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Recording Emerging Adulthood in Deaf Youth: A Summary Report of the READY Study

June 2019 - September 2023

Funded by



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With¹

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Acknowledgment: Sincere thanks to all the deaf young people who participated in this study and their friends, family, mentors, teachers and supporters who encouraged them to do so and facilitated the initial distribution of information to join the study.

Disclaimer: This report was prepared by the READY team. The views expressed within it are not necessarily those of the grant funder, the National Deaf Children's Society.

A BSL video summary of this report can also be accessed **here**.

^{1.} Many people have contributed to this study over the years in various roles including through internships offered throughout. We additionally acknowledge the contributions of: Khadija Grierson, Molly Redpath-Healy, Charlotte Sansome, Molly Dibblebrown, Emma Reilly, Rita Giacoppo.

Who is this study about?

This study is about deaf young people in Great Britain (England, Wales and Scotland) who are on the cusp of adulthood. READY stands for Recording Emerging Adulthood in Deaf Youth. Those in the READY study joined when they were aged 16 – 19 years. Some were still at school, some in college, some starting to enter employment, and a few who were not in employment, education or training (NEET). Deaf young people are diverse for many of the same reasons that all young people are whether in terms of disposition, background, identity characteristics, socio-economic circumstances or opportunity. They are also highly diverse for reasons associated with being deaf such as preferred means of communication and proficiency of language(s) used; in audiological terms their degree of deafness; when being deaf came into their lives; what kinds of hearing technologies they use or not; and how they understand the place of deafness in their lives.

At this age, all young people are trying to find their way in the world, are exposed to new experiences and challenges, and are questioning who they are and what they want to do and be. Autonomy and independence bring their own pressures and delights. New sources of support and relationships are formed amongst peers and beckon from the adult world, not all of which might be helpful. This study positions itself at those points of flux and diversity to find out from young people themselves what is it like to become an adult as a deaf person in Britain at this point in the **21st Century?** The timing is important because this generation of young people, sometimes referred to as Generation Z, are different from previous generations of deaf young people. In the UK context, as in much of the economically wellresourced countries of the world, the majority of these young people will have been screened for deafness at birth opening up the possibility of intervention to support language development in the first months of life. They have grown up at a time of advanced hearing technologies (digital aids, next generation cochlear implants) and at a time of formal recognition and widespread social acceptance of signed languages such as BSL (British Sign Language). They are digital natives, growing up with advanced online communication, sophisticated information technologies and social media.²

This study, commissioned by the National Deaf Children's Society was born out of a recognition that we needed to know more about how deaf young people navigate the opportunities and challenges of 21st century life and whether what we know about their needs and strengths from research about previous generations still holds true today. So... how are young deaf people doing in Britain today as they emerge into adulthood? As one participant put it when asked why they had taken part in READY:

To find out more about the background to the study and the description of the diversity of deaf young people who took part, go to: Young, A.M., Espinoza, F., Dodds, S., Squires, G., Rogers K., O'Neill, R., Chilton, H. (2023). Introducing the READY study: DHH young people's well-being and self-determination. JDSDE. https://doi.org/10.1093/deafed/enad002 [this article is free to access and download]

"Yeah, I think it is because the people who are not deaf and are like trying to decide stuff for us, they don't know what it's like to be deaf and they have no idea what challenges we all face."

What were the research questions?

In formal terms, the research study has investigated three questions:

Q1. What are the risk and protective factors relevant to deaf young people's achievement of: autonomy, social development, personal wellbeing, and educational and occupational attainment?

Q2. How do these factors operate and interact, and what are their differential effects given the diversity of deaf young people's profiles and varying familial and contextual circumstances?

Q3. Is it possible to predict the elements required to maximise the potential of deaf young people (in the domains of autonomy, social development, wellbeing, education and employment) between the ages of 16 and 24 years and how might these be enabled?

Or, alternatively, as one participant put it:

"I've had a lot of issues with...like support wise ... and I thought that like if my input into this study is going to make a change, then...I want to help...so that future deaf children won't have to go through what I went through."

How did we do the research?

