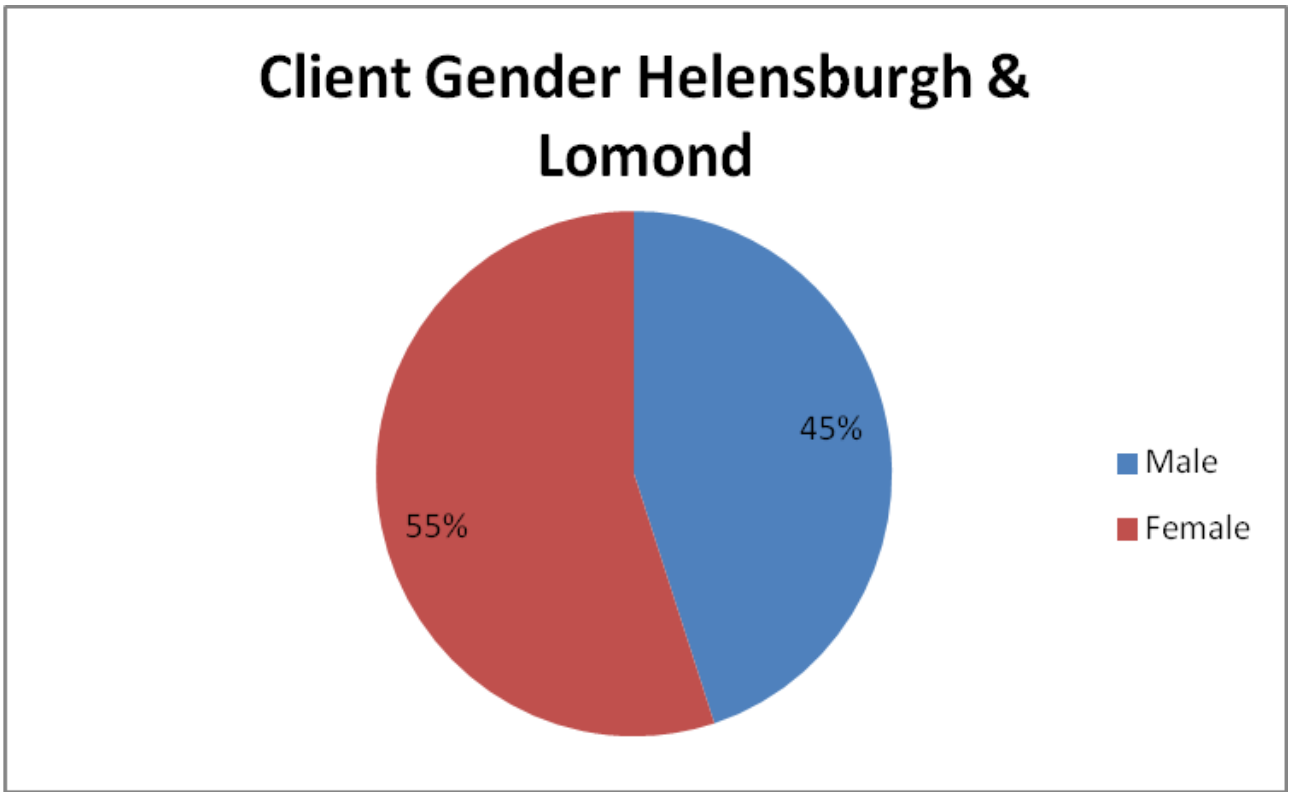


Figure 4: Ratio of male to female clients in Helensburgh & Lomond

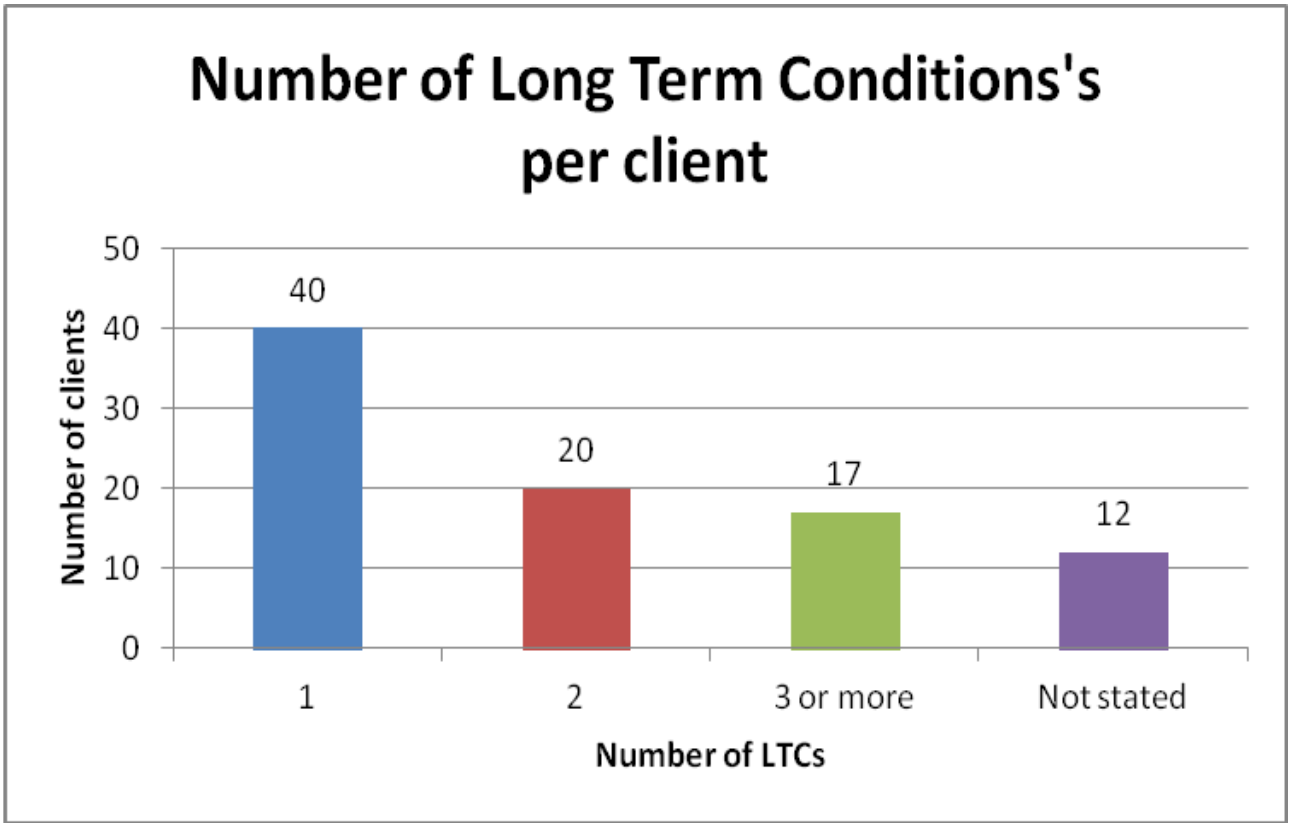


Figure 5: Number of Long Term Conditions per client in Helensburgh & Lomond

Helensburgh & Lomond Region Cont.

