

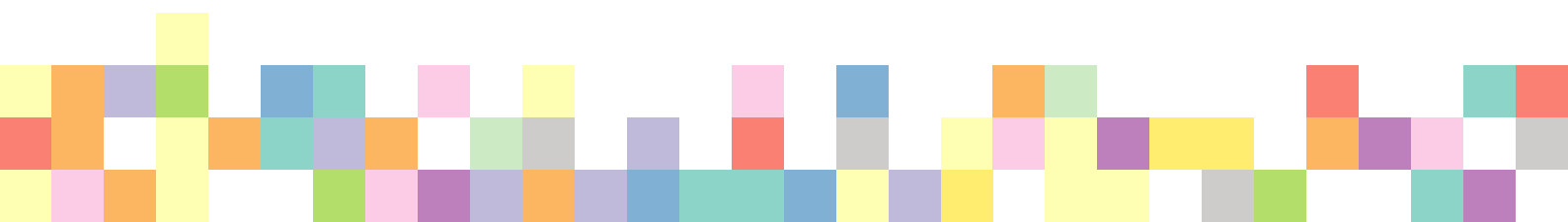


**REMEMBER
MY
NAME**

A SIGNIFICANT CASE REVIEW INTO THE LIFE OF

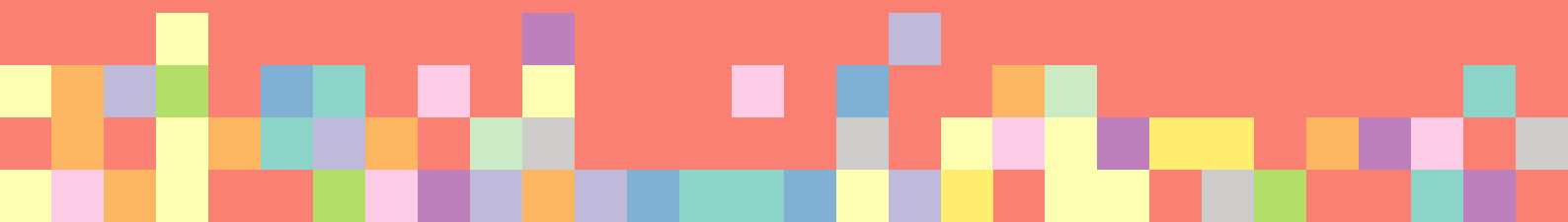
M A R G A R E T F L E M I N G

**M A R G A R E T'S
E N D U R I N G
V O I C E**



This report was prepared by independent reviewer,
Professor Jean MacLellan OBE.

M A R G A R E T ' S
E N D U R I N G
V O I C E



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Margaret's Enduring Voice

Introduction

Margaret cannot share her experiences, thoughts, feelings and hopes. This part of the Review gives voice to Margaret through the experiences, thoughts, feelings and hopes of individuals with learning disabilities as well as some family carers living in Scotland today - some of whom are the same age as Margaret had she lived.

Four groups were asked to assist with this aspect and brought a range of perspectives. They willingly did so and what follows is a testimony to each participant. They each committed to reflecting on Margaret's life as they know it as well as on the lives of people with learning disabilities that are being lived today. They also speculated about what the future may hold.

Some of the contributors made recommendations which appear within their Chapters. While they do not form part of the formal Significant Case Review relating directly to Margaret's life and circumstances, they have equivalent status in terms of the need to respond to them.

The first contribution is from some individuals with learning disabilities representing those who live locally. It is appreciated that this is illustrative, but nevertheless illuminating, giving viewpoints that are clearly articulated. It does not include those who have profound and multiple learning disabilities.

The picture that emerged was a positive one where participants made it clear that they have a good quality of life and that they also have aspirations and wishes that they hope to fulfil in future. They are optimistic in their outlook.

They acknowledged that they are supported and cared about and, although several had been bullied in the past, all would be confident to call out any potential harm to themselves or others should they become aware of it. It was evident that some group members knew each other and had a quality and depth of friendship with a willingness to talk through difficult subjects as well as entertaining one another with humour and laughter.

The second contribution is from People First (Scotland) who considered involvement in Margaret's Review as critical and important. This is a national organisation where anyone with a learning disability who lives in Scotland can be a member. Members provide collective advocacy and support and campaign to create a society where people with learning disabilities are meaningfully included and treated fairly and equally. They agreed to meet over a long period which enabled in-depth and deeply personal and trusting conversations that would continue over the sessions. Whilst they were balanced in their views, both positive and negative, they made clear that much is still to be addressed if their goals are to be achieved.

