

"Hear Our Voices We Entreat"

Även om jag inte säger något kan
jag ha något att säga

Even if I do not speak, I can have something to say

JAG, Sweden

A report to the Winston Churchill Memorial Trust detailing the status of severely disabled, non-verbal people in UK, Ireland and Sweden.

Post Script

My report contains recommendations for the Ministry of Health, Disability Support Services and Ministry of Social Development. Since my return I have been in contact with each of these organisations.

Recommendations for Ministry of Health, Disability Support Services, Ministry of Social Development:

1. That it be compulsory/legislated for all disabled people including those with profound disabilities to be consulted at all times when a decision is made which will impact on their lives and that they will be given the support required to make that decision in their best interests.
2. That “nothing about us without us” is applied to all disabled people in New Zealand as it does in the UK, Ireland and Sweden.
3. That profoundly disabled people are provided with appropriate representation in the Convention Coalition reporting on the UN Convention on the Rights of Persons with Disabilities.
4. That the Ministry of Health, Disability Support Services and Ministry of Social Development consult and work closely with appropriate individuals and organisations supporting people with profound disabilities to develop quality, sustainable services to meet the needs of this population.
5. That people who know the profoundly disabled person well and can communicate with them effectively are accepted as being able to speak or interpret on their behalf.
6. That the importance of the role of the family is recognised for all people and that it be acknowledged and accepted that for those with profound disabilities the family will usually be the main source of love, care and support. Even when they leave home, they do not leave the family who continue to offer a lifetime of involvement and advocacy

I have been advocating for the right of cognitively impaired, non-verbal people to be represented, included and consulted in all matters that impact on them for many years, hence my decision to apply to the Winston Churchill Memorial Trust to better understand the situation in other countries.

Personally it has been very empowering to be able to share my experience with Complex Care Group members and the Board. The Complex Care Group is contracted to the Ministry

Of Health, Disability Support Services to provide support for children and young people with complex support needs. Our members in turn have felt empowered to use my findings in appropriate forums as we all strive to ensure that our disabled family members do have a “voice” that will be heard, and that their complex health and disability needs will be met.

I have spoken at length with a number of influential people involved in the Disability sector and shared my experience with them hoping to gain their understanding and support of a “voice” for our family members. I have explained that this doesn’t have to be family member; that we would be grateful for all more able disabled people to advocate on behalf of those with complex care needs so they too can enjoy the same rights as all citizens in NZ. I have addressed a number of meetings building awareness of this population and how their “voice” is heard in the countries I visited.

Since my return I have spoken on a number of occasions with the Disabled Persons Assembly (DPA) who has been very supportive. I have also spoken with People First along with a number of others from the disability sector at various forums and workshops including the New Zealand Disability Support Network (NZDSN). I presented my findings at its conference in August 2017.

I also shared my research with the Office for Disability Issues (ODI) and organised a meeting with ODI and our members to discuss the draft of the Disability Strategy review. We were pleased to see that our input had been taken into account in the revised Disability Strategy 2016-2026. It is very clear in this new strategy that it is expected that ALL disabled people, including those who are cognitively impaired and non verbal, must be consulted and included.

Since sharing my findings with ODI, they have been happy to consult with us over matters impacting our children/young people.

In February 2017 I was asked to participate in the roundtable discussion on the *Legal Capacity in New Zealand* led by ODI to represent the population we support. I have discussed the outcome of my overseas visit with the Minister for Disability Issues, staff from Disability Support Services (DSS), and Waitemata and Auckland District Health Boards where, until recently, I was a member of their DiSAC committee.

I was interviewed by Malatest who are reviewing the composition of the Convention Coalition, part of the monitoring group for the United Nations Convention on the Rights of People with Disabilities (UNCRPD). Again, I was able to share my findings. We see having representation for our population as being very important but currently the criteria for membership of this group excludes people who are cognitively disabled and non verbal. We are eagerly awaiting the outcome of this review.

Recently I have been in contact with the Ministry of Health Transformation of the Disability Support System team. Our information is contributing to its work on understanding the diversity of the disability population. They have asked to *“come back to us to test their thinking when they have developed it further.”*

These are all very positive signs and I believe that we are certainly making progress since my return and sharing the knowledge I gained from the countries I visited. We are gaining better recognition and understanding of the need for a “voice” for our young people. The current mantra alongside “nothing about us without us” is now joined by “choice and control” which should be the right of all NZ citizens. Some of us just need more support than others to make that possible.

Jan Moss

July 20th 2017

Acknowledgements:

I wish to acknowledge and thank most sincerely the Winston Churchill Memorial Trust Board for granting me a fellowship to assist with my travel to the United Kingdom, Ireland and Sweden

My sincere thanks also to the Complex Care Group Trust Board who provided encouragement, support and financial assistance to help make this study possible.

My heartfelt thanks and gratitude to all the wonderful people I had the privilege to meet during this study.

- Pamela Shaw, Senior Participation Officer, The Council for Disabled Children, London UK
- Gail Walshe, Head of Parent Participation Contact a Family. Maureen Morris and Sherann Hillman, Co-Chairs and North East & Cumbria representatives, National Network of Parent Carer Forums UK,
- Zac Taylor, Head of Practise Strategy and Design and Bella Travis, Information and policy officer for profound and multiple learning disabilities, Royal Mencap Society.
- Viv Cooper, CEO, Holly Butcher, Family Support Manager and Jessie Humphries, Family Support Worker, The Challenging Behaviour Foundation, Chatham, Kent
- Chinyere Kejeh, and Balwinder Sandu, Family Carers who volunteer with the Challenging Behaviour Foundation.
- Anna-Karin Kingston Author of *Mothering Special Need, A different maternal journey*. Member of the MA in Women's studies teaching board, University College, Cork, Ireland.
- Julie Helen, Regional Field Officer, Cork, for Inclusion Ireland.
- Denis Sexton, Irish Society for Autism.
- Lennart Magnusson, NKA, The Swedish Family Care Competence Centre.
- Judith, FUB, the Swedish National Association for Persons with Intellectual Disability.
- Cecilia Blanck, Executive Manager, Kerstin Sellin, Maria Arvidsson and Hillivie Larson, JAG, Sweden.
- Marita Skoog Jacobsen, Geraldine Ferrand Noren, CEO and Camilla Strom, Autism&Asperger, Stockholm, Sweden.

Special thanks also to:

- My Family for their patience, their huge support and encouragement.
- My daughter Becky's Support Workers who provided her with the emotional and physical support she needed in my absence.
- Kay Murphy for her great support while in Ireland.
- Marianne Nilsson for her amazing support, translating skills and direction finding in Stockholm.

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Terminology:

- Intellectual disability, learning disability, cognitive impairment, intellectual impairment and developmental delay are used synonymously throughout this document.
- Profoundly disabled, severely disabled, profound and multiple learning disabilities (PMLD) and disabled people with intensive support needs or high and complex needs in this document are terms all used in this report to describe disabled people with multiple disabilities who are cognitively impaired and non-verbal.
- Autism Spectrum Disorder, ASD and people on the spectrum are used synonymously in this document.

Application brief:

I wish to travel to Sweden, Ireland and the United Kingdom (UK) to connect with individuals and organisations in these countries that provide support to severely disabled people and discover how they provide a "voice" for disabled adults (18+ years) with severe cognitive impairment who are non-verbal and communicate in such a unique way that only those close to them can understand.

This small but very vulnerable group are marginalised in New Zealand (NZ). They are currently not represented at a national level as are other Disabled Persons Organisations (DPOs) and their lack of recognition means that current policy and services do not meet their needs. Families and others close to them are not accepted by the disability sector in NZ as being able to speak on their behalf. It is this population that is over-represented in the media with stories of abuse and neglect.

Executive Summary:

Key Findings:

Legislation in the UK and Sweden ensures that severely cognitively disabled, non-verbal adults do have a “voice”, and are provided with the necessary support to communicate effectively. It was acknowledged and accepted that where necessary, those who know the disabled person well were able to speak on their behalf. This has ensured that relevant policies and services at both local and national level have been developed to meet their needs and appropriate individuals and organisations representing this population are consulted.

The situation for most disabled people in Ireland had seriously deteriorated since the fall of the Celtic Tiger (serious decline, in 2008, of the period of rapid economic growth in Ireland). Although there appeared to be no issues with cognitively impaired, non-verbal people being consulted, there were few services available to meet their needs, and there was no legislation requiring this. The “charity” model appears to have prevented rights based legislation from being introduced in Ireland and this has been the focus of criticism from both the European Union (EU) and United Nations (UN).

