EB Expert Panel Workshop Report

20th April 2024
Grand Canal Hotel
Dublin

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About Debra

We are Debra, the butterfly skin charity.

We might be a small charity, but make no mistake, our mission and our ambitions are colossal. We are here to tell Ireland and the world beyond about Epidermolysis Bullosa (EB) - a painful and distressing genetic disorder that affects the body's largest organ; the skin.

We are here to be a positive force for all those living with EB and all those whose lives have been impacted by EB. Our key working areas include EB Support, Advocacy and Research. We are here to help in all kinds of every day ways, to listen, support, empower and alleviate unimaginable pressures. We are here to lobby those in the halls of power. To command attention, demand and drive research and ensure imperative progress is made.

But above all, we are here to bring hope - not that passive, powerless, resigned kind of hope - but the active bold hope that moves things on.

Uniting for change for everyone with skin as fragile as a butterfly wing.

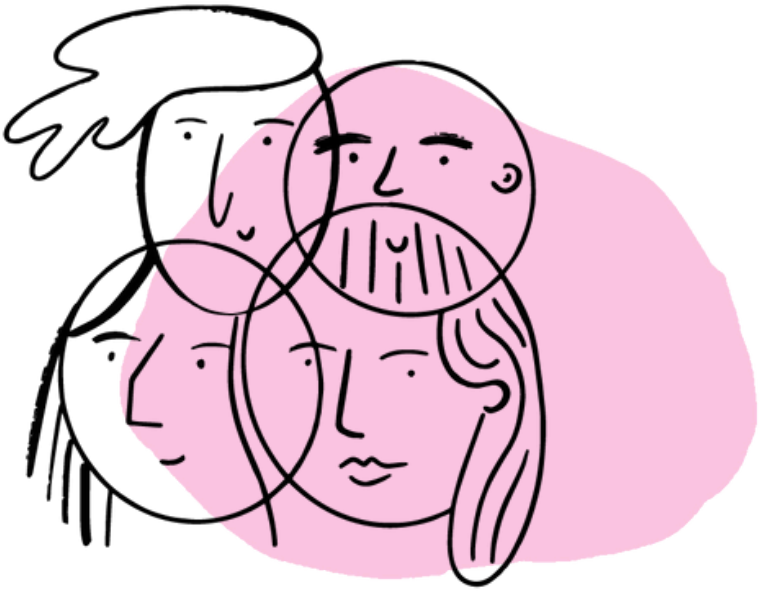
About the EB Expert Panel

We know that there is power in numbers. The more voices we have the stronger our work will be. In November 2022, we launched our EB Expert Panel, a group of those who understand EB the most and are willing to use their experience to shape our work.

The panel advise us on various topics related to what living with EB in Ireland is like now and what it should look like in the future. With their help, we can make sure we can provide support in the way that matters to them. As valued advisors, members of the EB Expert Panel provide advice to our Research, Advocacy and Family Support teams on projects they are working on.

The panel meets as a group twice a year. In between meetings, participants stay connected with Debra through one-on-one conversations with our team, when their advice is needed.

We would like to sincerely thank all members of the EB Expert Panel for their valued contribution to our work. We look forward to working with you further.



Opening Remarks

Sarah Mullins - Research Officer

Sarah opened the workshop by introducing herself and other members of the Debra team who would be managing the EB Expert Panel and facilitating the workshop; Kate Gibney, Eve O'Donnell, Sinéad Hickey, Rebecca Jackson, Marina Shatskikh and Ahmed Abdelghany.

She thanked those attending for giving up their Saturday in order to make a difference to the work carried out by Debra.

For any new members of the panel, she explained the purpose of the EB Expert Panel and how they can help the Debra team. She then went on to remind the panel that they meet for a workshop twice a year to discuss bigger topics as a group, with individual panel members being contacted directly on an ad-hoc basis in between workshops for smaller tasks.

All members of the panel are offered payment for tasks they complete, including workshop attendance, with payment levels based on the time and effort it takes to complete a task. Sarah thanked those who had returned after attending the workshop before and welcomed those who were attending their first workshop on the day.