This research study is not a snapshot with participants only asked once about their lives. This a longitudinal prospective study which means we have followed deaf young people in real time over several years. The first young people joined in 2019 and they were invited to participate again on two more occasions [Waves 1, 2 and 3]. This means the READY study captured also life during the COVID-19 pandemic and its aftermath. Every year, participants filled in a survey about their life today, their activities, opinions, thoughts and feelings. We also collected from them background data about their families and educational history as well as the different supports they had received in the past and now. Only young people supplied data about themselves. We did not ask parents, teachers or any other professional who might be involved. This was important because **it is a study about deaf young people entirely from their point of view.** In addition, participants were asked to complete three short questionnaires.

SWEMWBS (The Short Warwick and Edinburgh Mental Wellbeing Scale)	This assesses mental and emotional wellbeing (how "good" somebody feels) and psychological functioning (how well somebody thinks they are doing).
EQ-5D-5L	An assessment of health-related quality of life (measures health states in 5 domains and self- perceptions of health)
SDI:SR (The Self- Determination Inventory: Student Report)	This assesses skills in choice making, problem solving, decision making, goal setting and attainment, self-advocacy, and self- management (including self-awareness and self-knowledge).

Deaf young people could access the annual survey in Written English, Written Welsh, Sign-Supported Spoken English, Sign-Supported Spoken Welsh and BSL. However, we recognised that many deaf young people have diverse strengths in different languages or communication formats and will draw on these in everyday life. So, we created a new way for people to access surveys online which meant they could choose which language or format to use to help them understand what is being asked. This was possible on a question by question basis and therefore very different from a traditional survey where you have to choose one language from the start and stick to it e.g. English or BSL. Our participants could hop between languages and formats throughout the survey to match their preferences³. The questionnaires were available in Written English, Written Welsh and BSL with the exception of the SDI:SR that could only be completed in English or BSL. All are suitable for 'young readers'.

From our sample of **163 deaf young people**, 46 were also interviewed in depth about their lives today, their aspirations, friendships, challenges and becoming an adult. Half of these interviews were carried out by a group of young deaf adults (slightly older than the study sample) who had undergone training from the core researchers to carry out the interviews, to assist with the data analysis and to support the project in lots of different ways (the Co-Inquirers). They described their involvement and commitment to the study as personal because based on their own life experiences they wanted to contribute actively to making things better for others in the future⁴.

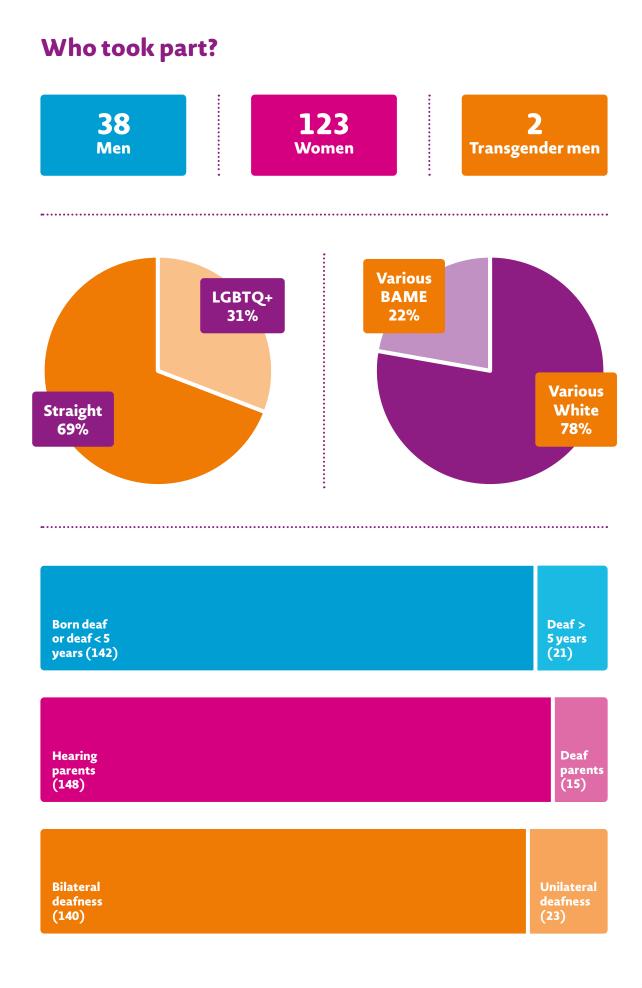
^{3.} To find our more about how we did this and why, go to: Young, A., Espinoza, F., Dodds, C., Rogers, K., Giacoppo, R. (2021). Adapting an online survey platform to permit translanguaging. Field Methods, 33 (4), 388-404. https://doi.org/10.1177/1525822X21993966

