

THE SAME AS YOU RECOMMENDATIONS YEAR 2000 AS VIEWED AND
REVIEWED IN THE YEAR 2010 FOR SAY 2020 VISION

SAY Inverness



a Same As You local implementation group

SAY Inverness (formerly S.A.Y L.I.G Inverness)

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The SAY - Same As You original recommendations

As the original LIGs were set up to think of or help with projects and services to fit the SAY recommendations, with the help of the Change Fund, we added the word SAY to LIG to reiterate our purpose to onlookers. We have now recently dropped the word LIG to become part of a bigger SAY Highland thus SAY Inverness. We also decided to look at the original SAY document and use it as a learning tool for ourselves, being a mix of Staffs, Experts, Carers, Voluntary and Public, and use our easy read outputs to help train other Experts in the future.

We use the word 'Expert' to mean a person with a learning disability and/or autism spectrum as they are the Experts of the implementation of their services on the ground. The following pages are set out with Expert friendly pictures in an easier read version, with a more official explanatory version following on the reverse side for staffs.

We went through the original SAY-same as you document (2000) and took out to use and understand:

- **the 29 recommendations which we numbered as such and personalised them to Highland by using the words Highland Council and NHS Highland**
- **the 11 recommended overarching recommendations which we felt related to strategy and numbered them A-K and again personalised them to Highland where local providers were mentioned.**

We, the Inverness Same As You inverness, heard that people in the other SAY groups, did not know what was in the SAY, or had never seen it or been trained in it and not all Experts with Easy Read versions had been helped to read it.

SAY Inverness looked at each recommendation separately at our round table meetings, we read out and explained and asked each person what they thought it meant then what the service should look like. We use quotes to show where our knowledge is now, even if it is wrong and write a paragraph to show what, collectively, we thought the recommendation should mean. We then wrote what we thought the challenges would be in Highland and asked Experts for a story to fit what the recommendation might look like to them and we asked the table for a good/poor story of how the recommendations in practice, had really looked like, as possible learning points.

We have allowed space for local contacts to fit the Experts own needs and their own region. These sheets are mostly from people based in Inverness areas, so are limited but as most change happens at an Inverness level before being shared, and changes in other areas are harder to hear about in Inverness, we have shared these sheets with other SAY groups.

Reviews

2003 make my day

2003 employment

2004 home + easy read

2004 hospital + easy read

2006 SAY review +easy read

**2010 Who will review the SAY and who to
SAY contacts
SAY web
E-SAY**

A. To be included in community life, in education, in leisure, recreation, employment, mainstream services, day and night (Less specialist)

Experts should be included in the planning of all aspects of community life. It should not be seen just as how Experts access these places but how Experts in all aspects of these facilities community are involved and included

STORY / \

An organisation set up to follow SE-scottish executive action saw that it had not included Expert adults or children. They have included this aspect to find ways of including groups with needs. The consultation groups that have been advertised from this organisations network also said they would provide accessible formats for Experts so that they can take part.

STORY / \

An organisation was set up to look at one aspect of Experts lives. They asked that a wide range of settings that Experts were in were to be included. Once the consultation started one group was not happy that another group was also asking Experts for their views.

Because of the competition for funding, some voluntary groups find difficulty in sharing work as funders focus on proving single goals thus increases inequity of Experts through their decisions or access to one group over another. There is a danger that Experts are seen as a single focus group thus we concentrate on designing an access point for that group but then tested when Experts want to access a mainstream service out with their label which of course is the aim of the SAY-same as you.

CHALLENGE: How to incorporate SAY-same as you with the DDA- disability discrimination act to community planners? How to allow cross access points between mainstream services and Experts services? How to allow advertising of those within Experts services?

We asked a selection of LIG members what they thought:

'you need to tie in staff needs to Experts reviews and where is there a carer social worker' 'staff too scared to let us go out' 'it's about time and they have to be back in time not us' 'I want to help at a nursery but staff say no, I don't know why'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

B. To improve, reshape, reorganise services and to aid/promote better understanding of people with Learning Disabilities and their needs, to meet this.

We wondered how recommendations A to K were graded, was it random, by importance or was an accessible order needed? We see the SAY points lettered A to K, like a structure to a bridge as we feel this point especially underpins this. These points have to be done and strong before the SAY points that are numbered 1 to 29 can and in ways that reach all of us. This point B above should be done not, for us or on our behalf but with the Experts especially when considering adults with Asperger Syndrome. Is it really acceptable that a parent carer speaks instead of a 40year old person? We don't do this in mental health or learning disability services automatically. Having ASC is not an excuse to exclude but an opportunity to train up and challenge the workforce and yourself

STORY / \

Everybody has to understand SAY and change. How is the SAY - same as you, given to public and front-line staff like supporters. We had note of a consultation for a change of service. We asked to be part of it and saw that we would need changes to the consultation before we could take part. The consulters then said they would change their questions for us to join in. Because it then became clear there was a hidden group within L D, they gave that group an extra meeting to allow the communication to meet the groups needs and access points

Challenge: Everybody has to understand SAY-same as you.

Everybody has to change to include the SAY-same as you. The public need to know about the SAY-same as you. Learning Disability is taken as holistic in its meaning, thus all LD is the same with no recognition of ASC or the different needs of ASC. Yet ASC is recognised in the SAY. If LD is the disability then is ASC the ability in a person with both diagnoses. Other conditions need to be recognised too within the same person.

We asked a selection of LIG members what they thought:

'staff say I am not allowed to vote' 'we need help to stand for our rights' 'some people can not speak so we have to' 'I help my friend speak (Expert friend)'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

STORY / \

A consultation on a new service for LD-learning disability: Even though it invited Experts and Carers to be involved, it was aimed at those planning for Experts and Carers. The involvement in practice, became resource led thus keeping a service going for those in the service. It missed the access points of implementation and those who could not use it.

C. To enable more person-centred and needs-led ways with the person and give the person better information and where wanted, an advocate, to enable the person's own control and choices in their life.

The SAY means being treated as everyone else and being enabled to make your own decisions to be equal but some Experts need more help to be the SAY and that help might not be equal. This could be down to the availability of the right people and the accessibility/ information/ clarity of some resources. Even though the Same As you is being treated as meaning the same as everyone else, the ability to or involvement in, being enabled to make your own decisions is varied and can end up in Experts having a barrier of not being equal to each other even before being equal in the community

STORY / \

An Expert was showing signs of being unhappy at a leisure group. On talking to him, it was that he had an interest to join a music skills group but as he lived within supported housing, the support was only given to meet group need. But by talking to the Expert, a 'walker' was found to enable the Expert to go to his chosen group.

STORY / \

An Expert was asked to take up a position in a planning group to represent Experts voices. There was found and finance were service led plus supports had no flexibility of an individual Experts needs as resource was led by majority need. The 'hats' that Experts can wear to be included or heard, whether to leisure or forums, is reliant on supports.

Because there seems to be a perception that the LD label means one type of challenge experienced by an Expert, only the most able or supported seem to access SAY benefits. Because the supports needed to enable the spectrum of LD differences are wide, it is difficult to plan for and access a wide enough variety of supports.

CHALLENGE: How to get the type of advocacy that can allow Experts to be given options of what is available and being helped to know what those options consequences might look like.

The criteria to get an advocate can be difficult if autism is involved and different types of communication are needed.

We asked a selection of LIG members what they thought:

'staff know things before we do and don't tell' 'staff keep review minutes' 'how does autism person know' 'I have an advocate' 'my friend helps me' 'the doctor talks to my carer not me'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

D. To improve systems with Local Area Co-ordinators, who co-ordinate support and services, act as a voice, and have a budget to buy new local cost effective services.

They are not care managers and they arrange services and there should be personal life plans if wanted. This could be for a person or a group. The co-ordination should be around the wishes of the individual or group with the needs in mind. The co-ordination should be across all services and community supports being creative and resourceful. The co-ordinators should not be bound by one service type i.e. education and child only or by one service hierarchy i.e. social work and employee position

STORY / \

No story yet as we have no Local Area Co-ordinators. Health and Happiness put in a bid to Highland Council out of the Change Fund 2006 and looked for a lottery fund to meet the rest of the costs for eight posts. The lottery bid process kept changing and use and monitoring of the Change Fund for updates was not clear. Community Connectors were finally agreed and are near the end of their three year fund

STORY / \

LIG's applied to Change Fund for LAC's. A person collected Experts and Carers views but the process of feedback was delayed. It was not Expert friendly and it was reported the final choice could not happen as it would be expensive and it may be seen to be similar to a social work post, the decision processes were unclear and inaccessible

Challenge: who reviews LAC work and do they approach those who have used the service to see how successful or the wider carer, Expert, staff, public who did not use the service to see real success

We asked a selection of LIG members what they thought:

'My dream is to go away to competitions but had to do finding out myself.' 'It's not coming from the co-ordinator but from the Expert or group for themselves.' 'The co-ordinator should listen and must tell the person.' 'Never heard of co-ordinator but I am interested. 'Like a link worker they must listen to you.' 'Not allowed to think for you or get you to do things for them.' 'Some people need co-ordinators to know them first.' 'I have a key worker who does for me; I did not have it as part of PLP-personal life plan.' 'I have PLP and got a booklet from NHS Highland and the men's group to help me.'