After her opening remarks, Sarah went over some house rules for the workshop and asked everyone to introduce themselves during a short icebreaker activity. She then gave a short update on research work which has been undertaken since the last meeting. Sarah then handed over to Rebecca, who was presenting on behalf the of Research, Policy and Advocacy team.

Advocacy

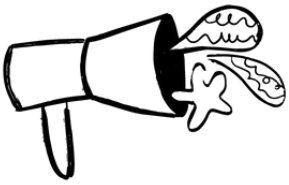
Rebecca Jackson - Policy Officer

Rebecca began by introducing herself to the panel as Debra's new Policy Officer. She then went on to give a brief introduction to advocacy, providing an overview of Debra's focus when it comes to local, national, and international advocacy. She asked the group to reflect on whether these priorities were still important to them or if there were any gaps or unaddressed needs that we needed to consider.

The panel then split up into their discussion tables, with each table representing a specific EB subtype so they could focus on advocacy asks that were important to their specific needs. The objective of the task was to assess if Debra's advocacy priorities sufficiently aligned with the EB Expert Panel's advocacy priorities. This allowed the Advocacy team to assess and fill any gaps, and to encourage more effective advocacy PPI participation in the group going forward. Several questions were outlined to guide the conversation, and participants were encouraged to answer the questions directly as much as possible. The aim of the discussion was to gather supplementary information to underpin the need for information to support advocacy asks and check in on what our panel thought our advocacy priorities should be.

Below are the summarised findings from the four discussion groups, with two representing EB Simplex and two representing Dystrophic EB and Junctional EB.

Advocacy



EB Simplex - Summary of Advocacy Priorities

Cost of EB:

- Dressings and comfortable shoes are expensive, posing financial challenges.
- Participants face expenses for medications, dressings, and specialized products, impacting their daily lives significantly.
- Need for government support for essential items and improved accessibility, especially in rural areas.

Access to Medications and Dressings:

- Access to bandages and medications can be problematic, especially regarding availability and affordability.

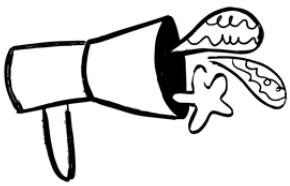
EB Awareness:

- Advocacy should focus on raising awareness among clinicians, providing practical support for essentials, and advocating for more lenient policies in schools regarding uniforms for those impacted by EB.
- “Invisability” of EBS seen as an issue and the public only associating EB with more visible subtypes. Education on differences is needed and unique challenges of each subtype.

Transportation Issues:

- Transportation poses challenges, requiring specific accommodations such as priority seating on buses and travel passes.

Advocacy



Dystrophic and Junctional EB - Summary of Advocacy Priorities

Support in the Home:

- High turnover of staff and lack of coordination among different agencies providing home care pose challenges.

Access to Medications and Dressings:

- Access to medications and bandages is problematic, especially in rural areas, requiring better coordination and support systems.
- Improved access to healthcare services needed also.

Emerging Treatments:

- Discussion centered on emerging treatments, highlighting the potential benefits for improving quality of life for EB patients and their families. These will need to be advocated for when available.

Care and Support:

- Participants emphasize the need for better respite care and support for integration into society.
- Support needed for independent living if the individual chooses to do so.

EB Awareness:

- Advocacy should focus on education about EB amongst healthcare professionals and healthcare system as a whole. Felt more support could be given to those living with EB in areas such as nutrition and physiotherapy for example.

Advocacy task conclusion

Overall, the discussions highlighted the financial, logistical, and emotional challenges faced by EB patients and their families, emphasizing the need for improved support systems and advocacy efforts to address these issues effectively. The EB Expert Panel were also asked how they would prefer to participate in advocacy tasks within Debra. All panel members agreed that in person meetings were the best format for these types of discussions, with one-to-one phone calls preferred when asking questions about very personal topics. They advised it was best to avoid Zoom/online meetings and to use surveys minimally for data collection.