In the UK: The *“They Still Need to Listen More”*: A report about disabled children and young people’s rights in England report commissioned by the Office of the Children’s Commissioner, U.K. in 2014, suggests that young disabled people face barriers to communication because providers lack training and awareness about how to communicate with them. A quote from the Voice, Inclusion, Participation, Empowerment, Research (VIPER) report published in February 2013, following focus groups with young disabled people, suggested that “people at the top should spend time with them to better understand them before they made decisions” (VIPER report, 2013, p.)

The *Winterbourne View* report (2012) highlighted the fact that families had not been listened to and were ignored when they raised serious concerns about the horrific abuse of profoundly disabled people in this establishment. The authorities vowed that this would not happen again and committed to work with individuals and families, and with the groups which represent them to ensure that this situation would never be repeated.

During our meeting members of The Challenging Behaviour Foundation said they believed that things had changed recently in the UK and that finally it was accepted that families played an important role in the life of all family members but most especially in the lives of disabled people with complex needs. The family were the ongoing, primary source of love, care, support and advocacy even once the disabled family member had left home. They felt strongly that family members speaking out on behalf of their loved ones had had a direct influence on both local and national government bodies.

In Ireland: Although there appeared to be no issues with parents speaking out on behalf of their severely disabled, non-verbal family members, because of the lack of funding and services there was growing tension between service providers and families and also between the families themselves as they fought over the limited resources available. It is unlikely that the *Assisted Decision-making (Capacity) Act 2015* which has replaced the *Lunacy Regulation (Ireland) Act 1871* and is yet to be entered into force will improve the situation for disabled people in Ireland.

According to Denis Sexton from the Irish Society for Autism in Dublin, the number of people with Autism Spectrum Disorder (ASD) is growing exponentially and 20% of all people in Ireland on the spectrum are non-verbal and have a combination of ASD and an intellectual impairment and will never be able to live independently. Traditionally, family is expected to provide all support necessary for family members and this attitude from government appears to perpetuate today.

In Sweden: The *Support and service for persons with certain functional impairments law (LSS) 1994* provides entitlements to all profoundly disabled people including the right to be consulted and make decisions as far as they are able and to be supported to speak out by a “god man” (Swedish for Trustee or Custodian) where necessary. Only a person with profound disabilities including an intellectual disability can be a member of JAG, the not for profit organisation who provide advocacy and support for this population. The disabled person with their god man makes all the decisions about employing their personal assistants (support workers) and only members can be on the board of JAG.

Recommendations for Ministry of Health, Disability Support Services, Ministry of Social Development:

7. That it be compulsory/legislated for all disabled people including those with profound disabilities to be consulted at all times when a decision is made which will impact on their lives and that they will be given the support required to make that decision in their best interests.
8. That “nothing about us without us” is applied to all disabled people in New Zealand as it does in the UK, Ireland and Sweden.
9. That profoundly disabled people are provided with appropriate representation in the Convention Coalition reporting on the UN Convention on the Rights of Persons with Disabilities.
10. That the Ministry of Health, Disability Support Services and Ministry of Social Development consult and work closely with appropriate individuals and organisations supporting people with profound disabilities to develop quality, sustainable services to meet the needs of this population.

11. That people who know the profoundly disabled person well and can communicate with them effectively are accepted as being able to speak or interpret on their behalf.
12. That the importance of the role of the family is recognised for all people and that it be acknowledged and accepted that for those with profound disabilities the family will usually be the main source of love, care and support. Even when they leave home, they do not leave the family who continue to offer a lifetime of involvement and advocacy

Background:

My involvement in the field of disability advocacy arises from my personal experience. My daughter Rebecca (32yrs) has marked learning disability; she is non-verbal and has a severe, rare epilepsy syndrome (Lennox Gastaut Syndrome). I co-ordinate and co-founded the Complex Care Group (CCG) which provides support and a collective voice for children and young people with profound disabilities and complex support needs, and their families We also provide feedback about the needs of this population to the Ministries of Health and Social Development.

The Complex Care Group (Originally the Complex Carers Group) was founded in 2001 following the release of the *Just Surviving* report commissioned by the Health Funding Authority and Child Youth and Family Service in 2000. This highlighted the isolation of families supporting a disabled young person with complex needs and the need for a collective voice to address these unique needs.

The Wilson Home Trust initiated a project in 2001 to set up a national body to provide support and the much needed collective voice. In 2002, the Ministry of Health made funding available for new initiatives to support family/whanau carers and in 2003/4 a pilot study was undertaken to inform the process for the development of the group nationally and to identify the specific needs of this population.

Though small in number, estimated to be about 1% of the disability population, many of the children and young people the Complex Care Group support are cognitively impaired and non-verbal and communicate in such a unique way that only those who are close to them and who know them really well will understand and be able to interpret or translate for them.

For the first time society is seeing a number of developmentally delayed children reaching adulthood with complex illnesses and disabilities, who would not previously have survived or would have been institutionalised? Although they are now resident in ordinary communities they are mostly invisible. They are not able to voice their needs in appropriate forums and for this reason their voices are not heard and policies and services have not been developed to meet their unique needs.

The Complex Care Group parents, like all parents, are anxious that these young people should *live well* into adulthood and fight constantly for their human rights to be upheld believing that they too have rights as all citizens do to enjoy activities and relationships irrespective of the difficulties. Families are currently the only people advocating for these young people and are often vilified by the disability sector for doing so

The young people CCG support are seriously marginalised New Zealand and some of the worst discrimination comes from within the disability sector. They are not represented by the Disabled People's Organisations (DPOs) reporting on the UN Convention on the Rights of Persons with Disabilities (UNCRPD). According to the information provided on the Office for Disability Issues (ODI) website;

The United Nations Convention on the Rights of Persons with Disabilities, in Article 4(3), promotes the active involvement by government agencies of representative organisations of disabled people which are governed by disabled people (or Disabled Peoples' Organisations)

The recognition of Disabled People's Organisations that are distinct from other disability sector organisations recognises that disabled people themselves should have the opportunity to be around the table in matters affecting them. This development is acknowledged as the basis of the new way of working together agreed between the Chief Executives' Group on Disability Issues and the seven Disabled People's Organisations in July 2014.

Monitoring rights of disabled people by the Convention Coalition:

The Convention Coalition (formed as a governance-level steering group by disabled peoples' organisations) will provide the civil society component because it can ensure full participation in the monitoring process by disabled people.

The disabled people's organisations leading the monitoring programme are: DPA, Blind Citizens New Zealand, People First, Deaf Aotearoa, Ngati Kāpo, and Nga Hau E Wha (a network of organisations of people with experience of mental illness) and Balance New Zealand.

None of the seven organisations that make up the Convention Coalition represents our young disabled people who are cognitively impaired and non-verbal.

According to the ODI website:

The term Disabled People's Organisation (or DPO) has developed to encompass a variety of organisations made up of, or primarily governed by, people with disabilities.

Attribute 3 of the DPO membership criteria states *“The organisation upholds and promotes the philosophy that people with disabilities have the right to participate collectively in decisions that impact on our lives (Nothing about Us without Us).* Attribute 4: *Goals and objectives need to follow the stated purpose of the UN Convention on the Rights of Persons with Disabilities “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UNCRPD Article 1).*

The disabled young people CCG support, because of their cognitive impairment and their inability to communicate in a way that is deemed acceptable by the DPOs are unable to have their “voices” heard or to be considered for membership of the DPOs that make up the Convention Coalition.

The “Nothing about us without us” near-universally accepted mantra of disabled people does not appear to include our young people in New Zealand. Due to the strength of the DPOs, few government agencies have sought to consult with organisations such as Complex Care Group (CCG) believing, as do the DPOs that only disabled people can speak on behalf of other disabled people. The DPOs have made tremendous progress in New Zealand over the past twenty years to ensure that their voices are heard and that their human rights are upheld which has done much to improve the situation for disabled people in this country, but we must also ensure that the human rights of all disabled people, including those severely cognitively impaired and non-verbal are equally upheld.

It was the long term and ongoing frustration about the exclusion from consultation with government agencies of cognitively impaired, non-verbal people; the difficulty to have this appreciated and the lack of services, policy development and participation at a national level that provided the impetus for me to apply to the Winston Churchill Trust to explore this issue in other like countries.

Methodology:

After making initial contacts with key people in each country I set about arranging appointments with relevant organisations and individuals.

I visited service providers and spoke to family members in all three countries to determine how non-verbal, cognitively impaired adults had their “voices” heard. I employed a qualitative method of gathering data for this report and met with a variety of organisations and also with family members at a time and location to suit them being aware of the unpredictability of their circumstances. I had contact with two families via e-mail when arrangements to meet had to be cancelled due to their caring responsibilities and spoke to

one family member by phone. Notes were taken and with the consent of all parties, our conversations were recorded.

Some of the staff of the service providers I visited, like myself, were also parents of young people with profound disabilities.