The third contribution is from the Scottish Commission for Learning Disabilities which came into being as a result of the recommendations in *The same as you?*, the seminal Scottish Government policy published in 2000. One of their current areas of work is about promoting the human rights of people with learning disabilities. So all the workshops were devoted to viewing Margaret's life and the lives being lived now through the lens of human rights legislation. It too, is powerful and thought provoking.

The fourth and final contribution is from pamis, a national organisation that supports and promotes the needs and wishes of individuals with profound and multiple disabilities and their family carers. They provide yet another set of perspectives in representing what it can be like to be someone with profound and multiple needs living in Scotland today and what the challenges and hopes may be going forward. These views were given by family carers with honesty and candour.

Chapter One: Workshops with Individuals with a Learning Disability who Live in Inverclyde Today

Introduction

It was essential to understand what it is like to be a person with a learning disability living in Inverclyde now so two workshops were set up with a total of ten participants for this purpose. Both men and women took part and their ages ranged from young adults to those who were older. Some were of a similar age to that which Margaret would have been now had she lived. Levels of independence and need for support varied considerably, from a few hours to twenty-four-hour care, to those who live with their parents. No-one had profound or multiple learning disabilities or appeared to have a dual diagnosis such as autism. The conversations centred on early life experience up to the present day including education, health, support and services, employability and safeguarding as well as hopes for the future.

Most spoke of enjoying nursery, one person saying that 'they were great to us and took care of us.' Some had attended primary and secondary schools for pupils with additional needs and commented that 'classes were split to support different people's needs.' They felt they had benefitted from the breadth of opportunities on offer including taking exams such as Standard grades before going on to College to the Step Course. The latter is focused on providing a mixture of conventional and vocational qualifications to become more independent. It was here that a sense of insecurity and uncertainty could creep in about the future.

Some had gone on to have work placements in a variety of settings from the local Council to garden centres. Employment was not something any of the group currently has.

Home was different for individuals in that some were living alone or with parents and siblings, while others were living in flat shares with other people with a

learning disability. Another individual was self-sufficient and very independent. One man supported his frail mother whilst another had taken over the tenancy of the family property after his mum had died. It was evident that several of those who participated in the workshops knew each other well, enjoyed each other's company and could challenge one another as well as share humour.

Others who were older had lived in long stay hospitals in the past and were glad to be in the community.

Most were aware of the importance of self-care in terms of health and wellbeing with some needing medication to manage conditions such as epilepsy. It was essential that some shielded during Covid because of underlying health conditions.

Spending time with family mattered a lot to those who had ongoing contact as well as spending time with friends. Leisure pursuits were highly valued and these varied enormously from football, swimming and shopping to knitting and dancing. Some said they would like to extend their range of hobbies further.

One participant brought her life passport and shared this with the group. She had been brought up in the east of Scotland, having been adopted. Her adoptive mother's illness meant that she moved to live in a large voluntary organisation facility in the west of Scotland. Her adoptive family always encouraged her to be as independent as possible, for example, giving her tasks in the home. In her adulthood, she continues to have work experience by helping in a canteen and charity shops. This had been curtailed because of Covid.

Safeguarding Thoughts

Some individuals had experienced bullying and had called this out with support and felt empowered as a consequence. So for them there was a wish that all

others knew what hate crime was and were able to tackle this. They spoke about knowing who to go to if they were worried about this or anything else.

What Would Make Life Better?

Individuals gave very individual responses to this question.

One young woman hoped for her health to improve. She totally understood the need for a healthy diet and exercise and put this into practice. Despite this, she had been hospitalised with Covid but recovered well and was very positive about the quality of care she had received while she was ill. Another woman spoke about her ongoing conditions such as arthritis, sciatica and dizziness which made supervision necessary for showering. She was very knowledgeable about, and accepting of, her conditions and confident in managing these, saying 'I have to stay healthy.' One young man talked about his ongoing ambition to have a job and how difficult this was to achieve, especially as his benefits might be affected. Another woman shared this ambition. One participant hoped to have a boyfriend

while another would like to see her favourite country and western singer.

Some asks were more routine - like getting a bedroom decorated or going back to the gym.

In summary, this group of individuals who have a learning disability and are living in Inverclyde today are very positive about their lives and circumstances. They feel listened to, have interesting and fulfilling lives and know where to go for support and protection if needed. They were not isolated and had friends and family to enjoy.

Chapter Two: People First (Scotland)

The Organisation

People First describes itself as The National Disabled People's Organisation of adults with a learning disability in Scotland 'run by our members for our members.' Any adult with a learning disability can be a member and there are over one thousand members to date. Members can then vote for the Board of the organisation or stand to become a Board member and can be chosen to represent People First in meetings.