Rebecca closed the discussion, thanking the panel for participating. She explained that the gaps they identified will be fed into the development of future campaigns. She also explained that there will be more opportunities for people to participate in advocacy-based projects going forward, including the EB Butterfly Review.

Family Support

Eve O'Donnell - EB Support

Eve began by giving an update on the Family Support Service Review, which EB Experts gave feedback for at the October 2023 panel meeting. Eve explained a report of this review is currently in publication and will soon be presented to the board. This report will give us invaluable insight on how we use our resources and deliver services while identifying any unmet needs and areas for improvement.

Eve also gave an update on the EB Medical Alert Card which is now available for anyone who would like to apply for one via the Family Support Team. The EB Expert Panel played a pivotal role in highlighting the need for an EB medical alert card and also in the co-design of the card at a previous workshop. The EB Experts were able to see a prototype of the card on the day and feedback received was fantastic.

Finally, Eve spoke about the success of the personalised storybooks designed to help children with EB transition into primary school. Eve explained the team's focus was now on teenagers with EB who are starting secondary school. With that in mind, the task for the EB Experts was to come up with challenges and potential solutions for teenagers starting secondary school. The Family Support Team would then aim to use this feedback to build on a resource pack for teenagers by September 2025 while gathering additional information for the upcoming online hub.

Family Support

Summary of Challenges faced by Teenagers with EB Transitioning from Primary to Secondary School

1. Fashion and Uniforms

- Shoes: Difficult to find suitable, fashionable, and comfortable shoes for both school and sports. Girls have more options than boys.
- Socks & Underwear: Finding suitable ones that do not irritate the skin is challenging, especially with uniform requirements.
- Uniform Restrictions: Dress codes often do not accommodate the needs of EB students, affecting items like shoes

2. Physical Barriers

- Heavy Backpacks: Carrying heavy backpacks can cause blisters due to shoulder straps.
- Locker Access: Lockers are far away from class or issues with accessing bottom lockers due to the need to kneel, which can cause blisters.
- Mobility: Moving between classes in large schools can be difficult due to blisters, pain and risk of students knocking off them.
- Curriculum restrictions: Some subjects can include compulsory field trips with walking which can exacerbate symptoms.
- Heat in the classrooms can worsen symptoms. Students can find it difficult for teachers to allow them leave for break.

3. Physical Activity

- Fear of Injury: Teens with EB are often afraid to participate in sports due to the risk of injury.
- PE Challenges: PE teachers often lack education about EB, leading to inappropriate demands or punishment for non-participation.

Family Support

Summary of Challenges faced by Teenagers with EB Transitioning from Primary to Secondary School

4. Financial Burdens

- Increased Costs: Higher expenses for suitable shoes, transport, and other necessities due to EB.

4. Lack of Awareness and Understanding

- Teacher Awareness: Many teachers, especially in PE, lack awareness and understanding of EB and its impact. Problem with teachers forgetting even after parents discuss EB several times.
- General Misconceptions: Misunderstandings about the nature of EB. For RDEB, it is assumed that they have burns, eczema or it's contagious. For EBS, assumptions are made that it's similar to RDEB or that it's "just blisters".
- Homework and Attendance: Lack of understanding regarding missed school/homework due to symptoms of EB and the time needed for treatment/recovery e.g. bandage changes.

5. Social Exclusion

- Reluctance to Participate: Teens with EB are often reluctant to try new activities due to fear of exacerbating their condition.
- Part-time Work: Limited options for part-time jobs.
- Beauty Trends: Teenage girls feel excluded from participating in beauty trends like getting lashes and nails done.
- Transportation: Inadequate transport options for socialising with friends.
- Exclusion from extra curricular activities: Students can miss out on school trips/holiday as walking and heat can be an issue.
- Peer Exclusion: Being excluded by peers for being different or not participating in activities.

