Women's Fund Asia

Sapda
Sentra Advokasi Perempuan, Difabel dan Anak

Laporan Penelitian

ADVOKASI BERFOKUS OTONOMI TUBUH & HAK SEKSUAL PEREMPUAN DISABILITAS DI INDONESIA

DAFTAR ISI

BAB I

LATAR BELAKANG & KONTEKS

1.1. Latar Belakang

Hidup sebagai perempuan disabilitas mempunyai beragam tantangan dan hambatan. Hal itu tidak hanya terjadi pada sektor pendidikan atau pekerjaan, tetapi juga berasal dari lingkungan terdekat seperti keluarga inti, pasangan, dan anak-anak yang dilahirkannya. Penerimaan keluarga secara positif terhadap keberadaan dan kondisi disabilitas menjadi sebuah kebutuhan mendasar bagi perempuan disabilitas, mulai dari usia anak hingga dewasa untuk bertumbuh kembang dan berperan sosial secara positif. Pemilihan pasangan menjadi sebuah perjuangan tersendiri bagi perempuan disabilitas di tengah stigma yang menyelimuti tentang urusan dapur, kasur dan sumur. Sebuah tanggung jawab domestik yang memosisikan perempuan disabilitas sebagai individu yang berbeda dan kurang berharga dibandingkan perempuan tanpa disabilitas. Maka, penting untuk memulai sebuah diskusi yang memperlihatkan bahwa perempuan disabilitas memiliki kehidupan yang normal bersamaan status disabilitasnya yang selama ini diabaikan.

Seksualitas pada perempuan disabilitas masih dianggap tabu untuk diperbincangkan. Hal ini diakibatkan oleh stigma dan mitos yang berkembang di masyarakat yang cenderung menganggap perempuan disabilitas adalah makhluk aseksual dan tidak memiliki hasrat berhubungan seksual maupun emosional. Meski tak juga dianggap hiperseksual, dalam banyak kasus gairah seksual mereka dikendalikan agar tak melampaui kuasa seksual laki-laki. Pengendalian terhadap seksual perempuan, misalnya, dilakukan dengan sunat perempuan dan penanaman nilai kepada anak perempuan bahwa seks sebagai hak laki-laki dan perempuan hanya wajib melayani. Dampak cara pandang ini berkonsekuensi pada hambatan yang berlapis dibanding dengan laki-laki disabilitas. Ia tidak hanya mengalami hambatan karena disabilitas yang disandangnya, tetapi juga mengalami diskriminasi dan stereotip sebagai seorang perempuan. Hal ini mengakibatkan perempuan dengan disabilitas tidak hanya rentan mendapatkan stigma yang sudah disampaikan di atas, namun juga rentan mendapatkan kekerasan seksual.

Penelitian ini akan memperlihatkan bagaimana seorang perempuan penyandang disabilitas memaknai kehidupannya, dalam hal ini terkait tubuh seorang perempuan penyandang disabilitas yang seringkali dianggap "tidak normal dan berbeda dengan perempuan lain", serta mengelola seksualitasnya diantara mereka yang menganggap bahwa perempuan penyandang disabilitas adalah individu yang aseksual atau hiperseksual dari cara pandang perempuan penyandang disabilitas.

1.2. Tujuan Penelitian

Penelitian ini mempunyai beberapa tujuan khusus yaitu:

1) Mendeskripsikan situasi perempuan penyandang disabilitas atas tubuh dan seksual dari kacamata perempuan penyandang disabilitas sebagai individu yang mandiri dan bermartabat, yang diterjemahkan dalam 5 poin kunci yaitu:
    a. Pemaknaan individu perempuan penyandang disabilitas tentang tubuh dan seksualitasnya.
    b. Aktivitas seksual, pilihan pasangan dan orientasi seksual dan konsekuensi atas diri dan tubuhnya.
    c. Penentuan pilihan dan siapa serta apa yang mempengaruhi pilihan pribadi atas tubuh dan seksualitasnya.
    d. Strategi seorang perempuan penyandang disabilitas dalam mengatasi hambatan dan tantangan atas otonomi tubuh dan seksualitasnya.
    e. Dukungan yang diperlukan perempuan penyandang disabilitas agar dapat menentukan pilihan atas tubuh dan seksualitasnya.
2) Menemukan kebutuhan dukungan bagi perempuan penyandang disabilitas untuk dapat menentukan pilihannya secara mandiri atas tubuh dan seksualitasnya, serta kebutuhan perlindungan khusus.

1.3. Pertanyaan Penelitian

1) Bagaimana situasi otonomi atas tubuh dan seksualitas perempuan disabilitas sebagai individu yang bermartabat berberbasis keberagaman budaya dan disabilitas?

2) Bagaimana peta kebutuhan dukungan penyandang disabilitas sebagai bentuk perlindungan khusus dan lebih bagi perempuan penyandang disabilitas dan potensi pemenuhannya?

1.4. Metode Penelitian & Analisis Data

1.4.1. Subyek penelitian.

Penelitian melibatkan 10 narasumber atau informan penyandang disabilitas yang mewakili setiap ragam disabilitas dengan usia kalender 20 hingga 40 tahun; merupakan perempuan disabilitas seksual aktif (mempunyai/pernah mempunyai pasangan, baik berpacaran atau menikah); mampu berkomunikasi dengan baik (dengan atau tanpa bersama pendamping/Juru Bahasa Isyarat). Narasumber/informan memiliki ragam disabilitas netra, intelektual, mental, fisik dan rungu wicara.

1.4.2. Lokasi Penelitian dan Alasan Pemilihan.

Penelitian berlangsung di 2 wilayah dengan basis budaya yang berbeda, yaitu Yogyakarta yang berlatar belakang budaya Jawa dan Kupang. Masing-masing wilayah mendapatkan 5 narasumber.

1.4.3. Pendekatan dalam penelitian dan analisis data.

- Penelitian ini merupakan penelitian kualitatif dengan narasumber/ informan dengan kriteria yang ditentukan sebelumnya.
- Penelitian menerapkan pendekatan perspektif gender dan disabilitas, dengan mengedepankan pandangan pribadi narasumber perempuan penyandang disabilitas yang memiliki kesadaran menyampaikan pendapat serta pengalamannya.
- Narasumber mendapatkan dukungan aksesibilitas melalui pendamping dan Juru Bahasa Isyarat sesuai kebutuhan untuk memudahkan komunikasi dan menangkap detail informasi yang diberikan.
- Observasi/pengamatan dilakukan untuk memahami situasi lingkungan dimana narasumber tinggal dan beraktivitas.
- Analisa data dilakukan secara mendalam dengan berbasis teori gender dan disabilitas.

BAB II

ANALISIS LITERATUR & KEBIJAKAN

2.1 Kebijakan Perlindungan Otonomi Tubuh dan Seksualitas di Indonesia.

Kebijakan yang menjadi acuan tentang perlindungan atas otonomi tubuh dan seksualitas perempuan penyandang disabilitas tidak dapat dilepaskan dari beberapa konvensi internasional dan regulasi di Indonesia yang berkaitan dengan penyandang disabilitas, perempuan dan kesehatan reproduksi-seksualitas.

Instrumen perlindungan perempuan penyandang disabilitas sebenarnya tersedia baik di level global, nasional, maupun level lokal. Di level global, Majelis Umum PBB mengadopsi Aturan Standar PBB Mengenai Persamaan Kesempatan bagi Orang dengan Disabilitas (*The United Nations Standar Rules on the Equalization of Opportunities for People with Disabilities*) dalam resolusi 48/96 pada 20 Desember 1993. Pada Desember 2001, Majelis Umum PBB mengadopsi Resolusi Mengenai Konvensi Internasional yang Komprehensif dan Integral untuk Memajukan dan Melindungi Hak dan Martabat Orang dengan Disabilitas. Pasca adopsi, berbagai konferensi dan perumusan kebijakan-kebijakan internasional dikembangkan untuk kemajuan pemenuhan dan perlindungan HAM orang dengan disabilitas.

Tahun 2006, Majelis Umum PBB mengadopsi Konvensi tentang Hak Orang dengan Disabilitas atau *Convention on the Right People with Disability* (CRPD) dan terbuka untuk ditandatangani negara anggota pada 30 Maret 2007.[1] Indonesia meratifikasi konvensi ini pada tahun 2011 dengan Undang-undang Nomor 19 Tahun 2011 tentang Ratifikasi *Convention on the Rights People with Disability* (Konvensi Hak-hak Orang dengan Disabilitas).

