

Independent Living Initiative steering group ...

...involving people from Aberdeen City and 'Shire

“The next steps for Self-directed Support”

Thursday 12 November 2009 from 10am – 3pm

Margaret Blackwood Housing, Raeden Court, Aberdeen

a Self-directed Support event

facilitated by Grampian Opportunities Voices for Change project

<p>Aberdeen Disability Advisory Group</p>		
		
	<p>Learning Disability Group of Aberdeen</p>	

An Independent Living Initiative Steering group event involving people from Aberdeen City & 'Shire with support from Grampian Opportunities "Voices for Change", Aberdeen City Voluntary Sector grant, Lloyds TSB Foundation and Awards for All grants

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The Independent Living Initiative (ILI) Steering group became Aware of the fact that although Direct Payments and Self-directed Support were expected to play a major part in the new way forward most people did not fully understand the proposals or the legislation

In light of this situation the ILI took the decision to hold a seminar for interested groups and individuals to help bring clarity to the area and hopefully empower people to fulfil the aims and objectives behind the legislation to enable people to live enriched, independent, flexible lives as part of the wider community.

We wish to extend our thanks to the Scottish Government for their support through the participation of Kenneth Pentland and Chris Raftery, members of the government's strategy group. We must also thank the Dp Caledonia Team and Aberdeen City Council in the shape of Jim Currie for their participation.

Rhona Kemp

Chairperson

Independent Living Initiative steering group

Independent Living

The purpose of the steering group is to initiate the setting up of an Independent Living Initiative involving and serving the people of Aberdeen City and 'Shire.

By Independent Living we mean disabled people of all ages having the same right to freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

Adapted from the definition by Independent Living in Scotland August 2009
<http://www.ilis.co.uk>

Self-directed support

Self-directed support has a significant role to play in the future of enabling people to live independently. This pre-consultation event provided an opportunity for people from Aberdeen City and 'Shire to meet with members of the Scottish Government Self-directed Support team. An opportunity to inform future strategy by sharing experiences and "*having a voice*" on what works, what could be better and suggestions for the way forward.

Key messages from discussion groups:

(KM) Self-directed support

Individualism

Right to choose

Mainstream

Respect for own rights

Information for all

More disabled people need to be involved at Government and committee level – people need to be asked what and how things should be tackled.

(DC) When we define Self-directed support it should be about controlling life's direction, with choice about the level an individual wants to manage the support they receive. Above all it's about choice.

(JP) People who use services should have freedom and confidence.

(CR) For all the good talk the actual reality is very different.

(RK) The questions in the assessment are wrong, a new list needs to be drawn up and disabled people involved. Disabled people need to be more in control.

The true meaning of Self-directed Support

The term Self-directed Support in its simplest definition should simply mean a person, their relatives, friends, and wider support network determining the direction of the individual's life.

At present there is an illusion that in order to direct their own support people must be able to be an employer, an accountant, and have an understanding of employment law, health and safety, and human resource issues - but after dealing with all this, there appears little time for living life.

Society doesn't expect young people to leave school and become a chief executive in a company right away. It does however appear to expect disabled people to either accept the basics from local authorities or go it alone and turn their home and life into a small business. If people could become apprentices in independent living maybe there would be a higher up take in direct payments and the Independent Living funds.

It is apparent that many local authorities underestimate disabled people's abilities and their desire (with the right support from others) to direct their own lives - a right which seems to be overwritten within a culture of eligibility criteria and risk assessment. People have become conditioned to a fear of taking risks, and this is perhaps why it can be easier to cope with disability as a child, as one has not yet learned the feeling of fear.

On the same point services need to be joined up to allow for a smoother transition from child to adult services. The minute people do not fit society's 'norms' is the same time they are treated differently and thought almost unfit to be equal citizens - systems then control their very existence and such systems de-personalise people .

If people had control over directing their lives, resources would be used more effectively, as people are the best judge of their own goals and life plans. Even people with profound complex learning disabilities have ways of communicating with those around them and thus have a way of directing their own lives.

Denise Cromar
12.11.2009

Independent Living Initiative Steering group

... involving people who use services in Aberdeen City and Aberdeenshire

The Next steps for Self-directed Support

Self-directed Support (encompassing Direct Payments) is when individuals receive funding to buy some or all of their community care support, instead of receiving services arranged by their local authority.

