

Mental health and wellbeing consultation response

Who this response is from

This response has been written by a small collaboration covering a range of stakeholders focused on the mental health and wellbeing of those affected by rare diseases and their families. We as a group believe that the rare disease community experiences health inequality in terms of mental health and wellbeing services. This belief is based on our professional and personal experience, and those of the community we collectively serve.

The collaboration consists of: Gene People, a charity that offers support and information to those affected by genetic conditions and a network of over 130 condition-specific support groups working with communities focused on one condition, Congenica, a digital health company specialising in diagnostic software used for the diagnosis of inherited genetic disorders, RaremindsCIC, a not for profit company offering free to access psychological services to adults affected by rare diseases, UCL Great Ormond Street Institute of Child Health, and Addenbroke's Hospital. Some members of the collaborative have personal experience of rare diseases within their families and the NHS services that support families, children and adults.

The rare disease context

There are approximately 3.5 million people affected by rare conditions in the UKⁱ, which means many more people from their wider families are involved in caring for and supporting them.

Estimates of the numbers of rare diseases have, until recently, suggested that there are around 7,000 conditions. Rare-X have published a report that posits that the number of rare diseases exceeds 10,000ⁱⁱ, suggesting a considerable amount of mis- and under-diagnosis. Approximately 80% of rare conditions have a genetic cause. Very few conditions are screened for currently, although projects like the 100,000 Genomes Project have been seeking to advance diagnosis for patients.

Most rare conditions begin to present symptoms in childhood, with a significant proportion of those conditions (more than 30%ⁱⁱⁱ) resulting in the death of a child before their fifth birthday. There are treatments for approximately 5% of rare conditions and access is defined by local arrangements.

Many rare diseases need high levels of health and social care interventions and can have a high impact on family life, including increased financial pressures and poor mental health^{iv vvi}
vii.

In many cases there may be biological (as well as psychological and social) drivers of emotional and behavioural symptoms. For example, there may be direct brain and behaviour interactions in relation to the genetic and neurodevelopmental under-pinning of rare diseases. Children with intellectual disability – which is common in the rare disease group - are also known to have greater need for help with emotional and behavioural symptoms and have higher rates of mental ill-health.

Having a family member with a rare condition can cause several social determinants of health inequalities, such as poverty, issues with employment, educational attainment, and housing^{viii}. It is the view of this collaboration that having a rare disease in a family is itself a health inequality, given the lack of services and understanding for these conditions. In terms of mental health provision for patients and families with rare conditions, it is clear that current mental health services are inadequate^{ixx}. This provision needs to be integrated into services for those with rare diseases.

It is to be noted that children with rare conditions have high rates of all the common child mental health disorders, and current evidence suggests that they respond just as well to the ordinary evidence-based treatments^{xi xii}, yet very rarely access them because of diagnostic over-shadowing.

How NHS rare services work

NHS services for rare conditions are not uniform in their delivery; for very rare conditions services may be nationally commissioned with very few specialist clinicians, other more common rare conditions may have local or regional specialist centres with expert clinicians.

These services tend to be focused on the physical health of the person with the condition. Spencer-Tansley reports that the majority of respondents disagreed with the statement: 'I feel my/my child's mental health is considered equally as important as my/my child's physical health by healthcare professionals involved in my/my child's care'^{xiii}. Equally, if the child is the patient they are seen by paediatric services who are not able to refer their parents for onward support.

The relationship between Genetic and Psychological Counselling

For clarity, there are distinctions to be made between genetic counselling and psychological counselling, albeit that there is an important and complimentary relationship between the two. Beyond this there is detection, diagnosis and treatment of more significant mental ill-health.

The role of genetic/genomic counselling is primarily to impart information to help individuals and families make informed choices based on the understanding of the implications of genetic testing^{xiv}. It is most usually focussed and short-term, often only two-three sessions. The role of psychological therapies is to help prevent and treat emotional difficulties including stress, anxiety and depression that may result from the complex and varied impact of a rare disease diagnosis over time. It may be short- or longer-term depending in resources and need.