[1] UNCRPD menjadi batu pijakan bagi pengakuan dan pelaksanaan Hak-hak Orang dengan Disabilitas di seluruh dunia. Sampai sekarang sudah terdapat 160 negara yang menandatangani dan meratifikasi, 92 menandatangani dan 88 negara meratifikasi protokol opsional; sebuah capaian kemajuan penting bagi perwujudan hak-hak penyandang disabilitas.

Adapun prinsip-prinsip UNCRPD adalah martabat yang melekat, non-diskriminasi, inklusi yang efektif, penghormatan terhadap perbedaan, kesempatan yang sama, aksesibel, kesetaraan gender, dan penghormatan bagi pertumbuhan kapasitas anak-anak dengan disabiltas (Wapling & Downie, 2012, pp. 18-19; Schulze, 2010, pp. 44-49).

Pada tahun 1979 United Nation General Assembly mengadopsi Konvensi Penghapusan Segala Bentuk Diskriminasi Terhadap Perempuan atau *The Convention on the Elimination of all Forms of Discrimination Against Women* (CEDAW). Sebanyak 189 negara meratifikasi konvensi ini pada tahun 1981. CEDAW mengadopsi pendekatan kesetaraan substantif/korektif yaitu memastikan awal yang setara, memastikan kesiapan lingkungan dan memastikan kesetaraan dalam hasil. Lingkup kesetaraan substantif ini meliputi akses, partisipasi, kontrol, dan manfaat.

General recommendation on women's access to justice yang di keluarkan oleh Commite CEDAW Juli 2015 di bagian pendahuluan secara jelas menyebutkan lingkup diskriminasi pada perempuan merupakan interseksi dari berbagai hal termasuk karena disabilitas yang mereka sandang.

> *"Diskriminasi mungkin ditujukan terhadap perempuan atas dasar jenis kelamin dan gender mereka. Gender mengacu pada identitas, atribut dan peran yang dikonstruksi secara sosial bagi perempuan dan laki-laki dan makna budaya yang dipaksakan oleh masyarakat atas perbedaan biologis, yang terus direproduksi di antara sistem peradilan dan lembaganya. Berdasarkan pasal 5 (a) Konvensi, Negara Pihak berkewajiban untuk mengungkap dan menghilangkan hambatan sosial dan budaya yang mendasarinya, termasuk stereotip gender, yang mencegah perempuan untuk menggunakan dan mengklaim hak-hak mereka dan menghalangi akses mereka ke pemulihan yang efektif. 8. Diskriminasi terhadap perempuan berdasarkan stereotipe gender, stigma, norma budaya yang merugikan dan patriarki, serta kekerasan berbasis gender yang terutama berdampak pada perempuan berdampak buruk terhadap kemampuan perempuan untuk memperoleh akses keadilan yang setara dengan laki-laki. . Selain itu, diskriminasi terhadap perempuan diperparah oleh faktor-faktor yang saling berpotongan yang mempengaruhi beberapa perempuan pada derajat yang berbeda atau dengan cara yang berbeda dari pada laki-laki dan perempuan lainnya. Dasar untuk diskriminasi lintas bagian atau gabungan dapat mencakup etnis / ras,status adat atau minoritas, warna kulit, status*

sosial-ekonomi dan/atau kasta, bahasa, agama atau kepercayaan, opini politik, asal kebangsaan, status perkawinan dan/atau ibu, usia, perkotaan/lokasi pedesaan, status kesehatan, disabilitas, kepemilikan properti, dan menjadi lesbian, biseksual, transgender perempuan atau interseks. Faktor-faktor yang saling bersilangan ini mempersulit perempuan dari kelompok-kelompok tersebut untuk mendapatkan akses ke keadilan "

Pemerintah Indonesia mengesahkan Undang-undang Nomor 7 Tahun 1984 tentang Pengesahan Konvensi Penghapusan Segala Bentuk Diskriminasi terhadap Perempuan (CEDAW).

Terbitnya Undang-Undang Undang-Undang Nomor 8 Tahun 2016 menjadi basis legalitas dan Pemerintah Daerah harus menindaklanjuti dengan menerbitkan Peraturan Daerah (Perda) dan kebijakan operasionalisasinya untuk mewujudkan layanan yang setara (*equality*) terhadap penyandang disabilitas terkait hak hidup; bebas dari stigma; privasi; keadilan dan perlindungan hukum; pendidikan; pekerjaan, kewirausahaan, dan koperasi; kesehatan; politik; keagamaan; keolahragaan; kebudayaan dan pariwisata; kesejahteraan sosial; aksesibilitas; pelayanan publik; perlindungan dari bencana; habilitasi dan rehabilitasi; konsesi; pendataan; pendataan; hidup secara mandiri dan dilibatkan dalam masyarakat; berekspresi, berkomunikasi, dan memeroleh informasi; berpindah tempat dan kewarganegaraan; dan bebas dari tindakan diskriminasi, penelantaran, penyiksaan, dan eksploitasi (pasal 5 ayat 1).

Undang-Undang ini menempatkan perempuan penyandang disabilitas secara khusus untuk mendapatkan perlindungan sebagai berikut; perempuan dengan disabilitas memiliki hak atas kesehatan reproduksi; menerima atau menolak penggunaan alat kontrasepsi; mendapatkan pelindungan lebih dari perlakuan diskriminasi berlapis; dan untuk mendapatkan perlindungan lebih dari tindak kekerasan, termasuk kekerasan dan eksploitasi seksual (pasal 5 ayat 2 c).

Perlindungan tersebut tersebut juga tidak terlepas dari pasal-pasal yang memuat tentang hak untuk berkeluarga bagi penyandang disabilitas, hak untuk menentukan keputusan serta mendapatkan dukungan untuk menentukan pilihan

atau keputusan tersebut. Untuk memberikan perlindungan kepada perempuan penyandang disabilitas sebagai individu yang bermartabat sebagaimana prinsip-prinsip yang termuat dalam UNCRPD.

2.2 Konsep Universal Perlindungan Otonomi Tubuh dan Seksualitas Perempuan Penyandang Disabilitas.

Perlindungan otonomi atas tubuh dan seksualitas perempuan penyandang disabilitas secara universal tidak bisa dipisahkan dari teori-teori feminisme serta martabat seorang perempuan penyandang disabilitas yang dilihat dari tubuh, suara, seksualitas dan politik/pilihan hidupnya.

2.2.1 Seksualitas

Pernyataan bahwa seksualitas adalah hak dan orientasi seksual yang menjadi pilihan penyandang disabilitas menjadi pilihan yang cukup pelik. Kompleksitas tersebut terkait dengan keterikatan sosialnya dengan lingkungan masyarakat, keluarga, dan orang-orang yang selama ini menunjang kehidupannya sebagai penyandang disabilitas yang tidak dapat menerima orientasi seksualnya yang masih dipandang sebagai perilaku menyimpang karena dianggap sebagai penyakit dan harus ditinggalkan atau disembuhkan. Sehingga sebagian besar dari mereka memilih untuk merahasiakan orientasi seksualnya karena tidak siap dengan risiko sosial yang harus mereka terima.

Sedangkan untuk penyandang disabilitas yang terbuka berkaitan dengan seksualitas atau pilihan relasi seksual belum cukup banyak, karena berkaitan dengan pemahaman mereka mengenai seksualitas sebagai hak individu, dan mereka mempunyai pilihan untuk itu. Hal tersebut tidak lepas dari peran posisi mereka dalam keluarga atau masyarakat, serta tingkat kemandirian secara sosial ekonomi dan interaksi dengan dunia luar.

Seksualitas tidak hanya terkait dengan biologi dan psikologi tetapi juga pengalaman dan makna subjektif di dalamnya. Sejalan dengan penjelasan Abraham bahwa konsep seksualitas tidak hanya mencakup identitas seksual, orientasi seksual, norma seksual, praktik seksual, dan kebiasaan seksual; tetapi juga perasaan, keinginan, fantasi, dan pengalaman manusia terkait dengan kesadaran seksual, rangsangan, dan tindakan seksual termasuk dalam hubungan heteroseksual dan hubungan homoseksual. Ini termasuk pengalaman subjektif dan makna yang melekat di dalamnya. Konsep seksualitas tidak hanya mencakup secara biologis dan psikologis, tetapi juga dimensi sosial dan budaya dari identitas dan kebiasaan seksual.[2] Pengertian seksualitas berdasarkan dimensi sosial, budaya, identitas seksual dan kebiasaan seksual penyandang disabilitas dapat dilihat dari cerita di atas, baik secara individu karena bentukan keluarga atau budaya.