We asked other SAY groups [] did they know
[] did they meet it
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E. To focus services on inclusion in the community, personal development, homes in the community, education, employment, personal fulfilment and flexible creative short breaks.

This means less shared living and more personal development for carers and support. Now that the New Craigs folk have moved out and celebrated their move, who is going back to see if the first Experts moved out into residencies, need help to move out or forward? For carers there are not many options to enable a move forward but plenty of counselling and issue groups which serve to keep carers as carers and not see themselves as individuals with potential. This also applies to professional training groups or departments, where is the future work force and where is carer experience valued? There is a requirement for all levels of care support to register and obtain SVQs, yet parent carers do the same job and at transitions have no qualification proof to state their experience. Will the SSSC help, can Highland Council training departments help to include; NHS do include in some courses if asked.

STORY / \

An employment group in partnership with school staff is now working with young people before they leave school. They have adapted PLP tools to help young people see work options before they make a choice. This is helping young people with ASC as well as LD.

STORY / \

A workplace employed Experts but did not help Experts understand the rules and policies of employment or discuss major changes. Policy was seen as something that belonged to able people or 'guardians'.

If Experts are entitled to the same health and safety and legal safeties as everyone else, then we need to challenge the legal to become more easy read and accessible and sit along side the jargon documents with as equal value as any other world language would be. Experts will know then they have rights and can call on them. If the law demands documents in employment or protection to be in legal speak then the DDA should demand the equality and equity.

CHALLENGE: this point is on inclusion and fits the community connector role but also questions how do the wider services and community know of the SAY so this should be a quest for its 10th anniversary

We asked a selection of LIG members what they thought:

'staff decide on where Experts go sometimes' 'my staff ask me' 'I have a good supporter' 'I don't get out, only to meetings' 'I would like to go on holiday' 'groups only go to pubs' 'why are there only group things' 'I have a special bath night with lots of nice things' 'I would like to have friends round but need help'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

F. To have the SCLD-scottish consortium for learning disability providing leadership and advice to agencies and to have someone to act for Experts, Carers and agencies.

This is not a clear point for ASC-autism spectrum condition. The NAS-national society for autism or SSA-scottish society for autism is not visible on their network or at joint events such as the Justice Group Consultation 2010. Do Highland Council provide this? If the SCLD are local, how and where? If the voluntary sector doing this SCLD service what happens when they close? A voluntary compact has been worked on by services and agencies to try to protect the sudden closures of the past, to provide exit strategies and social responsibilities for the Experts LD, ASC and carer community but this can feel like job protection to Experts and carers when finances are squeezed

STORY / \

A local Expert found a buddy to help them attend a central belt consultation on access to justice, and be an ASC representation on major national groups. They managed to get heard and make a change. The Expert formed a and is now asked to advise and represent their joint voices.

STORY / \

A Highland Experts one minute on DVD to represent Highland at a central belt location was hidden by a day of central belt attendees and voices other formats becoming tokens or agenda fillers. Unless you actually travel south, group Experts and carers find it hard to get support and attend and means Highland voices are stifled or controlled.

CHALLENGE: This is about the SCLD providing visible leadership and advice. This they do centrally but in Highland maybe, it is not as obvious as they are in the central belt. We should look at what they provide or how they provide it up here or make it visible in Highland where local services provide this support. Why is accessible format training only to service staffs and why not open it to all work, businesses, and carers? The central belt does this very well.

We asked a selection of LIG members what they thought:

'it's a A9 thing it feels as if groups don't talk together' 'I went to SCLD and spoke' 'I went to SCLD and liked it but I did not know if they have autism on their board' 'SCLD do good courses in Glasgow' 'what is SCLD'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
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G. To have clearer agency roles and inter-agency working, effective partnerships between agencies, professionals, Experts, Carers.

This is a balance in recognition of target and deadlines, need and numbers. This is also about the waiting lists for specialists and having less 'special' specialists and marketing everybody's responsibility to learn. Staff have a right to learn more and 'experts' deserve to be seen when needed. It is difficult to explain pain and waiting. Where communication formats are not considered this becomes a service led service for Experts instead of Expert led, this is seen even in agencies for Experts

STORY / \

There are networks at a day centre and posters on the wall. Parent carers are now involved and other departments in health are starting to come in and consult or plan with attenders groups. A care agency locally has openly invited family carers to a job fair recognising this hidden skill force. This is a first

STORY / \

Who tells Experts about roles and and work people have and do. consultations can target the more able so the more able see more actions. Targets are then aimed at those actions. But then when work or a role is at an end Experts with more needs are either rushed through or missed out or the end product is aimed at the wrong level.

CHALLENGE: there is a move to get services and staff to work together but these are members of the public. Some staff are very professional and do things past tick boxes but others can only work to a tick box so will need time built in to tick box to think of things missed and research. How do private subcontracted services get built in, as their front line are at the more 'public thoughts' end than the Equality and Diversity planner end? Also how do Experts know this has happened as a word such as 'review' may mean a meeting to them so not make a link

We asked a selection of LIG members if they had a Personal Life Plan:

'No' 'what is it' 'I can change my plan whenever I want' 'my supporter asks me' 'I had a map done' 'our clients all had one' 'I look at mine in a meeting at my review' 'I've never had a review' 'Can staff do the actions (training gaps)'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
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H. To help the public become aware and understand Learning Disabilities via an on-going awareness programme.

This is increasing using Experts and carers as trainers or speakers but there is an inequality in 'professional/staff speakers' pay and Experts, carers 'non pay'. Awareness inequality exists from disability to disability, groups and time limited project funds so when they stop the community wonders where the Experts are so there is no time to build bonds or the pay gap. Community Connectors need to make more use of community members and buddy to mainstream into community groups. The term volunteer gets used as a way to gap fill then a waiting list for volunteers grows, Experts wait for their calls or 'their turn'. If, re the Health and Safety and Adult Protection Acts, there are 20 people in a mainstream group and an Expert joins them, the community will help; the ones that don't were not going to change anyway but do we really need to create waiting list to try?

STORY / \

The web hate free highland and NHS promotion of equality and diversity and the no tolerance to bullying help all agencies work to solve an intolerant street, family, venue or service. But there is still a gap at private agency front line

STORY / \

The old style LIGS had no clear remit and a mixed control of spend and supports so there could have been a chance to involve the public more.

Challenge: we have a good 'Experts as peers' anti bullying workshop into schools and communities but should it be turned into pro inclusion so actions are focussed to create and include than stop and report? Also where is the space for others to get things wrong for instance the poor travel/transport stories from Experts, why don't planners build in trials to improve their services? It is not all about wheel chairs.

We asked a selection of LIG members what they thought:

'heard of hate free' 'got help to use hate free' 'don't know how to use it' 'saw shouting on bus wanted to report it'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

I. We must make better use of current resources as a start point and using the change fund to meet the huge changes

Now that money is not protected anymore and money comes through in a lump sum via Highland Council, there is an opportunity for all services to get together and plan together to make a big change instead of lots of little changes that usually do not last. We hear of people having to share posts and resources. The use of community volunteers is increasingly used in reports but some say Expert volunteers should be paid. Large amounts of money go on a new service but then it stops. Where is the sustainability and social responsibility? Also where are the handovers of information or resources when a service stops, to Experts and carers it feels like they have to input the same things over and over again?

STORY

Volunteer groups like Health and Happiness have been able to find new funding for workers. Multi agency groups like HLDRG have managed to find new partners for works. Supporters like KEY have found new ways to support Experts and show parent carers new funded opportunities like respite holidays.

STORY

The change fund is now sunk into an all uses budget with no ring fencing for development in learning disabilities needs or services. New monies can only move if an old project ends or an Expert moves or staff leave. It means a waiting list for people to forget an Experts request and a lot of reliance on volunteers as a cure all.

Challenge: How to meet needs rather than numbers. The more able provide good numbers as targets and are met first, if we targeted those with most needs first would we still get the more able through quicker towards the end of a project?