The Scottish Government is committed to increasing the uptake of Self-directed Support in Scotland to support and empower disabled people to live in the community and lead more fulfilling, flexible and independent lives.

You are invited to attend

“The next steps for Self-directed Support”

on Thursday 12 November 2009 from 10am – 3pm

Venue: Margaret Blackwood Housing, Raeden Court, Aberdeen

This “Independent Living Initiative” event is a unique opportunity for people in Aberdeen and Aberdeenshire to have their say on what they believe needs to happen to make self-directed support a reality.

Representatives of the Scottish Government Self-directed Support Team will be in attendance and they want to hear your views on the next steps for Self-directed Support Policy.

make contacts - have your say - exchange views and information

To book a place contact:

Grampian Opportunities Tel: 01467 629675

or Email: info@grampianopportunities.org.uk

Programme

Independent Living Initiative Steering group

... involving people who use services in Aberdeen City and Aberdeenshire

The Next steps for Self-directed Support

Programme

Thursday 12 November 2009 from 10am – 3pm
Margaret Blackwood Housing, Raeden Court, Aberdeen

10am -10:30am	Registration and Coffee
10:30am -10.45am	Welcome and Introduction
10.45am - 11.30am	Dp Caledonia – the role of a support organisation
11.30am -12 noon	Jim Currie - Self-directed Support in Aberdeen
12 noon – 1pm	Lunch and Networking
1pm – 2.15pm	The Way Forward workshops
2.15pm – 2.45pm	Questions and Answers
2.45pm – 3pm	Next Steps
3pm	Close

make contacts - have your say - exchange views and information

<http://www.selfdirectedsupportscotland.org.uk>

<http://www.ilis.co.uk>

Self -directed Support Pre-Consultation

Thursday 12 November 2009, Aberdeen

Independent Living Initiative Steering Group Event

PART 1: SELF DIRECTED SUPPORT – BARRIERS

1. Policy and Guidance

- Does current policy go far enough?
- How helpful is Scottish Government guidance?

2. What are the current barriers to uptake?

3. How could these be overcome?

PART 2: SELF DIRECTED SUPPORT – LEGISLATION

1. Need for legislation

2. Implications of legislation

.....

You may wish to discuss:

- How broad the definition of SDS should be
- Should direct payments be an opt-out rather than opt-in?
- How can carers benefit from direct payments - for their own assessed needs? For the person they support?
- Should all local authorities provide user led support organisations? How could this be funded?
- How should budgets for individual service users be allocated?
- How can we measure real choice for people directing their own support?
- What should the Scottish Government monitor to assess progress with SDS?

Group discussion feedback (1)

1. Self-directed Support – how broad should the definition be?

- Same Hymn Sheet
Simplifying definitions for Self-directed Support → this will help uptake
- Self-directed Support **definition should cover all terms** i.e. individualised budget, Direct payment
- **Everyone is individual** – people should be aware before any decisions are made. Respect for individuals own rights.
- **Choice** over method of delivery – not everyone wants Direct payment, too much work need full range of options
 - residential
 - agency
 - employer
- Change for changes sake
- **Assessment** is only as good as the person carrying it out.
 - **Process** of assessment needs to be respectful and carried out by appropriately trained people.
 - **Independent assessment**
 - **Advocacy** driven assessment if required
- Direct payments only work if the person has **enough back up**.
- **Emotional support** required for Direct payment users.

2. Should direct payment be an opt-out rather than opt-in?

- Yes – agree
- Need to **raise profile** → **Information** – *should there be a national campaign?*
- How do people know? Requirement on Local Authorities to produce a leaflet on services offered.

3. How can carers benefit from Direct payments – for their own assessed needs? For the person they support?

- **Benefit** by flexibility
 - Plan day
 - In control → **Peace of mind**
- Could do with:
 - **more support**
 - **payment for relatives**
 - **may have given up paid work**
 - **safeguards** required
 - emotional support – **someone to talk to**
- **Savings** – if support by relative but not able to use in a different way.
- **Freedom** to do what you want.

