>> Good morning, members of the Committee. You are welcome to this side event organized by agenciess. The office of the high commissioner for human rights but I miss someone, appall Jesus. This is about Arttle, 19, the right to independent living and be included in the community. Victoria, you have the floor.

>> Victoria: Thank you. Good morning, everyone. We have very happy you could join us. On behalf of the FRA, and the Office of the High Commissioner for Human Rights we welcome you. We have captioning but don't know how to hook it up. I have the honor of moderating today's side event. I am Victoria Lee. I am going to give a brief introduction in the subject. Drafting a general comment on article 19 we wanted to share with you some developments which could help you in the process for your consideration. The FRA is currently undertaking concrete work on establishing indicators with respect to article 19 and Martha Stickings will present on and give an overview of that. Nadia Hadad, board member of European Disability Forum, give will examples of how such a tool advances claiming and advocating for the rights in practice. Before we go into the that, I wanted to back up a little bit talk about why it is useful, why indicators and what is the role of indicators. We have been very privy to the wave of discussions about indicators in the context of the SDG but just to back up a little bit further that human rights instruments have been using indicators since their inception. Monitoring any human rights implementation of any human rights treaty requires seeking information, data, clues about the state and clues about the practical enjoyment and exercise of those rights by the right's holders. So indicators are simply elements that show and reflect what is the current situation. It is a way of measuring and seeing how much, how many, and to what extent. So we are talking about human rights indicators we are reflecting on how much and to what extent particularly human rights norms are being respected or not. So, for example, when we think about the right to education very broadly, indicators we take into account are rates of enrollment in school, completion of schooling, literacy rates to help us understand to what extent the right to education is being realized.

All of this very much assumes he have data available in order to generate the indicators. As you know, and highlighted in the dialogues, the main barrier is the lack or absence of data disaggregated by disability. If we are looking at school enrollment and literacy, if we don't have concrete data with how that reflects with children with disabilities, it is difficult to know what extent the state is realizing that right. And similarly, when we don't know exactly how many girls or children with indigenous backgrounds are going to school it infringes on the respect and protection of their rights.

So, it is not only useful for treaty bodies and human rights mechanisms to have indicators but first and foremost for states so they can measure what policies are being followed through, how they are targeting specific populations and, of course, for a civil society in order to hold the states accountable.

So, in the Office of the High Commissioner for Human Rights we have developed a method on human rights indicators and categorized them into three types. The first is structural, then process, and then outcome. We don't have to retain this jargon but we are basically trying to measure, firstly, the commitments the states have made, secondly, the efforts they are undertaking to fulfill those commitments and thirdly, to know what is the results; how are rights holders exercising those rights in practice? This is basically what you are doing in your everyday work speaking to states, finding out what laws and policies they have adopted, how those laws and policies are being fulfilled in practice, what budget is being allocated and to double check the information in the briefings with D PO and finding out whether the policies and institutionalal framework exists and asking them how are your rights being realized and how are you exercising those rights.

So, there is a discussion about the global indicators which represident-elect human rights norms in a general, broad way and we know we need bring it home and have indicators that are nationally specific and this is what you are doing in your work with the states catering the convention to those -- tailoring -- your questions to the concrete, everyday situations be it socio economic retallies or cultural differences when you are speaking with those states. In the work at the office, we are actually engaging in a project which is jointly being under taken with the European Union on developing human right indicators for the convention and on that bases we will be developing SDG policy guidelines for SDGs implementation. We want to make sure the implementation of SDGs is being informed and guided and by developing these tools we are trying to make it easy for policymakers to make that link so when they are engaging in policy, formulateing policy measures for SDGs it is serving to fulfill the convention also. At the same time, we are developing guidelines on data sources so to point out what surveys exist, disability specific and also not, where those policymakers can find the information to popuilate the indicator s that will be developed. Our whole basis will be the convention and the Committee's juris prudence. Our hope is in a few years we are all using the same basis, the Committee's own interpretation of the convention, to really promote compliance in all policy measures when it comes to persons with disabilities. We will be reaching out to the Committee and others in this work and we want to make sure that these tools are owned by the Committee and everyone is engaged to use them. We will be workering specifically with countries engaging with their government disability focal points, national statistic offices, and independent monitoring frameworks and organizations of persons with disabilities, of course. That is just a brief overview of our project. Of course, we welcome your questions. But before we go there, I would like to pass the floor to Martha so she can explain the concrete work on indicators specific to article 19.

