

Evangelical Alliance NI  
105 Ravenhill Road  
Belfast  
BT6 8DR.

10 September 2020

Dear Chair,

My name is David Smyth and it's my privilege to lead the work of the Evangelical Alliance in Northern Ireland. We represent our members, advocate and engage across a wide range of issues of social policy.

There has rightly been a lot of discussion about 'the most vulnerable'. Within this context, the specific concern we wish to raise is the effect of the Executive's COVID-19 measures on individuals who live with an intellectual disability – adults, children and their carers.

These individuals and families struggle as some of the most vulnerable in 'normal' times with the *necessary* support and care structures which have been assessed and provided through the Health & Social Care Trust and the Education department. This takes the form of overnight and daily respite care, and the daily interventions provided in education and therapies through specialised school placements.

Within the community sector, additional care packages are provided for the children whose diagnoses present in a level of significant complexity and challenging behaviours. Throughout lockdown, the support packages surrounding these individual children and families, which are often put in place to prevent family breakdown, and to sustain a level of wellbeing for the individual child – were instantaneously removed, with a profoundly detrimental effect on all within these families.

The combination of a lack of schooling, care services and respite has put severe strain on these children, their families and carers at home, to the point where many are in urgent danger of breakdown. The challenging behaviours exhibited by these children have increased dramatically, the mental health of these individuals and carers has plummeted. We understand that increased medical intervention has been the only form of intervention in many cases.

This issue has received extensive coverage in recent months locally on BBC NI news, and more widely through a recent Panorama documentary and the National Autistic Society's recent report, [Left Stranded](#).

We feel compelled to write given the urgency and seriousness of this matter and the particular vulnerability of those involved. Having engaged with this issue in various capacities, we share the concern of many for these members of our community given the ongoing and long-term impact of Covid-19, the stretched capacity of statutory services and the likelihood of further lock-downs and cuts to services. We are concerned that many of the needs of these families could fall into gaps between health, education and community and would like to raise

to the following issues with both the Ministers for Health, Education and Communities and their respective Committees.

1. Reflecting on the publication of the Education Duties (No.10) Notice (Northern Ireland) 2020 Bill **we have identified an urgent need to designate the care of these children through HSCT and Education, as requiring 'essential services'** and protecting them from potential negative impact of the 'best endeavours' clause within this legislation.
2. We are concerned that these families are falling into potential gaps between departments and services. If one has not already been established, **we propose a cross-departmental task group that includes community agencies be set up** to make sure tailored support is specifically provided to these children, their families and carers.
3. Having engaged with both individuals and families at grassroots level, and discussed with MLAs at government level, we can see a dis-connect between policy setting and grass roots level. Eg. Many representatives seem unaware that despite commitments that those with statement with educational needs were to be designated a school placement throughout Covid, all SEN schools (with the exception of one) were closed to these children. We would like to see a connected conversation, listening between those who make policies and those who live under the effects of policies in this area. **To this end we would like to offer to facilitate a meeting with you and your officials/committee members.** My colleague Donna Jennings is a parent of a child with profound autism, she is also an advocate for a non-statutory body and a governor on the board of a special school. By virtue of Donna's experience, relationships and our wider organisational remit in terms of public policy, several non-statutory agencies who were actively supporting these families would be willing to attend to share first-hand the daily experiences of the staff and the families the organisation serves.
4. We commend the coordination of resources across the community, statutory, non-statutory, charity and faith bodies which we have witnessed and been a part of across many aspects of the Covid response. This approach is vital to support these families now and in the ongoing effects of Covid-19. **We would like to explore with the relevant bodies and professionals in this area how churches could potentially play a part in meeting some of the heightened need as we look ahead.** This could be through the use of buildings, volunteers and other practical resources.

We look forward to hearing from you as a matter of urgency as together we seek to support these children and families in these most difficult of times – and into the future.

Kind regards,

*David Smyth*

**David Smyth**

Head of NI

Evangelical Alliance - [eauk.org](http://eauk.org)

Tel: 028 9073 9079 | Mobile: 07739307656 | Twitter: [@EANInews](https://twitter.com/EANInews)

[www.reimaginingfaith.com](http://www.reimaginingfaith.com)

One family's story:

*M is age 12, has diagnosis of Autism, ADHD, Severe/profound learning disability, sleep disorder and challenging behaviours. His family's assessed care package through the Children's Disability Team allocates 18 hours respite plus 4 nights per month in overnight respite facility as well as a specialised Individual Education Plan delivered through his specialised school placement, incorporating daily speech and occupational therapies.*