We asked a selection of LIG members what they thought:

'my Expert wanted help but I was told they had too many needs to help' 'I need help' 'I had my care hours cut, it's to help the government' 'I want to volunteer but supporter says I can't, why is this' 'it's about confidentiality – staff decide this' 'staff decide this' 'my activity stopped no-one asked me (there was a time lapse so forgot) I don't like the new one'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

J. To monitor practice and progress, development and maintenance of the changes with the help of the SCLD and Commission.

A measure of personal impact service changes will be far fuller Experts and carers lives. This would include Expert and carer involvement in own work and monitoring. Some major departments are being asked for and providing different formats without a request. National projects like E-SAY are highlighting the need to recognise the whole Expert and not necessarily service provide for one medical label or global need. Social models of disability and being taught and financial challenges will either help or hinder this as more care is to be given in the community and residencies take on social and leisure will we see more have and have not's

STORY

This is a difficult one, it is recognised good work goes on but the news of good work to others is not shared in easy read, visual or verbal formats is becoming more professional and further removed from the Experts original works or voices.

STORY

Reports happen, consultations happen reviews happen but information of those still does not get back to Expert, carers or frontline staff. Finance and targets are at one level with outcomes and level of quality and impacts at a lower level. It seems very difficult for both levels to exchange experiences and knowledge of impacts or results.

Challenge: it can be easy for a written plan to progress and develop and even win awards before being implemented? It is easy to turn real voices into bullet points so they mean all and nothing or become the next catch phrase on which to hang another tick box on. Bullet points defeat the 'talking outcomes approach', personal outcomes = end outcome. Leave the numbers to how many were happy, safe and achieving after using a service.

We asked a selection of LIG members what they thought:

'never heard of (that policy)' 'I was not consulted on changes (different names used at implementation stages)' 'it's all about money no-one asks us'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

K. To ask as much for Experts and Carers as we would ask for ourselves.

But where each planner or staff puts risk policy in their own minds, may stop staff asking or put off asking for Experts and carers. The social model of disability assumes that Experts will want, dream and achieve the same range of assumptions for life we make for ourselves. Government, planners and staff need to lead confidence and creativity to put quality and choice before risk protection. The law is owned by staffs, Experts are protected from the law by risk decisions taken on them practicing life. We should get better at planning for living not for servicing a risk. The law needs to be graduated to accommodate life learning which grows resilience and choice and not crisis and isolation

STORY / \

Two Experts liked each other, the lady wanted to meet her male friend in a café but staffing and rules did not let this happen. A buddy agreed to escort her to the café and sit away. The café was recognised as a good venue by many independent Experts. So a good place to trial independence in a relationship

STORY / \

An Expert goes to the usual expert pub visit group. Life is full of time tables and appointments and tea time tasks. What they really wanted do when asked was go dancing but there was no club near. They could have started one.

Challenge: who checks sexual health policy, 'love is ...- same as you' type decisions on the ground? Are reviews all about work, care needs and medication? Ground staff knowledge and even their freedom from managers to trial or freedom to request training needs review and are policies handed round or still in boxes in backrooms waiting for a review to find them?

We asked a selection of LIG members what they thought:

'I want to go out, I like him' 'staff don't have time to take me out' 'it's about health and safety' 'what is dangerous about a café' 'I go out for walks with my girlfriend, we go in the bushes' 'You should ask your supporter to leave you in the café and tell your boyfriend'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
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1.Highland Council should have a PIP-Partnership-In-Practice

The PIP-partnership in practice was how health and SW-social work worked together to deliver the SAY-same as you. A PIP Agreement was made which gave a list of Scotland wide documents that they read to help them do this. The documents were about health, speech and language, inclusion, needs assessments, work, houses, mental health, rights, disability and incapacity. These covered adults and children with Learning Disability and Autism, their carers and others who help in community planning and in the giving of services. All of this was with our local area in mind. So other PIP Agreements may look different but should cover the things the documents talk about. There are Highland Plans on how SW-social work and Health Partnership works with others covering council services, community care, communities, children, housing, carers, carers, advocacy, education, culture and sport, health and health improvement. These Plans in action look like, the work the Shirlye does, having a PCP-person centred plan, knowing about LIGs, knowing of the area children's services forums, having a SSA-single shared assessment, help moving in to your own home or living with support, getting Direct Payments or better transport or short breaks and planning for these early, before you become an adult in a Transitions Plan which will then help your life plan

STORY / \

Once we saw some of the plans in the PIP, we saw that some of us had been part of the PIP by being asked for our views or by being in a group or people came to tell us about a bit of work so knew how to join in.

STORY / \

We also realised that some of us were missed out. This was because we were not part of a group or a group did not bring us in or it was not done in a way we understood or we were only shown part part of it, so did not see how it fit.

Challenge: is how to keep past good flow on recommendations or gaps realised, tied into new agreements or policies – and how to get this passed managers to front line staff, the Experts and carers. Like a pincer movement if carers and Experts ask up, the frontline workers should ask or do and managers will have to react.

We asked a selection of LIG members what they thought the PIP was:
'the partnerships are to action the HAP' 'the review of the PIP is being done by people first, who or what was the first PIP?' 'I do not know' 'it is about hospitals, it is about doctor's surgeries, it is about SW and health' 'is it a group or a thing?' 'H+H got a post last year and it ended in Nov-ember and had people from HC placed in H+H to do the PIP. I do not know where it is but it was passed out to ordinary groups, so it is done' 'it is any partnership of more than one organisation involved to do a piece of work to aid this SAY document.'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

2. Highland Council should agree to have LAC's-Local Area Co-ordinators, and have had the initial training to put them in place

Who should have had the initial training? Who should have led the initial training? A LAC-local area co-ordinator is recommended to be based in the community, for children and adults to enhance community supports, with strong links to health, education, SW-social work and voluntary groups, working directly with individuals and families but is not care management, being within the investment and provision re-orientation and part of service systems and mainstream budgets but remaining independent. Nationally there are varied models, some of which it is argued do not fit with the pure LAC definition. Highland have no LAC under this definition though a report was commissioned to SCLD to find out Highland Expert's and carer's views as to what an LAC-local area co-ordinator service would look like. Thus a local group put in a bid to host a LAC service and this became 'Community Connectors'. There is one for each Highland region but the three year funding ends 2011

STORY / \

A child did not go out. They wanted to keep fit and meet friends. A LAC-local area co-ordinator identified a local club. They helped the activity worker identify ways of supporting the child through the chosen activity. The LAC-local area co-ordinator also identified Direct Payments to enable independence and outside skills.

STORY / \

A person needed help to go out to a favourite activity. His group did a different activity and he had to go with them. An LAC/Community Connector could have helped plan a route to the favoured activity or idea identified a buddy or other partnerships to plan around other needs.

Challenge: The funding for LAC/Community Connectors is near an end, so how to review and gap find, should it be reviewed from carer, Experts, staff, public not reached – then what to do?

We asked a selection of LIG members what they thought a LAC-local area co-ordinator was and what they did, then asked again for Community Connectors: 'Somebody who can help you or stand in for you' 'never heard of it, is it local employment, there is a bid in for activities, it's matching people up with the things they want to do.' And after the Community Connectors - 'one comes to my support group meetings' 'not seen one' 'I have one they help me get out'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

3. All Experts should have a PLP-personal life plan if they want one.

Experts should be told of these plans, what they could look like, who can help them make one and that the Expert should have one to own, to change and question. There was a PCP-person centred plan network set up in 2005. The network was not to do the plans but to spread the word about the value of having a plan and provide a directory of people trained to help Experts 'write' their personal life plan. The SHIRLIE project and some social workers are in this directory. Some service reviews have been done

STORY

There are networks at a day centre and a residency which make sure their Experts do and own and can change their Personal Life Plans. A school for Additional Support Needs also involve their leavers in Person Centred Plans to identify individual needs to match individual plans on Transition to adult life.

STORY

Who tells the Experts. A lady in a different residency has never been asked questions about choice. A man in a different residency wants a plan but thinks it is because of his diagnosis and support needs type; he is not helped to write one.

Because plans can mean change and doing things differently for everybody, we can share anxieties and do the changes together and trial together not say this is all we have so this is how things will be done. If we all go in to plans as sides then it will fail as there is no meeting place for the must do and want to do of policy and implementation.

CHALLENGE: Who is telling the Experts about the plans and who can get one? How do we capture what plans want with future supports needed? Should lack of monies stop trial and exploration?

We asked a selection of LIG members if they had a Personal Life Plan:

'I know what I would like in the future but I do not have it written for me.'

'No I have not got one.' 'Yes, I have one as I go to the PCP network as I am a rep for Corbett Centre. There are different people there like from Key Housing.'