>> Martha: Thank you very much, Victoria and good morning, everyone. Thank you for being here early on your Wednesday morning. For the Agency for Fundamental Rights it is a pleasure to organize this side event with our partners at the EDF and ORCHR and pleased they were able to join us. I would like to introduce the fundal rights agency briefly. We are an EU agency collecting data and providing advice to the European institutions and the member states of the Eu they are deviceing and implementing law. It is restricted to the 28 states of the European Union but we hope the tools and the research that we develop can be useful beyond the borders of the EU.

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My presentation this morning is going to be divided into four parts. There is a PowerPoint presentation I had prepareded which will be circulateed to you immediately after the event. You will have background material to look through afterwards. Firstly, I am just going to compliment what Victoria said about the role of indicators as a measuring tool for the convention, secondly I will talk about the development of FRAs human right indicators on article 19, and thirdly, I will present preliminary results of the application of those indicators and finally I will look ahead in terms of what we have learned through this process and how we are going to build on this work in the future.

So in terms of indicators as a measuring tool, we at the fundamental right agency see five components that are useful in assessing the human rights. First, indicators allow decision makers to see the state right implementation on the ground. In this way, they enable progress to be tracked and hopefully allowing for better policy development and policy implementation. Indicators can also allow for comparability across countries which can be useful in seeing where countries are relative to one another and they can also help to systematically identify practices that can be /TPRAPBZpered from one jurisdiction to other. They can highlight the data gaps and highlight the need for more and better data and when it comes to article 19 indicators you will see the lack of data is a really important component of what we hope these indicators will show. We have seen from work in other areas, with regard to roma, indicators can play an important role in generating political momentum. The governments want to avoid being seen as not making progress on a particular issue.

Turning secondly to FRAs indicators specifically on article 19 of the convention. This was a process of developing the indicators involving a wide range of stakeholders including some of the Committee members here today. We would like to express our thanks to all of the stakeholders from state parties who worked with us in helping develop these indicators.

The way that we went about preparing them was to try to identify some of the key elements of article 19. Our indicators are grouped around 21 issues when reflect different aspects of the article. Within these issues, we developed structure, process, and outcome indicators using the OHCHR model that Victoria introduced. Given the very wide scope of article 19, what we tried to do is focus our indicators on those elements of the article which are unique to article 19. So, aspects related specifically to, for example, employment, or education or accessibility. We haven't incorporated in the indicators for now on the basis that we would then look to be developing indicators on those other articles in due course.

So going back to those 21 issues regarding article 19, we have divided them into four elements. Three of those reflect article 19 A, article 19 B, and article 19 C. But the first set focused on cross cutting provisions when are partly encapsulated in the start of 19 but reflect the cross cutting elements that are incorporated in all parts of the article. These include issues such as the involvement of disabled personals, organizations, questions of non-discrimination and reasonable accommodation, the issue of awareness, of support and services that are available, issues related to empowerment, to the monitoring of services and quality standards for services, and issues related to complaints and re-dress, for example. Within each of those issues said, we developed some structure, process, and outcome indicators.

In terms of article 19A, so looking specifically at living arrangements we identified indicators related to institutional living arrangements, community-based living arrangements, and the involvement of person's with disabilities in deciding where to live.

In terms of article 19B, so specifically issues related to support services we looked at developing indicators related to the access to support services, to the transferability of support services particularly across different administrative areas, questions related to eligibility for support services in the community, user control that users are able to exercise over those services, issues related to informal support, and adaptations to the place of residents.

And lastly, in terms of article 19C, so related to general services -- here is a good example of where we actually didn't develop so many indicators because quite a lot of the things that could be incorporated are reflected in other parts of the convention. Here, we involved living arrangements and access to availability of services in the community.

So that gives a sense of the approach we took to developing the indicators. So really trying to break down article 19 into manageable nuggets that could allow us to develop indicators which can measure implementation on the ground. Now, I would like to move on to presenting some of the preliminary results of our indicateers which are in the process of being applied for all 28 member states of the European Union.

The data that we are using to apply these indicators was collected through desk research in each of the EU member states. While it is looking at the situation now, we also are trying to reflect changes over time. So we asked our researchers to identify whether there have been shifts or changes since 2010. So, the first indicator that I will highlight this morning is regarding strategies and strategies for independent living, or strategies for institutionalization because we saw strategies related to article 19 focused specifically on institutionalization rather than independent living as a whole. We see in five member states there is dedicated strategy for institutionalization processes. In 13 member states, there is a national disability strategy when includes measures related to institutionalization whereas in ten member states there is either no dedicated DI strategy or there is not concrete measures for the institutionalization within the general disability strategy.