*This provision allows the family to function, to maintain employment, and care for their son at home. The interventions M receives through these care packages and plans, maintain a level of wellbeing, mental health and self-regulatory ability that allow the family to care for him.*

*Since March, all provision through M's school were closed and unavailable to M, respite care was significantly reduced, despite calls for help, and communication from the Stormont Executive that he should be provided a school placement.*

*Without the structures of support and intervention, M's behaviours, mental health and wellbeing like many of his peers, deteriorated to a level which stretched the capacity of the family to care for both him and his younger sister effectively.*

*Many families whose children present with similar challenges, concerned for their ability to care for their children called social services in desperation for help to be told that no extra help – from school or health and social services was available. Moreover, increased medication to manage behaviours and anxiety seemed to be a common response.*

***A copy of this letter has been sent to the Minsters for Health and Social Care, Education and Commities and the respective committies.***



Charity Registration No: NIC100114

Parkmore Building  
284A Ormeau Road  
Belfast  
BT7 2GB  
Office: 02890 247600  
Mobile: 07714204088

12<sup>th</sup> October 2020

## Sólás Special Needs COVID Response Report for the Period (21<sup>st</sup> March to 30<sup>th</sup> September)

### About Sólás:

1. Established in 2009, Sólás is a special needs charity which supports children and young people with a broad range of additional needs including autism and ASD. We are based in South Belfast, however our work extends across Northern Ireland.
2. We have a number of social development, educational support and parent support programmes. As part of our social development programme we facilitate a range of after-schools, weekend and summer scheme initiatives for children and young people with ASD.
3. We also facilitate a number of weekly home support and respite initiatives, as well as parent support groups.
4. As part of our educational remit, we run an early intervention initiative called Back on Track and Kidz Den which provides support to children who have an additional learning need but do not meet the criteria for statutory support.
5. We also run an IT programme in primary schools called SchoolPodcast and we are currently developing a training and personal development course for the 18+ bracket.

### Response during Lockdown:

6. **Closure and re-shaping services.** Initially in the COVID lock-down in mid-March, Sólás had a suspected case of Coronavirus, and therefore closed for a period of 10 days to complete a full deep clean, to get some staff set up to work from home and to look at reshaping the services that we had so that we could best support the needs of children, young people and families in our care.
7. **Emergency Respite.** By the start of April we had an Emergency Respite Service operational, by which we transported children, one at a time, from home to our Parkmore site and provided 3 hours social support for the child in our premises which has a sensory room, outdoor playground, indoor social activity areas and is staffed by carers that children are very familiar with. This Emergency Respite Service initially was delivered by two staff supporting one child each morning and two staff supporting one child in the afternoon. From the start, the children using this service were, almost invariably, children with severe complex disabilities. The closing of schools had the most significant detrimental impact on these children's health and wellbeing and the lack of routine placed a severe strain on their entire family unit.
8. **Growth in demand.** This service grew exponentially over a very short time, as more and more families were desperate for help, and genuinely needed a break from the sleepless nights and the

challenging and unpredictable changing behaviour of their disabled child, who didn't understand why their world had changed so drastically. Children struggled with no school, no bus to pick them up, no Occupational Therapy or Speech & Language Therapy. Everything that they had been familiar with was suddenly taken away.

9. **Capacity.** From the outset, the Respite Service operated 7 days a week, Monday to Sunday. In June we opened a second space and we grouped children in twos and threes, (sibling groups were always kept together). We supported over 30 children with complex needs each week. Where possible, we tried to offer some of the more complex children a minimum of two or three respite sessions per week.
10. **Summer Programme.** It became clear that the demand for summer support was also burgeoning and we could not just focus on continuing to support the severely complex children. We had an obligation to deliver a summer programme for all the other children who would normally be in our Afterschool's clubs and Saturday clubs. By securing access to community venues and additional funding from the Lottery and ChildCare Partnership, we were able to employ additional summer staff. Between the 6<sup>th</sup> July and the 23<sup>rd</sup> August, we supported 89 children aged 5 to 12 years and 16 children aged 3 to 4 years in a summer programme, here at Sólás. The Emergency Respite Programme continued to run alongside the summer scheme, where a further 30 children continued to get respite and, where possible, summer scheme support.
11. **Home Support.** Alongside this Emergency Respite Service, a team of Sólás Home Support workers, who worked from their own homes, provided 'Home Support' to families of children in our care, and those referred by hubs and Social Services. The support included twice weekly telephone calls, help by making visual aids to support communication with their child, and dropping these visual aids to the home; help by making choice boards or PECs (Picture Exchange Charts) and dropping them to the home; help with food parcels (Sólás linked in with several food banks in the city); financial help for two families purchasing a cooker and a fridge; creating sensory packs for families and dropping these around to the homes, and writing social stories for families that provided parents with a resource that they could read with their child which would, hopefully, help change any unwanted behaviour that their child had started to display.
12. **Youth support.** This was given mostly online for most of the early period by offering zoom quizzes and scavenger hunts. However, as things started to open up we started bringing the young people together in small groups in the evenings and taking them for socially distanced walks.