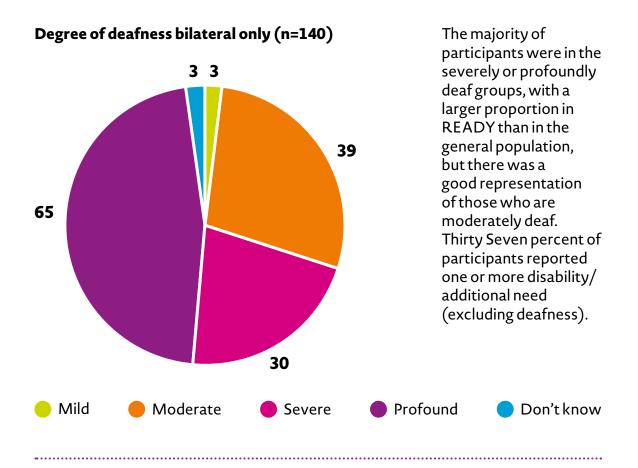
To read in full their articles go to: https://limpingchicken.com/2021/06/18/tomas-gerrard-find-out-more-aboutready-a-major-research-study-on-young-deaf-people/ and https://themeteor.org/2021/03/19/study-deafyoung-people/

"I consider myself a privileged young man, having been raised in a Deaf family with healthy ties to the hearing community... Yet, questions like 'Where am I going?' 'Will I be good enough for the next opportunity that presents itself?', 'Will there be a 'next opportunity' for me?', 'Will I be able to cope?' still plague my existence. As most deaf people know, we face a constant, draining, uphill battle with the ableist society we live in...This is what the READY study is for, to understand more about the choices we all make as young deaf people, to find some answers over the five years of the study and to present the results to those with the clout to make a lasting and positive change. To provide all of us with a better understanding of the support that we need and deserve to be provided with."

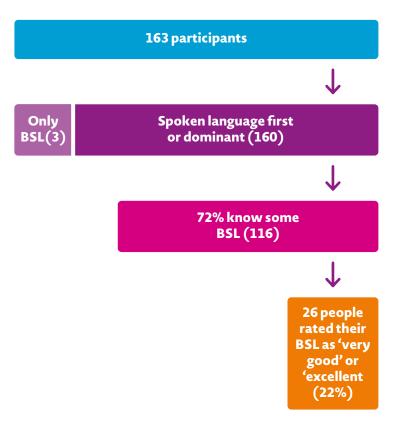
And:

"I'm hoping the results of this study will help people in the future to understand young deaf adults more, try to really find out what young deaf people really want, understand the challenges they face, and just be kinder to them and more inclusive...Remember that everything is possible... I cannot tell you how many times I have wanted to quit at certain critical moments in my life. You really get to moments when everything is overwhelming or too difficult and you just feel you are not well supported."

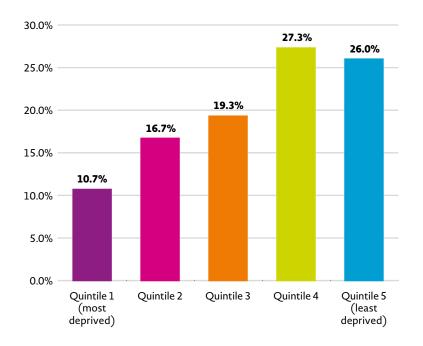




Participants' uses of language and communication:



The majority of young people in the READY group used spoken language as their first or dominant language but a surprising number also had BSL skills with over 20% rating these as very good or excellent. This is in line with a lot of recently research that shows the fluidity of deaf young people's approaches to language and communication in everyday life.



England, Scotland and Wales combined Index of Multiple Deprivation If there were equal participation by socio-economic status, 20% would be expected in each quintile of deprivation. In our sample, there was a skew toward those in the 'least deprived' guintile.