It is not yet clear to this collaboration where (or whether) the proposed training for the new genomics counselling workforce will be integrated with the framework for psychological therapies within the NHS,^{xv} or where genetic/genomics counselling would sit within – or in relation to - the proposed SCopEd framework for training and accrediting counsellors and psychotherapists^{xvi}. Either way, it seems there is a growing need for input and dialogue between and within the psychological professions workforce and genomics counselling workforce. This is in order to establish clear pathways for emotional support for patients and families, for both professions to learn from each other, and to ensure the provision of 'the right support at the right time'. Given the proposed roll-out of increased genomics testing over the next few years, it is essential that the ongoing mental health implications of this are given due weight in service and workforce planning for both genomics counselling and psychological counselling.

We also wish to draw attention to the greater need for more liaison psychiatry (both adult and paediatric) to treat both more severe physical and psychological consequences, and for rare conditions which entail organic psychiatric symptoms.

Condition specific support group landscape and services

The UK is fortunate in that there is a well-established voluntary sector, which means that voluntary groups and charities can be formed to support those with rare conditions. It is estimated that there are 300 formal groups with additional informal groups through social

media^{xvii}. Some conditions do not have patient organisations but are a loose collective of affected individuals.

These groups can be wholly volunteer-led and run, or highly developed charities. It is important to recognize that each are expert in their own condition; it is not feasible for a group with a small patient population to grow to the size of a charity serving the general population, such as Cancer Research UK.

Patient groups and organisations can offer a wide range of services, including peer support, trained adviser support and advocacy, information materials, and opportunities to meet others in the same situation through virtual and in-person events. Some may offer specific services to siblings, bereaved parents jointly, or parents in peer groups.

These groups are funded in a variety of ways from public donations and fundraising, corporate support, and potentially contracts for supplying services. There is no set rule as to where funding is from, which can create sustainability issues. It is well recognised that patient organisations provide a considerable amount of mental wellbeing support that contributes significantly to the emotional wellbeing and support of those affected. However, the burden on untrained and often unsupported 'peer practitioners' should also be acknowledged.

Critical periods for mental health challenges in the lives of individuals and families affected by rare diseases

The experience of individuals and families can be divided into three time periods where mental health challenges may arise. These are:-

Adjustment. This refers to the period at the outset of the patient and family's journey when they become aware of the existence of an issue, are interacting with the health service in search of a diagnosis, receiving this and coming to terms with the implications. Previously held aspirations and expectations may well have to be radically revised in the light of changed circumstances. Affected individuals, partners, parents and other family members will be impacted. Increased rates of mental ill-health may be part of the rare disease itself. In addition, issues such as coping with uncertainty, stress, blame, recrimination and grief may arise for the affected individual and amongst the wider family as they face the loss of their imagined future and adjust to their new future. Some families experience being given the diagnosis as a traumatic event. Some individuals may become unwell with anxiety, depression or other difficulties, which may require assessment, diagnosis and treatment in their own right. Others may view themselves as strong people in a difficult situation who need guidance on matters such as carers' rights. For this group, services that are not clinical mental health support services are important in order for them to adjust.

Adaptation (Management/ 'Living with'): The goal is for individuals and families to reach a kind of equilibrium after the initial emotional impact of diagnosis, developing coping strategies and personal networks of support. This may involve a mixture of statutory, voluntary, and/or other informal inputs. Given resource constraints in the Health and Social Care sector, families undertake much of the support and care of the affected family member, and advocate on their behalf when the individual with the condition needs this. Even where services and support are available, patients and families have to face additional stressors associated with caring for a child with a rare condition, often resulting in depletion or leading to depression, anxiety, frustration, and sometimes relationship breakdown - all of which adversely impact on their mental wellbeing.

It is hard for patients and families to assess what information can be trusted, with some information found by researching themselves, sometimes by accessing services provided by patient organisations. This may in turn provoke anxieties around the future, or identity issues

in relation to the impact of the condition on themselves or their families^{xviii}. There is a level of stress caused by the lack of coordination of care for the person affected by the rare disease^{xix}.

Siblings of a person with a rare condition are also impacted by this experience. Sibs, the national charity for siblings of disabled children and adults, was created to address their specific issues, including mental health and wellbeing issues^{xx}.