We think that each and every case we have worked on has been successful. This has included:, clients being able to move home after being “placed” in residential care; Clients feeling they are listen to and more confident. Complaints being taken seriously and feeling listened to. Clients have felt supported and empowered when attending meetings.

It leaves us saddened that such a number of clients in the Helensburgh and surrounding area are now without a vital and much needed service. However we have faith that the core service remaining in advocacy will continue to source funding to provide a future service once again.

We have increased our awareness far and wide of advocacy and demonstrated there is a significant need for this service.

Oban & Lorn region

Project worker
Anne Timmins

The project commenced in Oban in February 2017 and the project worker attended a week long induction training in Inveraray along with the other new LTC project advocates. This comprehensive induction brought the team together in order to build connections together, ensure clarity of information and setting clear operational standards and pathways that would work across all areas. The project began accepting referrals in February 2017.

The project worker promptly set to work sharing information, visiting services and meeting with health and social care services and providing talks to teams across a range of disciplines, and worked closely to develop referral pathways with third sector services.

To further enable the development of this project across all our communities we hosted a Focus Event in the seventh month of operation to assist us to learn what people living with a Long Term Condition felt was important that we undertook as part of our project. This took the form of a day long series of talks and activities to engage a wide group of individuals who have LTCs from across Argyll and public and HSC professionals. We had a representative from our HSCP provide a talk on the aspirations of our HSCP. Our funders at the Health and Social Care Alliance spoke passionately about Self Management.

Over 60 people attended and almost half of these individuals identified themselves as having an LTC. In partnership with Hope Kitchen, the HSCP, Healthy Options and Versus Arthritis, we listened carefully to people's views, wishes and concerns. We informed people of how we intended to help and support the local communities and other organisations to give those living with Long Term Conditions a voice to be heard.

The feedback and comments from the day were extremely encouraging and we summarised the day and provided feedback to people in how we would take forward ideas. We used social media to share information from the day and we kept links with those who attended.

Mull (Undiscovered Scotland)

A number of different promotional activities have also taken place: regular banner displays and information table at Oban and Lorn Hospital, contact information left with ward staff, specialist nurses, OT and ECCT leads.

GPs surgeries were provided with information, and talks were given on the project to GPs and community staff.

A Health Promotion Day was held at the Atlantis Leisure Centre, which we attended with our stand and information table. Two of our volunteers supported this day; this was a well attended event and in addition to making new connections and reaching more people, we also attracted a new volunteer to the organisation during the day.

Regular Drop Ins have been set up at Hope Kitchen and the Dove Centre, both of whom we have had a number of referrals from. We have made connections and links with many smaller grass root groups who are supporting people with LTC.

Efforts were made to engage with remote and rural areas, including the islands. Outlying communities and villages have information in village shops, halls and meeting places.

Oban & Lorn region cont.

Facts and progress

A steady stream of clients has ensued throughout the project, from a number of sources as the figures show, with varied and diverse requirements, some quite challenging.

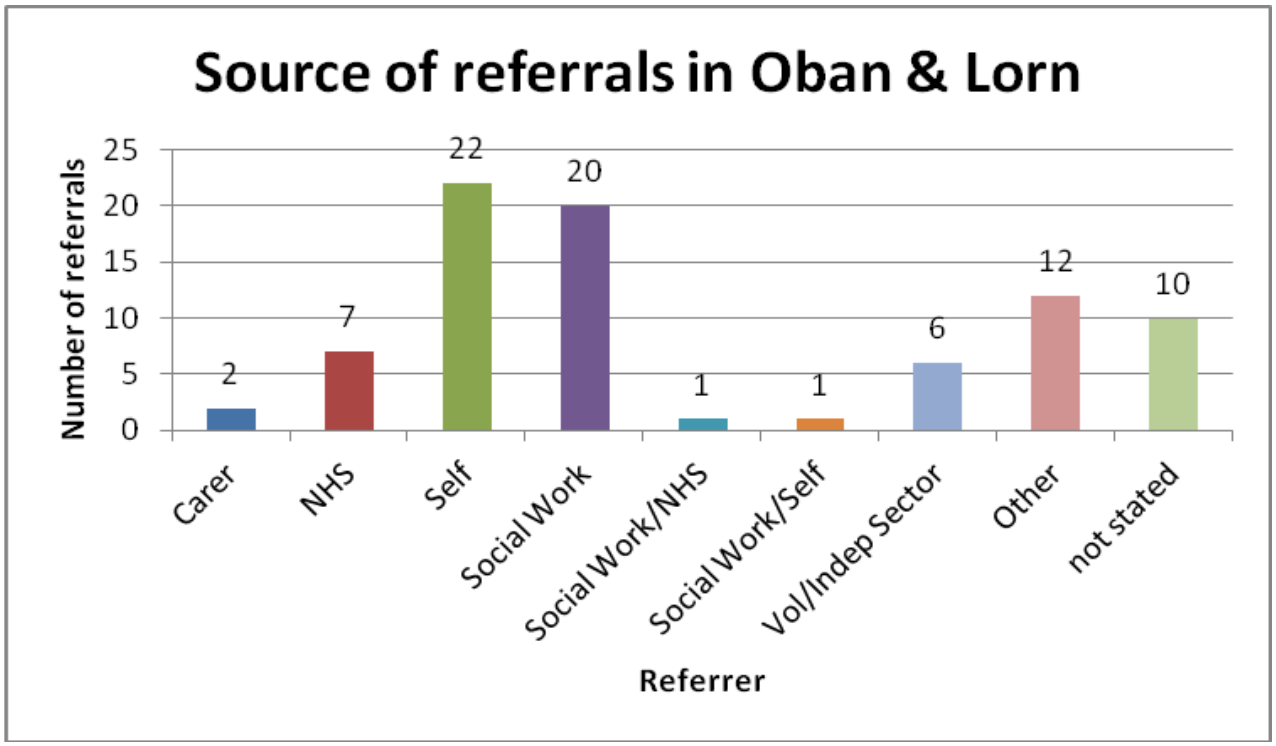
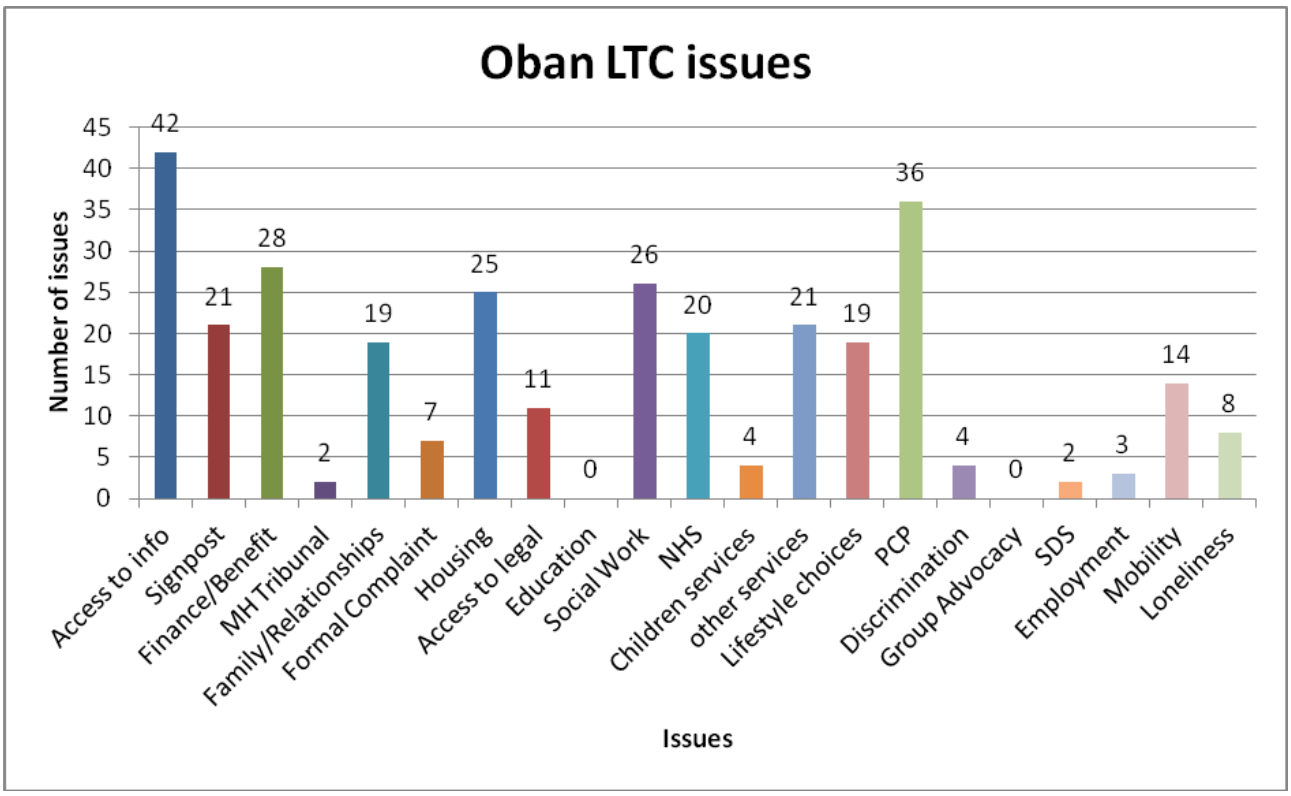