### **Impact on Families:**

13. **Exhaustion.** All families of children with disabilities experienced huge stress, worry and anxiety during the lockdown period. There was a sense that they had been forgotten. The worry and stress of navigating each day and night not knowing what was ahead or where they could turn to for help was sometimes unbearable. They felt alone and isolated and they felt that their entire family including their disabled child had been completely forgotten about.
14. **Uncertainty.** The uncertainty of not knowing if or when the schools would open had a huge impact. Parents /carers experienced extreme tiredness and fatigue. When we were able to offer respite, they were so grateful to get a break, even for a few hours.
15. **Mixed experience with schools.** Parental feedback about their experience with school during lockdown was very mixed. Some felt that the school staff lacked understanding by trying to engage children with complex disabilities through Google classroom, when this was obviously not going to work. Others felt frustrated that staff could have done more to help. For example, one parent recalls that she was emailed visuals which she had to print, laminate and Velcro before the visuals

could be useful. There was sometimes a lack of foresight on the teacher's behalf and an unwillingness to find solutions that could better work for the family. One parent recounted "Why could the teacher not have laminated the visuals and dropped them around to my garden?"

16. **Therapies, mental health and wellbeing.** Other parents reported that their child had not received any Occupational Therapy or Speech & Language Therapy since lock down and that their child was regressing in their behaviours and in their ability to be independent. Many parents commented on the fact that their child was experiencing poorer mental health & wellbeing as a result of not being in school.
17. **Raising concerns.** Parents felt that their concerns were falling on deaf ears. It is extremely difficult for them to maintain the energy levels that they needed to get through a day, never mind raising concerns with the statutory agencies, politicians or others who would have the influence to bring about changes.
18. **Extremely vulnerable.** There was a feeling that children with disabilities (particularly complex and severe learning disabilities) should have been more carefully considered. These children are extremely vulnerable, and as vulnerable children should have been prioritised in terms of access to school, access to statutory respite , and access to overnight respite. The panic that set in at the start delivered a set of reactions and outcomes that completely excluded this extremely vulnerable group.
19. **Lessons must now be learned.** Should further shut downs occur, then the specific needs of children with disabilities must be carefully considered and accommodated.

**Other issues that should be addressed:**

20. **Respite.** The most important service for a family during lock down is respite. This must be protected and provided as an essential service going forward.
21. **Support is needed from other agencies.** The BHSCT Disability team did work with us in terms of providing PPE and referrals over lockdown. There is a continuing need for BHSCT to work closely with the community disability groups to ensure that direct payments are available to families to pay for respite services that can be offered in the community sector.
22. **Community facilities** (particularly city council facilities) must be available for disability groups to deliver services over lock down. For example, SOLAS owns one building, and delivered respite services from this centre right throughout the lockdown period. Prior to shut-down SOLAS also delivered respite / afterschool clubs in Donegal Pass Community Centre (owned by the Belfast City Council), however this remained closed until the end of August.  
We did have access over the summer period to 6 other community centres, including the Baptist Church Hall on Malone Ave, Apsley Hall in Donegal Pass, Scoil an Droichid, Rosario Youth Centre, Windsor Women's Centre and Markets Surestart Centre, all of which were used to deliver our summer programme of support. The willingness amongst the community to support our work was very heartening.

### **Case study 1:**

A family of three children, two boys 11 and 12, both with Severe Learning Disabilities (SLD), including autism, and a younger sister aged 4, with no disabilities. The older boys attend a Special school which closed on the 17<sup>th</sup> March. Both boys experienced huge difficulties with the shut-down and their behaviours escalated, leading to several episodes, two such episodes resulting in dad experiencing physical bruising. We worked with the family and brought the boys and sibling sister into summer scheme together, every other week, for a week at a time throughout the summer. All the siblings were all in the same pod, and did not mix with any other children, thus giving reassurance to mum that they would be safe from the virus. On the weeks in between, the children were taken individually for respite for two sessions a week. Over time, the children developed a routine, and the family started to recover and gain some level of normality. On reflection, mum points out that by June, the family had reached breaking point, and without intervention the outcome would have been even more serious for all.