'The network has been difficult to get Experts to.' 'Key Housing reviews have been done and some PLP's have meant raised care and others were cut.'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

4. The SG-Scottish Government will set up a Change Fund for the Highland Council.

It was recognised that bridging funds would be needed to meet the old style service costs and the new service costs because both would run at the same time. The Change Fund could be linked in to help projects that met the identified developments in the PIP-partnership in practice agreement, as long as the spend was agreed. The PIP has now been linked to other documents such as the Indifference Recommendations to become a Decision Framework Model. Hopefully the downsides of meeting individual document targets will be overcome by having clear joint targets all services will have to meet, hopefully benefiting communities rather than silos

STORY

It helped the old Crumpets Café become independent for two years. Experts worked there. It gave the chance to become self sufficient. It gave the manager a job and relieve social work. The Change Fund also provided a job coach to the Corbett Centre without which a second job coach could not have been funded.

STORY

How to use the Change Fund for people outside the Highland Council, was complicated. Who to go to was not clear. There seemed to be lots of unclear things to match to and was not Expert or Carer friendly and Staffs were confused. There were also uses which were outside the LIG's, so knowing how much to aim a bid for was unclear

Challenge: The role and involvement of Experts with LD and ASC, all ages, in the PIP document agreement and follow on document, the role and involvement of Experts with LD and ASC of all ages in the identification of developments needed, the role and involvement of Experts with LD and ASC of all ages in the use of the Fund and prioritisation of spend, the role and involvement of Experts with LD and ASC of all ages in the review of spend and development and document effectiveness.

We asked a selection of LIG members what they thought:

'Heard of Change Fund.' 'Know about the funds that SAYLIG have been talking about.' 'Is it about changing money from one area to another, it's about giving money to the Corbett Centre and giving it to someone else.' 'When I started LIG we were getting money for things we were wanting to do then it got changed and went to New Craigs.' 'Money went to one place but are people with learning disability being treated right, it's our business.' 'Money for job coaches.' 'People like to hold on to money so it's difficult to keep the work going.' 'Now it's not ring fenced so where does it go now'.

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

5. Anyone who wants DP's-Direct Payments should be able to have them and could buy from the Highland Council as well as other providers

Highland is a pilot area for 'In Control' while direct payments are being reviewed with two workers for each service delivery for the duration of the trial. 'In Control' is for learning disabilities and wider needs. It is end goal orientated so considers that 'experts' will achieve and hopefully move on in life rather than get a service and stay with it. As this old style provision does not promote choice or review to change with the individual

STORY / \

Good as it covers autism spectrum condition as sometimes getting other benefits was very difficult as language covering ASC is medically descriptive and not based on each individuals characteristics. New respite ideas are helping people rethink about new uses and respite as an opportunity to learn or try new activities. For young people's entry into adult life can be as a young person and not as an adult.

STORY / \

Families can manage DP's but it is difficult to get staff from outside the agencies, so people still go to agencies and this grows. Child DP accounts were not flexible with bank interest, extra paperwork social work weekly accounts, matching of actual spends and costs.

Challenge: for more severe needs or Experts at home, who decides on needs to be paid for – availability of activities, services can come before an Experts real wishes or needs.

We asked a selection of LIG members what they thought:

'If got a DP you feel great you're independent but if it goes wrong you are left on your own and could loose support' 'somebody has to monitor the DP so if problems you can be picked up' 'difficult to get people to do over family' 'services back in my day were poor and could not pay people to do care and it took all our time to feed ourselves' 'you get money and organise your own support' 'there are bad point and good points...you get assessed first, they work out per week and per month what you get and agree with certain level of benefits and agree with your needs, if its not enough you can get in touch with the DP group', 'I got In Control and I now have my certificates for a job.'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

6. The SG-Scottish Government should set up a new SCLD-scottish centre for Learning Disabilities that gives advice, training and support to agencies, professionals, Experts, Carers.

This has been done but needs to re-scope who it includes. ASC is mentioned in reports and bits of work but not tied into SCLD psyche yet. Others services or partners don't recognise the whole ASC spectrum's needs. A bill for autism is going through the government so hopefully in 2011 the Act and Scottish Autism Strategy will be clear and a wider knowledge of the diversity of needs and manifestations in abilities, characters, life and medical needs will be sought and understood. Those experienced in ASC know that if a service aims to meet the ASC diversity it naturally brings in whole population needs from physical, neurological, medical to biological and benefits many not only the ASC spectrum

STORY / \

Experts with ASC have raised the ASC gap and the discussion we now have on the wider ASC and LD spectrum and who is involved for instance. They did this by setting themselves up as self advocates. But inequality still exists, if an LD occurs in adulthood, is that person an Expert? Should they get no or a lower quality of service just because they were diagnosed at 21 and not 16.

STORY / \

SCLD does a lot but it is not clear in highland how or who or what advice and training there is or support to agencies. Funding cuts or job saving is far clearer and carers and Experts still have to go through places and staffs. And professionals do not have a central point either.

Challenge: is that the government set up the SCLD and we know that is done as we do hear of their courses and Experts have gone to them in Glasgow and a carer went on their courses in Glasgow enough? Maybe the, 'what is in highland', point should be looked at.


We asked a selection of LIG members what they thought:


'it's a A9 thing it feels as if groups don't talk together' 'I went to SCLD and spoke' 'I went to SCLD and liked it but I did not know if they have autism on their board' 'SCLD do good courses in Glasgow' 'what is SCLD'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

7. The SSA-Scottish Society for Autism should with the NAS-National Autistic Society, NHS Highland and Highland Council, set up a national network for people with ASC-Autism Spectrum Condition

The SSA was central belt based. A portion of national money was given to HC for services but none as yet for adults with ASC. SASN was launched and provides a network for professional's questions and advice plus an advice focus for families and information they need. They were set up with the SAY in mind as a requirement to meet number 7 above

STORY 
Experts with asc have spoken out and led and guided services to include ASC in their service's consultations and provide for ASC. they are now asked to sit on new service planning for a new ASC service and have been included to plan on an adult diagnosis and mentor service.

STORY 
Highland lost one ASC agency and gained another but again central belt and national leads lead local changes. Monies and targets do not cover Highland needs. Highland has to see what is going to be given centrally then shout to be included. A new service for Highland is being discussed.

Challenge: This new service is happening in a recession. All services are being asked to cut back but how can you cut back on a service that was not there. If 'discrimination', 'social responsibility', medical and health inequality were the reasons for recognising the ASC population, which is larger than other conditions already provided for, then these newly recognised 'vulnerable' should be protected. There is a business case to the benefits the ASC population bring if included early. The adults with ASC are speaking out now but there is a danger they can be easily engulfed or ignored.

We asked a selection of LIG members what they thought:

'Where are they' 'the NAS and SSA speak to each other' 'we lost our SSA' 'I have been on courses in Inverness' 'SASN has a magazine, we hand it out' 'okay for children but nothing for adults'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

8. The SAIF-Scottish Accessible Information Forum should consult Highland Council, NHS Highland, Experts and Carers on how to provide a joint, one stop shop, free and accessible local information service for Experts, Carers, families in varied languages

We would like to add and provide formats to meet other E+D needs. Recognition of ASC needs has brought up different colour backgrounds and font on web and paper based materials, for instance, consultation documents and guidance are provided in different formats if sought centrally. NHS have a new accessible materials officer, HC need to do the same. NHS have the HHVN, HC need to have the same though they are looking at using user videos and forums. Community Care formats are still very abstract or meet 'service speak'. This serves to build planner to worker/volunteer inequality and Expert/carer lottery or isolation

STORY \ /

Carers, Experts and support staff had spoken out at not being heard or included in planning or being aided to it being understood. Now they are being asked in a range of different formats. Things are changing and being guided by NHS equality and diversity policy and they are now helping HC turn that corner too.

STORY \ /

An Experts group aided a consultation but did not recognise Experts with needs. Some Experts needed prompts or extra time. This did not happen. They felt left out and knew their friends with lots of needs did not know they were left out and felt sad for them.