There are local groups where members come together 'to offer advice, share news and speak up' for themselves. They also have a number of national

groups that 'campaign about the issues that affect people with learning disabilities' and collaborate on several Scottish Government policy development initiatives. They have a national Parents' Group, a Law and Human Rights Group and the Supporting Offenders with a Learning Disability Group. They have considerable expertise about many important topics such as communication and on supported decision – making, Their promotion of supported decision-making is of great importance in terms of what this does for people with learning disabilities in ensuring they have their best life.

Contributing to the Review

A group of individual members, supported by their Service Manager, committed to meeting with the Independent Reviewer once a month for six months on zoom to both share their thoughts about Margaret's life and circumstances and to offer their knowledge and ideas. Specific topics were covered such as education, benefits, health and wellbeing, life transitions as well as how to support people like Margaret today.

Members varied in age and lived in different settings, some independently, others with support and others

with their family. Some people had traumatic childhood experiences. Some view education positively while others remember difficult times. Health and wellbeing challenges were common. Most enjoy their lives and find People First to be integral to making that possible. Everyone is looking for more – particularly in employment and being valued there and in society more widely. So they have expectations and ambitions whilst recognising that individuals with learning disabilities can face prejudice, barriers and difficulties.

Reactions to Margaret's Death

Group members thought it was essential that they prioritised their involvement in the Review, with one person commenting that 'it is important to us.' Another queried 'how on Earth can this have gone on for years? Adding that it came down to 'who you could trust.' Another contributor summarised her deep fear and that of others by saying that 'this could happen to any one of us. We just don't know.' Being visible and being known were seen as ways to be protected.

They also stressed the importance of all those involved with a person with learning disabilities, particularly support staff, 'speaking to them and getting to know them.' They acknowledged, too, that a balance needed to be struck between 'keeping a watchful eye' and inappropriate intrusion.

Covid

Covid had made a huge impact, recognising that 'there had been so many deaths' of people with a learning disability and that mental health had been so adversely affected by isolation and by reduction and withdrawal of supports. Staff shortages and the crisis in care were mentioned and understood too. A recurring thought was whether services pre-Covid would ever return to their previous level. A consequence was that individuals felt more exposed and potentially at risk.

Zoom meetings, introduced as a result of Covid, had meant that members 'could be in contact with people from all over Scotland – not just locally and that was a clear benefit.' Others missed and looked forward to seeing one another face to face again.

Learning about remote communication had been enjoyable for those who were quite technologically

mindful while others had grappled with this, recognising that 'digital exclusion' was something that needed to be tackled to make these opportunities more equitable. One person, for example, needed to get her tablet organised by others and this sometimes meant that she struggled with getting the privacy needed to participate.

One lady who lives in supported accommodation who had asthma and had Covid spoke about how she and others were asked about whether they would wish to be resuscitated if they became seriously unwell. This had made her afraid.

There was great relief that the new normal was beginning and individuals and groups could meet again.

Education and Employment

There was acknowledgement that 'teaching has come on massively in the last forty years.' One member recalled being in hospital some years ago for long periods of his childhood because of a physical disability which required a series of operations and meant that he lost some of his education. He felt that 'people look down on you' and that in mainstream secondary school 'we become targets'. He doesn't like what he calls 'titles' or labels and feels that 'they mean that straight away you are treated differently'. 'It's like our opinions don't matter'.

Another participant described mainstream schooling as being 'not for him' because of bullying although this had been addressed by the Head of School. He ultimately moved to a Skills College with the support of his family which 'was absolutely amazing' where he spent a total of seven years and particularly enjoyed outdoor activities ranging from farming and woodwork. He then trialed a residential place and stayed for two years before getting a job there giving employment advice and support.

An individual with learning disabilities and autism said that life has not been easy although his family support him very well and he lives in a nice part of a city. He has early memories of people throwing snowballs at him and 'thinking that they were being

funny and getting away with it.' He delayed going to mainstream Primary School where he got learning support and was bullied. He explained that the bullying continued in secondary school and that he attended three secondary schools and one specialist resource. He stayed in the last for four years because he was in a base which provided scribe support and he got his qualifications there. 'They listened to what I wanted.' Then he went to College. He is a co-trainer in digital participation and enjoys connecting online.

He says 'philosophically it is difficult for people to understand'.

One of the others in the group spoke about her education in specialist provision as having given her 'confidence to learn things to do, things that I couldn't understand'. She then lived in supported accommodation in a city for a long time and was attending a local Day Centre.

Experience of volunteering and working is regarded as important but this, too, had disappointments with some saying that they were 'kept in the background doing menial and repetitive tasks'. Another concern was the potential implications of work affecting state benefits and the uncertainties that this could bring.

Benefits

A specific topic that was raised about the Benefits System was how difficult they found assessments, feeling 'put on the spot' by being asked for very specific answers to questions when 'it is not that simple.' An example was given of being asked how far an individual could walk and found it difficult to give one response as he does not like walking on ice.