Figure 6: Source of referrals in Oban & Lorn during the project

Clients have been supported on Mull and Coll, over the phone and by email, and supported to go to any mainland meetings in the locality where appropriate.

We have worked in partnership with a number of organisations, namely:

North Argyll Carers Centre, Crossroads, The Dove Centre, Hope Kitchen, OLIDG Hospital ward staff, specialist nurses, Womens Aid, Etive House, Eider Glinn, Social work, other Advocacy services, Women's Aid, Dunmar Court, Ford Spence Court. GPs, District Nurses, Carr Gomm, Welfare Rights Officers.



To see a client struggling with a neurological degenerative condition, and

Figure 7: Issues opened in Oban & Lorn during the project

struggling to have the confidence to speak up and gather information regarding life changing circumstances was challenging, but equally rewarding to see them gain confidence and control. Going from having no focus, energy or confidence on how to address their issues, through to being a more independent, stronger and confident individual who felt organised and in the driving seat of their life.

Kintyre Region

Project Worker
Sarah McFadzean

In summary the Project has been very successful in the Kintyre peninsula. The commitment and dedication of the Project Worker and the Team of Advocates in Kintyre, ensured the project got off to a flying start. Sarah was well skilled on the best strategies for leaving the starting blocks, she used her local knowledge and connections to establish contacts with a wide variety of agencies and groups across Kintyre.

Considerable work was done in the early days to promote the service to the Third Sector and engage in their groups, activities and collaboratively form and develop new partnerships to support the needs of the community. Extensive efforts were also made to increase dialogues with a wide group of agencies, local groups, forums, clubs and the HSCP Team.

We joined existing community and family events; this was to ensure information would grow and seep into the various paths across our diverse, remote and rural communities. We hosted an information event in Carradale and invited other agencies and HSCP Services to have a stand at our event; a substantial and wide ranging group of services came together with members of the community. This was held in some of the remote communities in Kintyre. We ensured we engaged with the island communities. Regular drop ins were held on Islay and information was provided to a representative of the service to disseminate in Jura.

We had a table with information available at the Campbeltown Community Hospital and we did this twice during the life of the project. This table was set up with stands etc. for a week, we had staff and volunteers taking slots at being available their most days for an hour or two. We had a similar stand and table set up at the Aqualibrium Leisure Facilities and we made opportunities to engage with the public there.

Advocacy partnerships were made with the local High School and Advocacy Workshops were delivered to 5th and 6th Year Students. This was a valuable learning experience for LAAS, The Grammar School and the students.

Information on the service was made available through the Dispensing Chemists. LAAS business information cards were included with all prescriptions. This allowed the service details to reach individuals who may be isolated and infirm.

The local Radio station promoted the Service; this ensured a wider audience was learning about the role that we can play in helping vulnerable people. The key aim was to try and get the message across to male listeners who can be more challenging to reach.

A Talking Newspaper is available in Kintyre, and Sarah arranged for an article to be available on advocacy in this paper.

Tarbert (The Guardian)

Kintyre region cont.

The Service assisted 82 individuals in Kintyre during the life of the project. Many of these individuals lived outwith the town of Campbeltown. Sarah worked with people from Carradale to Tarbert, and out to Southend and Machrihanish. The service also assisted people on Gigha and Islay. We also supported the training of a volunteer advocate for this area.