Keterbatasan lingkungan sosial penyandang disabilitas merupakan masalah tersendiri, jika ada pertanyaan mengapa mereka sangat takut kehilangan kelompok atau keluarganya dan lebih memilih untuk menyembunyikan orientasi seksualnya bahkan pasangannya, jawabannya ada masalah penerimaan sosial dari para penyandang cacat. Mereka perlu berkorban dan berjuang untuk mendapatkan pengakuan dan dukungan dari kelompok sosial dan keluarganya.

Pada kenyataannya penyandang disabilitas mengalami penindasan sosial, budaya, politik dan ekonomi. Penindasan tidak lagi melihat penyebab kecacatan: bawaan, perang dan kekerasan, malnutrisi, virus, kecelakaan, pekerja anak, dan bencana alam. Secara teori dan praktek, penyandang disabilitas terus mengalami penindasan dari dunia kedokteran, ilmu

[2] Lena Abraham, "*Introduction*" dalam "*Understanding Youth Sexuality: A Study of Collenge Student in Mumbai*", Unit for Research in Sosiology of Education, Tata Institute of Social Sciences, (Deonar: Mumbai, India, 2000), page 1

pengetahuan, dan kendali tenaga profesional di hampir semua sisi kehidupan, baik dari sektor publik, swasta bahkan yang sangat privat yaitu seksualitas yang sering terjadi akibat disablisme, rasisme atau seksisme yang berjalan bersama.[3]

Sehingga wajar saja jika seorang penyandang disabilitas ragu-ragu untuk bergabung dengan kelompok homoseksual yang mereka anggap eksklusif dan tertutup atau bahkan terkait dengan gaya hidup kelompok tertentu, namun penyandang disabilitas dengan orientasi yang sama tetap akan kesulitan mendapatkan pengakuan. Dari kelompok dengan kendala yang dialami individu dan sosial. Mereka bahkan ragu untuk menyampaikan bahwa mereka akan menjadi perempuan atau ibu tunggal dengan seksual aktif sebagai sebuah pilihan atas seksualitasnya.

Tantangan sebagian pihak untuk memposisikan penyandang disabilitas sebagai manusia utuh, adalah penyandang disabilitas sebagai individu yang bermartabat yang harus diakui tanpa memandang kondisi dan ragam disabilitas memiliki otonomi atas tubuh, berhak menolak tindakan medis terhadap diri sendiri, termasuk menolak kontrasepsi atau sterilisasi organ reproduksi. Mereka berhak menolak tindakan kekerasan terhadap tubuh dan pemaksaan/kontrol atas seksualitas mereka. Ini termasuk memaksa mereka, baik laki-laki maupun perempuan penyandang disabilitas untuk menjadi heteroseksual atau homoseksual, termasuk oleh komunitas LGBTQ itu sendiri. Menikah atau tidak menikah, melahirkan atau tidak melahirkan anaknya serta kapan akan melakukan hubungan seksual, serta kontrol atas alat reproduksinya.

[3] MD Mukhotib dkk, Kesehatan Reproduksi dan Seksual bagi Remaja Penyandang Disabilitas, Lembaga SAPDA, Yogyakarta, first Print, 2015

2.2.2 Feminisme, Gender dan Disabilitas

Membahas seksualitas dan perempuan penyandang disabilitas tidak akan lepas dari konsep feminisme dan terutama feminisme penyandang disabilitas. Dalam sebuah gerakan feminis disabilitas, Rose Marry, seorang perempuan penyandang disabilitas, mengatakan bahwa: "Wanita dan gadis penyandang disabilitas berasal dari segala usia, semua ras, etnis, agama dan latar belakang sosial-ekonomi, dan orientasi seksual; mereka tinggal di komunitas pedesaan, perkotaan, pinggiran kota. Perempuan dan anak perempuan penyandang disabilitas hidup di sudut disabilitas dan feminitas -dengan dua identitas minoritas sekaligus; diskriminasi dan beragam stereotip serta hambatan berlapis dalam mencapai tujuan hidup mereka. Meski begitu, banyak perempuan penyandang disabilitas yang mendapatkan kekuatan dan kreativitas yang sangat besar dari identitas berlapisnya; mereka selalu menghadapi konsekuensi diskriminasi. Perempuan penyandang disabilitas memiliki kebutuhan untuk mendefinisikan dirinya sendiri, namun mereka masih berada di pinggiran gerakan keadilan sosial, bahkan gerakan yang mengatasnamakan diri mereka -gerakan perempuan, gerakan hak penyandang disabilitas dan gerakan hak sipil- meninggalkan perempuan dan anak perempuan disabilitas dari semua latar belakang yang pada dasarnya tidak terlihat (Rosemarie Garland-Thomson dan Barbara Faye Waxman Fiduccia).[4]

Terkait masalah kesehatan reproduksi dan seksualitas, terdapat perbedaan yang sangat mendasar antara perempuan penyandang disabilitas dan perempuan bukan penyandang disabilitas. Saat ini sebagian besar perempuan penyandang disabilitas masih berusaha keras untuk menikah, membuktikan kemampuannya dalam melayani pasangannya (baca: suami) dalam melakukan hubungan seksual serta mampu hamil dan memiliki anak.

[4] Rosemary Garland Thomson, Integrating Disability, Transforming on Feminist Theory, Source: NWSA Journal, Vol. 14, No. 3, Feminist Disability Studies (Autumn, 2002), pp. 1-32 Published by: The Johns Hopkins University Press, URL: http://www.jstor.org/stable/4316922

Dengan menikah mereka dapat melakukan hubungan seksual dan dan melahirkan adalah kondisi yang ideal bagi kebanyakan perempuan penyandang disabilitas. Namun tidak semua perempuan penyandang disabilitas bisa menjalaninya, sehingga dianggap sebagai isu mendasar dan keistimiewaan bagi perempuan penyandang disabilitas yang bisa mendapatkannya. Ini sebenarnya tidak diperlukan ketika mereka memiliki pasangan homoseksual baik sebagai lesbian atau gay. Ini memperkuat teori Rose Mary bahwa "Wilayah ketiga dari teori feminis yang dikomunikasikan oleh analisis disabilitas adalah identitas. Teori feminis telah secara produktif dan ketat dikritik oleh kategori identitas perempuan, di mana seluruh usaha feminis tampaknya bertumpu. Feminisme semakin mengakui bahwa wanita menempati berbagai posisi subjek dan diklaim oleh beberapa kategori identitas budaya (Spelman, 1988). Ini adalah fokus laki-laki kepada perempuan untuk melihat lebih penuh pada aspek eksklusi, esensialis, opresif dan biner dari kategori perempuan itu sendiri. Ini merupakan salah satu identitas yang mengganggu realitas klasifikasi perempuan dan menantang keunggulan gender sebagai kategori monolitik.[5] Bisa jadi pemenuhan kebutuhan seksual yang tidak beresiko hamil, atau ketakutan melahirkan anak penyandang disabilitas membuat mereka memilih untuk menjalin hubungan bukan sebagai pilihan saat memiliki posisi tawar yang baik.

Dalam perkembangannya bahwa teori feminis ini kemudian bergerak menjadi konsep gender yang tidak hanya melihat perempuan tetapi melihat situasi ini sebagai sebuah konstruksi/bentukan sosial. Bahwa adanya konstruksi sosial dan budaya menyebabkan terjadinya pergeseran yang mendasar bagi pengertian gender, dari yang asalnya dianggap natural menjadi kultural. Kesadaran akan perbedaan pendefinisian maskulinitas dan feminitas disetiap masyarakat membawa kesadaran akan adanya bentuk-

[5] Ibid

bentuk pembagian kerja secara seksual (Saptari dan Holzner 1997:21)[6]. Sebagai konseksuensinya bahwa pembagian kerja secara seksual yaitu peran laki-laki dan perempuan ditentukan karena seksualitasnya dalam masyarakat dan bahkan lingkungan terkecil yaitu keluarga, bersifat tipikal dengan melihat dari kebiasaan/budaya masyarakat setempat sehingga bersifat lokal yang bisa jadi berbeda antar daerah/suku/bangsa; dan juga mempunyai perbedaan antara mereka yang tinggal di gunung dan pantai, mereka yang tinggal di pedesaan dan perkotaan, dan akan berubah/berkembang sesuai dengan perkembangan teknologi atau pengetahuan.

Sebagaimana gender, disabilitas juga merupakan konstruksi/bentukan sosial, terkait dengan perspektif, kebiasaan, tipikal, atau pengetahuan dari masyarakat yang sangat mempengaruhi bagaimana mereka melihat, memperlakukan, memposisikan dan menempatkan penyandang disabilitas dalam sebuah keluarga dan masyarakat, termasuk memposisikan/menempatkan masyarakat dalam sebuah relasi dengan pasangannya dan pengakuan dalam keputusan atas seksualitas dan reproduksinya sebagai individu yang otonom dan bermartabat.

