



**Feedback for DSDnet website
DSDnet workshop for individuals with DSD and their parents.
October 2016, Bologna**

In line with the objectives of Working Group 4 of the COST Action DSDnet, we formed a focus group led by a parent, who is a member of a national support group in the UK, to help formulate and facilitate a workshop to understand the experiences and needs of parents of a child with DSD or individuals with DSD who were either active health care users or active DSD support groups members. The group comprised of a range of people from different European countries. All had different backgrounds, experiences and journeys to share. The focus group believed that building collaboration between individuals with DSD and clinicians who provide care could be an approach towards narrowing the gap between what is considered important by individuals and communities and health providers. We recognise that the language we use can be difficult but in light of the growing choice of terms and the medical communities dialogue we will use DSD as an inclusive term for sex variation, intersex, differences in sex development being cognizant we do not wish to cause any distress to individual with DSD.

Both individual with DSD and parents were, in the most part, invited to attend by a clinician with whom they had shared a clinical experience and had known for some time. The workshop had taken twelve months to plan and was funded by DSDnet. The event ran over the course of an evening and the following day; this provided an opportunity for people to get to know each other and for the barriers between clinicians and individual with DSD to be challenged.

Three professionals who had been in regular contact during the planning phase supported their small groups during the course of the workshop with the event being facilitated by a parent. The group's explored experiences of childhood, youth and adulthood together, agreed feedback was shared with the wider group. A limited number of clinicians were included in the wider group and once the small groups gave permission were able to join these conversations. As part of the breakout session four clinicians presented key areas that focused on future DSD work in the areas of rare



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conditions, information needs, research direction and priorities, consent complexities and the role of the I-DSD and I-CAH registries.

Summative feedback from the small groups highlighted the need and value when individual with DSD, parents and clinicians worked in partnership. Significant topics focused on the importance of individuals with DSD and their families having access to services that provided knowledgeable clinicians, who could communicate clearly with them and other clinicians as well as provide guidance on how individuals with DSD can communicate DSD within their own social networks. The role support groups played in peoples' lives is considerable and clinicians working in this area need to be mindful that they repeatedly provide individuals with DSD with connections to groups either locally, nationally or internationally. The language and terminology around DSD continues to be emotive for individuals with DSD and this needs to be heard by the professional community in respectful and thoughtful ways.

The workshop evaluated well and a summative paper is being completed for publication. Furthermore, the workshop was successful in meeting its primary aim, to bring together a group with a shared interest. Additionally, individuals with DSD and parents led the dialogue providing clinicians with an opportunity to better understanding the influences and impact such rare conditions have in people's lives, communities and wider social discourse. The capacity to replicate the workshop at a local level is an important output from our event. In asking people to come together there was a strong belief that in the future clinicians should ask individuals with DSD and their parents locally to come together to inform practice. Such partnerships could facilitate local change in practice as well as build stronger working relationships with support groups. Together there is the opportunity to explore the wider social mandate, drive research and for individuals with DSD to lead initiatives in the future.