The following key questions formed the basis for my interviews and were made available to all participants prior to engaging in conversation with them:

- Is there legislation in your country that ensures that the “voice” of cognitively disabled, non-verbal people is heard?
- Do they have a “voice”?
- Who is able to speak on their behalf?
- Is it acceptable for family members and those who know them well to speak on their behalf?
- Has your country signed up to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)?
- If so, are these young people represented by those in your country reporting to the UN?

Information gathering:

From the UK:

Council for Disabled Children: London, UK. : Pamela Shaw, Senior Participation Officer, with particular focus on ensuring the voice of young people heard.

The Council for Disabled Children (CDC) is part of the National Children’s Bureau and the umbrella body for the disabled children's sector in England, with links to other UK nations. CDC provide support for all children and young people from 0-25yrs. It brings together the diverse range of organisations that work with and for disabled children and young people to support the development and implementation of policy and practice. Their work impacts on over 800,000 disabled children, young people and their families. CDC's vision is a society in which disabled children and young people’s life chances are assured, their needs met, their aspirations supported and their rights respected.

They believe that:

- Disabled children and young people should enjoy the same rights and opportunities as other children

- All disabled children and young people communicate and have a right to have their views heard
- The views of disabled children, young people and their families are vital to the development of an inclusive society
- All disabled children and young people should be fully included in every aspect of society

CDC works strategically with the Department of Health and Education, including providing training for professionals and support for young people with transition from school and ensuring their “voices” are heard. They support the development of policy and practise for social care and work with Local Authorities who are responsible for providing information, advice, and service provision in their area. Social Care in the UK is defined as “the provision of social work, personal care, protection or social support services to children or adults in need or at risk or adults with needs arising from illness, disability, old age or poverty”.

Recent legislation now supports the importance of listening to children and young people. One of the guiding principles of the Children and Families Act 2014 ensures the voice of children and young people is heard. Section 19 of the Act sets out the general principles that local authorities must pay particular attention to:

- The views, wishes and feelings of children, young people and their parents;
- The importance of them participating as fully as possible in decision-making and providing the information and support to enable them to do so

There is an appreciation at CDC that those whose voice is not heard are more vulnerable.

The following posters were displayed in the CDC meeting room stating *“Inclusion is being actively involved. Listen to us, Give us choices. We need to be a part of what’s going on.”*



A quote from the VIPER (Voice, Inclusion, Participation, Empowerment, Research) report done in collaboration with CDC to determine how young disabled people's voices are heard was particularly pertinent.

"People at the top should spend more time with disabled young people as they don't know our needs; they haven't got the experience to make the decisions." "For disabled young people's views and experiences to influence commissioning of services and local and national policy development, the impact of their participation must be recognised, valued and evaluated. "

"If more services took account of young disabled people's views in decision-making we would have better and more effective services." (VIPER report, 2013, p.37)

The CDC was commissioned in 2014 with Coventry University by the Office of the Children's Commission (OCC) to work with them to analyse the evidence obtained from data collection and focus groups to determine how the specific rights outlined in the UNCRPD of children and young people in the UK were being realised. In the report *"They still need to listen more"*, 18th November 2014, Article 7: Situation of Children with Disabilities, states *Disabled children and young people face barriers to communicating with others including professionals and service providers due to lack of training and awareness about how to communicate with disabled children and young people.*

The Mental Capacity Act, 2005 (UK) has had a significant impact on the way severely cognitively impaired people are treated. The Principles of the Act, set out in s1(2)-(6), include

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

This is similar to the Protection of Personal and Property Rights Act (PPPR), 1988 in New Zealand. The difference between the UK and the NZ Acts is that the decisions made under the Mental Capacity Act are for single events and assessments for determining who can make those decisions falls on the Local Authorities at that time. Parents or those who know the disabled person well and can best communicate with them are in most instances given this responsibility. A representative may be appointed by the Local Authority but the key driver is in the best interest of the disabled person. Many parent carers become a welfare benefits appointee or deputy to manage their son's/daughter's finances.

Under The Mental Capacity Act, 2005 (UK) parents must be consulted about any proposed care plan drawn up for their young person and the Local Authority must be able to show how the young person and their parent's views have been taken into account in the decision-making process. This is not compulsory in New Zealand.

Contact a Family, London, UK: Gail Walshe, Head of Parent Participation and
National Network of Parent Carer Forums, England: Maureen Morris and Sherann Hillman, Co-Chairs and North East & Cumbria representatives.

Contact a Family is a national charity for families with disabled children and young people. They provide information, advice and support and bring families together so they can support each other. They campaign to improve the families' circumstances, and for their children and young people to have the right to be included and equal in society.

Contact a Family is the delivery partner of the Department for Education in supporting parent carer participation in England. Working in partnership with the National Network of Parent Carer Forums (NNPCF), they offer a range of support to all parent carer forums in England, including administering a grant to forums on behalf of the Department for Education.

The NNPCF was launched in 2011 and is funded by central government. The aims of the NNPCF are:

- To ensure that good practise, knowledge and shared expertise about parent participation continues to grow and strengthen.
- To develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England.
- To strengthen the pan disability, parent led model of local forums and boost our collective voice.

Their motto is "Our strength is our shared experience."

Maureen Morris and Sherann Hillman, the Co Chairs of the NNPCF, were both parents of adult children with disabilities and passionate about improvements needed to ensure the voice of disabled people and their families were heard. This was highlighted in the Winterbourne View report published in 2012 which has significantly helped their cause. The Minister for State Care and Support, Norman Lamb, in the opening statement of the report states:

The scandal that unfolded at Winterbourne View is devastating.

Like many, I have felt shock, anger, dismay and deep regret that vulnerable people were able to be treated in such an unacceptable way, and that the serious concerns

raised by their families were ignored by the authorities for so long (Department of Health, UK, 2012, p.5).

The foreword signed by members of the National Health Service (NHS) Commissioning Board, Association of Directors of Adult Social Services Board and Local Government Association states:

This report lays out clear, timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging. Our shared objective is to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs, and working together to commission the range of services and support which will enable them to lead fulfilling and safe lives in their communities.

The Concordat which accompanies this report sets out our commitment to work together, with individuals and families, and with the groups which represent them, to deliver real change, improve quality of care and ensure better outcomes (Department of Health, UK, 2012, p.7).

The subject of Deprivation of Liberty (DOL) was raised. The Mental Capacity Act Deprivation of Liberty Safeguards (MCA DOLS) was introduced, as part of the Mental Health Act 2007, by the Department of Health in April 2009. The MCA DOLS are legislative safeguards and were introduced to prevent deprivations of liberty without suitable processes; including independent consideration and authorisation. For any form of restraint or restriction that is to be used there must be an application made to the Local Authority and if authorised there are strict guidelines that must be adhered to including regular reviews to be done by the Care Quality Commission

Maureen Morris and Sherann Hillman again commented on the Children and Families Act 2014, S19 which ensures that Local Authorities must work with young people and their families and respect their views, wishes and feelings and ensure they participate as fully as possible in decision-making and provide the information and support to enable them to do so. They were concerned about the push for inclusion and mainstream by some of the DPO's believing that all disabled people should be able to make choices about where they go, what they do and who they mix with. Both women said their disabled family members often expressed they felt more comfortable engaging with their disabled friends where they felt accepted.

According to Gail Walshe, the current Minister of State for Children and Families Edward Timpson has been particularly supportive of young people and their families. His mother had fostered disabled children throughout his childhood. They all believed that he had led a change of culture within government and that the current government and legislation were very supportive of ensuring that the "voice" of all disabled people and their families were heard. Gail suggested that Edward Timpson should be invited by our Minister for Disabilities to speak with our government.

Royal Mencap Society: Zac Taylor, Head of Practise Strategy and Design and Bella Travis, Information and policy officer for profound and multiple learning disabilities (PMLD).

According to the Royal Mencap Society UK website, they work in partnership with people with a learning disability, and all their services support people to live life as they choose, change laws and challenge prejudice. It was founded seventy years ago by parents of disabled children and now provides a wide variety of services and has a comprehensive multi disciplinary team involved. Zac is responsible for quality and providing flexible support to meet each individual need. They pride themselves with being willing to try a number of creative ways to tailor services.

They do provide services for Personal Budgets, the UK equivalent of our Individualised Funding and can if requested to be the employer of staff. Besides the administration role in this instance, disabled people and their families are also able to access all the other services Mencap provides, including quality monitoring. Zac emphasised it was really important to have the right manager in these circumstances who can build a good relationship with the family.

Bella and Zac were both adamant that if you could successfully support disabled people with complex needs then you would be able to support all people with learning disabilities. They again discussed the legal framework in the UK which ensures that the voice of all disabled people is heard and “listened to”.