Incident management: Any child can suffer from mental ill health, and the common disorders such as anxiety, depression, challenging behaviour are even more common in the rare-disease population. If such a mental health need arises, children need accessible and effective assessment and intervention. For some affected individuals, even where there is a support network in place there is the ever-present threat of a sudden crisis arising because of the inherent instability of the condition itself. Living with this uncertainty and fear can be extremely challenging to deal with. The ongoing threat of health crises/incidents can itself have long term or life-threatening consequences for the individual and their family and can cause chronic stress^{xxi}. In addition, how a crisis is dealt with may have significant psychological repercussions including remorse, guilt, blame and other distress including post-traumatic stress.

Impact of Covid

While patients with rare conditions and their families face mental health issues in non-pandemic times, Covid and the lockdowns have exacerbated these issues.

A coalition of organisations came together to research the impact of the pandemic on the rare disease community and published a report 'Making the Unseen Seen' in May 2021^{xxii}. It found that members of the rare disease community felt lonelier and more isolated than before the pandemic and carried a psychological burden from being at a perceived higher risk of mortality should they become ill, as well as being concerned about the level of care they might receive^{xxiii xxiv}. Parents felt the mental health impact of additional caring responsibilities when access to external care services such as schools, respite care, or carer support were curtailed. The report also notes that the general reduction in health and social care services for those with rare disease led to a direct increase in demand on patient organisations, which as shown above, differ in size and resilience, and may be run by those facing their own caring issues during the pandemic. Patient organisations additionally faced funding issues as many small, rare condition-specific support groups rely on community fundraising, opportunities for which were extremely limited during the pandemic.

Sibs conducted a survey of parents at various points during the pandemic with the last report 'Lonely Lockdown for Siblings' showing that 81% of parents reported that the mental health of siblings had worsened, and that 43% of siblings were providing more care in lockdown^{xxv}. While the survey was for parents of a child with any form of disability, not purely stemming from a rare disease, it is a reasonable extrapolation to assume that this could be applied to the siblings of children or adults with rare conditions that cause disabilities within their family.

Adult siblings reported depression, increased anxiety, and fears about their social relationships and job situations^{xxvi}.

While many have or are returning to 'normal life', for those with rare conditions and their families – some of whom are reluctant to abandon precautions - the pandemic will have a long tail and its impact will be felt for some time to come.

The length of time to achieve a diagnosis for rare conditions is known to have a negative impact on mental health (for example Myeloma UK's report^{xxvii}). It would be common sense to extrapolate that Covid-caused delays to diagnosis would exacerbate that impact.

Experience of mental health services

There is a lack of access to mental health services for adults, children and siblings (child and adult) who are affected by rare diseases. In most cases needs can be managed by generic mental health services, with support as needed from specialist clinical teams. In addition, there is a lack of a whole family approach, and not extended family services, i.e. including aunts, uncles, grandparents, which are especially important for rare diseases that are genetic in causation. Third sector patient organisations dealing with genetic conditions often adopt a whole extended family approach, sometimes offering specific services to sub-groups according to family relationship.

Patients and families report an inability to access mental health services as and when needed^{xxviii}, which includes prior to diagnosis or without diagnosis. Rare diseases have a different trajectory to other conditions; diagnosis of co-existing mental health needs may take many years and patients may encounter misdiagnosis; there may not be a treatment for the condition to ameliorate symptoms and some conditions are life-limiting. Patients and families might cope at points and then be unable to do so. It may be unhelpful for patients and families to wait for referral to general mental health services, and mental health care would ideally be integrated within rare-disease services.

As noted above, for parents who are caring for children affected by rare diseases there is no straightforward referral pathway. Paediatricians are not qualified to care for adults but can facilitate onward referrals. They can be instrumental in signposting and should have access to knowledge of adult services.

Mental health clinicians are not routinely included in the multi-disciplinary teams created around a rare disease patient. This would help to normalise mental health aspects around rare disease care and allow mental health needs to be considered from the outset.

In addition, despite recent strides around mental health generally, stigma remains about mental health in society. Parents report being afraid to show 'weakness' in case this triggers intervention by statutory services, particularly as parents of children with rare diseases are frequently not believed about their child's condition and a rare disease/condition diagnosis can take time to be established^{xxix}. This, in itself, can place considerable emotional burden upon individuals, couples and families. Trust in healthcare professionals (including mental healthcare) may therefore be low as a result.