Challenge: how do we help the public recognise E+D needs? The Hate Free Highland reporting website was set up. How do the Community Councils recognise wider needs and include those that some communities fear to go near. The Community Care plan and recession plans are pushing for more community based care and solutions. Stagecoach North is starting with their drivers and community to change an old service type. Scottish Government strategies like the licensing of all drivers, to meet a training which includes E+D and disabilities have helped kick start this wider public and service joint planning. We need it rolling out to other sectors

We asked a selection of LIG members what they thought:

'every thing should be in easy read' 'staff like easy read' 'use pictures, photos are good' 'I get a tape to listen to' 'I get help' 'I like big writing'

We asked other SAY groups

- [] did they know
- [] did they meet it
- [] locally – LIG Day Report 2010
- [] nationally – E-SAY

9. The first PIP-partnership in practice agreements should set out how Highland Council, NHS Highland and 'other health services' will set up and maintain services

Local learning disability registers are said to have been set up by most GP practices, so who will check those that have not? Voluntary health activity groups are very prone to stopping and starting because of funding and volunteer shortages like our sadly missed Falcon, which was then picked up by a very community minded carer. Should their consistency or stability be built into the PIP? Should they be left to volunteers? The PIP sadly was put away and not due to be reviewed. Its old leads retired or moved on. Experts and carers felt yet another 'consulted upon gone tomorrow' document had gone. The ASC community had only just hung on to its last proposed changes, felt left out again. But its partnership has picked the PIP up and other Expert carer consulted upon' documents and are putting them into one action plan to become a decision framework model

STORY \ /

Repeated voicing of the need to review and continue the PIP has led to it being merged with new documents so unfinished activities do not disappear. The ASC community are being embedded along with other hidden conditions and other LD co-morbid needs not recognised before.

STORY \ /

The PIP was passed and said to be ended as a document but the ASC community and some levels of the LD community and some agencies were not consulted with. Input was given but too late to go into the end document.

Challenge: why are LD services led by charity and time limiting targets, why are our vulnerable people not given a secure service? Single Shared Assessments are said to target the quiet in recognition of most need and maybe slipping out of society. The vulnerable don't know they are too quiet or that they are meant to shout, is it abuse to know that and use others excuses to cover our inaction or aid a low priority? We need Experts to be given a role in the identification of developments needed and implementations achieved. Can we have a shared 'expert' and carer paid post? A staff/Expert buddied paid post? Fife Council have an ASC Expert checking their policies, Glasgow have an LD Expert working in social work.

We asked a selection of LIG members what they thought:

'I do not know' 'it is about hospitals, it is about doctor's surgeries, it is about SW and health'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

10. The SG's-scottish government's review should be of the effectiveness of funding SaLT-Speech and Language Therapy for children and adults

And of other services like Occupational Therapy and where these services are and access no matter where they are for Experts. The SaLT/OT Report was produced. Work has just started on looking at joining OT/Physio, Community/Hospital, City/Rural lists so that 'special' posts do not exclude Experts from mainstream services and build waiting lists rather than serving care. SaLT services however are stretched and remain at the old levels and with the recognition of ASC needs; this capacity is not going to grow

STORY √

SaLT expanded to include an accessible information officer requests for Experts help and for information help is quickly increasing. His list of work has increased showing the need for this valuable service. Help is still needed in understanding ASC communication needs expanding in the Asperger Syndrome.

STORY √

But we are losing one SaLT due, no replacement has been confirmed. In preparation for financial cuts, leaving empty posts unfilled is growing and in one case left a waiting list. New trainees were said to be coming on board at some point. So at least a years money will be saved while people wait

Challenge: with cuts in finance and posts, how do we grow inclusion for Experts into mainstream departments and services but still grow 'specialism' awareness to allow this rather than use 'cuts' to cut back and create more specialist lists and mini special hospital or residencies? Do the government, NHS, HC ask for SaLT and OT advice on local things like transport, wheelchairs and posters?

We asked a selection of LIG members what they thought:

'we have a new SaLT' 'there is an Experts accessible info forum – the SaLT set up' 'I don't have a SaLT' 'I have an OT they helped me buy a microwave' 'my OT looked at my walker and got new bolt for it'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

11. The SE-Scottish Executive should encourage the development of local advocacy services

Are advocacy services meeting Experts and carers needs or are advocacy services meeting the needs set by the rules of access and funding? A global medical explanation of a person's need may not match the person's own individual symptom and can hinder access to advocacy. One person may need a full explanation of what is happening; another may need a full explanation of what could happen but this you could argue is not pure advocacy where options or outcomes in a specific subject could be limited

STORY / \

A consultation on advocacy missed Experts with LD and ASC, they spoke out and were included. Experts needed long term advocacy not targets, they spoke and were included. Experts with ASC needed options explanations as part of their advocacy. They spoke and are now now being included. Citizen advocacy is here in Highland.

STORY / \

Group advocacy seems to be having a harder time to find its place. Funding times and targets mean groups that need more help or support, don't have as free a voice as more able groups of people. Workers having to cut and corners just to get their more vulnerable to a table or get heard in a bullet point rather than in real time experiences.

Challenge: we all need to listen more how do we stick to a time table but leave actions open to continually change as more vulnerable voices catch up. How do we include a professional need to meet a set end of report time and officially 'pass' a document to be actioned yet keep it 'living' to meet the 'catch up'?

We asked a selection of LIG members what they thought:

'I have an advocate and they go to my meetings' 'some people can not speak'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

12. NHS Highland should make sure they have plans for closing long-stay hospitals for people with learning disabilities.

This has been done and an exhibition on whole history of work houses to long stay hospitals to personal living spaces in the community was held in 2009 in the Centre of Health Sciences. Because the move was staged over time, should we go back to those who moved out in groups into residencies albeit their own rooms and help the ones that are asking to move out of group living, into their own homes? With the recession cuts will happen in individual home and care supports as well as in residency out sourced activities. Which Experts will still end up with choice and still be happy where there is none

STORY / \

PLPs, compatibility plans, needs and wishes on decorations in the new flats to supports and how provided taken into account. The last group of Experts to leave long stay had access to global health plans and are already showing outward signs in individuals.

STORY / \

Some who moved into a joint residency see the newer single homes and want the same. Some say even 'own room' residencies are too noisy or cramped. However one residency sends everyone away on holidays or activities except one Expert who needs total peace breaks so he can enjoy his whole residence as his holiday.

Challenge: do we have a new starting point now? Is having an own room but shared diner, living room and activities enough for all. Most Experts enjoy the company but there are a couple who are stressed and would like to move to the next stage of their own front door.

We asked a selection of LIG members what they thought:

'I was scared to move but glad now' I like my house got all I want' I want to move' 'I don't know if I did the right thing but I like where I am'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

13. NHS Highland should aim to reduce their learning disabilities assessment and treatment places and plan appropriate community services.

At the moment once the last six people moved to their new individual homes, there were said to be only a couple of emergency beds left. The SAY even says that these should go as services should be so good, that people can get help in their own homes or their own communities. The Experts agreed that it could be nervous to move out and not like new places but they thought the old places held bad memories and they would say don't look back. Moving was all about new experiences, trying new skills or not, if they did not want to and having people to help them cope with their feelings, get confidence and having someone to talk to if you suddenly felt nervous about whether you had done the right thing in moving out. Health also had to come to them and they should be told where mainstream services are, this includes sexual health and enable mainstream services to be 'specialism aware'.

STORY / \

Notes of change to community services came to Experts, on how health, GPs, nursing needs and appointments could maybe go to the Experts and not the other way round. The experts got their wishes heard and they are still being heard, to look at health at home, dentists access and appointment needs. Carer poverty and health need is also getting recognised now that community health is discussed.

STORY / \

An Expert had lots of needs, lots of appointments, on lots of days. These took place and priority over activities and social outings. This Expert is missing out on social inclusion but his health is good.

Challenge: balance between quality and money, numbers and counting severe needs, possible later outcomes of not doing and evaluating during a roll out. How to meet complex needs and still have time to meet targets.

We asked a selection of LIG members what they thought:

The Experts wondered would some people get charged for some services as it seemed to be a problem for older people. They also said there was a need for more home carers and more people to get meals-on-wheels especially now the word 'cuts' is being heard more. Outside activity choice and residency activity choice and the balance between individual choice and losses was also an unknown

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

14. NHS Highland and their partners should develop services in the community with identified resources which will show up in the NHS Highland planning guidance and performance management arrangements.

Monitoring these resources and how they are used and even what changes they made in peoples lives should be identified too. We hear of projects being paid for, congratulated then staff move on to the next thing. Carers and Experts get consulted with, in part to give new staff guidance, then a report appears or a couple of launches or even a project then it stops. The carers and Experts then have to repeat themselves to the next staff. This happens in Highland Council, NHS and in Voluntary groups too. The carers and Experts hear these three sectors blame each other for a lack of money but we say that they all need to take responsibility to plan for a need then look into its future together and don't forget to ask the Experts first and ask in different ways because carers and Experts know that focus groups can only tell you about the needs present at the time

STORY

The NHS were looking at a plan for advocacy provision even though Experts were not invited and pointed out gaps for them. the NHS listened and restarted the consultation and in the review have included the Experts voices and not just sector staffs.

STORY

Staff decided on a service point for carers, then they consulted with the carers and told them the service point targets. On delivery it missed half of the carers attending needs. Staff then had to redesign to meet the other carers needs. This is a common experience for most carers of ASC.