The acronym for profound and multiple learning disabilities “PMLD,” has been defined by the Mencap’s PMLD Network to describe a person who:

- Has one or more disability
- Has a profound learning disability
- Has great difficulty communicating
- Needs high levels of support
- May have additional sensory or physical disabilities, complex health needs or mental health difficulties
- May have behaviours that challenge us

Bella shared with me the amazing work she has been involved with in collaboration with the British Institute of Learning Disabilities (BILD) called *Involve me*. *Involve me* is about using creative ways to involve people with PMLD in decision making and consultation. It looks at different ways of working with people who are often excluded because others find it difficult to understand their communication. *Involve me* has eight key messages about *how* to involve these people:

- Know the person really well.
- Take lots of time.
- Don’t make assumptions.
- Be responsive to the person.

- Be creative and use new ideas.
- Learn from what the person “tells” you.
- Act on what you learn.
- Help the person recall and share things about their life.

According to the information provided with *Involve me* people with PMLD are among the most excluded and disadvantaged people in today’s society and all too often their needs are ignored. We all agreed that in order to effectively support someone to be involved in decision-making you have to know them really well, understand them and appreciate their individual perspective on their life. They must be valued equally and included. Because they have complex needs and most are non-verbal, and many do not use assistive technology or recognised signs or symbols, we need to make sure that there are other ways of understanding their needs and preferences; their likes and dislikes, “what they choose and refuse”. Some of these people can only make their preferences known through their behaviour and their reactions. It is important that we acknowledge this as their form of communication and not use punitive measures to “silence” them.

Another suggestion was to have photos of some of our young people and adults at all meetings where they were unable to attend but where matters were being discussed that would impact on their population. When decisions were being made we should ask - “How will this work for John/Mary”?

The Autism Act, UK (2009) which remains the first and so far the only condition-specific legislation in England, was also discussed. The original Adult Autism Strategy *Fulfilling and Rewarding Lives* was published in 2010. In April 2014 this was updated as *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update*. Local Authorities and the NHS were advised that they needed to work in collaboration with local partners to take forward the key priorities in *Think Autism*.

Norman Lamb, Minister for Care and Support states in his foreword to *the Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy* (Department of Health, UK, 2015, p.3)

Autism should also not be seen as an add-on to services and with over half a million people on the autism spectrum in England, mainstream services will already be seeing or in contact with many people who have autism. By encouraging more innovation in the way services are delivered and through services making more reasonable adjustments, individuals can go to their local council office, GP or hospital feeling confident that those services are aware of their autism and knowing that adjustments can be made for them. Training and awareness of autism are key here.

Innovative ways of including people on the autistic spectrum that Bella and Zac spoke about included special showings at movie theatres in London for people on the spectrum where the lights were just dimmed during the screening, the sound turned down and people were free and it was quite acceptable for them to come and go as they wished. They also had an

“Autism’s got talent” event for those who delighted in being on the stage. It appeared that the public, especially in London were gradually becoming more accepting of people on the spectrum.

Bella also spoke about a creative solution they had developed to inform a young woman who was deaf and blind about what was going to take place in her daily life realising that not knowing was determined to be the cause of much of her anxiety. The method they devised was the use of essential oils to indicate various activities e.g. the smell of lavender indicated that she was going to have a shower or attend to her personal hygiene needs.

Continuing funding cuts have impacted on services for disabled people in the UK and Zac stated that there were 165 people currently being supported in hospitals in the UK many miles away from their local area. As expected there is a lot of variation in the quality of support and services provided by the 152 Local Authorities but Zac and Bella believed that having services funded through the Local Authority meant there was more ownership and understanding of the issues involving disabled people in their area.

Challenging Behaviour Foundation, Chatham, Kent, UK : Viv Cooper, CEO, Holly Butcher, Family Support Manager and Jessie Humphries, Family Support Worker.
Chinyere Kejeh, Balwinder Sandu, A family carer who also volunteers with the Challenging Behaviour Foundation.

On their website, the Challenging Behaviour Foundation (CBF) describe themselves as a charity for people with severe learning disabilities whose behaviour challenges. Their mission is making a difference to the lives of children and adults across the UK through:

- information about challenging behaviour
- peer support for family carers and professionals
- supporting families by phone or email
- running workshops to reduce challenging behaviour
- speaking up for families nationally

Viv Cooper founded CBF in 1997 after her son Daniel was diagnosed with the rare genetic condition Cri du Chat syndrome shortly after he was born. She says she had no idea what to expect following this diagnosis but that at the age of one, Daniel began to bang his head on hard objects and she was unable to find any practical information or support to help her manage the situation.

When he was nine, Daniel’s behaviours had deteriorated to the point that the family were all struggling at home, and the staff also when he was at school and in respite. It was decided that he needed to go to a 52 week specialist residential school which was over 270 miles from their home.

At the school they looked at the function of Daniel’s behaviours and at the same time they worked on developing new skills and improving his communication (Daniel is severely cognitively impaired and non-verbal but uses signs and symbols). The family were thrilled

at the progress he made but very upset that this information and support had not been available for them when he was first diagnosed.

Viv then decided to enlist support and advice from a range of individuals about setting up CBF, and it was registered in February 1997 as a charity. It was started with no resources, other than determination to ensure that individuals with needs like Daniel's and their families should be able to access "the right information and support, in the right place and at the right time."

From its earliest days the CBF has always believed in the principles of working in partnership with families and professionals, pooling expertise and sharing information and good practice. They believe that "challenging behaviour should be viewed as an indication of unmet need rather than as an inevitable characteristic of the individual or their associated diagnosis."

CBF employ 12 staff, including the CEO, Family Support Manager, Family Support Worker, Volunteer Manager, admin staff, policy writers and two interns. They provide a newsletter for 4,000 people and have a closed membership of 300 families. Along with providing information and support to families, they also provide free resources, workshops and drive change through the Challenging Behaviour National Strategy Group which they now Chair, working to promote high quality support for people "whose behaviour challenges."

Again the legal framework that exists in the UK to protect the rights of all disabled people and their families was discussed along with the role of the Local Authorities. They believed that things have changed in the UK more recently and that now it is accepted that families have an important role to play throughout the life of their disabled family member, just as they do with non-disabled members. They are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when they leave home, they do not leave the family, who continue to offer a lifetime of involvement, support and advocacy.

They felt strongly that the opportunity for family carers to speak on behalf of their disabled family members had a direct influence on both local and national government bodies.

They believed that DPOs in general did not tend to criticise family carers or prevent them from speaking on behalf of their loved ones, although self advocacy groups with mild cognitive impairment were not inclined always to acknowledge those who can't speak for themselves. CBF are often consulted both locally and nationally and are accepted as being able to speak on behalf of the people they support and their families, but sometimes the "bureaucrats" Viv says need to be reminded to include them.

Chinyere Kejeh: is a family carer originally from Nigeria who supports her daughter Chike (23yrs). Chinyere also volunteers at CBF. I spoke with her on the phone. Although non-verbal and with some cognitive impairment, Chike uses Makaton and YouTube to communicate. Chinyere had to give up her job, when Chike left school. She says it was too

hard, working and caring. She believes that much more should have been done when Chike was younger to support her to be more independent and that now the Local Authorities just want to minimise her potential. Culturally her family believe that they need to continue to push Chike to become more independent with a view to her eventually having a place of her own, possibly her current home, as Chinyere hopes to return to Nigeria where she has some relief from her arthritis. Chike will always need full-time support but her siblings will continue to live in the UK and look out for her

The Local Authorities are trying to insist that Chike has four days “out of home respite” per month instead, as requested increasing her Personal Budget. Chinyere believes this is not what Chike wants as she has never stayed away from home. Recently Chinyere had to return to Nigeria for her Mother’s funeral and was away for two weeks but Chike was well supported and happy with her siblings and carer. With support from her carer and her family, Chike enjoys sport, going to her club, the library, music class, swimming and she likes to do cooking with assistance. She attends Church with Chinyere in the evening.

Chinyere believes that the CBF has played a very important role in Chike and her family’s life; hence she is happy to volunteer her services when she can to support them. She believes that they work hard to empower family carers, are instrumental in ensuring that the complex needs of the families they support are recognised both locally and at a national level and that they play a very important role in advocacy and representing this population at a National level.