Another person had been called for an assessment, the trigger being that there was a mismatch between what his dad had said in completing his form with him and what the GP had said, the latter having omitted to list a lifelong physical condition. He was affected by

both the uncertainty that the assessment caused but also by the fact that issues relating to his mental health had been covered. He found the questions asked in assessment to be too personal e.g. how long he spent in his bath? And how long can you hold something in your hand? Underlying all of the above was a feeling that 'the questioning was pointless as having a learning disability was lifelong.'

He was hopeful that Social Security Scotland would lead to significant changes including fewer assessments.

Health and Wellbeing

Health and wellbeing was central to many. Several members had physical challenges ranging from having cerebral palsy to managing a shunt as a consequence of a brain tumour. Those who had a good GP valued this because of the trust in being able to talk to and be understood by such a significant professional.

Some shared concerns about medication, including understanding what it was for because of the complexity of the associated language and what alternatives that there might be. One member had been able to take these concerns to the Scottish Government Keys to Life Expert Group and hopes that medicines will be described in accessible formats including images.

Others spoke of the worry of being in hospital and being less able to exercise control, not least because

of a lack of information where 'asking questions is not encouraged.'

Difficulty in understanding Covid vaccines literature was given as an example of a wider information gap that created vulnerability with one of the membership having asked for Covid information to be read to him which he said was refused.

Underpinning many of these issues is the critical nature of information gathering and sharing – whether this is repeating your situation time after time to different professionals to having messages in accessible formats. He now has his own place run by a large voluntary sector provider and says 'I do what I want.'

Parenting

Another talked about the complexities of her family life both in the past and present involving family breakdown, homelessness, offending and deaths. In particular, she cast light on the difficulties and barriers with regard to parenting. She has two children and has struggled with mental health issues but her situation has now stabilised and she lives in the community with support. She is subject to Guardianship. She feels that

her life is much improved and has been able to go to College as well as to advocate to get the support that her daughter needs from Social Work.

Adjusting to Major Life Changes

An older lady lived with her mum until she died. She had a breakdown. She needed a change and got her 'own wee place' which she loves and pays for herself. Her two brothers and a sister live nearby and look after her. She had a stroke and People First advocated successfully on her behalf with housing to get her a ground floor apartment. She said 'I don't

keep as well' and that she has 'had some falls lately' because of weakness in one of her legs and an arm.' She particularly enjoys the women's' support from People First saying that 'they made things possible that weren't possible before.' She is proud of her involvement but says that 'there are still barriers'.

What Could be Better?

The following asks were made:

- That everyone has 'a watchful eye' that looks out for people with learning disabilities that protects but does not intrude. People First (Scotland) does this for its members.
- That our thoughts and ideas are shared as widely as possible with the right people. It is about human rights and it is about choice at the end of the day. 'We are not getting a choice in life, not being included in it. It is not fair that there is no time to resolve issues. We are the ones needing to be heard because we've been through a lot.' It is sometimes hard 'to get a foot in the door.'
- More opportunities to influence forthcoming policy and practice such as the experience People First has had with both the Rome Review and the Scottish Mental Health Law Review. Here we have been able to have representation and to contribute at every stage but would have liked more opportunities to contribute to specific aspects such as supported decision making.
- Understanding that limiting our participation without clear explanations from the professionals involved is disappointing and counterproductive.
- That the expertise that People First has in supported decision making is recognised more fully and widely and is better reflected in invitations to participate in key policy developments including the emerging National Care Service.
- That there are opportunities for people with learning disabilities to interview prospective staff at all levels in all Agencies that directly impact on our lives.
- That staff keep the promises they make.
- That waiting times are improved.
- To respect and act on requests for support workers with particular characteristics that match our needs and wishes. We should be respected for how we want things done – not just what needs done.
- A willingness to put the past in the past for those who have offended when they were young or their circumstances were challenging.
- More apparent and positive attitudes need to be shown towards people with learning disabilities in employment. Main elements of this would be through employer training and by recognising that we deserve to work in society and that we have all got different talents and skills.

Chapter Three: Report from the Scottish Commission for People with Learning Disabilities

Introduction

The Scottish Commission for Learning Disabilities hopes that the Review will prevent another situation arising for others in similar circumstances to Margaret and ensure that they may grow up with their human rights protected.

In Scotland, The National Taskforce on Human Rights Leadership recommended the United Nations

Convention on the Rights of Persons with Disabilities be incorporated into Scottish Law. This was committed to by the Scottish Government in their Programme for Government 2021-2022 and will be part of the new Human Rights Bill for Scotland. Given this, the Scottish Commission for Learning Disabilities has focused its Human Rights analysis of the comments of the focus group on the Convention.