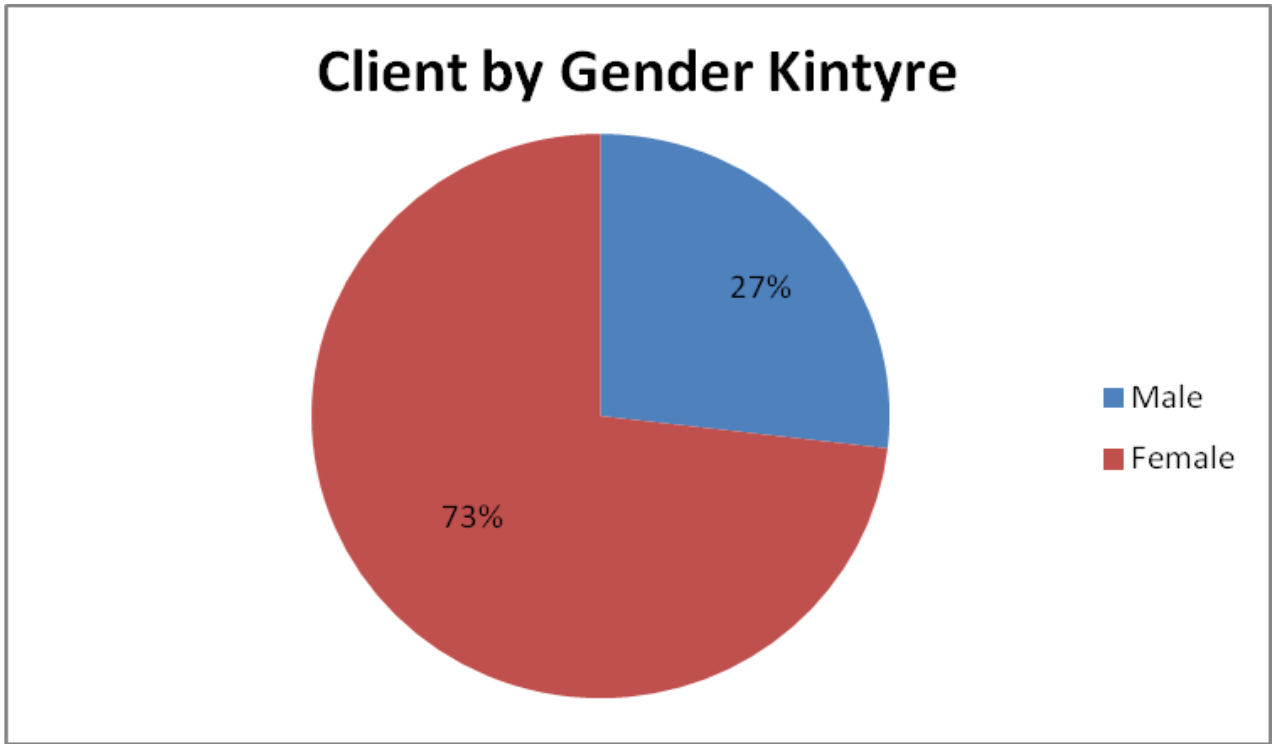


Figure 8: Ratio of male to female clients in Kintyre

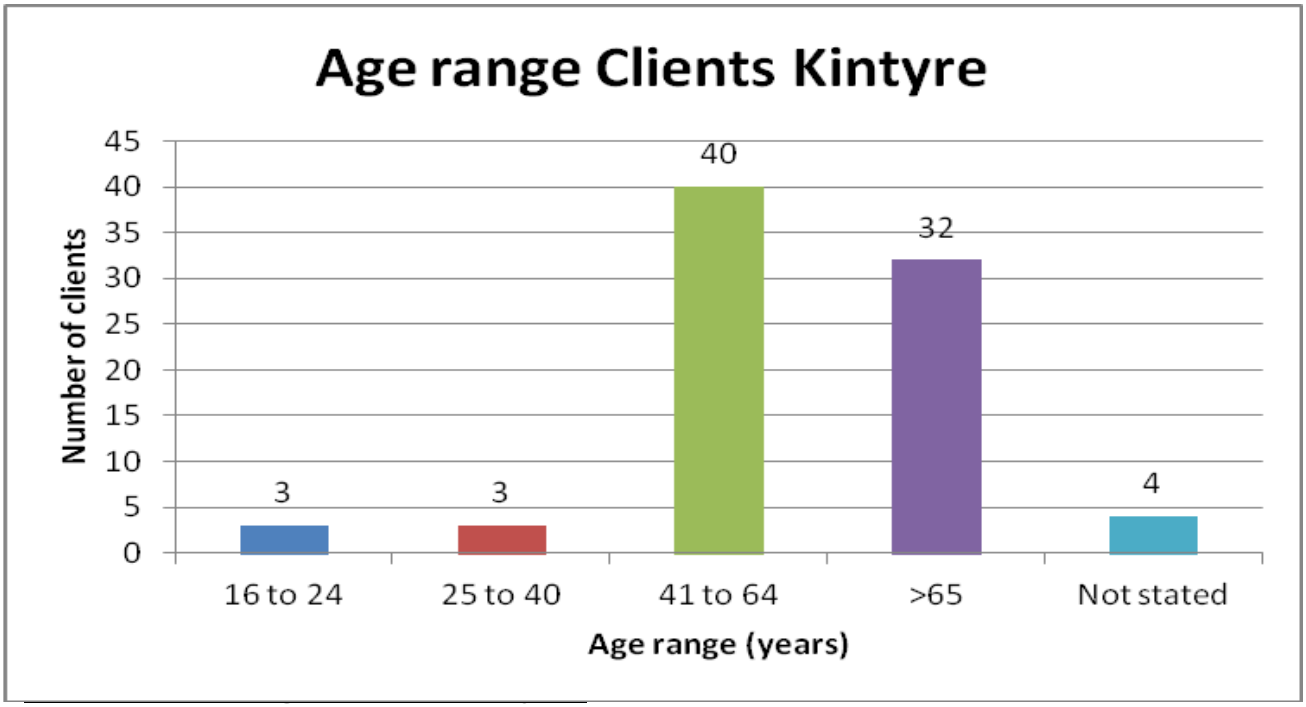


Figure 9: Age range of clients in Kintyre

At times there would be a referral for an individual where a conflict of interest was apparent. At this stage volunteers assisted with casework or the Coordinator would take on the referral. This worked well and on occasions some cross working took place between the core Service Coordinator and the LTC Worker. This was helpful during periods of annual leave.

Early into the project we became aware that handing out satisfaction surveys at the point of closing was not working, we didn't seem to get a good response rate, and we were inconsistent at how we passed these forms to people.

Another issue that could have impacted on the project was the worker moved on to another role a few months prior to the ending date. We were fortunate to be able to harness the skills and enthusiasm of the volunteers, who have undertaken some paid advocacy work. This has allowed the service to continue to be delivered across the region to the end of the project.

Cowal and Bute region

Project Workers
Simon Richardson
Anne McSeveney

The project commenced in January 2017 in the Cowal and Bute area. Simon, the project worker was well connected across Cowal and swiftly developed opportunities to meet with people and promote the new project.

Extensive efforts were made to reach into the small and isolated communities across the area. Talks were delivered to local community councils as well as attending church forums, meeting with the GPs, District nurses and other services such as the Post Office Staff.

LAAS already had strong connections in Cowal and Bute though our core service, but we were eager to share word of the Long Term Conditions project. A focus was made on engaging with HSCP Staff who specialised in supporting people with self management of their conditions.

We provided informative talks to Services across Cowal and attended staff team meetings on Bute for HSCP and Third Sector colleagues. We worked closely with them to have a high visible presence and accessibility, hosting information tables at Fetes and Gala Days.

Work was carried out to engage with the younger people in our community and efforts were made to ensure information on the project was made available in schools, sports and community facilities by Anne.

Facts and Progress

We have successfully increased our capacity to assist more people in Cowal and Bute, and have ensured the service had a greater visibility in the community. We have had an increase in HSC staff making referrals to the Service, and have provided networking and opportunities for more services to gain a greater insight into our role and function.

Rothesay (The Guardian)

The project has assisted 57 people in Cowal and Bute to have their voices heard. We have supported people to have challenging, sensitive and difficult conversations and ensure they feel included in choices, options and decisions regarding their health needs.

We have had an increase in referrals for and from those living outwith the main areas of population; it is satisfying to know that our efforts to engage with the remote communities in Cowal and Bute have had an impact.

Cowal and Bute Region cont.