Hal tersebut akan dipengaruhi oleh sistem budaya setempat, pengetahuan serta interaksi sosial diantara kelompok penyandang disabilitas dengan mereka yang bukan penyandang disabilitas. Tentu saja kebijakan/regulasi mempunyai peran sebagai sebuah rekayasa sosial yang mempengaruhi situasi dan kondisi yang ada dalam masyarakat; dimana situasi perempuan penyandang disabilitas di Indonesia timur bisa jadi berbeda dengan perempuan penyandang disabilitas yang ada di Indonesia Barat atau tengah, karena keragaman suku budaya dan agama yang pastinya akan mempengaruhi konstruksi disabilitas dan gender itu sendiri dalam sebuah masyarakat.

[6] Titi Surti Nastiti, Perempuan Jawa, Pustaka Jaya, 2016, hal 11

BAB III

ANALISIS TEMUAN LAPANGAN

3.1 Deskripsi Situasi atas Tubuh dan Seksual dari Kacamata Perempuan Penyandang Disabilitas Sebagai Individu yang Mandiri dan Bermartabat.

3.1.1 Pemaknaan individu perempuan penyandang disabilitas tentang tubuh dan seksualitasnya.

Literasi mengenai isu perempuan disabilitas dapat dikatakan masih terlalu sedikit, sehingga cukup banyak orang tua yang memiliki anak disabilitas. Masyarakat secara umum juga masih luput dari pengetahuan bagaimana melindungi mereka yang berkebutuhan khusus.[7]

Dari 10 (sepuluh) responden menunjukkan bahwa perempuan penyandang disabilitas secara keseluruhan mampu mengenali tubuh dan seksualitasnya sama dengan perempuan pada umumnya; dengan hanya 1 perempuan penyandang disabilitas yang tidak mampu mengenali diri dan tidak mempunyai keinginan untuk merawat diri dan kepercayaan diri untuk memahami tubuh dan seksualitasnya. Hal ini terjadi karena dia mengalami disabilitas intelektual setelah usia dewasa karena suaminya meninggal, sehingga dia lebih sulit untuk mengembalikan kepercayaan dirinya dan bangkit untuk menatap hidup dengan dukungan penuh dari keluarga dan pendamping. Sementara 9 perempuan disabilitas lainya tidak mempunyai persoalan dengan pemaknaan diri.

1) Perempuan disabilitas fisik.

Perempuan disabilitas fisik mempunyai persoalan terkait dengan pemaknaan terhadap tubuhnya relatif lebih besar dan dirasakan sampai dia dewasa. Hal ini terjadi karena mereka secara langsung melihat dan merasakan adaya perbedaan secara fisik, luka yang ditimbulkan pada perempuan disabilitas fisik akibat mendapatkan perlakuan yang tidak

[7] Ariani, Soekanwo, et al. 2011. Seksualitas dan Kesehatan Reproduksi Perempuan dengan Disabilitas Jurnal Perempuan. Jakarta

baik dimasyarakat yang akan terbawa sampai dewasa. Hal ini akan berdampak pada sebagian perempuan disabilitas fisik akan menujukkan ke orang lain bahwa dia mampu sama dengan perempuan non-disablitas. Namum hal itu tidak terjadi pada perempuan disabiliatas fisik yang mendapatkan dukungan penuh dari keluarga.

Perempuan disabilitas fisik yang mendapatkan dukungan dan perhatian dari keluarga akan mampu bertahan cepat beradaptasi dengan masyarakat. Perempuan disabilitas fisik tak jarang mendapatkan kekerasan dari sesama perempuan disabilitas karena adanya dorongan untuk menunjukkan kemampuan memimpin, dan menjadi panutan senior di komunitas mereka.

2) Perempuan disabilitas netra.

Pada kelompok perempuan disabilitas netra, mereka mempunyai kepercayaan diri yang sangat besar. Mereka cenderung cuek dengan lingkungan. Mereka juga mendapatkan kekerasan baik pada masa kecil maupun setelah dewasa. Perempuan disabilitas netra mampu mengenali lawan bicaranya dengan mencium bau tubuh. Perempuan disabilitas netra akan mudah cepat beradaptasi dengan lingkungan baru.

3) Perempuan disabilitas tuli.

Pada kelompok perempuan disabilitas tuli, cenderung lama dalam memahami kondisi tubuhnya. Ini terjadi karena tidak semua orang tua siap memiliki anak disablitas tuli, sehinngga mereka tak mempersiapkan diri menjadi orang tua disabilitas. Misalkan tidak semua keluarga mampu menggunakan bahasa isyarat, yang mereka lakukan hanya dengan oral sampai anak masuk SLB dan mendapatkan keterampilan tentang bahasa isyarat. Situasi itu berpengaruh pada pengetahuan dan pengenalan mereka dengan dirinya. Meskipun proses pengenalan dirinya dan lingkungan terlambat, namun perempuan disabilita tuli memiliki rasa persaudaraan yang kuat diantara sesama disabilitas tuli.

4) Perempuan disabilitas intelektual.

Untuk perempuan disabilitas intelektual, baik yang mengalami disabilitas intelektual dari kecil cenderung mampu memaknai diri dan mengenali dirinya sendiri lebih baik dari pada perempuan disabilitas intelektual sudah dewasa atau bahkan sudah menikah.

Pada perempuan disabilitas intelektual dari kecil mampu memaknai diri dan tubuhnya, dia mampu bergaul dan berinteraksi dengan masyarakat pada umumnya, mampu melakukan aktifitas yang positif seperti olahraga dan sekolah. Karena mereka mengalami perlakuan diskriminasi dari masyarakat sekitarnya sejak kecil, sehingga mempunyai daya tahan lebih baik, dia menyadari bahwa tubuhnya sangat berharga. Mereka juga mendapatkan perhatian yang lebih dari keluarga. Keluarga akan cenderung protektif pada anak disabilitas intelektual, sehingga dia mampu beradaptasi dan bergaul dengan lingkungan.

Sementara pada perempuan disabilitas mental yang baru mengalami pada waktu dewasa, banyak yang mendapatkan perlakuan dikriminasi lebih berat. Ada yang sampai harus hidup dijalan dan bahkan ada yang dipasung oleh keluarganya. Hal ini dilakukan karena keluarga tidak mau disalahkan warga ketika perempuan disabilitas intelektual mengamuk dan melakukan kekerasan pada masyarakat. Keputusan untuk melakukan pasung biasanya dilakukan atas dasar malu dan tekanan dari masyarakat. Karena kondisi kedisabilitasannya mereka cenderung abai akan kondisi tubuhnya. Hal ini terjadi karena perasaan putus aja yang lebih dan hilangnya semangat hidup.

5) Perempuan disabilitas mental.

Pada kelompok perempuan disabilitas mental, pemaknaan diri dan kepercayaan diri mereka sangat bagus, mereka sangat percaya diri dalam bergaul dan berinteraksi dengan masyarakat. Mereka tidak merasa ada yang berbeda dengan perempuan lainya. Mereka bergaul dengan

semua orang dan mampu bekerja seperti orang lain, meskipun mereka harus minum obat agar mereka tetap bisa fokus. Perempuan disabilitas mental juga mendapatkan diskriminasi dari masyarakat sampai mereka dewasa, bahkan sampai mereka bekerja. Hinaan berupa penyebutan orang "gila" masih mereka rasakan.

Perempuan disabilitas mental pada umumnya menekuni salah satu bidang olahraga, mereka akan fokus pada kegiatan tersebut. Itu terjadi di banyak perempuan dan banyak daerah, sehingga dia mempunyai kepercayaan diri yang tinggi.

3.1.2 Aktivitas seksual, pilihan pasangan dan orientasi seksual dan konsekuensi atas diri dan tubuhnya.

Di sebagian wilayah di Indonesia ada anggapan bahwa penyandang disabilitas adalah suatu kutukan atau aib yang telah dilakukan oleh orang tuanya dan dianggap aseksual. Anggapan itu membuat orang tua dengan anak disabilitas cenderung membatasi akses mereka dengan masyarakat luar; dan lebih parahnya masyarakat mengamini atau membiarkan hal itu terjadi. Akibatnya, informasi tentang hak kesehatan reproduksi dan seksual sulit terakses. Bahkan para orang tua pun minim terhadap pengetahuan hak dan kesehatan reproduksi dan seksual.[8] Hal ini tergambar jelas dalam riset yang dilakukan pada 10 perempuan disabilitas pada 5 ragam disabilitas: ada keterbatasan informasi tentang kesehatan reproduksi dan pendidikan seksual. Perempuan Disabilitas tidak mengetahui aktifitas seksual, sehingga mereka sangat rentan mendapatkan kekerasan seksual.