What did we find out?⁵

Wellbeing

"...if it [my mental health] wasn't that strong, I would feel quite defeated everyday with my deafness."⁶

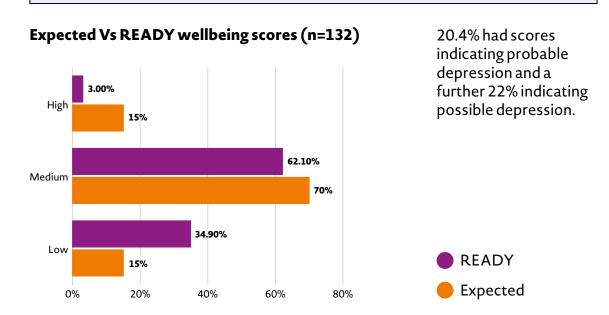
Subjective wellbeing encompasses both how good someone feels about themselves and how well they are functioning psychologically. We investigated the wellbeing of people in the READY study because wellbeing operates as an enabling trait in young people's transition to adulthood. It is crucial to positive mental health and protective against the development of a range of psychological and behavioural problems in young people including depression, social problems and maladaptive relationships with others.

^{5.} The following is designed to present the headline findings in an accessible way. Not all findings are summarised in this report. Full details of the data analysis on which this is based are being/have been published in a series of peer review academic articles. The details of these will be available via the READY website. https://sites.manchester.ac.uk/thereadystudy/

^{6.} Quotations in this findings section are from the interviews with young people in the study.

Scores overall

Overall, READY participants had much lower wellbeing scores on the SWEMWBS than the general population of young people of a similar age in the UK. More had low wellbeing and fewer had high wellbeing.



• These low wellbeing scores were not a result of the study happening during the Covid-19 pandemic and its aftermath. When we compared scores of the group prior to first national lockdown, after the major lockdowns and subsequently, the average scores did not significantly change.

What affected wellbeing scores?

We looked at characteristics that might affect wellbeing scores. We found that:

- Degree of deafness, ethnicity, socioeconomic status, disability/additional need (separate from being deaf) did NOT affect wellbeing scores.
- This remained true when we looked the same young people over time who repeated the assessment on an annual basis. Neither the average scores of the whole group or individual scores changed significantly over a year period.
- Educational attainment was not connected with wellbeing. Those with lower or higher educational attainment were not more or less likely to have good or poorer wellbeing.

It cannot be assumed that young people with greater degrees of deafness, or who are from minority ethnic backgrounds, or from poorer backgrounds, or have lower attainment at school are more likely to experience poorer wellbeing.

- Women had significantly lower wellbeing scores than women of similar age in the general population and lower wellbeing scores than men in the READY group.
- READY participants who identified as LGBTQ+ had significantly lower wellbeing scores than the READY group as a whole.

We are <u>not</u> saying that being a woman or being LGBTQ+ is a risk factor for poor wellbeing. We are saying that at this age there are factors affecting deaf young women and LGBTQ+ deaf young people that make the achievement of good wellbeing more challenging. It will be important moving forward to understand more about these factors might be to support these young people further.

Social Network Health (SNH) is a factor that combines such features as emotional closeness with others, social support, numbers and diversity of friends and connectedness with others as well as the range of social activities on a group or individual basis. The READY study created a new index of SNH specific to deaf young people. We found:

- There is a significant positive relationship between SNH and wellbeing scores meaning if one increases the other does too.
- The <u>quality</u> of relationships was identified as more supportive of mental wellbeing than simply the quantity of friends and social connections.

Diverse social relationships are important at this age for young people, but it is the quality of those relationships in terms of closeness, support, responsiveness and trust that are important in supporting positive wellbeing.

Self-determination

Self-determination is about those skills and traits that mean a person is able to decide what they want and act to achieve it. It includes decision making, goal setting, planning, problem solving, self-advocacy, self-management and self-awareness. For young people at the point of transition to adulthood it is important because there is a strong relationship between enhanced self-determination and academic performance in school. It is also a known predictor of post-school education, employment outcomes and community participation. The READY study adapted the SDI:SR for UK English and BSL in order to assess self-determination amongst the READY group.

Scores overall

The READY group had much poorer self-determination scores than the general population, disabled people or other deaf people (of all ages). This is a cause for concern.