But, of course, having a strategy in place is only one part of the story. So, in addition to this sort of main indicator, we also explored sub-indicators looking in a bit more depth at the question of strategies related to article 19. So, for example, we looked at whether the strategies in place include concrete targets to be met and a time frame during which those targets should be reached. Here we see that 13 of the specific strategies on the institutionalization or more general disability strategies include specific targets so that is about half of EU member states. Of course, some member states don't have any strategies but in five of the member states that do have strategies they don't include specific targets and that can call into question the efficacy of the strategies in the first place.

And a second element of strategies that we looked at was whether there is a monitoring system to measure implementation of those strategies. Specifically whether disabled person's organizations are involved in those monitoring mechanisms where they exist. We found that in 14 of the EU member states there are monitoring mechanisms in place for strategies and that these monitoring mechanisms in various ways include disabled person's organizations. In six member states, we found there are monitoring mechanisms in place but they don't include disabled person's organizations and in others we found that there are no monitoring mechanisms in place at all.

Turning then to second issue. Moving away from strategies we looked at whether there are legally enforceable quality standards for providers of services for persons with disabilities. That is both public and private providers of services. And here we found that in a majority of EU member states, so 20 of the 28, there are legally enforceable standards for all social and health services. However, those tend to be generic standards and there is few cases where those standards specifically relate to services for persons with disabilities. And furthermore, there is very little and often no data concerning how those standards are being implemented. So, it is very difficult to get a sense of the impact that those standards are having in practice and to assess their implementation.

Linked to that we also looked at the question of regular monitoring of service quality. So, we sought the question of monitoring is a major issue that arises throughout article 19 in terms of the way that services are devised and delivered. We wanted to look at whether the quality of services is subject to regular monitoring and again whether that monitoring is provided for in law and whether it covers both publically and privately provided severs for persons with disabilities. What we see here is in the vast majority of member states, so 26 of the 28, the regular monitoring is provided for in law. However, there are major differences in the feature of this monitoring. So, for example, in most member states there are at least two bodies with competence for monitoring the services and persons with disabilities. They can be organized in different ways. Sometimes geographically so particularly monitoring bodies responsible for particular areas of the country and in others they are organized according to the sector they cover.

We also see those issues related to the frequency and regulararity of monitoring. In two member states for example, the monitoring is not provided for on a regular basis. -- regularity. Or that legislation doesn't explicitly prescribe how often monitoring should take place. So we see that then those considerable scope for differentiations. In many states, it is conducted by states, bodies and entities and this leads to legally enforceable decisions for example, closed services that don't meet standards. However, it is the case that not all monitoring bodies have that power.

And then, of course, there is the issue regarding independence and whether monitoring bodies are independent of the services that they are looking at. We see that that is not universally the case. It is only in some member states that monitoring bodies are independent and that they can therefore issue independent opinions on the quality of services.

So that gives us a sense of some possible structure and process indicators. But we also wanted to try to close the circle by looking at the possibility of outcome indicators, so actually results on the ground for a person's with disabilities. Now, these indicators are particularly difficult to develop given the particular statistical data that is available. So, it is hard enough to get legal and policy information, but to get statistical data is even more difficult. But what we tried to do was to make the most of data that already exists within the European Union. So, for example, we looked at some of the major statistical surveys that are conducted on a regular basis. We identified what the outcome gaps are between people with and without impairments and in the jargon of the European statistical system that is called people with limitations and it looks at people with two different levels of limitations in their daily activity. That is how the question is praised. That meant when analyzing the data -- phrased -- we could look at the impact of degree of impairment so more severe impairments and less severe and other factors such as gender, age, educational level, and economic status. We see that those elements have a big role to play in analyzing the data. Of course, looking at existing statistical data is a far from perfect root to take because there are some really major challenges with that data and I am sure you are all aware of those challenges. But just to highlight many of the surveys in practice exclude certain groups of persons with disabilities either because the surveys themselves are not conducted in an accessible way or because the surveys are household surveys so they analyze results and collect data based on the household and don't include people in institutionalal arrangements. As a consequence of that, we see the proportion of persons with disabilities included in the surveys means that it is quite difficult to analyze the results by some of those other explanitory factors because you don't have the reliability of the data. You can analyze it by gender, for example, but not by economic status or by minority ethnic background.