Challenge: how do we monitor delivery especially if it is being sub contracted out? Who should present the end materials and whose responsibility does it become to review. If a service ends, who should end or ongoing materials be handed to? Experts and carers get fed up of the re-consultation which only serves to bring in new staff or new agency up to date.

We asked a selection of LIG members what they thought:

'We have not gone away, nothing changed, so why are we being asked again?'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

15. Highland Council and NHS Highland should map their services and develop modern, flexible, responsive support services in the community for employment, lifelong learning, social, mixed with those in the community.

A new website created by Highland Council to try to start mapping groups and services. Others have followed this to include rural issues. 'Flexibility' will come when a person does not have to go into several different groups to get what they need. Groups have become specialised so that they can only meet a special bit of a person but carers and 'experts' are whole people and we need groups or services to let the whole person in. On employment there are, in some job settings and applications a tick box to highlight if you have a disability thus getting that extra chance via a guaranteed interview. Carers need this consideration too as their starting skills pre being a carer can change dramatically in other directions but the skills are no less valuable but as they have no exam or record level, who helps give them a value

STORY / \

An Expert chose a job type and had no money for training so the Expert was left to wait until people volunteered their time to help. He was then shown 'in control' and helped because it looked at his personal needs and goals and focussed on his first step to action his dream.

STORY / \

An Expert was on supported employment waiting lists. To get funds agencies had to help more able Experts to keep money coming in to pay for staff as there were not enough unpaid volunteers to help. The criteria aimed for full time paid work so did not allow a long training term for this Expert.

Challenge: the importance of involving Experts in the way they need otherwise the "better" will be to our standards and our access thus missing the Experts. Is it their choice not to engage or be unable to engage? Our challenge is then not to accept what is put in front of us as being the 'whole' whether that be a report or a person especially where this is sub contracted out.

Quotes - " what is behind my make up' (a carer), "a person's needs are an iceberg not a strand" (co-op equality policy)

We asked a selection of LIG members what they thought:

'I think they have to do more actions to get out to find a job, for disabilities. I want to help them to find work for Experts'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

16. NHS Highland needs to develop a range of employment opportunities for Experts and NHS Highland and Highland Council should employ more Experts.

we all agreed that this was a good recommendation but both agencies and voluntary groups need more training in how to work with Experts and carers too. The agencies and voluntary groups need to include Experts and carers as trainers and to pay them as equals just as they pay themselves. it was thought unfair to have people charging as much as £200 for a day or for standing in events but using Experts and carers for free to do the same job. Also consultation has grown so much it is an industry now and people are using Experts and carers experiences and creative ideas to create more work for themselves but we still did not see Experts or carers getting more employment or pay. We were sad to hear one 'expert' who did get a job in a charity loosing their job this month because funding for the job had run out. We wondered why it was the Expert who lost their job and why the other workers did not get together to help give the person some of their hours or pay. it was also noted that once an Expert or carer comes off benefits was quicker than the delays in trying to get all the paperwork and assessments done again once the job was lost. It was also noted that some HR-human resource teams were keen to get Experts and carers into work but the actual department heads seemed to have more of a difficulty with this. So HR needs to see people in their own organisations to promote this and even call in people like Speech and Language. If a department manager is good then their staff would not be frightened or negative. There seemed to be a thought that Experts come with lots of paperwork also where a job such as laundry in a hospital needs a team of 30 people, surely there could be space for two fully paid Experts. Also you do not have to be able to read a menu if you only need word recognition for a set menu and what is wrong in having pictures on the menu of the food. We also wondered if people had heard of the £20 disregard for Experts and carers so that they can be paid £20 without it affecting their benefits. BUT this has been at £20 for at least 12 years yet pay rates have gone up! Also the minimum wage which only allows 3 hours work so it takes a lot longer for Experts and carers grow confidence and get a good work experience if they are limited to such a short paid time per week. Some volunteers say it is not hard to find yourself being a full time volunteer and there is no shortage of volunteer work So are Experts and carers being used? and how many volunteering hours do fully paid people put in?

STORY / \

An Expert had a wish to work and get paid. A buddy helped them visit and break the job down. After a while practicing the tasks, they moved over to doing the job for pay and they still do it today. They have pride in speaking about it.

STORY / \

An Expert had a taster job with a volunteer service helping but when they came to move from 'job tasting' into paid work, the department manager got nervous and worried about health and safety policies so the job did not happen.

Challenge: the role of major agencies is to lead and show others how employing Experts and carers can be done. Hobbies and volunteering are okay as starters

for some but it is wrong to keep offering Experts and carers this if you would not wish it for yourself for life.

We asked a selection of LIG members what they thought:

'I want to work in a nursery but staff told me I can't – is that because they can not break a staff rota' 'I want to get paid, plenty volunteering jobs' 'got to watch benefits for work'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

17. The Scottish Government with the Department of Social Security should raise areas of concern with benefits and support for Experts

we know that work and consultations are happening at Scottish government but they need to realise the benefits system and employment keep Experts and carers at a poverty level and different normal life events can push Experts and carers into becoming trapped into a poor social life or unhealthy way of living. It is as if benefits stop at one level and there is no sliding level to gain work and build yourself up to a safe level. Employment puts you at a safe level but if it stops you fall and there is no sliding level to catch you before you go all the way to the bottom of the pile again. The paperwork, proofs and assessments got us all down and the way one agency does not accept another's proof we could not understand. Why does a benefit agency not accept a life long diagnosis from health and need a visit to the central belt or letters from other offices. In 2011 some information centrally based may no longer have to be sourced and sent by the Expert or carer but found via the internet and verified

STORY √

A government officer visited Highland in 2009 to look at poverty and needs and not only picked up the inconsistencies in benefits and job help but also the entwined nature of Expert poverty and carer poverty because of the government criteria.

STORY √

Various agencies have campaigned or brought out carer user voice reports on benefits and problems caused by one policy change to help one group then damaging another. But still changes get announced that prompt agencies to have to flag wave again to protect different health or Experts groups.

Challenge: when government suggest promotions such as Udset and patient involvement, should local authorities and NHS then ask for government proof of personal consultations and qualitative review? And what of the government's own PPF, does it exist and under what name?

We asked a selection of LIG members what they thought:

'My benefits got cut and they did not speak to housing social worker so my rent never got paid' 'I had to get a person to sign my form but it was in Edinburgh' 'carers find it hard to fill in forms' 'if they cut from the Experts the, the carer has to pay' 'I would like a job but my benefit might go down'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

18. Highland Council should review local transport services and accessibility for Experts

this should also include pavement use and other styles of transport access such as mobility scooters, walking frames with wheels and signs for pavement users not just road users

STORY / \

Experts put forward issues about road use and pavement use. Police went to an Experts residency to hear for themselves and let their traffic division know. Highland council changed crossing types and crossing sound levels for other experts.

STORY / \

Roads staff were told of problems and given in solutions by Experts but were not listened to. A group asked a community connector to write letters to help experts get heard, nothing happened for them but a social worker used the experiences and contacts to help another Expert with the same issue and changes did happen.

Challenge: how do we set the need for other departments, other than health or social work to realise that equality and diversity is not just for the disability sector.

We asked a selection of LIG members what they thought:

'I waited for a bus but it could not fit my wheelchair on' 'I need help to buy my ticket' 'my walker can't get over the pavement' 'scooters go too fast on the pavement' 'cyclists give me a fright'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

19. NHS Highland should contribute funding and resources to developing community based short breaks alongside Highland Council who could bid for change funds

The Highland Children's Forum and Highland Community Care Forum are collecting stories for a report on respite types and lack of respite types. There are few places available and they are booked up. The Scottish government did put money out but once it was divided by the amount of carers and Experts it was a very small amount of money each indeed. Funds to the councils are not protected anymore so can get spent on other things. We heard of an Expert's parents who have set up a respite holiday home for other Experts to use. Maybe getting other services like the chamber of commerce or business help from HIE could help those in the tourist industry really look at changing what they offer to become more inclusive and accessible. Highland Council and the NHS could extend their training invites to include these other businesses or carers. The old Change funds were never that clear for carers and Experts to seek change. Funding now seems to set projects up which then employs people who disappear into other posts new remits are then no longer able to serve the carers or Experts original needs. Projects get bigger with more staff but the services on the ground do not change

STORY

Support staff seek out monies or an activity project that they can not access as staff but as the carer or Expert can access the funds. So they work together to enable the Experts access to an extra service.

STORY

A community plan had respite as a target but this disappeared from the next review. There have been many consultations but the topic seems to be so big as to frighten planners off from starting anything.

