Down’s Syndrome Scotland welcomes the opportunity to respond to this call for views from the Equal Opportunities Committee of the Scottish Parliament.

1. **Prevalence of social isolation in urban and rural settings**

People with Down’s syndrome face numerous social and structural barriers to inclusion and are often socially isolated. On one hand, social isolation may stem from attitudes within our society that continues to stigmatise people with Down’s syndrome. It is for example more difficult for adults with Down’s syndrome to find job opportunities and we know that employment is one way to contribute to society and feel part of a community. On the other hand, one cannot deny the challenges posed by structural barriers such as the use of technologies or the lack of transport/facilities in rural areas for example. These can also significantly hinder the ability of people with Down’s syndrome to develop and maintain friendships and be part of their local community.

In 2014 Down’s Syndrome Scotland secured funding from the Big Lottery Fund to run a three-year project, ‘Friends Connect’, which aims to help people with Down’s syndrome to build friendships and community connections. Ahead of the project, we sent a ‘Friends Connect questionnaire’ to 100 adults with Down’s syndrome from our membership. Members were asked if they needed support to do activities in their local area. Of the 39 returns, 95% said “Yes”. The second question asked if they needed help to set up meetings and do things with their friends. Again, the majority said "Yes" at 87%. We also wanted to identify whether adults with Down’s syndrome knew how to find out about what was going on in their local areas, 79% said "No".

2. **Impacts of social isolation, for instance loneliness, ill-health**

The impact of social isolation may result in low self-esteem and confidence for people with Down’s syndrome. Relationships not only improve people’s quality of life but they also have a significant impact on health and wellbeing. For people with Down’s syndrome, social isolation may also result in slower progress, or even loss, in communication skills because of the lack of interaction with other people and low confidence.

Moreover it is important to consider the impact of social isolation in combination with other mental health issues such as dementia. People with Down’s syndrome have an increased risk of developing early onset dementia (from age 40). Developing interactions in their local community can be difficult for people with Down’s syndrome and it becomes even more challenging for those amongst them who are diagnosed with dementia which may lead to further isolation and increased levels of dependence on family/support workers.
In fact, it is also essential to understand the impact social isolation may have on parents and carers of adults with Down’s syndrome. As the case studies below demonstrate (see point 5), people with Down’s syndrome can at times heavily rely on their parents/carers for social activities. As a result, carers often do not have opportunities to take a break from their caring role and such commitments may also be detrimental to their own wellbeing in the longer-term.

3. **Best practice and ideas that could be shared across Scotland**

Our Friends Connect project is still in its initial phase with the first friendship groups starting in the next few weeks. Our evidence will thus focus on the format and aims of the project as it is too early to share any findings. We would be happy to update the Committee on the project as work progresses over the next couple of years.

The project will provide 8 friendship groups in different locations around Scotland for young people and adults with Down’s syndrome. Over the three years each group will meet on 23 occasions supported by the project manager, 1 project worker and volunteer mentors. Volunteer mentors will be recruited from each of the locations so that they bring local knowledge to help members make community connections. Volunteer recruitment and induction workshops will involve a trainer with Down’s syndrome.

In addition to the group meetings, members will meet with each other (matched into pairs) and the volunteer mentor at least twice between friendship groups. This means they will have meetings every 2 weeks. Each friendship group will have 8 members and 4 volunteer mentors. The volunteer mentors will support group members in connecting with each other, developing friendships and accessing local community amenities. Members will be encouraged to build their skills in finding out what is on in their local areas, accessing resources and activities, making and maintaining friendships, independent travel (if appropriate) and handling money. They will also develop their self-esteem and confidence.

The Friendship group meetings will use an asset based approach and graphical representation to encourage participation and support learning for those involved. Topics covered during the project life will be: what makes positive friendships, appropriate behaviour, dealing with bullying and harassment, what is on in your community, keeping in touch with friends (including the use of social media), peer support. Through fun and accessible exercises participants will get the opportunity to explore further their hobbies, interests, skills and gifts which will help them think about activities and amenities available in their local areas that may be of interest to them. It will also assist matching similar interests in group for potential friendships.