Balwinder Sandhu: is also a family carer who volunteers at CBF. She was unable to attend our meeting on the day organised but kindly offered to provide information by e-mail. Below her e-mail reply – in red, to my questions:

1. Does your son/daughter live at home? If so do they have the support they need? If not, are you satisfied with their living situation? *My daughter doesn't live at home. I have been trying to bring my daughter home into a purpose built annex in my back garden due to the very basic support provided at the care home.*
2. Are you able to speak on behalf of your child and are you listened to? *For little things that don't cost a lot I do feel I am listened too but when it comes to major things like my daughter's care package than I don't feel I am listened to. On many occasions I have put in complaints so that my daughter's voice is heard and her wishes addressed.*
3. Do you believe there is recognition at both a local and national level of the skilled support needed to provide our young people with a good life and are there quality services and funding to meet their needs? *I believe now there is recognition that skilled support is needed to provide our loved ones with a good quality of life but due to the tight budgets commissioners aren't prepared to give that level of support. Those people who are highly*

qualified and can understand the policies, they can get the adequate support that is required as their knowledge is power and they use the language (jargon) that commissioners understand.

4. Do you believe society in general is becoming more accepting of our disabled family members now? To be honest I do agree with you on this point, I have noticed a big shift in the thinking and acceptance of my daughter's generation and below as opposed to older and my generation. My own uncles, aunts, dad, brothers, sisters and cousin have completely different point of view and thinking compared to my nieces and nephews and grand children.

Information from Ireland (Eire)

Dr Anna Karin Kingston, Cork, Ireland: Author of *Mothering Special Needs, A different maternal journey*; Member of the MA in Women's studies teaching board, University College, Cork, Ireland; Mother of a young man (24yrs) with autism, epilepsy and acquired brain injury.

The situation in Ireland according to Anna had deteriorated rapidly since the fall of the Celtic Tiger and the austerity measures that Ireland was forced to take. There have been huge cuts in the disability budget and some service providers are facing insolvency. Issues with some of the large religious institutions, traditionally providing residential disability services, and recently exposed issues around the exceptional high salaries being taken by two of the CEO's of these institutions has meant that faith and trust in these organisations has been badly affected. Along with the financial situation many families are facing this has meant substantial reduction in the amount of funding donated that these institutions had previously enjoyed. Anna believed that Cork was possibly worse off than other areas in the country.

According to Anna, who is originally from Sweden, culture and religion have had a big impact on the provision of disability services in Southern Ireland. The charity model has prevented rights based legislation being introduced. The mothers' place is in the home and what happens behind closed doors is very private. The Government has been happy to accept this model. There are no rights-based services once a disabled young person reaches eighteen years and in fact legally, currently, the parents have no responsibility for their children after this age.

Anna believed that there were no issues around parents speaking out on behalf of their adult family member but there were increasing tensions between parents and service providers as their financial situation worsened. This has led to lack of unity amongst parents now with all "fighting over the crumbs." Funding is provided nationally from the Health Board but there appears to be little accountability for it once in the hands of providers.

Ireland has also been the focus of criticism from both the EU and the UN in the past for its lack of commitment to conventions on human rights. A special delegation went to Geneva in 2002 to raise concerns with the UN Committee on Economic, Social and Cultural Rights protesting against the appalling conditions people with learning difficulties were living in in Ireland. A large number of people with intellectual disabilities were still living in psychiatric hospitals.

In 2004, the Irish government published a new Disability Bill in the context of a National Disability Strategy which provided the right for disabled people to have an individual needs assessment. Legal experts and disability campaigners felt this did little to guarantee funding for services on a sustained basis but whilst the Celtic Tiger generated unprecedented wealth for Irish Society, better services and support were demanded and anticipated by disability groups.

However this was not to last as mentioned earlier. The latest attempt by the government to make amends in the sector has been the long awaited repeal of the Lunacy Regulation (Ireland) Act 1871 which has been replaced by the Assisted Decision-Making (Capacity) Act 2015. According to the government, this “ground-breaking” legislation will result in significant improvements in the lives of persons with intellectual disabilities as their ability to make decisions for themselves will be enshrined in law. Currently Ireland has not ratified the UNCRPD but it is expected the new Act will remove a significant barrier to ratification.

Inclusion Ireland is the national association for people with an intellectual disability. They provide a central forum for their members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability in Ireland. They have been lobbying, campaigning and advocating for the introduction of capacity legislation for well over three decades and they were pleased to see this legislation finally becoming reality. However, they were disappointed to learn that the legislation will now take at least six months to enter into force.

Despite the Assisted Decision-Making (Capacity) Act 2015 being passed, there seems to be little understanding as to how this will play out practically and my attempt to meet with the someone from Inclusion Ireland in Dublin was ultimately rejected at the last minute, the explanation being that the organisation was in chaos following the dysfunctional state of the government after the recent elections and their inability to determine what is happening with the new Act. Anna confirmed that this was totally understandable under the current circumstances. Another major concern was that non-government organisations (NGOs) and service providers would be responsible for disseminating information to disabled people and families with regard to this new Act but that it was very likely they would not have the funding to enable them to do that.

Inclusion Ireland, Cork: Julie Helen, Advocacy Project worker:

Anna was however able to introduce me to Julie, a young physically disabled woman, who now worked for Inclusion Ireland in the Cork region. Julie’s mother was on the Board of Inclusion Ireland and her twenty-eight year old brother has Down Syndrome and was moderately intellectually impaired. Julie had become involved with the sector because of her brother’s need for advocacy and was passionate about her role describing it as her “dream job”.

She shared with me that Inclusion Ireland had started in the 1960s as a parent advocacy group. Julie herself was very much into self advocacy and the right to choice and control but she appreciated the need for her brother to have assistance as although verbal, he did have difficulty with understanding and articulating his needs. “Nothing about us without us” was without a doubt a mantra that was very much a part of Julie’s philosophy. She was about to start a project the following day to design training for professionals on the unique ways in which people communicate. Social Role Valourisation (The principal of normalisation) was important to her and would form part of her training but she also felt passionate about the

need for people to build good relationships with non-verbal people and to observe what they enjoyed and liked and how this was expressed.

She spoke about the Health, Information Quality Authority (HIQA) which was established in 2013 and according to their website, is an *“independent authority established to drive high quality and safe care for people using our health and social care services in Ireland. HIQA’s role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered. It aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions.”* This was instituted after there were a number of scandals in residential care centres where disabled people’s human rights had been seriously violated.

She also discussed the Assisted Decision- Making (Capacity) Act 2015 and likewise shared that she was unsure how this would work ultimately; and that previously people with “unsound mind” were governed by the Lunacy Regulation (Ireland) Act 1871 and responsibility for their decisions had fallen on parents or in many cases for older people “guardians”, as they had been automatically made wards of the court. Although consideration was to be given to what was “in the best interests of the disabled person”, Julie assured me that this was not always the case.

She shared with me that despite being adamant about self-advocacy and disabled people having choice and control over their lives, she still became very anxious at times about the decisions her brother was making where she felt his safety was compromised because he had little understanding of the risks. A dilemma many of our parents face.

Under the Lunacy Regulation (Ireland) Act 1871 there was a presumption of lack of capacity. The new Act reversed this, creating a presumption that all people are presumed to have capacity, and “lack of” needing to be proven. From Julie’s understanding there is to be a new independent agency established known as the “Decision Support Service”. She felt it was unfortunate however that this is to sit with the Mental Health Commission. There will be three levels of support:

1. The lowest being a “Decision Making Assistant”. This person is appointed by the disabled person to help them to better understand information and make informed decisions. The disabled person can appointment as many Decision Making Assistants as they wish, but all must be registered with the Decision Support Service.
2. The second tier is a “Co-Decision Maker”. The disabled person can appoint only one of these to advise with legal, financial or health issues beyond their comprehension.
3. The third tier is a “Decision Making Representative”. This person is appointed by the Court to make decision for and on behalf of the disabled person. As in the UK this person is appointed for specific decisions (rather than on a permanent or general basis).

Julie pointed out that there has in the past been a lot of legislation passed in Ireland which has only partially entered into force, usually because of lack of resources and she fears the same may happen to the Assisted Decision-Making (Capacity) Act 2015.

With regard to the UNCRPD, she stated that Ireland was one of the first countries to sign the convention, but was probably going to be the last to ratify. Although the Assisted Decision-Making (Capacity) Act 2015 would go some way to removing the barriers to ratification, it still had not repealed the part of the Lunacy Regulation (Ireland) Act 1871 under which it is a criminal offence for someone with an intellectual disability to have a sexual relationship outside of marriage. She understood that the purpose of these provisions was to protect people who were intellectually impaired, but again reiterated the fine line that one walks when trying to balance rights and protection. All residential services in Ireland are segregated and if services are seen to be facilitating relationships they are technically breaking the law.

Like Anna, she spoke about most services being bulk funded with little accountability about how the funding is spent by providers. She felt that her brother and their family had little control over how his funding was spent. They are trying to arrange the equivalent of Individualised Funding but currently she thought there were only about 20 people in the country in receipt of this type of funding. Julie had recently got a new wheelchair after an assessment but had no choice over which one she received. She strongly believed she could have bought one that was better for her and more cost effective but was not given the option.