The Scottish Commission for People with Learning Disabilities Approach

In discussion with the External Independent Reviewer about how best to support people with learning disabilities to participate in the Significant Case Review, it was agreed that this would be through a series of virtual discussions with a small group. It was acknowledged that these discussions were likely to be difficult for at least some of the participants, given the circumstances of Margaret's life. The Commission therefore gave a lot of thought about group membership. It recruited a group of six individuals with learning disabilities and briefed them about the purpose of the discussions.

The participants and the Commission agreed together that those involved would be able to contribute to the Review; they understood that some of the discussions would be difficult. Measures were put in place to make sure that everyone understood they could leave a meeting at any time; they could go to a breakout room and talk to a member of staff if they wanted to. Each meeting started with an upbeat icebreaker, and ended with an optimistic discussion e.g. 'What are you looking forward to doing this weekend?' After each meeting the Commission considered whether a follow-up call to any participant was needed; in the event this was never needed.

The group was made up of two female and four male participants from across Scotland. Participants were all of an age where they experienced life stages at a similar time to Margaret or before she did, so they were able to relate to what life for people with learning disabilities was like at that time.

We held three 90-minute Zoom sessions, and participants were asked to attend all three if possible. Six, four and five participants respectively attended the three sessions.

In the first session, the Independent Reviewer explained the purpose of the Review and gave a summary of the main events in Margaret's life. Sessions two and three gave participants a chance to share their thoughts about each area of Margaret's life and discuss where things could have been different. Often this related to their own experiences in life, for example where things had gone well for them in terms of resolving life issues, or where there had been issues that they felt were not resolved as well or as quickly as they could have been.

This report is a summary of the discussions across the three sessions. These have been grouped in themes and related to relevant articles of the UNCRPD.

Key Themes from Focus Group

Support for Transitions

Human Rights Analysis

Article 19 of the UNCRPD states that people with disabilities should have access to "...a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community".

This is balanced with obligations to ensure people can choose where they want to live. For more information, please refer to Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on living independently and being included in the community.

At the time Margaret left school not everyone was given support to plan the next stage of life. This was a common experience for young people with learning disabilities at the time, as transition had not yet been recognised as the critical time for young people that it now is. The Scottish Government is currently discussing a Transitions Bill that would see people offered more support at this time in their life. When asked about transition, one group member said:

"To me, ok, you maybe don't get a lot of support because you still live with your family, but I feel that you should still have extra support when leaving school as sometimes family don't give you the support as my family didn't."

The participants remembered that they had received little support when leaving school. The options they were given were a College place or a Day Centre or nothing. Some of the group said that it was only support from family or friends that was available at this time and that formal support was not always available.

Members of the group recalled that it was difficult to get adult Social Work support if they lived with their families but not everyone's family was willing and able to ensure that the person got the support and information they needed to live an independent life.

The group all agreed that more support at this time might have been beneficial to Margaret. They agreed that Transition was not the single event of leaving school, but rather that extended period of someone's life as they entered adulthood: after Margaret left College she became isolated from friends and professionals who might have looked out for her.

Participants felt that there should have been someone to 'keep an eye out' at this point as well.

The group thought that there should have been involvement from adult Social Work and that the decision to leave Margaret without a Social Worker because she was starting College was a mistake. They said her Social Worker seemed to have had a good relationship with Margaret and provided her with something that she needed. The important role of Social Work in providing support was highlighted by one group member who said:

"Social Workers should be nice but they should not just be someone's friend, they should do the job they need to do and make sure someone has the support they need."

After Margaret left College she was not referred to Social Work again to ensure that she moved onto a positive destination. The group felt that instead of offering friendship, the role of a Social Worker should be to help someone to get the support they need to live. For Margaret, this might have meant a place in a Day Centre, or another kind of support that could have acted as a safeguard for her.

The group made the point that there are different transitions in a person's life, not just leaving school but changing home, starting a job or the death of a family member. In Margaret's life one of these periods was when she moved in with EC and AJ. At that time, Social Work had already closed her case and Margaret had left College so she had no support from outside of the family, she also had very little contact with anyone outside of the home.

Support for Margaret and the Whole Family

Human Rights Analysis

Article 19 UNCRPD states that, “community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

General Comment Number 5. (2017) states, “Often, persons with disabilities cannot exercise choice because there is a lack of options to choose from. This is the case, for instance, where informal support by the family is the only option, where support is unavailable outside of institutions, where housing is inaccessible or support is not provided in the community, and where support is provided only within specified forms of residence such as group homes or institutions. “

This appears to be key to the issue Margaret faced: her only support available was her family and when her relationship with her mother became challenging she was left without any choices other than to move in with EC and AJ which placed her in a situation of risk.