But nevertheless, despite the issues with it data we were able to develop outcome indicators reflecting the different elements of article 19 so the more cross-cutting issues, questions related to living arrangements, access to specialize services, access to general services and one indicator is based on a question from the European quality of life survey and that asks respondants the extent to which they agree with the statement "I feel I am free how to decide to live my life" and you can see analyze the data in terms of respondents who say they agree or strongly agree with this statement. At the EU level, we see that 69.2% of persons with limitations, so that is persons with disabilities for the purposes of this survey, answered that they agree with the statement "I feel I am free to decide how to live my life". The respective rates for other persons, so those who don't identify as having limitations, are 76.9%. So that means there is a 7.7% point difference between persons with and without limitations in the EU.

Of course, at the national level that discrepancy varies widely. There is a much bigger difference between persons with limitations and persons without limitations in countries such as Lativa versus places like Greece where there is little gap. Here we see other factors I was mentioning at the beginning have a significant impact. For example, people are a higher education level are much more likely to feel they are free to decide how to live their life. Even if we control for the impact of education level, then we still see there is a gap between persons with and without disabilities. And the same applies for unemployment. For people who are unemployed, they are much less likely to feel that they have control over how they live their life but even then there is still a difference of nearly 10% points between outcomes for persons with disabilities and persons without disabilities.

So, looking back over the process of developing and now applying the indicators, I think it is useful to reflect a little bit on some of the things we have learned through this process. The first to say is that while there is a lot that is being done to implement article 19 we can see that there remains a long way to go to realize the provisions and that includes with respect to shifting the way that services are organized and provided in the community as well as adequately reflecting a human rights model of disability in the design and implementation of services. In terms of the statistical results coming from the analysis of statistical data, these confirm unequal outcomes for persons with disabilities in the EU and help to highlight some of the other factors which contribute to these outcomes. As I said, gender, age, education level, socioeconomic status, etc. Thirdly, as I mentioned at the outset, in many areas the lack of data inhibits efforts to measure the implementation of article 19. You can't actually apply the indicator you would like to apply because the data doesn't exist. So, instead, you can ask or present data on whether information is even available rather than what that information actually tells you. And there we can see even within countries there is a big discrepancy in the way data is collected and that is before you even try to get to comparing among countries. The data gap is a very profound one. We also hope that by developing these indicators and identifying some of the challenges in applying them that we can also we can feed into discussions about CRPD data compliance and pinpoint some of the types of data that is needed to be able to meaningful measure implementation of the convention.

So, finally, in terms of looking ahead and what is coming up next. Of course, indicators themselves are only going to be part of the story and only one tool through which you can get a sense of the implementation of the convention. And from this perspective, we are combining our indicator work with local level research on drivers and barriers of the institutionalization process in five member dits, bullgeria, Italy, Ireland, and conducting interviews with relevant actors in the country to get a sense of what is is driving this process, what is holding this process back at the local level. And those findings bill be available in 2018. But before that, and as my final word this morning, the indicators I presented today, the full set of indicators will be available this year published on the 30th of October for all 28 member states and I hope have to the community to discuss those with some of you then. Thank you very much.

>> Thank you, Martha, for sharing this concrete indicators related to article 19 and some of the lessons learned in the exercise as well as some of the barriers that remain when we are talking about indicators. So, I would like to invite Nadia to take the floor.

>> Nadia: Thank you. I will reduce a lot of my presentation in order to leave the floor also to the audience so you can discuss a little bit. So, I am here on behalf of EDF. I will briefly represent the European disability forum. It is a European umbrella organization defending the interest of more than 80 million people with disabilities and more than 30 countries in Europe. The mission of EDF is to ensure disabled people have full access to human rights and policy implementation in Europe. Like you know, EDF submitted a free report and from the Committee on the gaps in the opportunity report. We are still following this up. But today, I just wanted to, before I start with concrete examples on the importance to have indicators to highlight the intention about the importance about the definitions. A lot of definitions especially what does independent living mean. Independent living is the daily demonstration of human-right based disability policies. It is possible through the combination of various factors that allow persons with disability to have control over their own lives. So, this includes the opportunity to make real choices and decision regarding where to live, with whom to live, and how they will live and also the services must be available, accessible to all and provided on the bases of equal opportunity free from consent and allowing person with disability flexibility in their daily life. I will come back to the link but article 19 and all the other articles mentioned and I will go now and show a little bit of how this has an affect in the regions inside Belgium.