“Decongregation” – the Irish equivalent of our “deinstitutionalisation” was beginning to happen but again hampered by lack of resources. This involved moving 10 or more people with intellectual impairment into the community from some of the large religious institutions. Inclusion Ireland had been instrumental in advocating for this for many years.

Irish Society for Autism: Denis Sexton, Pat Mathews CEO, The Irish Society for Autism was founded by parents in 1963, and is the longest established specialist service for people with Autism in Ireland. As in other countries there are a number of organisations in Ireland now associated with Autism and Aspergers Syndrome/high functioning Autism.

The Society was formed with the goal of creating awareness about Autism, and convincing authorities that early diagnosis and specialised education would greatly enhance the quality of life for people with Autism. They provide information, training and support for people on the spectrum, families and health and education professionals. They also have residential services for adults in Dublin, Galway, Kildare, Meath, Westmeath and Wexford. The Irish Society for Autism is a founding member of Autism Europe and the World Autism Organisation and Pat Mathews was the first World President and responsible for the EU Charter for persons with Autism 1992.

Denis and Pat are both parents of adult children on the Autistic Spectrum with severe cognitive impairment who are non-verbal. Due to Denis’ education background and the situation in the 1980s the organisation’s initial drive was for suitable education for children

on the spectrum culminating finally in the Government's Special Education Review Committee (SERC) report 1996 where Autism was finally recognised as a disability and not as previously, as an "emotional disturbance" and under Mental Health. In 2004 the Special Educational Needs (EPSEN) Act was passed and a National Council for Special Education set up. Here field officers were appointed to assess needs of disabled children and co-ordinated their support. Special schools and units in mainstream schools were set up specifically for children with autism and Special Needs Assistants (SNAs) were employed, whose primary role was for personal care.

The National Disability Authority (NDA) is an independent statutory body which provides information and advice to the Government on policy and practice relevant to people with disabilities. In 2005 they supported the development of the Disability Act 2005 which required six Government departments; Health and Children, Social and Family Affairs, Transport, Communications, Marine and Natural Resources, Environment, Heritage and Local Government, Enterprise, Trade and Employment to collaboratively prepare plans (known as sectoral plans) that set out how they would deliver specific services for people with disabilities. The departments published their plans in 2006. Denis and Pat both played instrumental roles in this by increasing the understanding of issues facing people on the Autistic spectrum.

Previously all people with special needs were catered for in primary schools, irrespective of their age, but now provision has been made for disabled young adults to be in the most appropriate setting in secondary schools.

Denis and Pat had both been instrumental in setting up the first residential home owned by the Irish Society for Autism for adults with ASD and this is where Denis's son (31yrs) is living. They stated they have robust policies and protocols to protect their residents with a great team of Key Workers and Team Leaders. They also have a robust, monitored and audited financial system which is responsible and accountable for all personal spending of the residents. According to Denis all the families who have disabled members resident there have a great relationship with the staff. He believes that this is partly due to the fact that their organisation is parent driven. His son is very happy there and has now reduced his time in the family home to brief fortnightly visits. The home in Dublin where he lives is on 75 hectares and consists of four houses and apartments accommodating 35 people with complex needs. They have workshops and training centres including horticulture. Each person has their own funding and pays rent. He appreciates how fortunate their son is to have this opportunity, realising how difficult it is now for younger people to access any out of home placement or support.

He acknowledged, as did Anna and Julie in Cork, the desperate need for respite (short break) support for families. According to Denis, in Ireland, 20% of all people on the spectrum are non-verbal and have a combination of ASD and intellectual impairment and will never be able to live independently and 30-50% will need ongoing intermittent support. Currently the government depends on families to provide ongoing support. Dennis and Pat acknowledged the exponential rise in people on the spectrum world-wide. Denis said when

his son was diagnosed in 1987 the incidence of ASD in Ireland was around 17 per 10,000, now the figures in Ireland are 1-100 and 1-80 in the US. According to Pat the cause has to be “environmental” with food and air being the main factors we all have in common?

They did not believe there were any problems with family members or those who know the disabled person well being able to speak on their behalf. The Irish Society for Autism is a parent driven advocacy organisation respected in Ireland and in the EU and globally. There was no doubt that through their advocacy big changes had been made, especially in education for people with Autism in Ireland, perhaps at the expense of other disabilities, but most especially by their lobbying for a decent education with appropriate support.

Information from Sweden:

Nationellt kompetenscentrum anhöriga (Nka) Lennart Magnusson RN, Associate Professor Geriatrics, Public Health and Psychiatry, Linneaus University, Sweden

Nka is the Swedish Family Care Competence Centre and is commissioned by the National Board of Health and Welfare Sweden via the Ministry of Health and Social Affairs. Nka believes in promoting strong partnerships between parents and professionals.

Lennart was co-author in 2015 of an article in the European Journal of Special Needs Education entitled *“Professionals’ and parents’ shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities”*. He has also been involved along with his wife, Professor Elizabeth Hanson in a number of research and development studies involving people with profound disabilities for Social, Health and private services.

According to FUB, a Swedish intellectual disability organisation and the National Board of Health and Welfare it is estimated that there are approximately 7,000 people with profound disabilities in Sweden which has a population of 10 million although Lennart believed it was likely to be more.

In providing a brief history of the situation for people with disabilities in Sweden Lennart stated that in the 1980s a law was passed making it illegal for children to be placed in institutions ensuring that now “every child grows up in a family”. Some between the ages of 18-20yrs could move into sheltered accommodation but in general they continued to be involved with their families. In 1994 a law was passed giving all people with special needs the right to have an assessment for individual funding which could be managed by the disabled person, family member or a provider. Sweden was also one of the first countries to ratify the UNCRPD in 2008 and the UN Convention for the Rights of Children which includes their right to have their voices heard.

All disabled people in Sweden are entitled to disability service, and now they can request a co-ordinated plan with a key person who will organise all identified services to come together to develop a “plan”.

There is a three tier government system in Sweden with different responsibilities for Health and Welfare. Parliament is responsible for passing the general laws around Health and Welfare and has a monitoring function but provides no detailed instruction regarding these laws to the 21 Counties are responsible for the administration of the Health Care Act, or the 300 Municipalities who are responsible for administering the Social Care Act. A large amount of tax from each person goes to the Municipalities who are responsible for all disability services along with their many other responsibilities; a lesser amount goes to the Counties and only a portion to the central government who have little say in how the Municipalities and Counties spend their funds. According to Lennart this results in variable outcomes for disabled people throughout the country depending on the priority each Municipality gives to disability services.

Lennart also spoke of the three different forms of guardianship which exist in Sweden: guardian (for minors under 18), custodian (god man) and trustee (förvaltare). A custodian is usually appointed when a person is unable to manage his/her own financial affairs and has no other means of assistance. The request for a custodian (god man) can be made by the person concerned, the immediate family and the chief guardian or the Public Trustees' Committee. An application is made and sent to the Public Trustees' Committee, along with a social welfare report outlining the reasons for the application. If possible this is approved by the person for whom the request is being made. If not, the application must be accompanied by a medical certificate stating that the person in question was unable to consent. The Public Trustees' Committee then carries out an examination and submits an application to the District Court (tingsrätten) who issues a god man authorisation where appropriate.

Initially parents could not apply to be a god man for their own child, but an outcry from disabled people, families and some disability organisations led to the reversal of that policy.

The appointment of a trustee (förvaltare) involves a similar procedure but the District Court, in this case, prefers to examine the person for whom the application is being made verbally. A doctor's report must be provided and statements obtained from the spouse, close relatives, the Public Trustees' Committee and the Social Welfare Committee.

In 1928 a "Heritage Fund" was set up to collect money from Swedish people who died leaving no will. Over the years Lennart says this has become a valuable source of funding and is divided between projects/research for children, youth and disabled people of any age. Applications for funding are considered and approved five times a year.

FUB, The Swedish National Association for Persons with Intellectual Disability: Judith Timoney.

FUB is an advocacy organisation that supports people of all ages with an intellectual disability to "lead good lives." It has 27,000 members in 150 branches throughout the country and includes intellectually disabled people, their families and professionals who work in this area. Their National Office works at a political level advocating for people with an intellectual disability.

Judith is also the parent of a young lady with Down syndrome and shared her belief that young people cannot become independent if "parents hang around." She was adamant that all disabled people could communicate no matter what their level of disability and believed that the ability to communicate with the person they were supporting must be the top priority for anyone working in the sector.

Judith spoke about the Law of Special Services Act (LSS) introduced in 1994 concerning *Support and Service for Persons with Certain Functional Impairments*. This Act specifically provides for people with profound disabilities who require a high level of support. This milestone was the first to enable individuals in Sweden to make their own choices and be included in society and sits alongside the Personal Assistance Act (LASS) which provides support and services for people with lesser needs.