- The READY group scored <u>lower</u> for self-determination overall and in each domain (section) of the measure in comparison with large data sets of young people 'without disabilities' and young people 'with disabilities'.
- They also scored lower in comparison with young deaf people in the USA.
- These low self-determination scores were not a result of the study happening during the Covid-19 pandemic and its aftermath. When we compared scores of the group prior to first national lockdown, after the major lockdowns and subsequently, the average scores did not significantly change.
- Young people who did the assessment more than once demonstrated that over time, the average scores for the group as a whole as well as individual scores did not show any significant change.

What affected SDI:SR scores?

"There've been quite a few times when I've had a mental breakdown. But there are also times when I just pick myself back up and just get on with it."

- No significant differences in scores were found according to age, degree of deafness, ethnicity, sex, socio-economic status or educational attainment.
- Those without additional needs/disability (separate from being deaf) had significantly higher average SDI:SR scores than those with additional needs/ disabilities.
- The sub-group of READY participants who were LGBTQ+ scored significantly lower than heterosexual/straight participants in the READY group overall and in every domain of the SDI:SR
- The only factor that contributed to differences in self-determination scores was wellbeing. Its influence far outweighs any other characteristic including being LGBTQ+ or having additional needs/disabilities.

Higher levels of self-determination are a predictor of higher levels of wellbeing, outweighing the influence of any socio-demographic characteristics. There is a strong argument that to improve wellbeing amongst deaf young people we should improve their self-determination. Self-determination is a trait that continues to be open to development well into young adulthood.

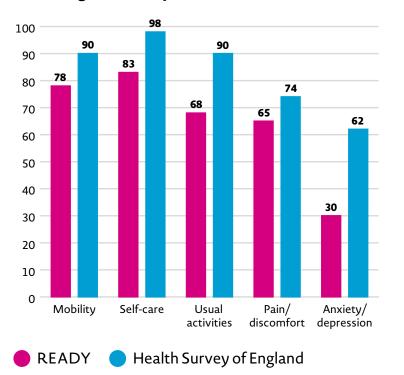
Health-related quality of life

Health related quality of life examines the impact of health status on quality of life and involves the self-perception of mental and physical health of individuals and groups against what the norm might be for any country, age group or language population. It is an important measure in determining how any supportive interventions should be targeted to any given group who may score lower than expected and be at risk.

Overall scores

It is of concern that the health related quality of life of deaf young people in the READY study is significantly worse than that of young people of the same age in the UK in the general population.

• The Health Index status score for the READY group is highly significantly different than that for young people of the same age in the general population in England (0.76 compared with 0.88).⁷ This means the deaf young people in the READY group had much worse health related quality of life.



Percentage with NO problems

In each domain of health (usual activities, pain and discomfort, self-care, mobility and anxiety and depression), the proportion of people who people reported 'no problems' is smaller among READY respondents than in the comparable general population.

Health status was most obviously worse in the domain of anxiety and depression.

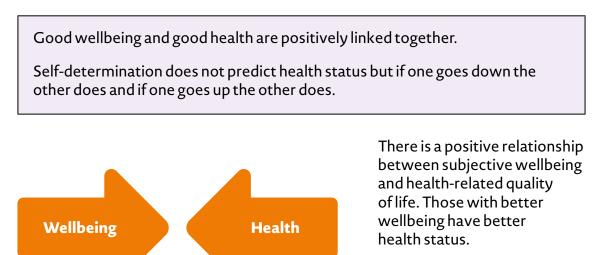
 READY: 0.76 (95% confidence interval: 0.71-0.80); Health Survey of England: 0.88 (0.86-0.90 confidence interval). (p<0.0001)

- READY study participants' self-perception 'of your health today' (average: 73.0) was also significantly worse than that of young people of the same age (average: 80.8).
- These results were not affected by the conditions of Covid-19 with similar patterns seen before the first lockdown and over the next 2 years. Nor were they affected by any differences in the number or composition of the comparator (the Health Survey of England, 16 – 19 year olds).

What affected health related quality of life?

- Women in the READY group scored much lower than men on average.
- The health status of LGBTQ+ participants was significantly worse than that of heterosexual/straight participants.
- We found no evidence to suggest that degree of deafness influenced health status but the additional needs/disabilities (separate from deafness) did. Those with additional needs were less likely to say they had 'no problems' in any of the 5 domains of health.
- Socio-economic status had some protective effect with those with better health status being concentrated in the 50% least deprived group.