Healthcare professionals often refer patients and families to condition-specific support groups that are charities. As noted above, there is a huge variety in size of organisation and the services each offer. Some have been professionalised, others are purely volunteer-led and run. Healthcare professionals frequently do not know what is offered by whom or if there is a group available for the specific condition. It would be beneficial if there was wider routine use by healthcare professionals of resources such as Orphanet^{xxx} and other databases to research and signpost to patient organisations. There is usually no feedback loop to NHS services and the healthcare professionals who referred the individual.

Moreover, condition-specific support groups can be overwhelming for parents in the early years after diagnosis as they frequently find it hard to see people further along developmentally and/or may not feel able to cope with the reality of the future.

Parents caring for children may not be able to attend services due to lack of time^{xxxi} and, where there is no provision of care for the child of the requisite level and specialism (some need very specialised care). Some parent carers report, informally, that telecare also brings challenges.

Good service examples

The consultation asks for examples of good mental health services. The following are case studies of services that make a difference to patients and families affected by rare conditions.

Cambridge Children's Hospital

The Cambridge Children's Hospital is being created to treat the 'whole child' with physical and mental health in total parity of esteem. The aim is to be "...a hospital built with children at its heart." As well as combining access to physical and mental services in the same place, the Hospital will use latest technologies such as genomic medicines and telemedicine.

The physical and mental health wards will sit alongside 'universal' beds. The staff will be dual trained to remove the artificial distinctions between mental and physical health and will be able to work across all settings.

A whole family approach is employed so as to ensure their ability to maintain their capacity to care for their child.

Referrals for either child or parent are made post-discharge with clear feedback mechanisms to and through the Hospital to other services and, if needed, NHS Trusts.

The importance of rare diseases in paediatric medicine is recognised.

It is a partnership between Cambridge University Hospitals, the University of Cambridge and the Cambridgeshire and Peterborough NHS Foundation Trust.

<https://www.cambridgechildrens.org.uk/>

RareMinds CIC

RareMinds is a third sector organisation that provides professional counselling services for those affected by rare conditions, and support patient organisations that work with condition-specific communities. They have developed the first Continuing Professional Development (CPD) programme for counsellors, psychotherapists and psychologists on 'Counselling for Rare Conditions.'

As part of improving the quality of services delivered by patient organisation, Rareminds has been working with Genetic Alliance UK to provide 12-week programmes to support and train support workers and community leaders. They are also about to launch a series of workshops with Beacon on the 'Psychological Impact of working with Rare, Genetic and Undiagnosed conditions in your Patient Community' and 'Supporting those in Emotional Distress' to build capacity and resilience within the rare disease support community. They are also working in partnership with Medisc4RareDisaeses to develop a training module for medics and allied healthcare professionals on 'Rare Disease and Mental Health'.

<https://www.rareminds.org/>

Mental Health Drop-in at Paediatric Hospital

A pilot Mental Health Drop-in was held at a major paediatric hospital and a subsequent research paper published reporting the outcomes for parents and how this impacts on outcomes for their children. This was focussed on chronic conditions, rather than rare disease, although the findings could be applicable to the rare disease community.

The Mental Health Drop-in was held in the paediatric hospital to remove multiple barriers to accessing mental health services, such as time and cost. The Drop-in was for parents of, and children with chronic conditions and their siblings. Being placed in a setting already being visited for the physical needs of their child removes some of those issues and the whole family approach meant that those family members who needed mental health interventions could at the time that they needed them.

Children (patients or siblings) were offered self-help materials or online resources, further assessments, signposting to internal or external services or a brief psychological intervention.

Parents were offered self-help materials or online resources, or signposting or referral to internal or external services, such as IAPT.

While limited in timeframe and a relatively small-scale pilot, the Mental Health Drop-in was shown to have provided 'cost effective, acceptable interventions' that 'increase access and facilitate early intervention with benefits for the parent and the child.'

What we would like to see offered

The vision for mental health services for those affected by rare diseases and their families is a family-centred care approach, consisting of a network of support including peer support, patient organisations, and a range of professional mental health support provided by counsellors/psychologists/psychotherapists/psychiatrists, with referrals by genetic counsellors and other professionals in the healthcare system around the patient and their family. We believe this should include not just the affected individual but – due to the care burden on carers and families, and the genetic component of many rare diseases – include support for carers/partners, parents, siblings and extended family.