There was some discussion in the group about what support there should have been for Margaret and her family, specifically to support her to live with her mum after her dad died. The group felt that the level of support offered by Social Work was not sufficient and that there should have been other social care support, both for Margaret and for the family. Had these things been in place she may not have moved in with EC and AJ; even if she had, there would have been someone else who might have been alerted to her situation.

Members of the group were able to recall times when they had challenges in life, from having to challenge a decision to move them into care, to dealing with the emotional and practical challenges of losing a family member. Mostly the group members had people around to give them support and guidance. Sometimes this was friends and family, sometimes it was paid staff in a service like a day service.

One member of the group spoke about when they were a teenager. They talked about how they had behaved and thought they had behaved ‘badly’ at

times, and that they ‘grew out of it’ when they were older. This individual could understand why Margaret’s behaviour was challenging and difficult for her mum to manage, since she was going through a lot emotionally at the time. The group member who spoke about this said that their family and their school had told them that they had to change their behaviour, but it took them some time before they were able to.

Some members of the group spoke about the importance of being able to access Social Work support. Some had experienced times when their named Social Worker was off sick and no one else would help them till they got back. They made the point that it is not the fault of the individual Social Worker, but that the system does not always support people when they have an issue that arises suddenly. Participants also emphasised that this flaw in the system can have serious consequences for the individual that is let down.

Being Part of the Community and Being Noticed

Human Rights Analysis

Article 29 of the UNCRPD states that Governments shall guarantee persons with disabilities “participation in non-governmental organizations [NGO’s] and associations concerned with the public and political life of the country, and in the activities and administration of political parties”

For the focus group members, having links with organisations such as NGO’s as well as social groups and wider community links acted as a safeguard for them.

The group discussed whether there should be someone responsible for ‘checking up’ on people with learning disabilities to make sure everything is OK. There was discussion that for people who are actively involved with organisations like dates n mates, get2gether or ENABLE Scotland, for example, someone would notice if they failed to show up to meetings or events after just a short time, and someone would check up on them:

“We all have people who would notice if we were absent. Margaret didn’t have that in her life, so some people are not getting the care they need”.

People talked about how change can be hard and that for some people moving to a new area, they may still like to keep their old contacts like their doctor if the new area is in travelling distance.

One person suggested that supports like Neighbourhood Networks could be really helpful, something that provides an individual service, but which also builds good communities. Other things like Neighbourhood Watch were mentioned as useful informal safeguards – sometimes they go further than their stated purpose of looking out for criminal activity and can spot if people need extra help or if anything else unusual is going on. The point was made that these kinds of safeguards would need to know what to do when they have concerns that someone might be at risk of harm, by making referrals under adult protection legislation, for example.

A Named Person?

Article 22 of UNCRPD states that, “No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.”

Article 10 states “People with disabilities have the right to life. Countries must take all necessary measures to ensure that people with disabilities are able to effectively enjoy this right on an equal basis with others.”

The key issue in the discussion was how to protect someone’s right to life, and their right to freedom from abuse (Article 16 below) without breaching their right to privacy. Offering people protections and safeguards early, when they are able to make informed choices may be a way to balance these rights.

There were several suggestions that there should be a professional, or a number of professionals with responsibility for checking in with people to see if they are ok. One participant said:

“she slipped through the net, she disappeared for so long without anyone knowing. People with learning disabilities should have someone to oversee what was happening. Did EC and AJ take advantage of the fact that no one would notice?”

It was suggested that there should be someone checking up as EC and AJ may have realised that no one would notice if Margaret went missing.

Most of the group agreed that there should be a person tasked with checking in and keeping in touch, with a protocol to follow if they were concerned or unable to get in contact with the person. There were a number of different people suggested who could do this role:

- Friends
- Social Workers
- Doctors
- The job centre
- Other social care staff such as those linked to a Day Centre.

It was noted that most of the time people have someone to look out for them but there needs to be something in place for the small percentage of people who do not have these natural supports. The group discussed that while this sounded like a good idea it would not be something that everyone would like in practice, because they would see it as an intrusion into their privacy. Having a phone call once a week might be acceptable for some people but having people coming out to do a home visit especially unannounced could be intrusive.

One person spoke about how much they hated the respite service they went to. The staff at the respite service told people what to do and this was unpleasant. The group thought something similar might happen with someone whose job was to check you were ok. They might not let you live the life you want. It can be easy for people in authority to manipulate people, even if they do not mean to, and to make decisions on behalf of people with learning disabilities because they make assumptions about what they are able to do and understand.

Safeguarding

Article 16 of the UNCRPD outlines that, “States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.”

This underlines the importance of the group’s point that having safeguarding measures in place when Margaret moved in with EC and AJ may have reduced the risk facing Margaret at that time.

It was suggested that the change of home and the acceptance of EC and AJ should have triggered a Social Work referral to check that they were safe and reliable:

“someone should have been in to check when she was moving in with these two other adults.”