The County and the Municipality share responsibility for health and medical care, habilitation, rehabilitation and the provision of disability aids but the municipality bears the ultimate responsibility for providing support based on the disabled person's individual needs. The Municipality provides access to support that facilitates an "ordinary" life, including personal assistance services, respite care services, home care, assisted housing, housing adaptation grants, and transport services.

We also discussed the "guardianship" issue as FUB had spoken at the last UNCRPD meeting about the importance of retaining their trustee (förvaltare) category for those who, under certain circumstances, had no possibility of understanding information and consequences thereby putting themselves at risk of physical harm or loss of property and means of support.

FUB are also working with KAIH, Kenya's Association for Intellectually Handicapped, as a development partner to assist them to establish a National Office and co-ordinate branches.

JAG: Equality, Assistance and Inclusion

Cecilia Blank, Executive Director, Maria Arvidsson, Information, Hillevi Larson, JAG member

The word "JAG" in Swedish means "I" or "me". The members of JAG who all have profound disabilities requiring a high level of support provided by personal assistants, state they are "subjects, individuals, and not (as before) objects of care". The word "JAG" is also formed of the first letters of the Swedish words for Equality, Assistance and Integration – "immensely important words for JAG's members."

JAG is made up of two not for profit organisations. The "association" works with issues related to personal assistance and antidiscrimination and the "co-operative" is the employer arm made up of the users of personal assistance. Only a person with multiple, severe disabilities including an intellectual disability can become a member of JAG. Others may be "supporting members." Only a member of JAG can be on its Board of Directors. JAG's members are, in most cases, represented by their legal guardians or god man. Most of JAG's members are non-verbal and communicate in their own unique ways. Some of the staff at the central office are parents of members of JAG, and thus have valuable experience and knowledge of JAG's members' situations and needs. They believe that anyone who needs assistance in speaking for themselves should get it from their legal representative who is able to interpret their needs, wishes and communication.

Cecilia explained that prior to 1970 people with intellectual disabilities in Sweden had the limited choice of either living in hospitals or other institutions, or living with their families. Families struggled to keep their loved ones out of institutions but were then required to provide 24/7 support with no possibility of working and received little income depending on the attitude of the local Municipality.

In the early 1970s, some parents of children with multiple disabilities formed a working committee within the Swedish National Society for Persons with Mental Handicap (FUB).

This committee, lead by the original director of JAG, Gerd Andén, struggled to convince Swedish government officials at all levels of the need for personal assistance for people with intellectual disabilities. A few years later however some Municipal Social Service offices in different parts of Sweden began to provide services in the form of personal assistance. At that time, the committee believed that the assistance had to be organized within the framework of public services, since these users are not able to supervise their own assistance. However, the users' experiences gradually identified other possible solutions, and in 1992 JAG was formed as a small-scale cooperative financed by contracts with its members' Municipalities. Quite a few of the people whose parents fought in the 1970s for personal assistance are now members of the cooperative JAG.

When the assistance reform came into force in 1994, and personal assistance became an individual right, a large group of people with multiple disabilities were granted the necessary funding for their assistance, and JAG membership increased. In March 1994 the cooperative had 13 members, and at the end of the year there were about 100 members. JAG now has around 450 members, and is still expanding. JAG employs about 3, 900 assistants and is one of the largest non profit organisations in Sweden.

The *Law of Special Services (LSS) Support and Service for persons with certain functional impairments* is for disabled people with intensive support needs who require assistance for more than 20 hours per week with basic needs such as washing, dressing, eating, mobility and communicating. They must also have one or more of the following:

- A developmental disorder, autism or related disability.
- Considerable and durable impaired intelligence from brain damage in adult years caused by violence from an external cause or physical illness.
- Other durable physical and mental disabilities not caused by aging.

There is no age limit for the assistance allowance as long as it has been granted before 65yrs and you don't live in an institution or group home. The assistance funding is administered by the Social Insurance system. The disabled person can chose who will be the employer. It may be a co-operative like JAG, a private company, Municipality or they may chose to be the employer themselves. The disabled person with their god man decides who, where, when, with what and in what way assistance is provided. If the disabled person is unable to supervise the assistants themselves and they use the JAG co-operative then they have their own "service guarantor" to fill this role according to their needs and wishes. In JAG this is a voluntary role although this person will also work as a personal assistant and be employed for this. They must be available when needed to provide cover in the case of illness or emergencies. Training and support for those employed through JAG is provided for all those who become service guarantors. This role may be held by a family member or god man. JAG also provides orientation and ongoing training for all assistants and this is funded by a compulsory deduction of around \$0.50 per hour from every disabled person's personal budget.

Cecilia explained that both she and her mother Gerd Andén, who was the original director of JAG are both god man's for her brother Magnus who is profoundly disabled and has been Chair of the JAG Board since 1992. She explained that Magnus, 50 years, was one of the most profoundly disabled people of his age in Sweden. People often question the fact that JAG has all profoundly disabled members making up their Board but as Cecilia explained they all have their god man present who understands the unique forms of communication each member uses. Magnus, she says is able to agree or otherwise by pointing his finger. Cecilia describes JAG as belonging to the Civil Rights movement rather than the Social Rights movement. She says it should be seen that they have the same struggle as those with race and sexuality issues. They believe the UNCRPD should be about a package of values not just support.

Cecilia Blanck explained that JAG belongs to the Independent Living Movement which started in the 1970s in the US as a militant group fighting for civil rights. It empowers its members and like the disability movement in Sweden in the 1980s, were saying NO to discrimination, the medical model, institutions and giving power to "the experts". Instead they were saying YES to power to organisations of disabled people, power in the lives of disabled people using personal assistance and a sense of belonging for disabled people through peer counselling and congregating to share activities and inspire other disabled people.

Hillevi Larsson (25 years) one of JAG's members, attended our meeting with her personal assistant and her mother **Maria Arvidsson** who worked for JAG. Maria set up a power point presentation Hillevi had "prepared" with her personal assistant. Maria admitted that she may be pushing Hillevi "outside her comfort zone" with regards to the lobbying she was doing but believed it was something we all needed to do to grow. She spoke about their visit to Brussels where Hillevi Larsson presented to the European Network of Independent Living and the Commissioners in the EU Parliament and how appalled she was that everywhere they went volunteers were offering to help Hillevi Larsson. "She had her personal assistant so was quite independent and, like non disabled people didn't need help".

Hillevi employs 10 personal assistants. She has both physical and intellectual impairments and epilepsy and uses a wheelchair. She is non-verbal, and her personal assistant communicated with her both verbally and using sign language. She has 28 hours of support per day with four hours with two personal assistants.

Hillevi's mother Maria was passionate about the rights of profoundly disabled non-verbal people. The day I met with JAG, their members were preparing for a protest outside the City Hall in Stockholm. It appeared that the relatively new Social Democratic government was planning to reduce the budget for personal assistance to accommodate the rising costs of accepting refugees; and their recently appointed Minister for Disabilities was refusing to respond to their requests to meet with her. They had been protesting every Thursday for the past few weeks and intended to keep it up until they got a response. The government have already reduced the flexibility of funding so that it can't be accumulated and any hours not used cannot be carried over. Maria was particularly concerned about what would

happen at times like Christmas when extra support and funding was required if it could not be accumulated.

Like the local councils in the UK, the Municipalities are responsible for all those living in their area and must respond in times of crisis to provide a safety net. They believe that profoundly disabled adults should not be dependent on relatives to lead a “good life” although most will continue to have close relationships with their family as non disabled people do.

After our meeting we toured the JAG facility. Hot pink was their colour and appeared in many furnishings and curtains as well as their logos and mugs. The offices and environment were in stark contrast to those I had visited in the UK. Light, airy and beautifully furnished, complete with gym, training facilities and a cafe where many of the members and their personal assistants were enjoying lunch together.



The JAG Board. Magnus Andén Chair third from the left

According to their promotional material, JAG works to increase the members’ opportunities to a good life by:

- Equality, assistance and integration.
- The best possible personalised assistance and attention in all of life’s situations with respect for human dignity and integrity.
- Living life on their own terms, together with their family, and as others in society, having stimulating experiences and encounters safely and confidently.
- Promoting physical and psychological well being in every way and encouraging other interests.