Each Friendship group meeting will also have planning time for participants to arrange to meet up between meetings and to share feedback, on how things have gone since the last meeting, sharing their successes and learning. These will be recorded in members’ diaries, which will also include particular challenges that the members set themselves and are supported to achieve, to build their skills in community connecting and maintaining their friendships.
In year three the project will begin the process of fading out. This will involve encouraging the members to increasingly arrange and maintain their friendships and community connections with less support from their volunteer mentors and their individual challenges will reflect this increasing independence. In the final three months the groups will come back together for celebration gatherings and to evaluate the project.

Beneficiaries receive support via group meetings and 1:1 from volunteer mentors as well as peer support through positive friendships established within the groups. The support helps to increase awareness of what is on in their local areas and motivate members to try new activities such as community classes or events, leisure and sports clubs, voluntary work or simply taking advantage of local resources and interesting and social places such as museums, leisure centres, coffee shops etc. Through the activities, members’ increased confidence, wellbeing, social contact and improved opportunities will contribute to better coping mechanisms.

For adults with Down’s syndrome who still reside at home, it is important to note that the project will also benefit their parents/carers. Indeed we know through our Creative Breaks Fund that there are parents/carers who are living with long-term health issues or disabilities themselves and that a large proportion of them are also considered elderly carers over 65. Giving them a break from their caring responsibilities, allowing them some free time to access community resources should they choose to do so will help to improve their health and wellbeing and maintain their caring role.

In addition the 32 volunteer mentors will directly benefit from the project too, gaining awareness of Down’s syndrome and of disability issues as well as their own increased community opportunities and work experience.

For young people and adults with Down’s syndrome, by year 3 it is our objective that the project will have:

- increased their social and communication skills
- developed new friendships and their abilities to maintain these relationships
- developed connections within their community
- increased self-confidence and self-esteem
- reduced social isolation and improved physical and emotional wellbeing
- learned skills and knowledge about positive relationships and how to manage these, including using social media safely
- increased their knowledge about facilities within the local area
- have experienced accessing a range of community facilities
- increased their community connections and opportunities within their area

4. Potential ideas for improvement and influencing policy

In terms of policy, many recommendations contained in the Keys to Life strategy launched by the Scottish Government in 2013 will help towards tackling the issue of social isolation if implemented fully. Indeed, as an example, in its ‘independent living’ section the strategy itself emphasises the importance of activities to people with learning disabilities who then benefit from greater opportunities to meet friends and
be part of their local community. The strategy also identifies barriers to socialising which are reflected among our membership; these include a lack of support staff, inflexibility in support provision or lack of transport/appropriate facilities. As mentioned previously, employment is also key to tackle social isolation and again the strategy addresses this issue. It is therefore crucial that the recommendations outlined in the new strategy are implemented fully and within the given deadlines as and when appropriate.

With regard to dementia, the second Scotland’s National Dementia Strategy 2013-16 outlines a series of commitments by the Scottish Government, including Commitment 16 focused on early onset dementia, dementia as a co-morbid condition and equality issues. The strategy specifically refers to people with Ds who have a ‘significantly increased risk’ of developing dementia and ‘at a much earlier age’. We understand that work on Commitment 16 has just begun and we would encourage the Scottish Government to consider the issue of social isolation in establishing a care pathway for people with Ds suffering from dementia. We look forward to seeing timeously progress on this commitment now.

Finally it must be recognised that efforts to tackle social isolation need to be sustained in the long term. Building self-confidence and self-esteem is a long-term process and the nature of relationships itself means that it will also take time for adults with Down’s syndrome to get to know new people and build new friendships.

5. Case Studies

Case Study A: Angela

Angela is a 45 year old woman with Down’s syndrome who lives independently in her own house. She has been living on her own for about 9 months. She has a support worker in the mornings and evenings to help with meals and housework. Angela works one day a week. Angela has some mobility problems which affects her ability to travel on public transport. She has a taxi card and uses taxis to get her to places. She relies heavily on her nieces for social activities and outings. Her niece also helps Angela go swimming once a week. One of her nieces is a recovering addict and has mental health problems and on occasions has support herself. She is also a single mum to a young child so there can be issues with child care.