[8] Komnas Perempuan. Temuan: berbasis budayaPerempuan dengan Dissabilitas dalam kajian tematik dan kajian kekerasan terhadap perempuan. 2012; Tim SRHR Komnas Perempuan. 2015. Prosiding Workshop Persiapan Pengembangan Policy Berief SRHR. Komnas Perempuan. Jakarta; Tim SRHR Komnas Perempuan. 2015. Hasil Kunjungan Lapangan di Yogyakarta, Bandung dan Balikpapan. Komnas Perempuan. Jakarta

1) **Perempuan disabilitas fisik.**

Dari 2 perempuan disabilitas fisik yang menjalani wawancara dengan latar belakang budaya, kondisi geografis, dan lokasi berbeda, secara umum mengenal seksualitas pada usia yang sudah dewasa meskipun mereka mengenal lawan jenis rata-rata di usia 17 tahun. Namun mereka tidak melakukan aktifitas seksual. Pada Perempuan disabilitas di Yogyakarta mengenal aktifitas seksualitas setelah menikah. Karena keterbatasan informasi akan seksualitas. perempuan disabilitas cenderung tidak paham akan aktifitas seksual meskipun sudah menikah. Keluarga juga tidak pernah memberikan pengetahuan akan aktitas seksual.

Hal berbeda terjadi di NTT dengan latar budaya yang berbeda, dimana perempuan disabilitas di NTT memilih untuk berhubungan dengan laki-laki disabilitas tanpa ikatan resmi. Hal ini karena di NTT ketika akan menikah maka pihak laki-laki harus menyediakan mahar yang sangat besar, sementara disabilitas sebagian besar kelompok miskin sehingga tidak mampu membayar mahar perkawinan, sehingga memilih untuk berhubungan tanpa status. Perempuan disabilitas cenderung tidak mampu memutuskan karena situasi dan kondisi memaksa perempuan menerima kondisi hubungan tanpa ikatan, meskipun mereka akan mengalami rasa ketakutan akan dampak dari aktifitas yang mereka lakukan.

2) **Perempuan disabilitas netra.**

Dalam wawancara yang dilakukan pada perempuan disabilitas netra, mereka melakukan aktifitas seksual setelah menikah resmi. Hal tersebut mematahkan asumsi masyarakat kalau penyandang disabilitas aseksual. Perempuan memiliki kesuburan sama dengan perempuan pada umumnya. Terkadang prasangka masyarakat yang menganggap penyandang disabilitas adalah aseksual membuat mereka terpinggirkan

(marginalisasi). Masyarakat juga menganggap perempuan penyandang disabilitas tidak mampu menikah dan merawat anak. Padahal perempuan penyandang disabilitas juga bisa memiliki keturunan, hanya perlu dukungan selama kehamilan dan perhatian medis lebih.[9] Hal ini dialami perempuan disabilitas netra, dimana mereka seringkali dianggap tidak mampu merawat anak, sehingga banyak dari perempuan disablitas ketika mempunyai anak diambil oleh keluarganya. Namun tidak sedikit perempuan disabilitas netra mampu merawat anak-anak mereka sampai dewasa.

3) Perempuan disabilitas tuli.

Perempuan disablitas tuli rentan mendapatkan kekerasan seksual, Hal ini terjadi asalah satunya adanya hambatan berbicara yang membuat pelaku kekerasan merasa aman melakukan kekerasan. Dari wawancara yang dilakukan, diketahui bahwa perempuan disabilitas tuli mendapatkan kekerasan lebih dari satu kali dan pelakunya adalah orang terdekat. Artinya keluarga mengenal dan mengetahui pelaku kekerasannya tapi mereka tidak mampu melakukan apapun, karena mereka tidak bisa membuktikan, ditambah perasaan malu mempunyai anak disabilitas menjadikan mereka cenderung menyembunyikan termasuk ketika terjadi kehamilan. Mereka juga malu membawanya ke Puskesman. Hal lain yang terjadi pada keluarga dengan disabilitas Tuli adalah mereka akan melakukan pengawasan ketat kepada anaknya, dengan mendampingi semua aktifitasnya, sehingga rata-rata disabilitas tuli akan terlambat mendapatkan pendidikan dan memahami dunia luar; termasuk mengenal dan pemahami pendidikan seks.

[9] www.betterhealth.vic.gov.au. Domestic Violence and Women with Dissabilities. The Better Health Channel, Australia

4) Perempuan disabilitas Mental

Kondisi perempuan disabilitas mental juga rentan mengalami kekerasan seksual. Dari wawancara yang dilakukan, diketahui keluarga mempunyai peran yang sangat penting dalam menjaga perempuan disabilitas mental. Perempuan disabilitas mental yang mengalami disabilitas dalam usia dewasa. karena satu peristiwa tentu tidak akan paham akan seksualitas. Hal ini yang membuat meraka rentan kerena mereka tidak tahu dengan apa yang orang lakukan dengan tubuhnya. Sementara pada perempuan disablitas metal yang dialami dari kecil akan lebih mampu memahami aktifitas seksualitas. Namun dengan informasi yang tepat dan dukungan keluarga perempuan disabilitas mampu beraktifitas di ranah publik dengan baik.

5) Perempuan Disabilitas intelektual

Perempuan disabilitas intelektual rata-rata mempunyai sifat yang sangat ceria dan ekspresif. Mereka mempunyai kepercayaan diri yang lebih. Mereka mengenal kecantikan dan memahami bagaimana merawat tubuh mereka. Perempuan disabilitas mental juga sangat rentan mendapatkan kekerasan seksual, karena mereka tidak paham akan apa yang dilakukan orang pada tubuhnya. Hal ini yang membuat mereka sering mendapatkan kekerasan karena mereka tetap akan terlihat ceria (seperti menikmati) dan dilakukan lebih dari sekali, sehingga pada kasus kekerasan seksual pada disabilitas mental sulit mendapatkan keadilan karena cara pandang penegak hukum yang belum responsif disabilitas. Misalkan terjadi pemerkosaan pada perempuan disabilitas sampai lebih dari kali, asumsi yang dipakai penegak hukum/penyidik adalah bahwa ia diperkosa lebih dari satu kali dan mereka tetap bahagia, sehingga banyak yang tidak berlanjut ke proses hukum. Padahal mereka sering diperkosa karena setiap hari lewat daerah yang sama karena hanya jalan itu yang dia tahu. Pemahaman akan kebutuhan disabilitas yang berhadapan dengan hukum sangat komplek, mulai dari pemahaman dari keluarganya,

ditingkat penyidikan, hingga persidangan yang perlu pendampingan yang intensif pada perempuan disabilitas intelektual. Mereka mengalami kekerasan seksual tidak hanya satu kali tapi berkali-kali, bahkan ada yang setiap minggu mendapatkan kekerasan. Keterbatasan informasi tentang seksualitas membuat mereka tidak paham sudah melakukan aktifitas seksualitas, bahkan sampai pada kondisi hamil.

3.1.3 Penentuan pilihan dan siapa serta apa yang mempengaruhi atas pilihan pribadi atas tubuh dan seksualitasnya.

Dalam hal penentuan pilihan perempuan disabilitas seringkali tidak mampu melakukan negosiasi dengan pasangannya. Perasaan mengalah dan ketakukan ditinggalkan pasangan akan membuat mereka diam dan mengikuti keputusan pasangannya, termasuk mendapatkan kekerasan dari pasangannya. Pada sebagian perempuan disabilitas seringkali tidak dapat menikmati aktifitas seksual seperti pada perempuan dengan cidera tulang belakang. Sebagian mereka tidak dapat merasakan aktifitas seksual mereka, meskipun ada juga yang tetap mampu menikmati. Ketika mereka tidak mampu menikmati aktifitas seksual, mereka akan merasakan sakit. Begitu pula pada perempuan disabilitas mental yang tidak memahami akan apa yang terjadi dalam tubuhnya, mereka hanya merasakan enak tanpa mampu mengetahui dampaknya. Dari kondisi ini perempuan disabilitas membutuhkan akses informasi alat kontrasepsi yang sesuai dengan kondisi tubuhnya, bukan pemaksaaan pemasangan kontrasepsi yang dilakukan pada sebagian perempuan disablitas dengan alasan agar tidak hamil terus menerus karena kekersaan seksual yang mereka dapatkan. Biasanya, alat kontrasepsi ini juga diberikan oleh keluarganya dan bahkan mengalami paksaan, terutama penyandang disabilitas mental dan intelektual. Untuk penyandang disabilitas tertentu, mereka mungkin kesulitan untuk memakai dan melepas kondom dan untuk mengkonsumsi hormon karena obat lain dan sebagainya sehingga perlu diberikan informasi, keterampilan dan dukungan. Alat kontrasepsi kepada perempuan dissabiltas ini seringkali diberikan oleh

keluarganya, bahkan dilakukan sterilisasi paksa. Ini banyak di temukan pada penyandang disabilitas mental (psikososial) dan intelektual. Hal ini terlihat dari wawancara yang dilakukan.