4. Should all local authorities provide user led support organisations? How should this be funded?

- Use service users – they know.
- **Funded** by Local Authorities.
- **More security if funded by Scottish Government.**
- Should be across Scotland.
- Local Authorities should have more **internal quality monitoring systems**

5. How should budgets for individual service users be allocated?

- Terminology – service user! Don't like term.

Group discussion feedback (2)

1. Self-directed Support – how broad should the definition be?

- Needs to be looser and broader. Take into account **Independent Living Funds**. Question: *Do you want to be a manager before you have lived your life?* Could **enhance life chances**.
- Booking holidays a real problem. **Advocacy role** very important for people with learning disabilities. Social work departments taking on responsibility they know little about!
- **Take out the bureaucracy and focus on people's decisions.**
- Direct Payment should be **supported by grass roots organisations** e.g. independent living initiative.

2. How should money be allocated?

- Does anyone understand how an assessment a social worker carries out relates to money paid out?
- Resource Allocation System (RAS) is used by “In-Control”
- Self Assessment: *Question: How can an assessment be done without the individuals voice being heard?* Social Worker's alone just don't know. Single Shared assessment was designed for older people and very focussed on care not risks, opportunities or outcomes.

“Don't want to be made better – just to live my life.”

3. Who is the boss?

- **Really listening** to people's choices.
- **Split-funded** time between council funded time and Independent Living fund money
- More use of **circles of support** – not just social work led assessment. Care managers can't assess the person's needs better than the person themselves.

- Use experience coming out of England.
- **Go for best value outcomes.**
- People know how they want to spend their own money – **give us a voice!**
- **Embed person-centred planning/ essential lifestyle planning into policy- draw on people’s networks and circles of support in assessment.**
- Use people with disabilities as consultants. Look at examples like Barking and Dagenham, and national **good practice.**
- **Lack of support** for Direct Payments in Aberdeen City.
Questions:
Why doesn't Aberdeen City not have a support organisations like Dp Caledonia?
Will an Independent Living Initiative be able to position themselves to do this?
Is there a need for Grampian Service Brokerage again?
- Need **choice of support service(s)** to help you with Direct payment and spending your own money

4. How can we measure?

- Not just **quantative measures**
- **Fulfilled lives**
- People **not having to complain and campaign.**
- Self-direction does not necessarily mean **man-management or financial management.**
- **Not having to run the service to get the service.**
- **Reduce the complexity** and work involved in Direct payments and uptake will increase.
- If it didn't involve service users in **employment law** it would be easier.
- **“Homes” not workplaces!**

5. How can carers benefit from direct payments?

- **Flexibility** eg support for going on holiday – not respite units. Lots of constraints and barriers to getting carers to go on holiday.
- What “**special circumstances**” are waived for employing close friends and family members? Not one single example of exception for paying a relative for support in this area.
- **Question: Why can't you reimburse a volunteer for being out of pocket?** This would work out as less cost than a salaried carer plus subsistence – but as things stand a friend / volunteer can't be paid for a meal with you. [example given that paying for a season's ticket for a companion to attend football matches with a disabled person can be done in England]
- Problem: Direct Payment has to be for assessed needs.
Move to outcomes not just hours of assessed support
- Problem: Demands of managing a big package can reduce the capability of parents and family carers to **maintain caring role** if they don't have the right support.

6. Should direct payments be an opt-out rather than an opt-in?

- No-one should be made to have Direct payments but people should be **facilitated to direct support** the way they want.

Questions: Why isn't the Council consulting more actively? Who has access to the commissioning strategy?

- Independent Living Initiatives need to be **primed with funding**.
- **People's lives don't stay the same.** Future planning is important. Needs don't stay the same. Taking money back if under-spent → but hard to see how you would get money back quickly if your circumstances changed.
- **Funding** “short-termist”. People need to see budgets over lifespan. Service users are occasionally under spent, but never allowed to overspend!

- If the Government is assessing Self-directed support uptake... get feedback from service users on how easy it actually is to get things set up. Put questions out to people who haven't taken up Self-directed support – get real feel for the barriers. Government should turn around terminology and talk about choices and life direction NOT running a mini business and paying your own staff.

Questions: Is the stumbling block “risk aversion”? Is the stumbling block “big Government”? Have there been too many constraints on Local Authorities which have put up barriers to creativity and flexibility in directing support?