There were no checks done on EC and AJ when Margaret moved in and the group felt that there should have been. The group discussed how to balance the

need to keep everyone safe with the fact that only a small amount of people need this protection. Police checks and disclosure schemes were mentioned and that there are other professionals such as social care workers who might be around to notice things. One person raised concerns that abuse can happen anywhere and not just from family or unpaid carers.

They asked:

“How do we protect people from the people who are supposed to keep us safe?”

Would Human Rights Laws Help?

The group were asked if they thought that having specific human rights law for people with learning disabilities would help ensure they got the things they need. They discussed the specific question of whether a law could ensure that people with disabilities had the same rights to live where they want, just as other people do. This would mean that although there would be the same limitations in availability and affordability that everyone else faced, they would not be denied options simply because they have a learning disability.

“I think it would have helped, I had to help my brother and I think it would have helped him in his situation”.

“a law has more weight than just saying it’s a human right. Some laws are overlooked if it’s a busy local authority. A positive side would be that people should have these things as part of their training and should know what they should do.”

“It would be better to be there than not to be there.”

What Might Keep a Future Margaret Safe?

The group was asked to suggest some things that could help to prevent a situation like Margaret's from arising again. These suggestions were:

- A 'neighbourhood networks' system that connects young people leaving school with other young school leavers.
- Put on activities suitable for disabled people but for the whole community to join in: sports, coffee mornings, lunch clubs, and night-time activities. The point in a lunch club beyond getting lunch is it's a whole set of eyes on each other, it's an early warning system. If people drop out of an active community, then people notice.
- Citizen advocacy, befriending, buddy system. If this was implemented for young people leaving school there would be a person in their life to look out for them. A person that is there by invitation, not something imposed.

Conclusion / What Would Make Things Better?

Participants in this group discussed in some depth the various ways that young people with learning disabilities can be kept safe, and have their human rights protected so that they are free to live independently and participate as fully as they wish to in community life.

The group thought that agencies had an important role to play, and that laws were important to force these agencies to do what they were supposed to do.

There was support for legislation to improve the support that young people get to move from childhood into the adult world.

There was a clear recognition that Social Work had an important role to play in putting supports in place that were not intrusive but were both enabling and protective.

However, the group agreed strongly that the community has a really important role to play in keeping people safe, through a range of semi-formal and informal networks.

As such, the role of protecting people's human rights cannot be left to duty bearers. Instead, 'keeping people safe' must come from strong and healthy communities, where individuals take responsibility for each other and show leadership in nurturing all the 'community values' that the group identified: of respect, care and consideration.

Chapter Four: pamis – The Views of Parents

Introduction

Two workshop sessions took place with pamis (promoting a more inclusive society) which describes itself as the only organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families 'for a better life.' Their services range from family support to digital passports that promote and assist inclusive communication.

Participants offered their lived experience of caring for their children, in the past and to the present day, and

highlighted strengths and improvements in services as well as gaps and concerns. They recognised that their contribution related primarily to those individuals who had profound and multiple learning disabilities and that their thoughts and ideas were about how to protect and enhance the lives of those who may be the most vulnerable.

Caring Experience

There was a shared view that it was imperative 'to speak up for', and to advocate on behalf of your child and 'to hold organisations to account' but that this required time and energy that carers did not always have because of exhaustion. This could also mean that there may not be enough representative voices in national consultations of those with multiple and profound learning disabilities.

They spoke of 'constantly having to fight for resources' and the 'postcode lottery' that this could be. They also talked about the importance of listening 'to hear what was actually being said.' A related perception was that those with more capacity in terms of their ability to communicate and articulate their needs 'who are a bit more outspoken do not have the same vulnerability' as those with more profound and complex needs who are

'easier for someone to abuse.' Some spoke of the wish 'just to be a mum' and not a carer.

Covid was said to have put immense strain on families because of there being reduced or no support. Most coped but some were concerned about those who were not necessarily known to services and how they could be particularly isolated. There was an appreciation, too, that a balance needs to be struck between potentially intruding unnecessarily in lives and being supportive. There was a fear that, having made progress over the decades, that this was under threat of 'going backwards.' Digital observation of overnight care, for example, was increasing and parents are concerned about the potential risks.

Strengths and Improvements

Although those who participated were distressed by what they knew or heard about Margaret's life, they were clear that there has been much positive progress in terms of legislation, policy and practice since then. They thought that there was still room to make legislative change more accessible so that individuals and families were then better able to exercise their rights.

The Adults with Incapacity (Scotland) Act 2000 was cited as a first key example of change which set out to protect individuals aged over 16 who lacked capacity to make some or all decisions for themselves. This statute had also been valuable in supporting families and carers to manage and safeguard the individual's welfare and finances.