Challenge: with the cuts this area might be allowed to grow into opportunities for skills holidays, exchanges out of area and out of service but who will collate these and share them. If things get better will we be having new discussions on old consultations in 10, 20, 30 years time?

We asked a selection of LIG members what they thought:

'I got respite as my GP said I need a rest for stress' 'I had two weeks in Brora for xmas but one week this year' 'the wrong type of respite was offered to me on a farm for a person with OCD!' 'my residence is noisy I would like respite from it'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

20. The Scottish Government and Highland Council should review guidance and procedures to ensure that they can arrange flexible short break and shared care arrangements for children and adults with little bureaucracy

This has not been met and families have to source charities or do a lot of web based research on what could be available. This option can bring new holiday models to services but is only being trialled by a few

STORY / \

A couple with an Expert looked into how they could use their experience of respite woes and created their own service which as now also open to other Experts.

STORY / \

An Expert went on an emergency holiday because services failed. He has now received a bill that he did not expect or ask for. Because the bill was very late he now needs help to sort out the paperwork and legal impacts. This person needs help to plan for regular short breaks so that respite is normal.

Challenge: respite gets given in emergency situations but the person can still be left with a situation and still need respite. People do stay home and entertain so better support for experts to practice this can help them enjoy where they are. Is there an opportunity for HIE and businesses and services to aid carers skills? would hotels and other resorts open off peak or provide SAY peak time opportunities for respite thus maybe solving housing, respite and inclusion for at least a couple of interested families?

We asked a selection of LIG members what they thought:

'we arranged our own holiday and went on the web , he has been lots of places around the world but it is time consuming' 'the paperwork is a lot and needs meetings' 'it's difficult to fit the rest of the family in' 'its difficult if you live on your own, support comes in for an hour'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

21. There should be a long term programme to promote public awareness about learning disabilities and/or autism spectrum and inclusion in the community, from early school years programmes up

On the autism spectrum side, awareness and inclusion do not seem to be visible. The Scottish Government have published an Autism Toolbox but it was not widely promoted and does not seem to recognise that services other than education need this training. Drummond school now has the Pines Resource Centre next door as an autism partner and can open the door to parent carer training and though not widely promoted, a Makaton training session was held for Drummond School parents. Adults with autism spectrum are not recognised at all and still they quietly have to hide behind mental health or learning disability labels. The challenge here is for paying providers to request that the services they contract to and show that they have included this group beyond their silo. If this is expected by government, NHS and Councils then the organisations they contract to should do the same. On the learning disability side there is more recognition of Experts but still the 'brain typical' workers are the people you hear from and not the Experts and they can clump Experts views into one lump so it misses the individual needs or diversity of needs. If the workers feel the view does not fit their work then it will not be heard. The challenge here is Experts should be helped to speak out as there are more Experts than workers and if workers are concentrating on speaking for Experts at meetings then who is going to go out to the public and inform them. So where in organisations plans is there a measure to count wider community involved?

STORY / \

Experts were helped by a day centre to do anti bullying talks and go on tour to schools to tell young people what difficulties Experts have and how including them makes a big difference to everyone. It has helped young Experts in schools.

STORY / \

'Hate free highland' reporting web site was set up. A secondary school had an inclusion week. People seem to find it hard to distinguish unacceptable behaviour being the same as bullying and why, so report it in the school. There is a new influx of pupils every year so there is a need to re-do annually and the impact will change as the inputting young Experts change.

Challenge: how to change disability issues into community and business issues – sell the benefits to community, businesses and the social losses by not including.

We asked a selection of LIG members what they thought:

'Another challenge is SAYLIG's were set up to look at the SAY- same as you and inform change bank monies for projects which would include the community too and in the Experts words be an 'Offwat' for services and there are no funded SAYLIG workers.' 'the SAY is 10 years old, is it done, NO, are there new challenges, YES, we need a SAY 2020

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

22. The Scottish Government's National Care Standards Committee will develop Standards for residential and care homes and look at assessing and risk management for vulnerable people

All the government groups that look at services are grouping together so that they can share what they know about people's needs as well as how good or poor a service is. Before they just looked at one thing each, like education or care homes or people's involvement. Now they have to show how they are working together to make caring for you better no matter if you are in school, your home, a shared home or hospital; no matter if you are ill physically, mentally or need help to do things. Staff should ask Experts how well they are doing, Experts should expect to be asked how well their staff are doing, and everyone should feel fine to say if things are going wrong and be asked for ideas. Maybe then when this is a natural and every day thing we can talk about quality instead of risk; trying things out instead of being safe or being allowed to do; building a social diary of people who know the Expert instead of building a team of 'appropriate' people to escort the Expert

STORY

Still chasing better PLPs, better investment, better recognition of hidden conditions, like the Mr Q story of a man with ASC in the mental welfare report or the lady with LD in hospital being recognised for her condition rather than support for their needs.

STORY

An Expert had an SSA-single shared assessment and had the volunteer sector and numerous staff involved but still managed to have their health deteriorate. Standards were being applied to the service given rather than individual or personal outcomes. If we use forms then the person must be involved regularly.

Challenge: what happens if we embrace personal outcomes instead of congratulating ourselves with target numbers reached? Would the qualitative goals reached provide new targets reached which were hidden or unmet before? The challenge then will be to allow financial targets to embrace new outcomes. Now that the last Experts from places like New Craigs' have gone into their own homes, shouldn't we go back to those who moved out in groups into their own rooms and help the ones that are asking to move out of 'own rooms' into own homes?

We asked a selection of LIG members what they thought:

'the care commission should help give ideas as they look around but nothing changes on the ground' 'maybe they should do shadow shifts and not, just visit' 'clinicians should do shadow shifts as they do not ask daily staff' 'I do not get asked, they only speak to my supporter' 'they say they listen then go off and do what they like' 'I got help to attend a QIS visit and I did notice Experts having trouble to attend'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

23. Highland Council with NHS Highland and 'Other Health Services', should develop policies and guidelines on protecting vulnerable people and together use a Care Programme Approach to see if needs are caused by disability or vulnerability, SW- social work should review guardianship procedures

There is a need to help Experts find ways to tell people when things feel wrong and ask in their own ways for help and for this to be recognised by staff and the legal system. Highland Council is working on a pathway for help and looking at all types of harm so that staff, carers and Experts can talk about them and also looking at how to help the Expert protect themselves as well as others keeping them safe without taking 'experts' life or social choices away. The Adult Support and Protection (2007) Scotland Act is now in a new guideline along with the Scottish Governments 'Act Against Harm' stories, as staffs have not always had a clear contact or path to managerial staff. Experts did not know the rules and laws were their rights or enabled to 'tell'. The Act Against Harm campaign 2009 puts rights into stories so other vulnerable people can see its not just about a disability and decision making. It also covers dementia, Id, ASC, brain injury, MH, stroke. Guardianships are at a standstill with no-one reviewing carer, Expert outcomes meanwhile

STORY √

A group grew a friendly atmosphere, an Expert felt safe enough to tell their story – they were listened to and helped. Other Experts saw they were listened to and are not afraid to sit and talk over problems.

STORY ✗

An Expert asked their chosen safe person to help them. Instead of everyone rallying round and learning about aiding and changing, the safe person is as seen as a trouble maker and the Expert lost trust in the support and tell system. An other Expert saw this and thought it 'best not to tell'.

Challenge: we all need to be ready to be told stories we may feel uncomfortable hearing but realise the honour of being chosen and take strength from the enabler role we were given over others. Unfilled posts need to have Expert, carers impact reviews and not just remain empty to cut costs.

We asked a selection of LIG members what they thought:

'they don't take in needs of staff – can they do the job' 'minutes sit on the desk' 'Expert knows meeting has happened but not know what they said' 'I don't get a review' 'maybe the different words for meetings confuse everybody so you don't know which one you should have'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

24. The Scottish Government should consider a new duty on Highland Council to identify a responsible person to advise, help the Expert and family implement the FNA-future needs assessment

What do you say – PLP – PCP – SSA – FNA? NHS has enrolled a LTC- long term condition officer to recognise whole person needs and whole family or carer impacts and needs. This will take services into the iceberg of equality and diversity rather than along a straight strand. HC is working with NHS to change the SSA-single shared assessment into an outcomes and Expert/carer led assessment rather than a services available document. This will hopefully let staff assess and serve the person or rather than follow and service a form

STORY √

An agency involves and aids and reviews SSA with their residents. Each resident knows the review date and can tell us what changes they asked for

STORY √

The SSA is a tick box and leaves Experts or carers to follow on actions but as many are not seeing or filling in their own assessment, the Expert and carers are often left in the dark as to actions unfilled.