We believe mental health is everyone's responsibility. Therefore, all health care professionals involved in caring for families and individuals experiencing rare or genetic conditions and those without a diagnosis should receive training in acknowledging, recognising, and addressing mental health aspects. Pragmatically, specialist rare disease mental health provision will involve the statutory and third sector working together to provide the breadth and range of provision needed.

Services should be fundamentally patient/family-centred and accessible at the point of need. A whole family, cross-disciplinary approach is needed: rare disease healthcare professionals should be able to make referrals for family members as well as patients irrespective of the age at which a diagnosis is received. While this is especially important when the patient is a child and the mental health of their parents has a direct impact on the child's health outcomes, it is important not to negate or ignore the importance of a whole family approach for adult patients. The Rare Diseases Framework UK^{xxxii} commits to aligning with other policy areas that affect the rare disease community, including policies relating to mental health; this is the opportunity to ensure that this alignment occurs.

Recommendations

The following recommendations are made with recognition of the devolved health systems in the home nations of the UK. The recommendations would require steps to implement them in each country taking into account those differences. They are listed under headings reflecting the questions in the consultation where possible.

General

- Emotional wellbeing and mental health needs assessments to be routinely integrated into ongoing care for rare disease patients and families
- A range of outpatient services should be available to families to access at the point of need according to their needs and wishes, to provide a 'safety net' of support (e.g. one size does not fit all, Peer Support (on and off line); Psychoeducational Resources; professional psychotherapeutic counselling for Couples and Individuals (including siblings and extended family members); Family Therapy; psychological interventions e.g. Cognitive Behaviour Therapy for pain management/ fatigue, behavioural issues; genetic counselling.
- Mental health provision should be included in service specifications for those with rare diseases, especially those services commissioned nationally and through the Highly Specialised Technology process that is the means to approve funding of innovative drugs.
- Need for mental health provision to be culturally specific, and also sensitive to the needs of groups such as LGBTIQ+ communities, both of which can be additionally marginalised.

Prevention

- Additional pressures should be alleviated and removed from the lives of families affected by rare diseases as much as possible. This includes the coordination of care to remove unnecessary stress, for example, through the provision of rare disease nurses.

Early Intervention

- Training for educational psychologists in understanding the support needs of children with rare conditions is needed, and for more liaison with psychiatrists given the cognitive and biological drivers of mood and behaviours that can exist with some rare conditions.

Improving quality and effectiveness

- A mental health professional to be included as part of the multi-disciplinary team to support both decision-making and be available to patients and families impacted by rare conditions as necessary.
- Upskilling nurses and doctors to recognize symptoms of mental health conditions for specialist referral.
- There is a need for educating healthcare professionals and others who support those affected by rare conditions in the roles and responsibilities of genetic and psychological counselling to ensure that patients and their families receive the help they need promptly.

- The right intervention at the right time can be transformative. When signposting to other services, care should be taken in signposting to the right organisation first time to avoid additional distress and due governance arrangements need to be in place. When healthcare professionals refer to third sector organisations they should be treated as partners in that individuals care and a means of working together to share information created.
- Many small rare disease groups are led by untrained, front line support workers and charity leads with limited support; many deal with a significant degree of patient and family distress, sometimes at the same time as managing and processing their own experience of rare disease. Investment in this part of the mental health and wellbeing ecosystem is needed to improve quality and sustainability.
- Child and Adolescent Mental Health Services may need support from specialist centres so that the presence of a rare condition does not over-shadow the need to treat – in the ordinary way – for example attention deficit hyperactivity disorder (ADHD) or anxiety.
- Recognition and education that neurodevelopmental conditions such as ADHD, autism spectrum disorder, intellectual disabilities (global and specific) are all over-represented in rare and genetic conditions. These need timely assessment, detection/diagnosis, and intervention.
- The common child mental health problems such as anxiety, depression, challenging behaviour are all more common in chronic conditions/rare conditions. There is no evidence that they do not respond to the ordinary evidence-based interventions, and these should be offered to children and families.

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