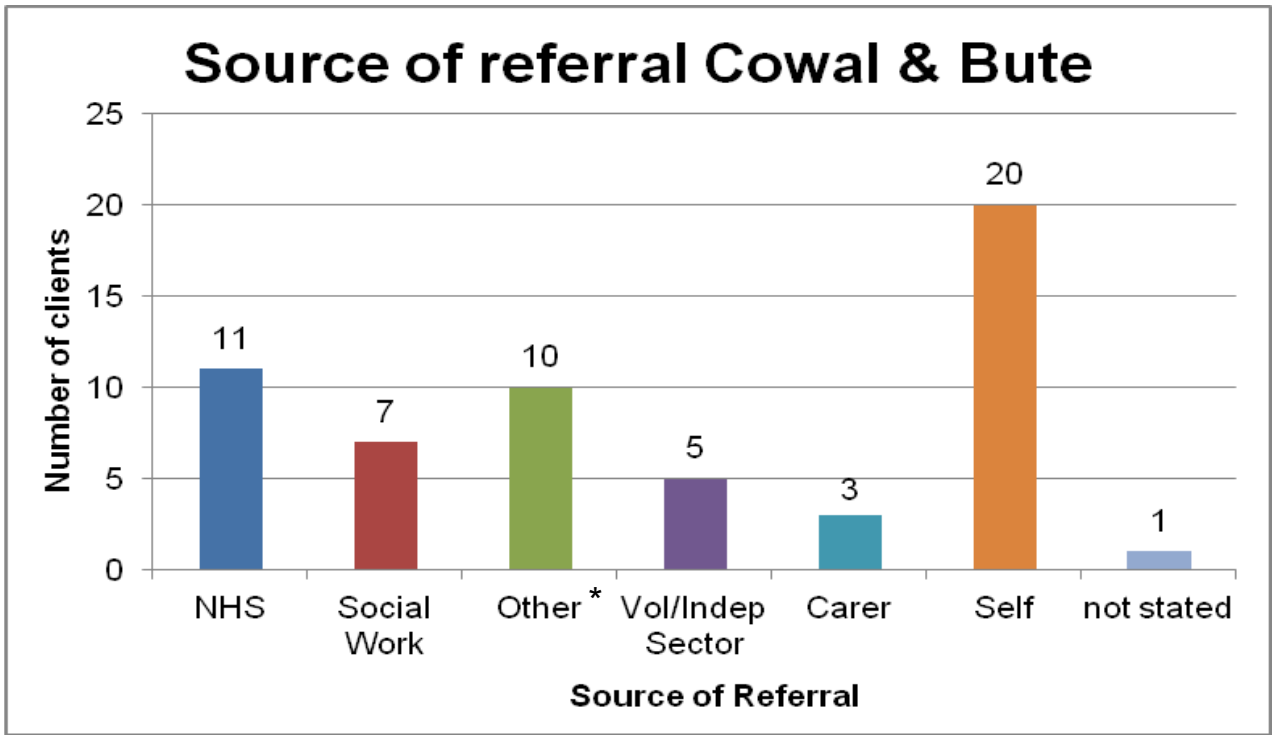


Figure 10: Source of referrals in Cowal & Bute during the project

**Other can include joint referrals from NHS/Social Work or NHS/Self*

Risks and Changes

The service in Cowal and Bute has had two advocacy workers during the project life. This meant there was a period where we had referrals being allocated to our existing core team coordinator. This could have been disruptive to the existing individuals we were working with, and also to the wider services we were trying to build and establish contacts with. However, we were fortunate that the post was filled promptly and the new member of the team had considerable experience and skills and was able respond promptly to the needs of the individuals we assist.

The core team and the volunteers made themselves available to ensure individuals continued to receive quality advocacy support during the vacancy period.

When the project was commissioned it was originally due to end in March 2019. Our advocate had committed to the project only for this period. However this meant that we did not have an advocate in place for the remaining six months of the extended project.

The service therefore ceased to take new LTC referrals from March 2019. Existing clients continued to receive support from both the Core services advocate and the Mid Argyll LTC advocate.

Visitors at the Riverbank Medical Practice Country Fayre hanging words on our Advocacy Tree

An Advocacy Journey:

An individual living with Parkinson's was referred in to LAAS by Parkinson's UK.

The client was feeling overwhelmed with considerable paperwork that needed attention on sensitive matters, and was unsure on how to deal with the issues most effectively. The individual said they felt unsupported, and that they lacked knowledge on the subjects that needed attention. They said they felt overwhelmed, isolated and alone and had therefore avoided addressing the issues.

The client was eager to be assisted with the pressing issues they had to attend to, and be in control of sensitive and complex matters. However due to the nature of their health conditions they found addressing the problems too exhausting, and were unable to attend to matters due to their failing health.

The advocate spent time with the individual assisting and enabling the individual to make decisions about how they would like to attend to some financial matters. They looked at the priorities of the issues that required attention and worked on issues at a pace that was right for the client. Support to write letters and respond to matters eased the stresses on the individual, and they reported to the advocate that their help had been pivotal in supporting them, which in turn helped ease some of the negative symptoms of their illness.

On organising paperwork it was also noticed they were not in receipt of a benefit that they were entitled to access; a simple telephone call with the support of advocacy to the service resolved this and new up to date documents were issued.

The individual was supported to attend to and respond to sensitive health and financial matters. They were assisted to consider options, explore choices and solutions and make decisions that they felt were right for them. They said they felt considerable relief and that they were better placed now to manage their health condition more effectively.

The person reported feeling more in control and felt they were better placed now to focus on their own health and wellbeing. They said they hadn’t been going out to socialise for sometime, but intended to start attending a local support group for people with LTC again.

Advocacy puts the people who use the service first. The client was struggling and finding they were unable to access support to assist with certain tasks. The client was eager to be in a position where they were able to self manage these parts of their life and they didn't want to become reliant on services or others making decisions on their behalf. The advocate assisted the individual to have control over matters and decisions that affect their life.

One of our Advocacy games at a local gala day was a bit hit with bringing young people and their families together to learn about Advocacy

Value of project - do clients feel better after working with an advocate

At the start of the Advocacy process:

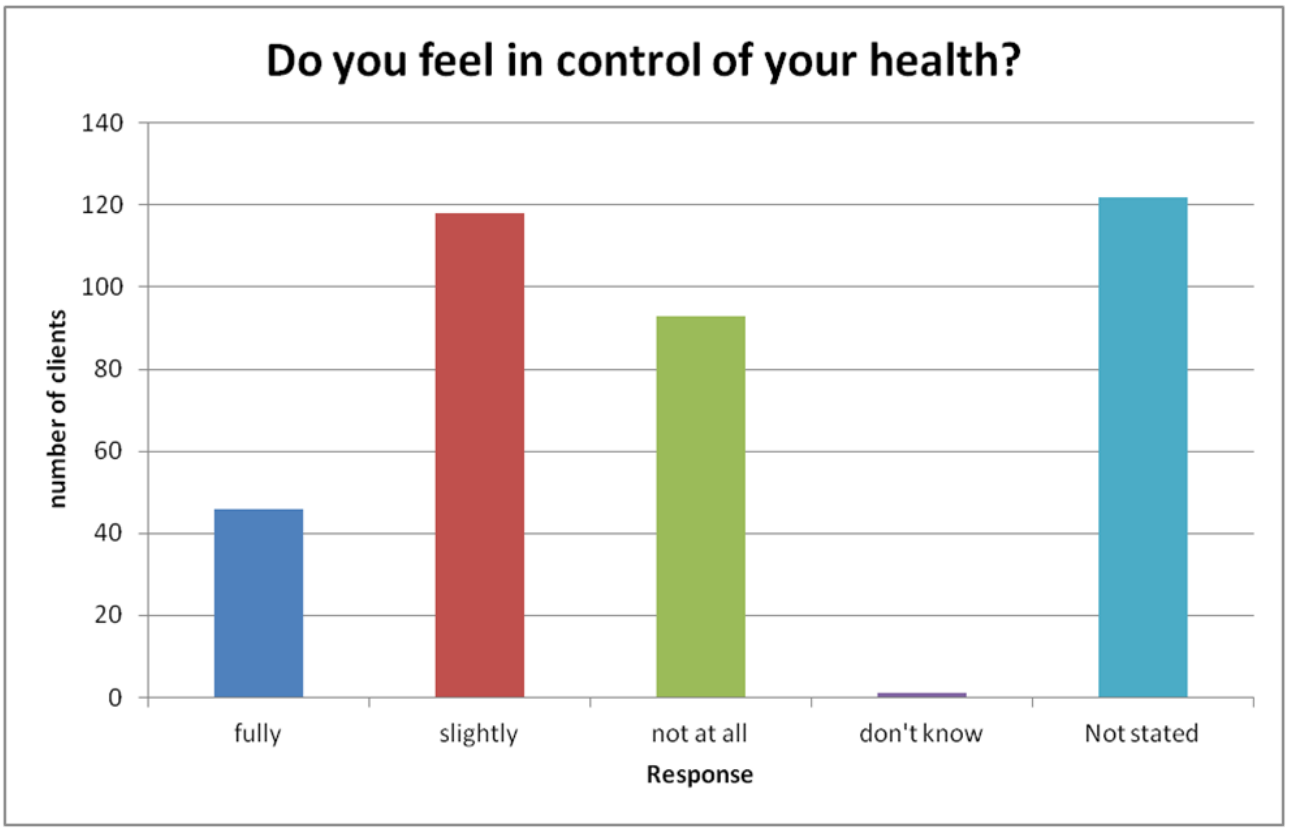


Figure 11: Clients were asked if they felt in control of their health at the start of the Advocacy process

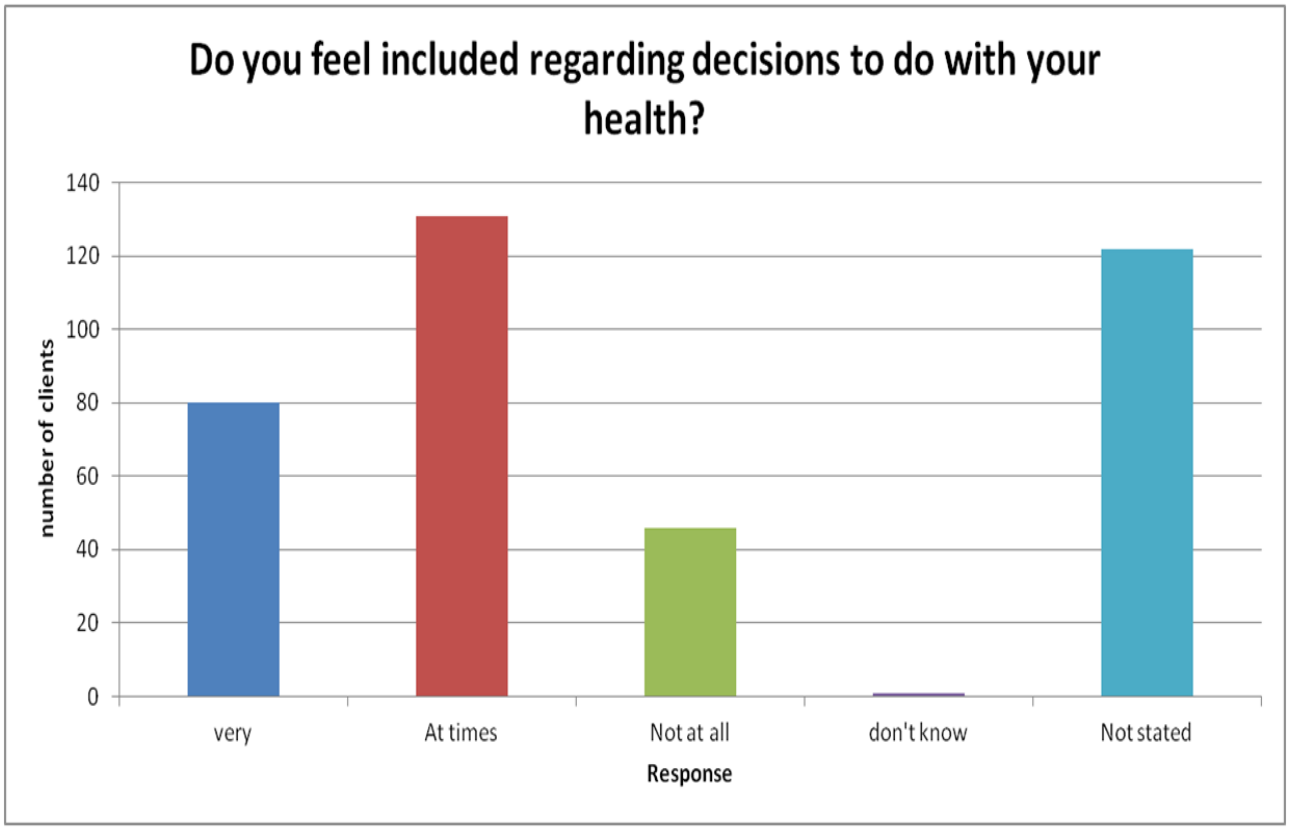


Figure 12: Clients were asked if they felt included regarding decisions to do with their health

Clients were asked at the start of the Advocacy process if they felt in control of their health and if they felt included in decisions that were being made to do with their health. They were then asked once Advocacy involvement had ended.