Angela was asked:
Do you go out and about and do things in your local area?
“T used to have a befriender and he took me to things like the cinema and concert, it was really good. I don’t have one now so my niece take me to concerts when she can. I don’t go to the cinema any more. I try to go out and walk a wee bit. I’m a bit slow but it helps to lose weight so I keep going. I go to my church.”

Do you meet up with friends?
“I have friends at the church and my work but I don’t see them unless I’m there. I used to have a few friends from college or the centre but I find it hard to keep in touch. I don’t see them anymore.”

What would you do if you had a volunteer to help get out and about?
“I would love to try a nail beauty class. I could meet up with a friend and go for coffee or the cinema. We could go to the theatre and see a musical. I might even try weight watchers. It would help my niece too. She does a lot for me.”

Note: Angela’s name has been changed due to personal content of this case study.

Case Study B: Judith

Judith lives in her own flat. She is a woman in her forties with Down’s syndrome. She has 2 jobs which occupy her most of the week during the day. She gets direct payments and has personal assistants every week day up to 3 p.m. They support her at her work and with independent living. She sees her mum and dad every Monday evening. After 3 p.m. each week day and at weekends Judith does not do much. She spends a lot of time on her own in her flat. She does not go to any social activities or clubs in the community or run by other organisations and has no friends. She regards her personal assistants as close friends. She has become very dependent and ‘clingy’ with one of her personal assistants. She has also become very attached to a doll which seems to be a substitute for a baby. However, the attachment has increased over the last 2 years where she is reluctant to leave it at home and wants to be with her all of the time when she is on her own. Her personal assistant feels her loneliness in the evenings and at weekends has fuelled this attachment.

Judith took part in a Big Plan run by Down’s Syndrome Scotland where both her and her PA asked for help. The Big Plan encourages people to invite friends and family to be on their ‘team’ to help them think about their interests, hobbies, skills and gifts with the aim of putting together action steps to help achieve a good life. Judith invited no-one other than her personal assistant. She was reluctant to put together action steps but on occasion did get excited and enthusiastic about activities when motivated or if they involved her personal assistant.

Judith, like many people with learning difficulties sees support workers as friends and becomes very reliant on them for social activities and friendship not just support with independent living as intended. This can often lead to problems if the person does not have other friendships or social activities to increase their opportunities. When Judith lived at home she had the support from her family to help her get to things and motivate her to go along to clubs. She completed a Duke of Edinburgh Award and took part in swimming competitions, French and poetry classes etc. When she talks about her past activities and social life she seems proud of her achievements and shows some excitement, almost lights up. We think Friends Connect would help Judith build up her low self-esteem and confidence and open up opportunities once again. Judith’s support worker also thinks a friend from the group and volunteer mentor to motivate and encourage her to go out in the evenings and weekends would be invaluable in helping her loneliness and self-isolation.

Note: Judith’s name has been changed due to personal content of this case study.

Case Study C: James
James lives with his mum. He is an artistic, kind man in his twenties. He has Down’s syndrome and autism which affects his communication skills. James used to use some verbal communication but now chooses to not talk at all. During week days he works on a farm and attends a centre. In the evenings and weekends his social activities relies heavily on his mum. His dad sadly died last year and mum is in recovery from cancer.

James’ mum feels increased social activities and contact with other people of the same age would “really open up doors for James”. She hopes it would encourage his use of speech again and help him get out and about more without her. She also thinks James enjoys the company of his peers and she notices a difference in his mood and wellbeing.

Down’s Syndrome Scotland recently facilitated a person centred plan for James in which he indicated he would like to try new things and do more social activities. However, James needs 1:1 support and to do these, he either needs a support worker (which he does not have and social work services cannot provide funds for) or mum becomes the support worker when mum, herself, has her own grief and illness to cope with.

*Note: James’ name has been changed due to personal content of this case study.*

We trust these comments assist the Committee with its enquiry. Please do not hesitate to contact our office on 0131 313 7452 or by email at rachel@dsscotland.org.uk should you have any questions.

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