So, in 2010 we had 35, 261 people in flounders who were living in residential care and 3800 had a budget inside the community. There was a long waiting list for disabled people. We had 21, 419 people waiting on a place to be stuck in an institution and we had 5, 779 people who were waiting for a person assistant budget in order to relieve their family and to be able to live inside the community. In 2013, the council had the combination toward Belgium because a lot of families from children with disabilities and also others went to the court and so Belgium was condemned. In 2014, Belgium received general comments and recommendations from you, from the CRPD committee members, and there was mention there was a lack of N DI plan and lack of budget allocated to person with disability, and also awareness and a lot of other requirements. In response, in 2015, the government decided to have a perspective 2020 and introduce the following founding with two main objectives. The first effort was to give disabled person control of their lives by working in a demand culture system and the other objective was to guarantee care and support for those with the highest needs.

So, this personal following finding is working with two tiers. The first is a basic support budget and its right to a monthly flat rate free to spend. The second one is following the budget itself and this one is allocated for two people with approval more intensive, more frequent, and more specialized support need. But the whole personal following finding was based on the concept that there was a need of socialize care and support. So the government tried to make it a common responsibility to care. Before then, people could have for any support they need to apply to five co-circles. The first circle is the circle where the disabled person person and what can he do by himself, the second circle is what can the partner do, the third is what can neighbors and family caregivers take over, the fourth circle is family care services and social services and only if all those circles have been passed through then you can go to the fifth circle and that is the circle with the specialized disability services and where you can get special funding.

Excuse me, just a small technical problem.

Back to the papers, because technology doesn't work... so, the basic support budget is a monthly fee of 300 euros and that is paid by the health care and it is based on the yearly solidarity contribution that each family pays. There is no special procedure to follow. It is automatically allocated and this is to avoid unnecessary administrative burden and it will be paid to people who have been on the central registration list that I mentioned before. Those people were on the waiting list and they are the first ones who will have the right to have that allocation. This offers them a certain relief in anticipating of an answer of their demand care. So then we go back it the personal budget allocated to persons with a proven more intense, frequent and specialized need. In order to obtain this, they need to prepare a kind of support plan and they need to pass through those five circles to determine what kind of support they need. And the last type of support will then be found by the agency for personal disability. So, after this type of assessment plan, people can fill it out by themselves or they can be helped by support services. Once this plan is finished, it needs to go through a team that indicates the budget and after that it needs to go in front of the regional priority commission and provincial evaluation commission to see how urgent the people is needed and how the support need is and how much and if it is tolerable to live in that condition or not. Then the person receive a letter from the government that indicates the budget category and also the priority group. But it is only when the government has an available budget that the person can finally start with his personal budget and this personal budget exists in three forms. One part, you can have it as a cash budget, you can have it as a voucher that you can use inside institutional community-based services and the third possibility is a combination of all of it. So the very positive part of this new system is that since the first of January, 30,000 people inside institution received this budget. So there was no direct financing to institution anymore. The second good thing is that the disabled person can spend and control their own budget wherever they live. And then painful parts that still need to be worked on is there is still a lack of budget. In sufficient budget. The waiting lists are still there are no perspective and also those priority groups is kind of an authority measure because only when you are in really critical condition you belong to the first priority group and then you have, maybe the right to a budget, when the budgets are available. And also support needs for disabled personal must be a government no service possibility and not something that must rely on the community and it must be a guarantee for all levels of support needs, not only were the highest support needs. Then there is still a difference in the financing when it is in cashier when it is in voucher -- cash. The use of those circles to support the assessment is something that indicators need to make possible to avoid them. And the budgets are based on only special disability support needs and all the extra costs related to disability are not covered at all. And last but not least, the quality of life is not used as a criteria in the whole process. Thank you for your attention and I give the floor for questions.

>> Thank you for sharing this concrete example of how and why indicators are important when we are looking at article 19 and how it can highlight the gaps, measure progress, and really the need to keep at the heart of all these tools the conventions, principles and your interpretation of that provision.

So, we are really running out of time. I don't know if we can -- no, we cannot permit ourselves one question. But we will be here a little bit this morning so if you do have questions, please, approach us. We will be happy to discuss with you or contact us by e-mail as Martha said we will distribute the PowerPoint's so you can study that in more detail. Thank you very much to the speakers for being here and sharing with us these very important elements we hope will contribute to advanceing your work on the general comment of article 19, thank you to the members and we look forward to staying in touch on this. Thank you.

>> Thank you so much. The side event is adjourned but we will reconvene at 10:00 a.m.