After the Advocacy process:

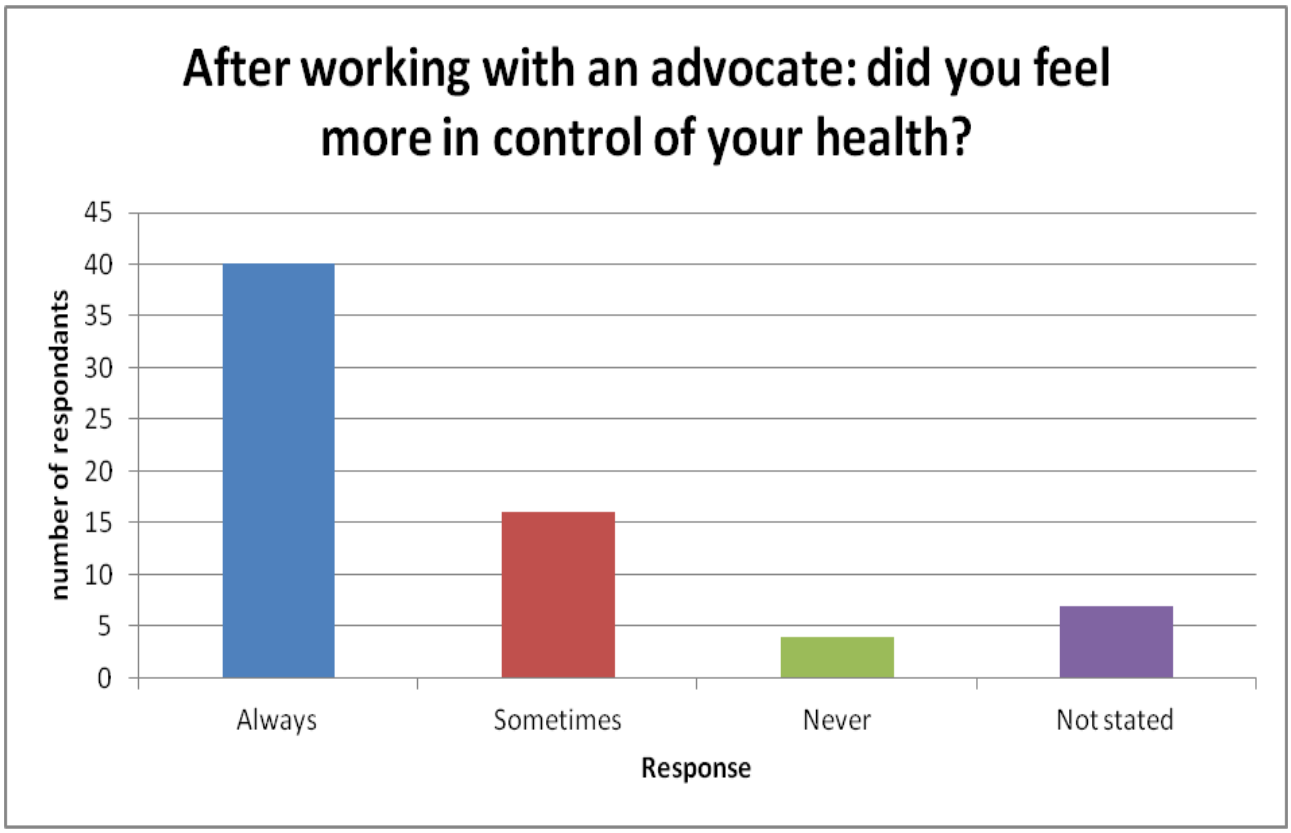


Figure 13: After their advocacy journey had been completed, clients were asked if they felt more in control of their help

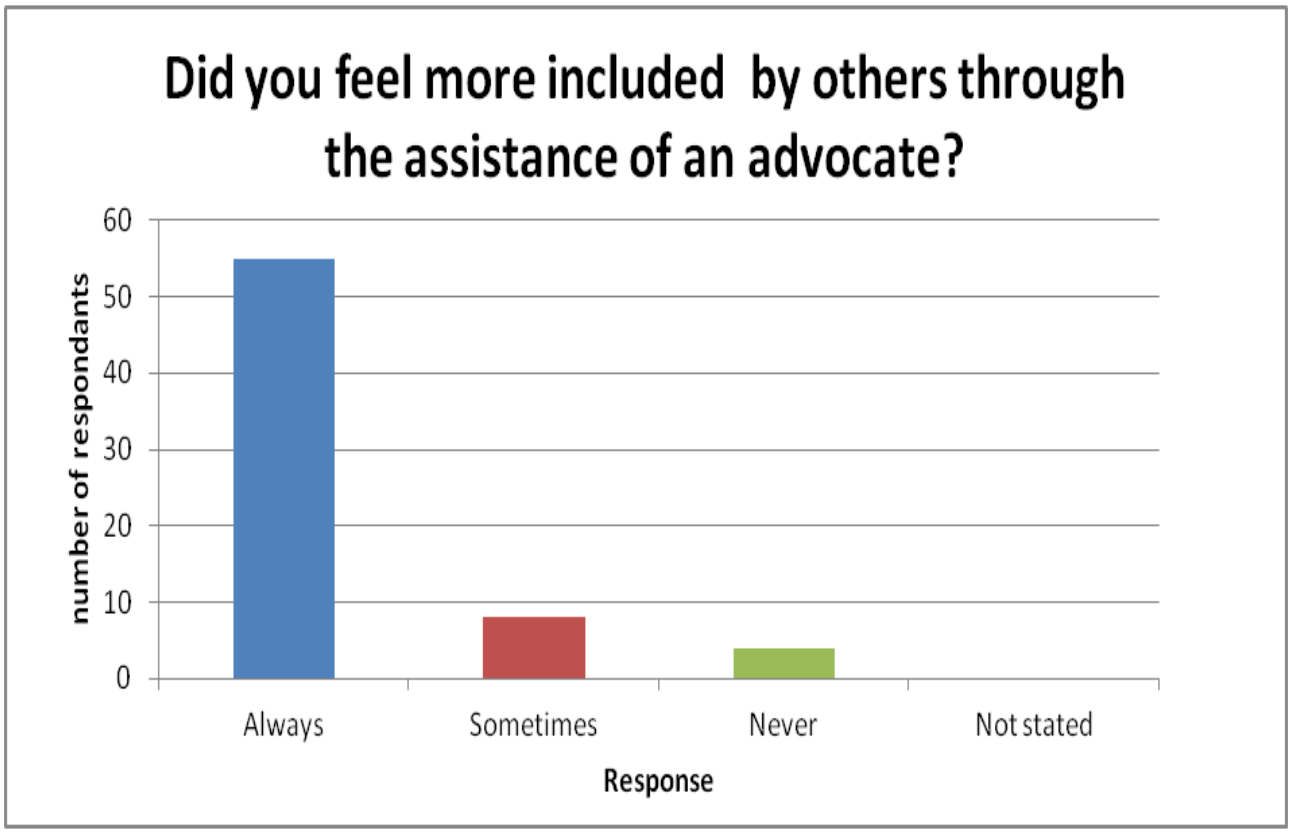


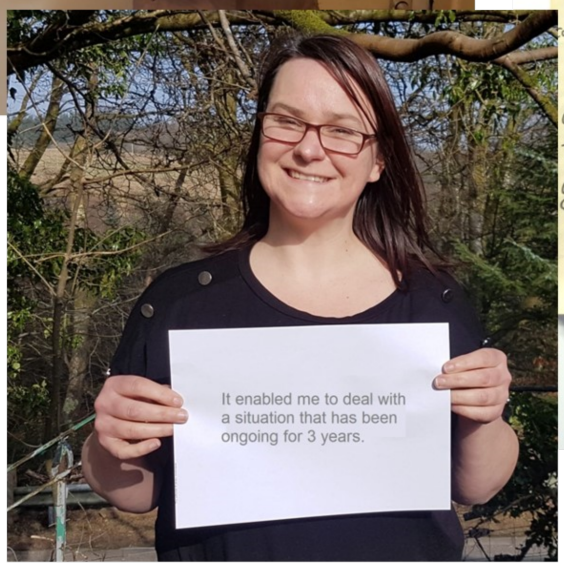
Figure 14: After their advocacy journey had been completed, clients were asked if they felt more included by others