The Carers (Scotland) Act 2016 was also mentioned as having led to improvements in increasing the rights of carers in identifying their personal outcomes and needs for support.

The Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill, currently going through the Scottish Parliament, was also welcomed in terms of its provisions to have a Scottish Government Transitions Strategy and a Minister responsible for improving opportunities for disabled children and young people moving into adulthood.

They welcomed the Review of Mental Health legislation and were hopeful about the National Care Service proposals, appreciating the need to update and consider how the different measures could be combined to be more effective. There was a concern that the National Care Service 'will be geared toward older people and adults who have complex care may fall through the cracks again.'

There were questions, too, about whether all staff were sufficiently familiar with existing statutes which then impacted on their ability to practice to their optimum. They stressed the importance of extensive training on any new provision that might arise.

Gaps and Concerns

It was agreed that Education for children and young people with profound and multiple learning disabilities has improved. However, more education is thought to be required for family workers in schools, Health and social care 'to understand communication styles, open dialogue so we can work together as society and advocate for people with learning disabilities.'

The transition to adult services was described as a period when 'everything children have known changed drastically.' They talked about how they are 'then left to their own devices but that isn't possible and needs to be addressed.' Some see the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill as the means to significantly improve processes and practice. They are hopeful that this could also lead to more focused personalised centred adult services. Linked to this was the importance of having whole life care from birth to death that was of a consistent standard.

Respite can be problematic because of a 'lack of facilities with specialist carers to help.' An example was given of a young person who has been advised that respite can only be provided in residential care

some considerable distance from home when they make the transition to adult services.

Support for children in hospital was seen to have improved although the same progress was not thought to be universally available to adults. A recurrent theme expressed by several participants was about risks when their child was admitted to hospital. It was not always possible for their pre-existing social care staff to continue to support them in that setting. This was allowed in some areas and created a confidence in families that their child's specific needs in terms of medication, handling, etc. would continue as before. It was also reassuring to know that there would be familiar faces in the ward – especially if there was to put an invasive procedure of some kind.

Planning for the future was seen as hugely significant with parents saying that it was 'terrifying being in a position where you don't know what will happen to your child if you pass away.'

Safeguarding Thoughts

It was agreed that 'there will always be people who slip through the net' and that 'there are not enough Social Workers and other professionals who may notice abuse.' Others thought that the multi-agency nature of safeguarding could mean that one Agency may think the other was in the lead and so opportunities could be missed.

Some members of the organisation had experience of reporting potential risk of harm and had not felt that their concerns had been taken seriously enough. Others were of the view that there could be 'more encouragement to highlight abusive situations.' One participant had direct experience of reporting abuse of a young person who was experiencing 'undue pressure'. This took a long time to resolve, involving a change of environment, before the perpetrators were charged. The intervening period was stressful for all concerned and, for the parent, emphasised the criticality of believing and acting as soon as is feasible to avoid further harm. Other parents spoke of challenging and very personal experiences they had which led them to believe that 'there is still a lot of work to do'.

The need to have Guardianship in order to be heard was also emphasised as well as the expense that this incurred in ever more pressed family budgets. Some commented that there are supposed to be bi-yearly checks on Guardianship which may not have taken place for over three years because of the impact of Covid.

Social Work and social care staff were acknowledged by parents and valued for 'the wonderful service' but that staff turnover, sometimes linked to pay and conditions, meant that there were gaps and

inconsistencies in the care that it was possible to provide. Others were more critical based on some negative experiences they had had. Replacement recruitment is seen as challenging, with more Social Workers being needed who are specialised and who understand the needs of people with a learning disability including differences in severity and the challenges that this may bring.

The workshop sessions also included students who were on placement with pamis and they offered their thoughts on their professional training courses in terms of readiness to practise, indicating that the role was so extensive that not everything could be covered. They were also aware that Social Workers grappled with a wide range of expectations which could lead to sickness absence and burnout.

There was general support for a means of ensuring that all individuals with a learning disability were known. The possibility of a named person type Register had a mixed response with some being broadly supportive and others viewing this as an 'overreach'. There was consensus about a mechanism that would ensure that there was 'a yearly awareness that someone is at least alive, particularly if they haven't been known to services before.'

The recently announced annual Health checks for people with a learning disability were seen as a potential route. They were also viewed as a means to inform and enhance good practice. A number of examples of what this could mean included being better able to distinguish the different types of learning disability diagnoses to informing the need for service development around topics such as advocacy and creating service and support Hubs.





REMEMBER
MY
NAME

A SIGNIFICANT CASE REVIEW INTO THE LIFE OF

M A R G A R E T F L E M I N G

M A R G A R E T ' S
E N D U R I N G
V O I C E