1) Perempuan disabilitas fisik.

Keputusan untuk menikah atau hidup bersama dengan pasangannya tanpa ikatan merupakan keputusan yang harus diputuskan oleh perempuan disabilitas fisik. Namun ada perbedaan mendasar dalam hal ini keputusan melakukan pernikahan tentu keputusan yang lebih gampang dengan konsekuensi yang yang relatif sederhana. Bilamana keptusan yang harus diambil oleh perempuan disablitas untuk tinggal bersama tanpa ada pernikahan resmi dan adat harus dia ambil dengan alasan budaya, konsekuensi yang akan perempuan tanggung lebih berat, mulai dari dicemooh oleh masyarakat sampai pada harus ditinggalkan pasangannya. Begitu juga pada saat mereka hamil, dukungan dari pasangan sangat di harapkan. Pada wawancara yang dilakukan, pasangan dengan pernikahan resmi mendapatkan dukungan baik dari pasangan maupun dari keluarganya. Sementara pada pasangan yang tanpa ikatan tentu dukungan yang diterima perempuan sangat terbatas.

Begitu juga ketika meraka memutuskan untuk menggunakan alat kontrasepsi. Pada disabilitas fisik mereka dapat menentukan pilihan terhadap alat kontrasepsi yang mereka inginkan.

2) Perempuan disabilitas netra.

Dalam hal keputusan melakukan perwakinan, para perempuan netra seringkali juga berpasangan dengan disabilitas netra dan sebagian berprofesi sebagai tukang pijat. Ketika terjadi kehamilan perempuan disabilitas netra mendapatkan dukungan dari pasangannya, namun karena perasaan takut akan hamil dan punya anak responden di Kupang tidak memberitahukan ke suaminya. Hal ini karena dia belum siap akan hamil dan punya anak. Keterbatasan informasi menjadikan dia ketakutan dan

cemas ketika punya anak. Namun berkat dukungan pasangannya, akhirnya dia mampu menerima kehamilannya dan rajin memerikasakan kandungannya ke puskesman terdekat.

Perempuan disabilitas netra dalam memutuskan menggunakan alat kontrasepsi rata-rata diawal mereka menggunakan KB susuk. Namun banyak yang terjadi pendarahan sehingga mereka memutuskan mengganti alat kontrasepsi setelah mendapatkan informasi yang tepat dari dokter. Pasangan mempunyai peran yang sangat diharapkan dalam penentuan keputusan menggunakan alat kontrasepsi.

3) **Perempuan disabilitas tuli.**

Kekerasan seksual banyak dialami oleh perempuan disabilitas tuli. Hal ini tergambar jelas pada responden di Kupang, dimana ia mendapatkan kekerasan seksual berulang, bahkan sampai mempunyai tiga anak dari laki-laki yang berbeda. Keterbatsan informasi akan pendidikan seksual dan alat kontrasepsi membuat kehamilan yang berulang dengan kekerasan. Responden ini tidak memiliki otoritas terhadap tubuhnya. Sampai kehamilan yang ketiga dia tetap tidak mendapatkan akses alat kontrasepasi. Sementara responden di Yogyakarta mengalami kekerasan dengan pelarangan keras dari suaminya untuk memakai alat kontrasepsi, sementara ibu terus memaksa dia mengguanakan alat kontrasepsi. Pertentangan ini yang sangat membuat dia bingung menentukan pilihan. Pilihan menggunakan alat kontrasepsi tanpa pertimbangan yang matang membuat dia memilih alat kontrasepsi yang salah, sehingga menyebabkan pendarahan selama 6 bulan. Hal ini membuat kemarahan yang besar pada suaminya.

Ketika terjadi kehamilan perempuan sangat membutuhkan dukungan dari pasangannya. Namun hal itu tidak didapatkan dari responden di Kupang. Akses kesehatan ke puskesmas tidak dia dapatkan sampai melahirkan. Baru pada kehamilan ke-3 responden memeriksakan kandungannya ke puskesmas.

4) Perempuan Disabilitas Mental

Pada perempuan disabilitas mental, mereka tidak mengetahui informasi akan alat kontrasepsi. Biasanya keluarga yang akan mewakili mereka untuk menyetujui memakai alat kontrasepsi dan tidak jarang juga terjadi pemaksaan pada mereka tanpa bertanya akan keinginanya. Sterilisasi banyak menjadi pilihan keluarga kepada anggota keluarganya yang mengalami disabilitas mental. Padahal sebenarnya perempuan disabilitas mental masih punya hak dan kewenangan untuk memilih alat kontrasepsi yang mereka inginkan.

5) Perempuan Disabilitas intelektual.

Dari responden yang sudah memiliki anak diketahui kalau dia ketika hamil tidak mengetahui sampai usia kandungannya 5 bulan, karena dia adalah korban pemerkosaan yang dilakukan oleh lebih dari 1 laki-laki. Orang tuannya yang membawa ke puskesmas. Namun begitu dia menikah dengan salah satu pelaku kekerasannya dan menerima anak yang dikandung responden, keluarganya tidak menerima dan melakukan kekerasan dengan mengatakan hal yang menyakitkan sehingga dia memilih untuk keluar dari rumah mertuanya. Keputusan ini bentuk dari perlawanannya. Dalam keputusan menggunakan alat kontrasepsi, dia tidak tahu. Tiba-tiba saja satu hari setelah melahirkan dia dipasangi alat kontraspesi spiral. Namun anehnya ketika dia mau melepas/mengganti spriralnya, itu sudah tidak ada di rahimnya.

3.1.4 Strategi seorang perempuan penyandang disabilitas mengatasi hambatan dan tantangan atas otonomi tubuh dan seksualitasnya.

Diskriminasi atas hak seksual dan reproduksi pada perempuan disabilitas masih berlangsung. Perempuan dengan disabilitas sering dianggap aseksual dan tidak menarik secara seksual dan tidak bisa melakukan aktivitas seksual. Kalaupun dipandang mampu melakukan aktifitas seksual, mereka dianggap aseksual moster; tidak bisa mengontrol dorongan seks dan perasaan seksual; tidak bisa bertangungjawab atau mengurus anak.[10] Hal ini terjadi karena pemahaman kultural, mitos dan stigma yang mempengaruhi pengalaman seksual penyandang disabilitas. Perempuan disabilitas mengalami beban bertingka. Di satu sisi dia harus melakukan kompromi penerimaaan atas kondisi tubuhnya, disisi lain dia harus mampu mengatasi diskriminasi dari masyarakat. Dalam riset yang dilakukan perempuan disabilitas, setiap ragam disabilitas memiliki strategi yang berbeda.

1) Perempuan disabilitas fisik.

Dari responden di Yogyakarta yang mengalami disabilitas sejak kecil, dia mengalami diskriminasi dari kecil. Bahkan ketika memutuskan untuk menikah dia masih mendapatkan diskriminasi dengan cibiran masyarakat dengan meremehkan; dianggap tidak bisa melakukan aktifitas seksual dan apalagi hamil dan mengurus anak. Namun dengan dukungan keluarga dan tekad yang kuat, responden ini mampu membuktikan meskipun disabilitas bisa punya anak dan mampu merawat anak dengan baik. Sementara responden di Kupang memilih untuk tidak menikah karena alasan kemiskinan. Responden Kupang menjalani kehamilannya dengan penuh perjuangan. Dia melawan semua diskriminasi yang ditujukan ke dirinya karena hamil di luar nikah. Untuk mengatasi

[10] Penchan Sherer, PhD, dari Department of Society and Health Faculty of Social Sciences and Humanities Mahidol University, Thailand dalam acara the 6th Asia Pacific Conference on Reproductive and Sexual Health and Right di Grha Sabha Pramana UGM

kesulitannya, responden di Kupang menitipkan anaknya kepada keluarganya agar dia akan mampu bekerja dan mendapatkan uang untuk menghidupi anaknya.

2) Perempuan disabilitas netra.