### **Case Study 2:**

A Foster carer of a little boy aged 8 with Severe Learning Disabilities, and sight impairment, availed of the SOLAS respite service and summer service for her child throughout lockdown and is now continuing with respite support in our afterschools clubs. The foster carer is also the boy's granny. She is in her 60s and has poor health. The wee boy is very boisterous, climbs into everything, has no sense of danger. He has very little communication skills and sleeps sporadically. Granny struggles to support his needs on her own. Since lockdown, we picked him up twice a week for respite sessions, and as the summer programme came on stream, we were able to offer the family 3 weeks of summer scheme support as well. Granny needed respite, as she was exhausted from looking after him on her own. To add to the complications, the little boy was due to change schools this year. The E.A. offered her grandson a school in Newtownabbey, which was not a feasible option. Taking up this option would have meant that her grandson would not be able to access respite afterschools clubs at SOLAS, due to the logistics and the distance between the proposed school and SOLAS site. We supported granny making the case to the E.A. to get a more appropriate offer, that would better suit her grandson's needs and her needs and would have enabled respite outside of school to be delivered to support the family unit.

### **Case Study 3:**

A child in our 2-3 year old programme was due for final E.A. assessment with the Educational Psychologist on the week of shutdown. The assessment was subsequently postponed and the child was not offered a space in a special pre-school unit (as the statutory Statement of Need could not be concluded by the Ed Psychologist without the final assessment). Mum was determined that her child had special needs and would not cope at all in a main stream pre-school unit without support. That support could not be put in place without the requisite Statement of Need. SOLAS worked with the Educational Psychologist at the E.A. and the family to facilitate the child's final assessment on site in our facility. The E.A. did not have a facility available to them for statutory assessments over lockdown. Going forward this needs to be addressed by the E.A. We are happy to work with the E.A. to facilitate these assessments, as we know how important they are to the continuity of care and educational support needs for each child involved.

## Summary :

Lessons must be learned from the last shutdown.

23. **Priority access to services.** Families of children with disabilities must be prioritised, and have access to services even during lock-down.
24. **Schools must remain open** - particularly special schools.
25. **There has to be better co-operation** - especially between statutory services and the community sector.
26. **Financial resources.** These need to be freed up to support the community sector now and into the future. The community sector has the ability to quickly shape services that can respond to need, however very often what impedes the sector is the lack of resources.
27. **Respite.** When everything else is stripped away, the one thing that families of children with disabilities need most is respite. They need to feel that someone cares about them and understands that as carers, they need a break from their child, and they need some rest. We can never neglect families so blatantly again that they reach the point of no return.
28. **Return of services.** As normality returns, these families need to see the other services kicking back in, particularly the OT and SLT support.

We can only ever judge a society by how well it treats its most vulnerable citizens. I think we can all agree that we can do better.

Yours sincerely,

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Dr Joan Henderson

Managing Director

Sólás Special Needs Charity



Thankyou for the time allocated to both agencies that allowed the education committee to hear the experience of families with severely disabled children during lockdown, to highlight the significant gaps in the process and to suggest ways forward.

I very much appreciate the communication taken on behalf of the committee to the Department of Education.

Can I highlight once more – the key fault underlying the DE and EA response and the failures which have so greatly impacted these families – as stated repeatedly in my presentation – is that both SEN (which is DE remit) as well as respite facilities (which is HSCT remit) were never, and are still not designated as ‘essential services’ for these children.

Without this designation, Principals were and still are under no accountability to provide these services, they have no mechanism within which to compel teaching and non-teaching staff to come to work in the school workplace, and they are and were not resourced into being able to fulfil these ‘essential services’. Under ‘best endeavours’ and without essential services – these schools are currently shut, and will be shut again in the foreseeable future.

Without the designated ‘essential service’ status – these services will not resume, they will not be resourced and they will not fulfil their remit – as essential. They have been and will continue to be covered as ‘best endeavours’ – which amounted to zero endeavours.

The Cross-Departmental Actions document refers to these as ‘essential services’ to be ‘sustained’ – however within Education, these have not been granted. And so, this is the first course of action, to be taken swiftly along with a resourcing into this status.

Please, I ask you – this is the key message that DE needs to hear in order to go forward and to mitigate against the ongoing and future impact upon these families.

Many thanks,

Donna Jennings

**Donna Jennings**

Church & Mission Coordinator, Northern Ireland

Evangelical Alliance – [www.reimaginingfaith.com](http://www.reimaginingfaith.com)

Tel: 028 9073 9079 | Mobile: 07851 987118 | Twitter: [@DonJen000](https://twitter.com/DonJen000)