Group discussion feedback (3)

Way Forward

- Timescales
- Access to information
- Choice/ consistency of carers
- Change of attitude
- Social workers committed to client control
- Personal Assistant's as mentors
- Less red tape
- One-stop-shop for all care needs
- Health and Social work communicating
- Learning / day service
- Full access to care package (open and transparent)
- Flexibility / Freedom / Creativity / Confidence / Outcome based
- Less emphasis on costs and tasks
- Client to manage process
- Allow progression → review outcomes regularly / request

Barriers

- Levels of support available
- Lack of information
- Direct payments not offered by all care managers
- Being an employer
- Lack of consistency
 - different carers
 - different standards
 - care managers
- Limitations as to what can / can't be done
- Social needs in care plan
 - care plan content should consider wellbeing
 - need to be more aspirational
- MONEY
- Health and Safety used to prevent people doing things
- Red tape
- Lack of training – social workers etc.
- Recruitment
 - size of package
 - rural locations
- Person (service user) not at centre
- Inflexible

Group discussion feedback (4)

The Scottish Government want to get as much information from people both challenges and solutions. What are current Barriers?

- In Aberdeen (and shire) .. Council are slow in relation to Direct payment – both in **putting in place and letting people know** about Direct payments.
- **Council workers don't understand** about Direct payments – added to this, staff can be cynical about Direct payments – creating more work – staff don't offer Direct payments and how it's described is not positive.
- Social workers don't feel confident in applying Direct payments. **Social Work feel they are losing control.**
- Social worker core skills can be very limited in **understanding** the issue in general which in turn limits the approach to Direct payments.
- Little **communication** with the Council – need strong leadership - really need positive examples of Direct payment and Self-directed support.
- **Leadership** – senior leaders buy into Self-directed Support idea but middle managers often act as a block.
- **Local implementation** is often more restrictive
- Not a big difference between city / rural
- Audit trumps care – finance team are example as a controlling factor. Practice of “no surprises” adopt this – applies to **claw back**.
- Issues about acting as and employer – for PA fund only allows one worker, but in an outcome focused / personalisation environment - role of control is to focus care not necessarily manage it. In this scenario facilitation should support total arrangements between individual budget holders.
- Experience suggests Direct payments are getting more tightly monitored rather than less.
- Major issue is what is being said doesn't reflect reality.

Group discussion feedback (5)

- Current policy does not go far enough, it is too restrictive for the client and too open for the council or other provider to interpret as they wish.
- Guidance provided should be clear and easy to understand, at present we do not believe it is worded correctly.
- Basic principles need to be laid down. We believe the Scottish Government should introduce ring fencing to ensure money intended for Direct payments and Self-directed Support are not re-directed into other areas.
- Greater rights for disabled people will help overcome some of the present barriers and restrictions.
- It is time local authorities put the individual first and the money second.
- At the present time local authority contracts always seem to go to the cheapest provider, this is against the instructions in the legislation where it is stated they should be awarded to the one who shows they are providing best value.
- There should be no need to be reassessed when a person moves; one assessment should cover all of Scotland. Basic elements should cover all of the country from the Borders to the Orkney's or Shetland. Outcomes from clients support should be the same, while acknowledging that funding needed could be different due to distance and travel costs.
- Surveys should be done every six months with uniform consistent questions being asked so that comparisons can be done - if and what trends appear then these should be taken into account and used to adapt legislation if required.
- At the moment carers hours are all about "Personal Care" and the bare essentials of living assistance. If someone lives alone they should be allocated time and assisted social time.

Questions and Panel discussion

General questions:

Questions were raised about assessments and the need for people to understand what they were being assessed for, and the implications of decisions made. It was recognised that Dp Caledonia was not funded to help people prepare for assessment, but provided a service to help people use Direct payments to meet their assessed needs. It was noted that on a visit to Glasgow Centre for Inclusive Living support to prepare for assessments was one of the services they were funded to provide.

Lack of clarity about eligibility, assessments and decision making → Fear

During later discussions the right to appeal or challenge decisions was highlighted as an extremely difficult process.

Two hours per month was identified as the level of additional support people may have to coordinate their care package. It was noted that this did not cover the day to day challenges of managing a package, e.g. help if a carer doesn't show, help coping with feelings of anger and the emotional effect of depending on others. Sickness cover was discussed and the idea of a register of relief staff explored. The Glasgow Centre for Inclusive Living is reportedly funded to hold a list of care staff. Dp Caledonia can give ongoing support but are not funded to support at this day to day operational level.