Hambatan perempuan disabiitas dalam hal aktfitas seksual hampir tidak ada. Mereka mampu melakuakn aktifitas seksual mereka dengan normal. Tindakan diskriminasi muncul justru dari masyarakat yang mempertanyakan soal pengasuhan anak mereka, dimana perempuan disablitas netra dianggap tidak mampu merawat anak. Namun mereka membuktikan bahwa dia mampu, termasuk mampu mengatasi terhadap stigma masyarakat dengan terus bekerja. Dukungan dari pasangan yang sangat berpengaruh pada kekuatan dan rasa percaya diri mereka.

3) Perempuan disabilitas tuli.

Perempuan disbilitas tuli rawan mendapatkan kekerasan seksual bahkan dari keluarga terdekat. Mereka tidak mengalami hambatan dalam aktifitas seksual, namun kerentanan pada tindak kekerasan sangat nyata pada perempuan disabilitas tuli Menurut responden DIY, cara yang dia lakukan adalah dengan berorganisasi dan berteman dengan banyak teman-teman tuli dan saling berdiskusi terkait dengan aktifitas seksual mereka. Peran keluarga menjadi penting untuk memastikan perempuan disabilitas mencari reverensi seksual pada tempat yang benar. Sementara responden di Kupang, karena akses informasi yang sangat terbatas serta kemiskinan keluarga, mereka menjadi korban kekerasan seksual berkali-kali.

4) Perempuan disabilitas mental.

Pada responden di Yogyakarta, cara dia untuk mengatasi hambatannya adalah dengan rajin minum obat. Dukungan keluarga sangat dibutuhkan untuk responden yang mengalami disabilitas pada usia dewasa. Sementara rensponden di Kupang, yang ia lakukan untuk mengatasi hambatan adalah dengan menjadi altet dan banyak bergaul dengan banyak orang.

5) Perempuan disabilitas intelektual.

Pada responden di Yogyakarta yang mengalami kekerasan seksual berulang, Hal yang dilakukan adalah dengan memakai alat kontrasepsi dan mengindari untuk bertemu dengan orang yang dia tidak suka. Dia akan menolak ketika diajak oleh laki-laki yang dia tidak suka. Dia sadar kalau melakukan aktifitas seksual akan mengalami kehamilan. Pengalaman dia hamil membuat dia selalu mengingatnya. Sementara responden di Kupang tetap menjaga jarak dengan pacarnya supaya tidak, melakukan aktifitas seksual.

3.1.5 Dukungan bagi perempuan penyandang disabilitas dapat menentukan pilihan atas tubuh dan seksualitasnya.

Dalam menjalani kehidupan, perempuan disabilitas mengalami diskriminasi sejak lahir. Ketika keluarganya miskin dan tidak siap dengan kehadiran anak disabilitas, maka yang akan terjadi akan mendapatkan diskriminasi dari keluarga. Namun berbeda dengan perempuan disabilitas yang lahir dalam keluarga yang berkecukupan. Dia akan mendapatkan dukungan meskipun terlambat, namun secara umun dia akan mampu melewati hidup dengan lebih baik. Keluarga masih menjadi faktor utama dalam hal dukungan pada perempuan disabilitas dan lebih khususnya ibu dari perempuan disabilitas. Dukungan dari kawan sebagian sangat dibutuhkan ketika keluarga tidak mampu memberikan dukungan untuk mengatasi hambatan yang ada. Kemudian yang terakhir dukungan dari

pasangann. Kenapa ini menjadi yang terkahir karena tidak semua perempuan mendapatkan pasangan yang memahami akan kondisi tubuh dan seksualitasnya. Sebagian perempuan disabilitas ketika mengalami kekerasan seksual otomatis dukungan dari pasangan tidak didapatkan.

3.2 Peta kebutuhan dukungan perempuan penyandang disabilitas dalam menentukan pilihan secara mandiri atas tubuh, seksualitas serta kebutuhan perlindungan khusus.

Berdasarkan kondisi dan situasi pada perempuan disabilitas dalam hal kebutuhan akan kebebasan menetukan pilihanan atas tubuh dan seksualitasnya serta kebutuhan perlindungan khusus, berikut dukungan yang diperlukan:

a. Memastikan adanya akses informasi pada perempuan disablitas akan pentingnya kesehatan reproduksi
b. Melakukan pendidikan seksualitas khusus pada penyandang disabilitas sesuai dengan ragam dan kebutuhannya secara intensif
c. Melibatkan keluarga dan orangtua dengan anak disabilitas dalam kegiatan-kegiatan pendidikan bagi disabilitas.
d. Adanya akses informasi yang jelas tentang alat kontrasepsi
e. Adanya layanan yang aksesibel terkait pelayanan /konseling yang berhubungan dengan alat kontrasepsi.
f. Adanya klink khusus bagi orang tua dengan disabilitas.

LAMPIRAN:

DESKRIPSI NARASUMBER

Deskripsi Elmi, Disabilitas Fisik (Kupang)

Pada 20 Februari 2021, pukul 18.00 WIB, Berti dan Elmi pergi ke rumah Desi (bukan nama sebenarnya). Kami menjemput dan mengajaknya makan. Akan tetapi, hari itu tidak ada satupun warung yang membolehkan pelanggannya makan di tempat. Rumah Desi ramai. Kami kemudian putuskan ke rumah saya (Berti). Wawancara dimulai pukul 19.00-20.30 WIB. Setelah selesai, kami bertiga makan malam.

Saya dan Elmi menelpon mobil yang mengantar kami untuk membawa Desi kembali ke rumahnya. Desi berangkat pukul 21.10 dan tiba dirumahnya pada 21-30. Saya dan Elmi memberikan uang Rp150.000 kepada Desi dan membayar transportasi mobil Rp100.000.

Identitas Informan

Desi adalah seorang perempuan difabel yang lahir di Kabupaten Timor Tengah Selatan. Gadis berusia 33 tahun ini memiliki rambut hitam lurus dengan panjang sepinggang. Desi memiliki ukuran tubuh sekitar 55 cm. Desi memiliki kelainan pada bentuk kaki sehingga membuatnya tidak bisa berjalan cepat. Desi kerap mengalami kesusahan saat menaiki kendaraan.

Desi belum menikah tetapi pernah pernah punya anak. Namun, anaknya meninggal ketika berusia 10 bulan. Desi tidak pernah bersekolah sehingga tidak bisa membaca dan menulis. Dia sehari-hari berjualan sirih pinang di kios kecil dekat terminal Kota Kupang. Desi memiliki seorang adik perempuan difabel yang baru saja lulus SMA. Postur tubuh adiknya sama seperti Desi.

Pemaknaan terhadap diri

Desi seorang difabel bertubuh mini mengalami kelainan pada kedua kakinya sehingga membuatnya kesulitan berjalan. Dia percaya diri dan bisa membaur dengan tetangga dan masyarakat dalam kehidupan sehari-harinya. Selain berjualan, Desi sehari-hari juga membantu mengasuh dan menjaga anak saudaranya yang baru berusia beberapa hari.

Desi pernah mendapat perlakuan diskriminasi. Tidak jarang anak-anak memanggilnya anak kecil. Di dekat tempatnya berjualan, pernah ada seorang laki-laki yang di*bully*. Melihat hal itu, Desi memberanikan diri menyemangati orang tersebut. "Kamu lihat saya seperti apa? Sama saja. Bukan berarti kamu sempurna, kamu hebat. Kamu punya tangan, saya punya tangan. Hanya dari postur saja yang berbeda," kata Desi.

Tidak hanya itu, pernah juga ada orang yang menatap sinis ke arah Desi. Kakak Desi yang melihat hal itu langsung marah. "Kenapa melihat lama ke adik saya seperti itu?". Desi hanya diam melihat kakaknya marah. Desi sudah tidak peduli lagi mengenai anggap orang pada dirinya. "Banyak orang yang membuat tidak nyaman tapi saya cuek saja." ujarnya.

Desi sudah berdamai dengan dirinya. Dia tidak merasa ada yang aneh dengan fisik tubuhnya. Dia justru kecewa dengan orang tuanya yang pilih kasih memperlakukan dia dan adiknya yang juga difabel (Yansri). Sejak kecil Desi tinggal dengan tantenya. Dia sedih karena merasa dibuang oleh orang tua. Waktu tinggal bersama tantenya Desi tidak bersekolah karena jaraknya terlalu jauh. *"*Saya sangat kecewa kenapa tidak sekolah seperti sodara yang lain yang bisa sekolah*"*, ungkapnya. "Orang lain bisa baca, saya tidak bisa baca," tambah Desi. Desi tidak pernah berpikir dan merasa beda karena lingkungan pertemanannya tidak membedakan satu sama lain. Dia bersyukur dengan kondisi tubuhnya.

