

Breaking Down Barriers

Findings from the BDB Interim Evaluation (2017)

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The Sylvia Adams Charitable Trust



Alström Syndrome UK
Strength for today, hope for the future

Why do an interim evaluation?

- To review progress to date
- To highlight areas of strength/areas for improvement
- To get an early insight into the extent of outcomes achieved
- To inform planning for the next year of BDB
- To highlight any unintended/additional outcomes of the work
- To assess the experience of BDB member organisations and how that can be improved
- To highlight issues/gaps around monitoring and data collection

What did we look at?

- Grant monitoring form
- Participation form
- Session/workshop feedback forms
- Anecdotal feedback collected over the course of the project
- Observations from Kerry, Oscar and the BDB Advisory Group

The BDB Outcomes

1. Increased participation in genetic counselling and increased diagnosis
2. Families will report that they feel better supported
3. Educated patient groups who can manage their disease more effectively and lead a better quality of life
4. Empowered patient groups who know of the reproductive options available to them and the consequence of carrier status
5. Advocacy services for those people who are not able to express their needs directly
6. Support services available to the whole family

The BDB Outcomes (*continued*)

7. Improved general awareness of genetic conditions (e.g. Amongst the general public, people from minority communities, people in your organisation, policy makers, etc)
8. Comprehensive guidelines produced to help break down the barriers experienced by families which can be used throughout a range of different services
9. Increased awareness of cultural issues amongst patient organisations, support groups and medical professionals
10. Patient organisations and support groups will feel better equipped to support diverse communities
11. Services and current practices will improve and become fully integrated and inclusive
12. Patient Organisations and Support Groups will evolve and become more inclusive and diverse

Impact of the BDB grant: Self-reporting

We asked member organisations to self-report on the impact of BDB funding:

‘To what extent has the first year of funding enabled you to achieve the 12 BDB outcomes?’

All achieved an average (mean) score equating to between ‘somewhat’ and ‘very much’.

Highest scoring outcomes	Lowest scoring outcomes
<ul style="list-style-type: none"> • Educated patient groups who can manage their disease more effectively and lead a better quality of life. • Improved general awareness of genetic conditions (e.g. Amongst the general public, people from minority communities, people in your organisation, policy makers, etc). 	<ul style="list-style-type: none"> • Advocacy services for those people who are not able to express their needs directly. • Comprehensive guidelines produced to help break down the barriers experienced by families which can be used throughout a range of different services.

Impact of capacity building: Self-reporting

We asked member organisations to self-report on the impact of ‘taking part in BDB’:

This relates more to BDB outcomes 7-12. All scored between ‘somewhat’ and ‘very much’.

Highest scoring outcomes	Lowest scoring outcomes
<ul style="list-style-type: none"> • Services and current practices will improve and become fully integrated and inclusive. • Patient Organisations and Support Groups will evolve and become more inclusive and diverse. 	<ul style="list-style-type: none"> • Comprehensive guidelines produced to help break down the barriers experienced by families which can be used throughout a range of different services. • Patient organisations and support groups feel better equipped to support diverse communities.

“Sharing information & experiences helps us become more aware and sensitive to cultural needs. It also provides opportunity to discuss how to overcome difficulties.”

Summary: Key learning points for members

- Have needed to revisit the materials and information they are providing before they can move on to new areas of work.
- Have needed to look at the demographics of the people they support (and the data collected when members join) to understand their communities, identify areas of need and plan services/approaches to engagement.
- Developing an information leaflet is extremely complex. Many have needed to revisit and reproduce, and consider the technicalities of producing a good quality leaflet.
- Translating materials is useful in some situations but it is not necessary/effective to translate all information into different languages.
- Translating medical information is complex and translators need a good understanding of the language, medical terminology and the specific medical condition.

Summary: Key learning points (*continued*)

- Verifying translations is difficult, often relying on family members to review the information.
- It is often the case that there is no word in another language to translate into, for example, there is no word for 'gene' in Urdu.
- Consultation is vitally important when developing resources, but it can be very time consuming.
- Many of the BDB member organisations are 'user-led' –i.e. people affected by the condition- this can help to build trust and engagement with families. It can also make the work challenging.
- Face-to-face contact is often easier for those representing ultra-rare conditions as they often do not have the same capacity issues and can form relationships with families.
- Delivering fun, engaging activities as a starting point can then lead to more in-depth conversations and the sharing of health and genetic information.
- Consanguinity was not specifically addressed by any member organisation in the first year.

Summary: Issues with process

- Different timelines for organisations that joined BDB late – less efficient in terms of managing funding, monitoring and evaluation.
- Work being funded in year 1 not completed by the end of the year – organisations overly ambitious in their action plans? Unforeseen difficulties already covered? Other factors...
- Plans for monitoring against year 1 grants not actioned – e.g. impact surveys
- No fixed guidance on applying for funding/completing the action plan – possibly challenging for organisations joining BDB late?
- Evidence of impact duplicated across several forms – responses to online participation forms often covered the impact of the funding