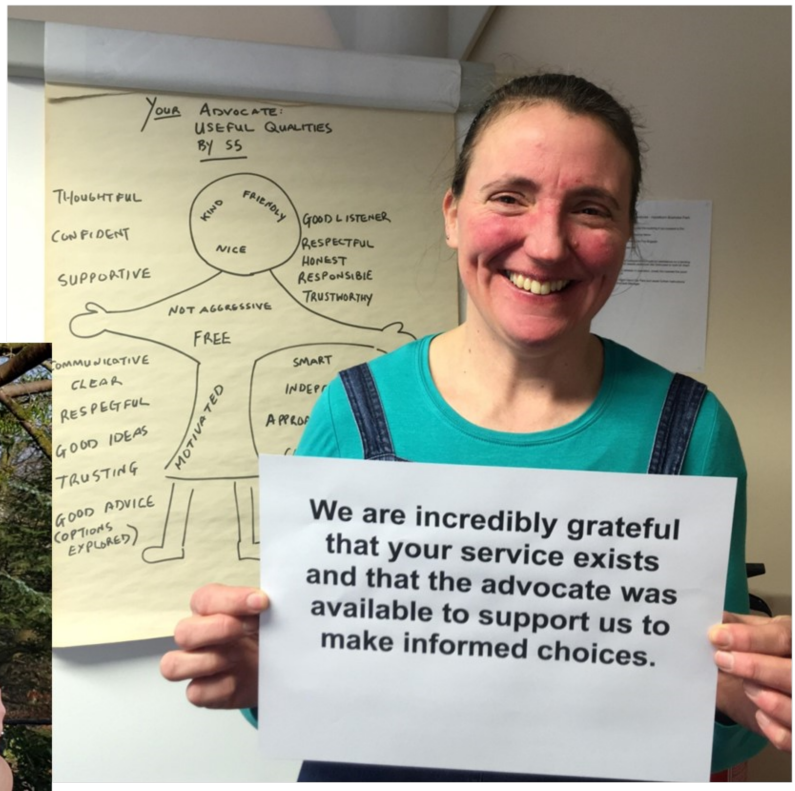
Her efforts have made a long term difference

I didn't know which way to turn before I got the help and support offered so thank you for the work you do.

I could not have coped without them.
Big big thank you

I was amazed how good this service was. Has helped me so much


It enabled me to deal with a situation that has been ongoing for 3 years.


YOUR ADVOCATE:
USEFUL QUALITIES
BY SS
THOUGHTFUL
CONFIDENT
SUPPORTIVE
KIND
FRIENDLY
NICE
GOOD LISTENER
RESPECTFUL
HONEST
RESPONSIBLE
TRUSTWORTHY
NOT AGGRESSIVE
FREE
COMMUNICATIVE
CLEAR
RESPECTFUL
GOOD IDEAS
TRUSTING
GOOD ADVICE (OPTIONS EXPLORED)
MOTIVATED
SMART
We are incredibly grateful that your service exists and that the advocate was available to support us to make informed choices.

Client Feedback

1

84% of clients

Found it helpful working with an Advocate

2

98% of clients

Found that their advocate treated them with dignity and respect

3

88% of clients

Said that their advocate supported them to think about their self management plan

4

84% of clients

Felt better listened too and more included by others through the assistance of their advocate

5

94% of clients

Would recommend Advocacy to others

Our New Project:
Living Well Long Term Condition Project Helensburgh

Our new Living Well LTC advocate Jane Rolling with Team Leader Argyll & Bute

Future of this project

The Service is in the process of making its final steps through the funding from the Health and Social Care Alliance. The learning gained, and the connections made across the area will not be lost. We will continue to work closely with a wide range of HSCP Staff and aim to have a greater visibility in the community whilst ensuring that our Service can continue to work with those in need.

The commitment and desire to see this project re-launch itself with additional funding is significant. We will continue to look at all possible sources and work to encourage the HSCP to see the benefit of advocacy for people with a LTC. We are passionate about ensuring the people in Argyll & Bute who are most vulnerable are offered advocacy and we will endeavour to encourage others to make this a priority.

New funding:

We have recently received funding from the Argyll and Bute HSCP Self management fund to provide LTC advocacy in the Helensburgh and Lomond area of Argyll & Bute. We will be working closely with the HSCP and LiveArgyll to provide Advocacy and support to access self management techniques, pain toolkits and living well strategies.

We remain positive that we will receive funding for the wider area of Argyll & Bute for LTC advocacy and will continue to investigate future funding.

We believe that everyone who is struggling to be heard and whose human rights are being imposed on should be able to access independent advocacy regardless of any “labels” or health conditions.

Independent advocacy is about addressing any imbalance of power.

Further information links:

Find out more about independent advocacy and code of conduct about how we work

Organisation	Website	Contact details
SIAA	https://www.siaa.org.uk/	0131 510 9410
Health and Social Care ALLIANCE	https://www.alliance-scotland.org.uk/	0141 404 0231
Argyll &Bute HSCP	www.argyll-bute.gov.uk/health-and-social-care-partnership	nhs.abhscp@nhs.net
ABAN	www.argyllandbuteadvice.net/	housingadmin@argyll-bute.gov.uk
ALISS	www.aliss.org/	hello@aliss.org

Humans of Scotland eBook from the Alliance - Short stories from individuals living with Long Term Conditions

https://www.alliance-scotland.org.uk/blog/resources/humans-of-scotland/

Thanks and acknowledgements

Huge thanks goes to the Health and Social Care ALLIANCE for supporting our project. Without this funding we would not have been able to support these 380 clients with Long Term Conditions.

We also must thank all the organisations and individuals across Argyll & Bute who worked with us to make this project a success.

Long Term Conditions Team

Argyll & Bute HSCP

MS Argyll

ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

Community Organisations

The people of Argyll & Bute

Community Education

LAAS Board and Volunteers

A&B Council

The individuals who accessed our LTC Project

Third Sector Organisations

LAAS Staff Team

Left to Right: Our LTC advocate Annie, with Core Services advocate Ann and Mid Argyll volunteer Sharon

You can take at look at our series of videos on our Long Term Conditions Project here:

http://laas.org.uk/2019/ltcproject/

More information about LAAS can be found on our website and on our Facebook and Twitter pages

@LAASAdvocacy

Some of our Core Service and LTC staff from across Argyll and Bute

Lomond & Argyll Advocacy Service

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Aros, Blarbuie Road,
Lochgilphead PA31 8LE
Tel: 01546 606056

Cowal & Bute
Riverbank Surgery,
Kilmun PA23 8SE
Tel: 01369 840250

Oban & Lorn
15 Lochside Street
Oban
PA34 4HP
Tel: 01546 606056

Kintyre Office
34 Hazelburn Business Park,
Millknowe
Campbeltown PA28 6HA
Tel: 01586 553428

Helensburgh/Lomond
LAAS Head Office
155 Glasgow Road
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New LTC project Helensburgh:
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