Family Support

Summary of Challenges faced by Teenagers with EB Transitioning from Primary to Secondary School

7. Emotional and Psychological Challenges

- Emotional Strain: Feeling embarrassed, different, and isolated can lead to emotional distress.
- Self Confidence: Self image can be affected which can cause struggles with dating.
- Family Impact: Siblings and parents also face emotional and psychological challenges, needing support and breaks.
- Peer Support: Positive experiences from peer support groups and events organised by Debra.

8. Practical Support

- Educational Support: Lack of awareness of entitlements like laptops, exam support, and special exam locations.
- SNA Support: Mixed experiences with SNAs, ranging from being too careful to not careful enough.
- Teacher Training: Need for comprehensive training for teachers and SNAs on the specific needs of students with EB.

Family Support

Summary of Solutions for these Challenges

1. Practical Solutions

- **Uniforms and Aids**:
  - Flexible uniform policies with comfortable options like tracksuits.
  - Use of lightweight backpacks or rolling bags.
  - Assign accessible lockers and provide books at desks.
  - Laptops for note-taking and assignments.
  - Passes to leave class early or when too hot.
  - Use of scooters on field trips.
  - Adapted PE programs with safe exercises or study sessions.

2. Emotional and Psychological Support

- **Counselling and Guidance**:
  - Regular check-ins from guidance counsellors or SNAs.
  - Access to psychological support and the Debra counselling grant.
  - Building resilience and coping strategies for bullying and challenges.
- **Peer and Family Support**:
  - Peer mentorship programs pairing older and younger students with EB.
  - Family engagement initiatives to prepare for the transition and support siblings.

3. Social Inclusion

- **Buddy Systems and Peer Support:**
  - Implement buddy systems to pair students with EB with supportive friends.
  - Inclusive social activities with necessary accommodations.
  - School-based support groups for sharing experiences.
- **Community Building:**
  - Organize inclusive events tailored to EB needs.
  - Ensure participation in school trips with accommodations.

Family Support

Summary of Solutions for these Challenges

4. Awareness and Education

- **Teacher and Staff Training:**
  - Comprehensive training on EB for teachers and staff.
  - Awareness campaigns using resources like medical info cards and leaflets but being mindful not to make student stand out or feel different.
  - Debra representatives to educate school communities.
- **Awareness Initiatives:.**
  - Partner with local sports organizations for EB-suitable programs.
- **Practical Information:**
  - Discreetly identify students with EB in staff rooms.
  - Inform teachers about EB before the student transitions.
- **Student education:**
  - Teach the student with EB how to advocate for themselves.
  - Provide guidance on they can prepare themselves before school e.g. what they want to say/not want to say.
  - Scripts or guides on how to explain their condition.

5. Financial and Resource Support

- **Financial Assistance:**
  - Provide financial support for medical and school supplies.
  - Access to government grants or funding for additional EB costs.
  - Advocacy for free education and automatic resource provision.
- **Resource Allocation:**
  - Ensure access to technology aids like laptops.
  - Extra classes or tutoring to help students keep up academically

.

Closing Remarks

Sarah Mullins - Research Officer

Sarah thanked everyone for attending the fourth workshop and said she hoped they enjoyed themselves and that they would continue to engage with the team as EB Experts. She then explained the plan going forward is to hold another workshop in September/October this year, and to approach the panellists individually for smaller tasks between workshops. The frequency of individual tasks will depend on the Debra team's needs as well as on the availability of the EB Experts. Most of these sort of tasks should not take up a lot of time and the majority of them will be remote and will not require travel.

All input provided will be invaluable to the team so Sarah emphasised how grateful the Advocacy, Family Support and Research teams are for everyone's participation. She also reminded the panel that being an EB Expert did not mean they have to say yes to every opportunity that arises and that the Debra team totally understand if they cannot participate in everything that is asked of them. She reminded the panel that for anything they do say 'yes' to, they will be fully supported by a member of the Debra team.

Sarah then asked members to fill out a feedback form related to the workshop, which will allow the team to make improvements to these events going forward.

Further Information

For further information on the EB Expert Panel or any information within this report, please contact Sarah:

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EB expert workshop report
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Charity regulator number: 20021726
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