Autism and Asperger Association, Stockholm: Marita Skoog Jacobsen, Geraldine Ferrand-Noren, CEO, Camilla Strom

According to their website, *The Autism and Asperger Association in Sweden was founded in 1973 and is a non - governmental organisation working with people on the spectrum of all ages. Their membership is made up of people with autism, aspergers or “autism-like” conditions, families and professionals. They have upward of 13,000 members spread over 24 regions.*

Their aims are to:

- *Raise awareness and improve understanding and knowledge about autism.*
- *Improve living conditions and employment for those on the spectrum.*
- *Provide opportunities for all members to meet and share knowledge and experiences.*
- *Support research and participate internationally.*

The regional groups of which Autism & Aspergers Association, Stockholm is one, organise lectures, social activities, group meetings and camps along with providing information on diagnosis, legal rights, schooling and accommodation. The Association lobbies politicians, authorities and organizations on the rights of people with autism, with and without intellectual disability, and provides information to the public through the media to better inform them. They also work collaboratively with other organisations to improve the situation for people on the spectrum. Some funding comes through the government and membership fees approximately \$50.00 per year but the majority is provided from the Swedish Inheritance fund (discussed above).

The Education Center (Education Autism AB) is a non-profit company owned by the Autism and Asperger Association. The Education Center offers trainings to professionals, disabled people and their families.

The law requires that all people with disabilities must be consulted and must have the support they need to communicate effectively and to reach their potential. They use human rights legislation to ensure that disabled people on the spectrum can enjoy the same rights as all citizens. The association employs a lawyer to provide advice for disabled people and families when required.

We again discussed the structure, roles and responsibilities of the various government entities. Municipalities, of which there are 26 in Stockholm, are responsible for all practical

help including home support, personal assistants and group homes for disabled people and the regional councils are responsible for all health related issues.

Geraldine discussed the “habilitation Service” that provides a range of services funded by Stockholm County Council. Habilitering & Hälsa (Habilitation and Health) run habilitation centres and teams throughout Stockholm and have several habilitation clinics, residential care centres and information and “knowledge” centres. They offer support and treatment for children, adolescents and adults with profound disabilities, including intellectual disabilities, autism, impaired mobility and also those with brain injury and deafblind. They provide support and counselling for parents and relatives, have a crisis line and are currently collaborating with the police to improve their understanding and management of people on the spectrum. Their goal is to *“make life easier for people with disabilities and thus create conditions for greater participation in society.”* They provide support to disabled people to develop and maintain mobility and motor skills, enhance their communication and linguistic ability and to manage their homes.

Disabled people in Sweden over the age of 21 years are entitled to some form of accommodation. This may be a group home or assistance in their own apartment. They receive a State pension and can also receive extra benefits to cover their rent if necessary. As in most major cities there is currently a shortage of accommodation and they may be offered a home in another Municipality although their local one must cover the costs.

The law also entitles all disabled people the opportunity to have respite in “short-break units” for up to 12 days a month. Geraldine stated that there are a number of private companies getting into this new market offering good quality services. These companies were often started by parents. Both Geraldine and Camilla spoke highly of the services their members accessed, saying the children and young people loved going there, they did “great things and learned life skills”.

According to Geraldine, Swedish society was based on everyone of working-age working and paying their taxes to support their Social Insurance Scheme which ensured that adults, whatever their difficulties were never totally reliant on their family and that parents were able to continue working if they wished rather than being forced to care.

The god man is the key in Sweden to ensuring all cognitively disabled people who are non-verbal can have their voices heard. The god man must know the disabled person really well and be able to communicate effectively with them. There can be more than one god man for each disabled person but they must all be registered with the Municipality.

Conclusion:

The “voice” of cognitively impaired, non-verbal people does appear to be heard in the UK, Ireland and Sweden. People were genuinely surprised that this would be an issue in New Zealand.

The UK and Sweden have legislation ensuring that all disabled people are appropriately supported to communicate and make decisions for themselves, wherever possible. It is accepted that where necessary the most appropriate people, who know the disabled person well and can communicate effectively with them can speak on their behalf. Often this is a family member or long time associate.

This differs greatly from the current situation in New Zealand where the opportunity for cognitively disabled, non-verbal people to make decisions is variable and totally dependent on how this population is valued by the people closely involved with them. Only disabled people who can communicate in a recognised and accepted manner are able to be involved in the Convention Coalition reporting to the UNCRPD and government agencies often fail to consult with individuals and organisations who represent this cognitively disabled and non-verbal population when developing policies and services.

In Ireland the Assisted Decision- Making (Capacity) Act 2015, once in force, hopefully will go some way to ensure that profoundly disabled, non-verbal people there will also be given the same rights.

In the UK and Sweden one of the striking features was the great relationship between the organisations I visited and their ability to work collaboratively to determine solutions to provide better outcomes for those who are profoundly disabled

Many of the organisations I visited in each of the three countries were headed by parents or family members of disabled people who were using their personal experiences to try and improve the situation for those following.

My experience in all three countries was that the organisations I visited were regularly consulted at a government level regarding policies and services which impacted on the people they represented.

In both the UK and Sweden, disability services are an entitlement, unlike New Zealand where only disability support services provided by ACC are an entitlement. Due to the LSS law in Sweden and their Social Insurance Scheme, their profoundly disabled population enjoys many benefits in adulthood such as guaranteed accommodation and personal assistance with a range of opportunities to “live a good life”.

The UK and Sweden have ratified the UNCRPD but it appears as though it may be some time before Ireland is able to do this. All three countries at the time of my visit were also

governed by the Human Rights policy of the EU and this appeared to be as equally important to them as the UNCRPD. In the UK and Sweden the people I spoke with felt strongly that the rights of people with profound disabilities were upheld and that they were appropriately represented at a national, EU and UN level.

There was no suggestion by the people I met in any of the three countries that disabled people's organisations (DPOs) prevented family members or those who knew the disabled person well, from speaking on their behalf. They believed that it was imperative and they went to great lengths to support all disabled people to "have a voice". One organisation suggested that some of the self-advocacy groups were inclined to forget that there were some people who were profoundly disabled who needed more support than they required; and that occasionally government agencies also required prompting.

The situation for people with disabilities in Ireland was dire due to their current financial and government situation. The UK was also experiencing some major issues around budgetary constraints and since my return has voted to exit the EU and had a change of leadership. Sweden was also starting to feel the impact of the influx of refugees.

The one certainty in life is that nothing will ever stay the same. We must embed robust policies to ensure the human rights of our population are protected, that their "voices" are heard and that they are provided with quality support and services so they too can enjoy the best life possible.

We're not asking for more rights, just the right to equality.

From Council for Disabled Children's poster

Jan Moss

Research undertaken: May 1st – May 28th 2016

Report Submitted: October 2016

References in the order in which they appear:

Organisations' websites referred to in this document:

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Council for Disabled Children UK www.councilfordisabledchildren.org.uk

JAG Sweden www.jag.se

Complex Care Group NZ www.complexcaregroup.org.nz

Wilson Home Trust NZ www.wilsonhometruster.org.nz

Challenging Behaviour Foundation, UK www.challengingbehaviour.org.uk

Contact a Family UK www.cafamily.org.uk

National Network of Parent Carer Forums, UK www.nnpfc.org.uk

Royal Mencap Society, UK www.mencap.org.uk

British Institute of Learning Disability (Bild) UK www.bild.org.uk

Inclusion Ireland www.inclusionireland.ie

Irish Society for Autism www.autism.ie

National Disability Authority (Ireland) www.nda.ie

Nka (Sweden) www.anhoriga.se

FUB (Sweden) www.fub.se

Autism & Aspergers Association, Stockholm www.autism.se/stockholm

Habilitering & Halsä (Sweden) www.habilitering.se

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Reports referred to:

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***They Still need to Listen More* report. (2014) UK:** published by the Children's Commissioner about disabled children and young people's rights in England

***Winterbourne View Report: Transforming Care: A National Response to Winterbourne View Hospital* (2012) UK.** The Winterbourne View hospital inquiry occurred at Winterbourne View, a private hospital at in South Gloucestershire, England. An investigation broadcast on television in 2011, exposed the horrific abuse suffered by people with learning disabilities and behaviour that challenges. It was investigated by the Care Quality Commission.

***Just Surviving: Talking with parents of children with very high disability support needs about how they get by.* (2000) NZ**

***Fulfilling and Rewarding Lives; Adult Autism Strategy.* (2010) UK.** This document included a commitment to review the strategy three years later. In 2013, the Government asked for feedback from adults with autism, parents, carers and professionals about how well the 2010 strategy had been implemented.

***Think Autism. Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.* (April 2014) UK.** This report resulted from 2013 feedback as above.

Statutory Guidance: (March 2015) UK Following *Think Autism* (2014) the Government published a new report which replaced an existing guidance from 2010. This informs local authorities, National Health Services (NHS) bodies and NHS Foundation Trusts what actions should be taken to meet the needs of people with autism living in their area.

SERC report (1993) Ireland. The report of the Special Education Review Committee was of great importance in the development of special education in Ireland. It recommended the establishment of a continuum of educational provision to meet a continuum of special educational needs.