Monitoring standards of service was considered - Dp Caledonia is not registered with the Care Commission but operate to a Service Level Agreement (monitored by Commissioning team contracts officers)
For support workers recruited by disabled people, they recommend the use of a probationary period to give employer and employee time to consider the appointment.

Questions as to why family cannot be paid if they cover for workers who don't show etc. was raised and it was noted that family can be paid in exceptional circumstances. Rural areas where no carers can be found was considered to be the type of situation where this may be approved, but there was limited information available on what was an "exceptional circumstance".

Participants were informed that Aberdeen City Council Commissioning strategy would be out for consultation and issues such as self assessment and the cost of services (budgets) were covered in the draft strategy.

Questions to the panel:

Q: Assessed care needs can be very basic, but there are people who need social hours to get out of the house. This is important to their health and wellbeing but who decides?

- Assessment of need is dependent on the judgement of social work, but it was felt that moving to a more outcome focus assessment should ensure a more holistic assessment of need.
- Eligibility criteria reflect budget restrictions , but evidence shows people using Self-directed Support spend it better than Councils – once that happens, and budget savings can be made, it is hoped the tightening of eligibility can be loosened up, with the option to look at more holistic provision
- People need the right access to the right resources when they need them. It is important that outcomes are not determined for you, but that the role of the Care Manager may be to assist you to determine these.
- Community Circles are a model of support used in different areas - this places the individual at the centre. Choice should be inherent to the outcome but who better to know than the individual.

Q: There are different budgets and some can come with different restrictions. Supporting people money is one that is no longer ring-fenced and Local Authorities can decide how best to use different budgets. How can different budgets be used for the benefit of individuals?

- Self-directed Support is a mechanism that supports packages of care that may need less money. This is one of the reasons it is critical that people can direct their own support, because of the attention to detail they can give to working out their own priorities.
- The arguments are not about money, but about choice, and how that money is used.
- Basic human rights transferred to disabled people

Q: Why do people who have already been assessed as eligible for Disability Living Allowance need to be assessed and reassessed for services?

- This can be linked to the allocation of money, and look at changing criteria/ eligibility. Some people who were eligible for a service may no longer be eligible, as criteria is tightened.
- It is believed that Self-directed Support will deliver more – more control and savings will lead to more sharing of money available

Q: Taxi card was taken away in Aberdeen City from those on the higher rate of Disability Living Allowance. These are the people who are recognised as having the higher level of mobility needs, and the group which may also have more trips to hospital, GP etc and less choice of travel options. How can this be right?

- Recognised that some of the decisions made have not been fully thought through and some decisions may have cost the Council more – because people have needed more assistance.
The Council does need to manage money well and consider how to save because they cannot continue to spend money they don't have

Q: Perhaps if they had consulted on the decisions this could have better informed decisions?

- Need people to help decision making

Q: Self-directed Support lead to a number of issues where people are responsible for themselves. This raises questions about risk decisions, for agencies carers and employees working with a client.

- Health and Safety issues, Legislation, Training and Guidance/ best practice examples are all areas which need consideration. Risk enablement is a difficult issue, one of great concern, and one which it isn't always possible to legislate for. It is a wider issue, at times a cultural issue and linked to people being scared of making mistakes – fear of Government and fear of the Press.
- Learning from mistakes and support to learn from mistakes –as happens in life for everyone else is an important part of the process.
- There followed a discussion on a statement on principle within legislation and it was considered that there may be a statement of principle within the strategy. It was highlighted that we are not living in a nanny state and a sensible approach to informed decisions on risk was needed.

- Self- directed Support; including Direct payments for social care is linked to support to enable people to access the same services as everyone else. It is designed to be all about enabling people and getting away from risk aversion.
- Eligibility criteria and risk assessment are taking away from living life and just being who you are. People need to be recognised as individuals who want to be involved in their communities - not something to be frowned upon. Assessments and rules should not be used as an added restriction – people are just people.

Q: One plea was the suggestion that part of the solution lies in self-employed PA's . This can simplify the employment element for a disabled person and could be built into a contract / employment law. Can the position on Self-employed PA's be clarified?