Challenge: making time to listen, learning what to look behind and prompting past the surface given, looking past the carers jokes and the experts 'yes'. Research has shown patients and vulnerable public use humour or wish to please or sense of duty and want to help the agency or government rather than 'cause problems'. This is high with ASC

We asked a selection of LIG members what they thought:

'I have not had a PCP' 'I have a plan I can change whenever I want' 'there are no carer PCPs and the assessment is worthless if no-one does anything' 'I had a carer assessment but I filled it myself, is there a carer social worker?' 'big difference between a PCP and meeting or a form which is the staffs' 'the Experts should keep their plan not staff'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

25. NHS Highland and Highland Council should ensure that trained professionals can look out for early signs of dementia to give assessment and response and service

A trainer on Dementia/Alzheimer's has been taken on to train staff. New projects have started to enable patients to recognise the symptoms, learn about aids and supports that could be used or needed later and family members being recognised as carers and signposted to supports

STORY

A condition awareness training programme to staff included a carer as a trainer. Another package included Experts in their condition and access training

STORY

Trainers can write up programmes as staff training packages but not have the implementation experience that a practitioner, Expert or carer will have. So some training becomes a book exercise to back up the tick box culture.

Challenge: great challenge for all staffs to be knowledgeable on varied conditions, to recognise them slowly appearing under a LD and or ASC or other label and then changing their service to meet the persons changing needs; rather than us blaming the changes on the Experts original diagnosis and therefore missing the new needs. Highland Council and NHS also need to check up on packages if they are sub contracting training out

We asked a selection of LIG members what they thought:

'we have a button to press for help but it is broken' 'I think the bed alarms and door alarms are a good idea' 'don't know about Alzheimer's' 'you are supposed to keep active so everybody knows' 'there are going to be more in the future so will some carers become double carers'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

26. Life Plans for Experts who live with parents should plan for when parents are no longer around or needing care themselves

This can not happen if carers are not helped to look up from caring. Young people should be getting used to being involved in planning before they leave school. Experts and carers should be trained up to help other Experts and carers plan for the future. Sometimes people who work for groups sound judgemental and this just helps keep a wall up between carers, Experts and staffs. Experts and carers can make planning real and not just make it a list of rules to follow. Carers are also left out of planning for their own futures. Parent carers are the worst affected, those of hidden conditions like ASC the most missed out

STORY

Not done, people seem to shy away from helping Experts and carers with this subject. When carers or people with ASC are proactive enough to ask for guardianship or red flagging to meet the subject of death and responsible planning, services say it's not a crisis, so is not on the services priority list. So whose outcomes? The carer experience in the MR Q (MWC) case can be replicated across any service in 2010.

STORY

There are many stories where Experts are alone at home to deal with a death and changes in life or supports. Some end tragically. There have been national reports after LD deaths, LD bullying, LD abuse but where are the reports. On carers and the steps that failed them as 'partners in care'.

Challenge: we all need to be aware and plan early for later life. Talk openly to the carer and include old age and death on PCPs. How will the new carer/Experts SSA-single shared assessment pick this up? Help the Experts speak about their old age and death and plan positively and creatively for it. Use body learning programmes and life visits. With more care at home and in the community, carer barriers need to be urgently recognised. Help ASCD positively learn about body and self care early so it becomes a norm and not so scary, also explain inner body sensation not just 'feelings'

We asked a selection of LIG members what they thought:

'no-one speaks about it' 'no-one asked me' 'it's too sad' 'I want nice music, I went to my aunt's funeral' 'I wanted to go to my friends funeral but staff couldn't take me (Expert in same home)' 'I worry about my child so had to do it myself, the will, social work and funeral – people who are not carers don't have to think so early'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

27. NHS Highland and Highland Council should ensure there is appropriate specialist support for Experts with challenging behaviour to support mainstream services to provide in the home

This also means giving carers the training they need for when there are no staff or services around. The term challenging behaviour does not cover the reasons for using behaviour to communicate. We are afraid that still people concentrate on calming people down then walking away with out using the quiet time to look at what was being communicated. Carers are still not being helped to talk about behaviours openly and even though sexual behaviours are being opened out to more staff, some staff still think training can't go to parent carers, yet they and siblings see and try to deal with things the best they can. Why is training so 'special'. Some people make money from training so it becomes special to them but staff should feel enabled to share what they know

STORY / \

There is an LD access nurse and courses which are looking at but still nervous of carer involvement. Carers get support and courses at the special needs schools as their partnership with staff gets better recognised under the new GIRFEC and transitions protocols.

STORY / \

The Mr Q story from the Mental welfare commission can still happen in Highland for people with LD or ASC. Where a carer is left to explain and aid staff or the system over a long time. Barriers for outside special staff to enter another agency need to be removed if 'partners in care' is to work.

Challenge: skills in anger management, holding and handling sexual behaviour are special skills but should not be specialist. The more specialist the behaviour becomes the more courts and institutions have to be involved and the further away skills confidence and community become. We need to teach recognition of 'challenging communication behaviours' so that the person and their hidden needs are recognised; and the word challenging becomes our challenge and not to an Experts blame.

We asked a selection of LIG members what they thought:

'supporters need training as they came problems too' 'I don't have challenging behaviour (explanation given) – smiles – okay maybe sometimes' 'one person I helped was not told what was wrong and was so sorry when he was told' 'a lot of Experts have not had the chance to learn'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY

28. The Scottish Government should look into people in prison who are Experts and assess the care, assessments, appropriate adults, needs with Police, Highland Council, and NHS Highland for 'experts'

This is an area that carers worry about especially around those with learning disability or autism spectrum from an early age. The discussions needed around this area are left to research papers where the one to one differences and difficulties; and day to day, individual to individual coping strategies are left out. Professionals need to create a safe place to learn from carers directly and not leave it to third parties to put into 'group' speak. This area covers misunderstandings and obsessions with frustration covering a very little talked about area which manifests in ways people would see as criminal. The police reporting system often jumps past other report and learn systems such as the procurator fiscals. Why is it we view people as being vulnerable until they enter the criminal system. Why are vulnerable people not enabled to have the same protection within a criminal setting as they would be outside?

STORY √

A major event gathered many levels of justice staff to discuss access to the law and changes proposed Scotland wide. A policy like the 'love is' and 'act against harm' bring the right for Experts to own their own responsibility and right to learn and know about the law.

STORY √

Young Experts got into trouble and even though the services did not understand the needs or need for protection, brought in community support for the young Experts. Another Expert landed in court because staff had not explained the law to him. His distress was very real once explained, who should have been in court?

Challenge: how we support the Experts to learn safely and take control while we supportively protect rather than protect from having to support tie in staff training to the Experts review/CPA meetings to make sure they can carry out recommendations

We asked a selection of LIG members what they thought:

'some people can not speak for themselves' 'a lot of hidden Experts with autism in prison' 'Experts should not be in prison' 'if an Expert is in prison it is not a reason to stop help' 'police don't know enough about autism'

We asked other SAY groups

- [] did they know
- [] did they meet it
- [] locally – LIG Day Report 2010
- [] nationally – E-SAY

29. Highland Council with NHS Highland and Voluntary Sector should look at the extra needs of those with profound and multiple disabilities and those of their carers. The SCLD should set up a network of support to local providers who offer advice and training on the extra needs of people with profound and multiple disabilities

The LDN-learning disability network are looking at and going to start putting lead people into place to cover all planning or professional groups looking at different health or social areas. LD has been looked at as a speciality area that staff have to work extra to get into so while the majority of the population can go into a service and expect professionals to meet their needs, Experts have to wait for 'special' staff to come along instead of all staff being used to looking at what an Expert needs. Some areas of learning to need to be specially learnt such as autism communication, sensory or medicine needs but it does not mean staffs have to be special to learn this

STORY

The LTC-long term condition group are helping all types of Experts to peer support rather than leave it to trainers to educate on what the experts already know.

STORY

Payments and initiatives still target the easily reached. A carer was told they could not access a community project as adult had too profound needs.

Challenge: a lot of projects are time limited or fund limited so it is easy to help the easiest helped and as time runs out the harder to help get approached but loose out as they need the longest time so how do we help the most profound in the least amount of time at the start and give them more practice time then catch up the more able at the end of time?'

We asked a selection of LIG members what they thought:

'numbers are used instead of people' 'my group has stopped and we stay in' 'I was told mine had too many needs so could not get help in the project' 'some people can not speak, only people who can speak got heard so we will be quiet now and let them speak' 'I've not seen a project worker isn't their money stopping soon?' 'I got help'

We asked other SAY groups [] did they know
[] did they meet it
[] locally – LIG Day Report 2010
[] nationally – E-SAY