How do health related quality of life, wellbeing and self-determination link with each other?



Deaf young people with higher wellbeing have a better perception of their health.

Self-determination and health related quality of life are linked. One does not predict the other, but if one improves or worsens then the other does too. However, as noted earlier, higher levels of self-determination are a positive predictor of higher levels of wellbeing.

"I think also probably growing up with it [my deafness], I think, has made me a lot more resilient and sort of confident in a way as well because growing up, obviously like I have had real highs and lows about it and sort of like coming to terms with it and I think yeah, it's ultimately it's given me a lot more resilience and you know and a bit more of like a like a confidence, like you know, I can, I can do this and you know, I'm not going to let this stop me sort of thing."

Attainment and aspiration

The READY group on average has higher levels of educational attainment than deaf young people as a whole in the UK and a significant proportion are achieving at a similar or better than standard than the general population.

- 34 participants had no recorded qualification however the majority of these were yet to get the results of their first exams. Only 6 had definitely taken examinations and not achieved any qualification.
- Of the 124 where a qualification was recorded, 93% had at least a level 2 qualification (GCSE or equivalent) and 90% achieving this in English and Maths in the higher grades.
- For the 66 where verified data was available on the number of GCSEs or equivalent achieved at the higher grade, 80.3% had achieved 5 or more, and 53% had achieved 9 or more.

This relatively high achieving background of the READY group is an important context because this group is not representative of many deaf young people who might struggle in school. But we have also shown that educational attainment is not a predictor of any of the major outcomes we have looked at: wellbeing, health and self-determination for this particular group of young people. This group is achieving very well at school despite the group on average having such poor outcomes on other measures.

- READY participants' career aspirations were in line with comparative data from the general population of young people of the same age except more wanted to go into the health and social care, and the publishing and broadcasting sectors.
- Most aspired to Level 3 (higher vocational) or Level 4 (professional/ managerial) careers which was not inconsistent with their level of educational attainment at the time of data collection.

"I sort of like all areas of computer science... So, I've taken the subject to find out what I really, you know, whether I want to continue programming, or if I want to try something new, or, yeah. But, hopefully something within technology is the end goal, I think, yeah."

Overall conclusions

- → There is a great deal more information and analysis generated from the READY study than we have had the space to discuss here including further data on language and communication, friendship and loneliness, and non-electoral political participation. However, in answer to the initial questions about risk and protective factors for transition to adulthood and what makes a positive difference there are some bottom lines.
- → Despite good levels of educational attainment which we expect to be important for future education, employment and economically better opportunities, the READY group as a whole are facing some key challenges and disadvantages that set them apart from others of the same age. These related to significantly poorer wellbeing, quality of life and self-determination than would be expected.
- → The picture is much more complex than suggesting that those with greater degrees of deafness are likely to experience greater challenges and disadvantages. In fact, how deaf a young person might be is not primarily associated with differences in gains or disadvantage socially, educationally or in terms of health and wellbeing.
- → Young women and LGBTQ+ young people face additional vulnerabilities in achieving good wellbeing, health related quality of life and self-determination. This is not because sex and sexuality are risk factors. It is more likely because their needs are not well recognised nor systems of support necessarily designed to respond to this diversity.
- → Higher socio-economic status has a marginally protective effect in supporting better wellbeing but is not directly linked to better educational attainment.
- → Deaf people with additional needs/disabilities face greater challenges to health related quality of life at the point of transition to adulthood than those without. Acting preventatively to avoid potential negative impacts would seem desirable.

- → Acting to increase the skills and strategies associated with selfdetermination will have a positive impact on wellbeing which is important for health related quality of life. Collectively these three are known to impact on education, employment, friendship/social networks and quality of life. Therefore, intervening early to boost self-determination will have important positive consequences for deaf young people into adulthood.
- → The degree of self-reflection, commitment to other deaf young people and effecting positive changes to society shown by the READY cohort is remarkable.

As one READY participant put it when asked why they had taken part:

"It's an opportunity for me as well personally... [to] sit back and actually think, how am I actually feeling about it (being deaf) and how am I able to cope with it? And I think that's really important... if you have a disability, to process rather than just pretend. Not pretend it doesn't exist but pretend like it's not a factor of just day to day life." We are the National Deaf Children's Society, the leading charity for deaf children.

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