Q: The iLi steering group are trying to get up and running - when can we start to see Self-directed Support taking off in Aberdeen.

- At Government level a Self-directed Support strategy is currently being developed.
- Aberdeen City's Commissioning Strategy will be out very soon with a programme of consultation. Once adopted then this will become a working strategy and people will be able to hold the Council accountable. (Jim Currie can provide an email link to the draft Council strategy)
- It was suggested that it is not only an issue of accountability, and the issue is often more about approachability, with some people more approachable than others. It was suggested that there was a need for openness and a willingness to let people come on board and discuss matters. People are able to be involved but formal procedures can be difficult to access.

Q: What help is there when things go wrong? Mechanisms are often not in place or sufficient when things go wrong. Local Authority procedures can be too long winded, and where do you go to for support? It is difficult to fight an Authority; there seems nowhere to go with your concerns. There needs to be strong mechanisms in place - like advocacy, but there are not enough to go round.

- The limited number of advocacy services was recognised.

Attendance list

Independent Living Initiative Steering group

... involving people who use services in Aberdeen City and Aberdeenshire

The Next steps for Self-directed Support

Thursday 12 November 2009 from 10am – 3pm

Venue: Margaret Blackwood Housing, Raeden Court, Aberdeen

	Name	Organisation
1	Jim Currie	Aberdeen City Council
2	Rhona Kemp	Aberdeenshire Disability Action
3	Ian Kemp	ADA support
4	Angela Forbes	Advocacy Service Aberdeen
5	Jackie Mathers	C-I-C
6	Belinda Gillespie	C-I-C
7	Susan Bracken	C-I-C
8	Linda Keith	C-I-C
9	Sandra Turnbull	Computers and Integration
10	Alastair Williamson	Disability Advisory Group
11	Andy Thomson	Disability Advisory Group
12	Joanne Scott	Dp Caledonia
13	Denise Robson	Dp Caledonia
14	Tracey Loakes	Dp Caledonia
15	Kevin McCahery	Future Choices
16	Kimberely McCahery	Future Choices
17	Gladys Annand	Future Choices
18	Denise Cromar	Grampian Opportunities
19	Edwina Smith	Grampian Opportunities
20	Emma Rennie	Grampian Opportunities
21	Linda Singer	Grampian Opportunities
22	Barbara Lamb	Grampian Opportunities
23	Andy Strang	Grampian Opportunities
24	John Picken	Grampian Opportunities
25	Alastair Minty	Inspire
26	Linda Eddie	Inspire service user
27	Gordon Edgar	Joint Futures Group
28	Suzanne Nesvadba	Margaret Blackwood Housing
29	Dorothy Strachan	Momentum
30	Karen Vass	Momentum
31	Tracey Bell	PAMIS

32	Kenneth Pentland (speaker)	Scottish Government Self-directed Support Team
33	Chris Raftery	Scottish Government Self-directed Support Team
34	Jeanette Sutherland	carer
35	Helen Sutherland	
36	Helen Calder	
37	Margot Fairclough	carer
38	Pete Richmond	Aberdeen City Council

Apologies:

Ian Stones, Learning Disability Group of Aberdeen

Heather Gibson, Aberdeenshire Disability Action

Euan Burr, Grampian Opportunities

Ray Strachan, Dp Caledonia

Agnes Stewart, Aberdeen Action on Disability

Barclay Bisset, Aberdeen Action on Disability

Elaine Grant, C-I-C

Vikki Smith, Momentum

Sheena Thomson, Aberdeenshire Council

make contacts - have your say - exchange views and information

<http://www.selfdirectedsupportscotland.org.uk>

<http://www.ilis.co.uk>

***38 people attended representing 14 different organisations/ agencies.**

***19 (50%) are unpaid carers or have personal experience of disability.**

Membership of steering group

Independent Living Initiative steering group ...

...involving people from Aberdeen City and 'Shire

Current membership:

Aberdeen Action on Disability Ltd

Aberdeenshire Disability Action

Direct Payments Caledonia

Disability Advisory Group for Aberdeen

Future Choices

Grampian Opportunities

Momentum

The Learning Disability Group of Aberdeen

Advisors from:

Aberdeen City Council

Aberdeenshire Council