Dia menyadari bahwa diri, tubuh, pikiran, dan suaranya berharga. Desi mengatakan bahwa tidak ada yang kurang pada dirinya. "Saya punya kaki, punya tangan lengkap, mata juga ada." Desi yakin Tuhan punya alasan memberinya tubuh seperti itu.

Saat naik kendaraan umum atau di terminal, orang sering menatapnya lama. Melihat hal itu, Desi langsung bereaksi dan bertanya, Ada apa Ibu? Pernah juga ada laki-laki yang melihatnya dengan tatapan yang dia tidak suka. "Mungkin mereka belum pernah melihat orang seperti saya," katanya. Kakak sepupu Desi pernah membentak orang yang memandangnya dengan cukup lama. Desi sendiri memilih diam saat itu karena dia tidak mau menambah masalah.

Seksualitas dan Reproduksi

Desi merasakan jatuh cinta pertama kali saat berusia 17 tahun. Dia pernah pacaran dengan pria bernama Andre. Mereka bertemu dan saling kenal di tempat berjualan. Desi juga mengatakan dirinya pernah pacaran dengan lebih dari 5 pria yang dikenalinya lewat HP.

Tentang seks yang saya tahu adalah berhubungan badan. Desi tertarik dengan laki-laki. Dengan pacar pertamanya Desi hanya bertemu di tempat berjualan. "Saya takut dan tidak mau diajak jalan, saya lebih jaga diri karena tidak tahu sifat laki-laki," ujar Desi.

Saat usia 25 tahun (tahun 2011), Desi mulai tahu tentang aktivitas seksual ketika bertemu dengan pacarnya. Pacarnya juga seorang difabel. Awalnya mereka hanya ciuman hidung. Pacarnya kemudian mengajak Desi berhubungan badan. Desi merasa senang saat berhubungan seperti suami istri karena suka sama suka. Desi senang dan mau setiap kali diajak berhubungan. Tetapi ada keinginan dari dirinya sendiri untuk berhenti karena takut hamil. Alasannya adalah karena hubungannya belum diketahui orang tuanya, sehingga dia takut kalau sampai hamil.

Meskipun senang tapi Desi takut karena belum ada kejelasan hubungannya. Desi tahu dampak dari berhubungan seksual, yakni hamil. Oleh karena itu, ketika berhubungan menggunakan kontrasepsi.

Desi akrab dengan seorang kader Posyandu dan kader mendatanya untuk bisa dipasangi susuk. Pacarnya mengizinkan Desi untuk memasang susuk. Desi beberapa kali datang ke rumah pacarnya yang berjarak 1 jam dari rumahnya. Keluarga Pacarnya tahu saat Desi datang. Desi disediakan kamar sendiri.

Saat pacaran, Desi senang sekali dipeluk pacarnya. Desi tidak pernah mengatakan kalau dia ingin berhubungan. Dia hanya berhubungan ketika pacarnya meminta. Desi memakai kode "mau dimanja" kalau ingi dipeluk pacarnya. Sang pacar lalu akan memeluknya. Tidak ada aktivitas seksual yang Desi tidak sukai karena suka sama suka dan pacarnya selalu melakukan posisi berhubungan seksual yang Desi suka.

Reproduksi

Saat ini periode menstruasi Desi tidak lancar. Bulan ini dia hanya haid satu hari. Padahal biasanya dua sampai tiga hari. Desi pernah punya keinginan punya anak setelah menikah. Akan tetapi, dia justru mengalami kehamilan yang tidak diinginkan (KTD) pada 2012. Kejadian itu terjadi saat dia mulai bekerja sebagai pengasuh bayi dan asisten rumah tangga di ketua organisasi difabel di NTT, yakni Nana (bukan nama sebenarnya).

Di rumah tersebut Desi tinggal bersama sahabatnya, Lena (bukan nama sebenarnya). Nana tinggal dengan suaminya dan salah satu anak angkat perempuannya yang berusia sekitar 5 tahun dan mengadopsi seorang bayi laki-laki korban pemerkosaan.

Tugas Desi ternyata bukan hanya mengasuh bayi tetapi juga mengerjakan pekerjaan rumah tangga lainnya. Dia bekerja dan tinggal di rumah tersebut dari Senin hingga Sabtu dan dibayar Rp250.000 per bulan. Dia membeli keperluan sehari-hari dari uang tersebut. Jika ada kegiatan-kegiatan organisasi, uangnya akan dipotong. Setiap hari kerja Desi dipebolehkan pulang ke rumahnya. Kesempatan itu dipakai Desi untuk berhubungan dengan pacarnya. Setelah 6 bulan bekerja (2012), Desi hamil. Dia sadar kehamilannya adalah akibat berhubungan seksual dengan pacarnya yang tidak menggunakan kontrasepsi. Pacarnya mengetahui kabar kehamilan ingin merawat anak dalam kandungannya itu.

Desi baru berani menceritakan kehamilannya setelah usia kandungan tiga bulan. Dia menceritakan ke sahabatnya, Lena. Lena tidak percaya. Akhirnya Lena menceritakannya ke Nana. Lena lalu diminta ke Apotek untuk membeli alat tes kehamilan. Keeskokan harinya Desi melakukan tes dan hasilnya positif. Nana kaget dan mengatakan hal-hal yang tidak baik pada Desi dan menyalahkannya kehamilannya. Selain itu, Desi juga tetap melakukan aktivitas-aktivitas berat, menjaga bayi, membersihkan rumah, mencuci pakaian pakaian dan kurang istirahat.

Desi pernah putus asa bahkan sempat mencoba menggugurkan kadungannya karena takut kalau orang tuanya tahu. Desi sempat mengkonsumsi Bodrex dan minum Sprite sebagai upaya menggugurkan kandungan. Sebab orangtuanya belum menyetujui hubungannya dengan sanga pacar. Bibinya juga baru tahu saat usia kehamilan 6 bulan. Selama hamil keluarganya hanya berpikir Desi gemuk.

Sahabatnya Lena menasehati agar merawat janin tersebut. Pacarnya juga mendukung agar janin dirawat dengan baik. Akhirnya Desi putuskan untuk terus merawat calon bayi. Saat usia kandungan masuk 8 bulan, Desi berhenti bekerja di Nana. Dalam menjalani kehamilannya Desi kadang ditemani Lena ke Puskesmas untuk periksa kandungan. Pacar Desi tidak pernah menemani periksa ke dokter. Dia hanya memberikan sedikit uang jika bertemu.

Waktu usia kehamilan sudah sembilan bulan, Desi memutuskan untuk ke RS Umum. Desi memaksa pacar mengantarnya untuk persiapan kontrol dan persiapan melahirkan. Dokter menganjurkan untuk operasi karena tubuh Desi yang tidak memungkinkan untuk melahirkan secara normal. Semua biaya persalinan terbantu dengan kartu BPJS. Biaya lainnya ditanggung oleh pacarnya. Proses persalinan lancar, Ibu dan bayi selamat. Namun, Bayi tersebut meninggal saat berusia 10 bulan.

Setelah melahirkan, Desi pulang ke rumah bibi dan merawat bayinya. Desi memberikan Asi ekslusif selama 3 bulan. Saat usia bayi 3 bulan, pacarnya meminta berhubungan seksual. Sebagai pasangan Desi menuruti. Desi tidak mau bertengkar dan buat dia marah. Desi memilih menjaga perasaan pasangannya.

Saat anaknya berusia 40 hari, pacarnya kembali ke Oesao untuk bekerja. Desi memutuskan untuk pulang ke rumah orang tuanya. Saat di rumah, saudara laki-laki Desi marah karena pacarnya tidak mengirimkan uang atau makanan. Desi akhirnya memutuskan untuk meninggalkan bayinya di rumah orangtuanya. Desi memilih kembali bekerja menjual sirih pinang di kupang dan meninggalkan bayinya selama 3 bulan.

Setiap ada uang selalu Desi mengunjungi anaknya. Desi kerap bertengkar dengan ayahnya dan mamanya saat mau kembali bekerja di kupang. Mamanya marah dengan pacar Desi. Adik laki-laki Desi juga mengancam pacaranya untuk tidak boleh bertemu Desi dan bayinya. Keluarga menganggap pacarnya sudah tidak ada. Akhirnya Desi memutuskan untuk kembali ke Kupang dan tinggal dengan bibinya.

Desi pulang menengok bayinya setiap dua minggu sekali saat ada uang. Desi pernah mencoba bawa pergi anaknya saat orang tuanya tidak ada di rumah. Namun, Desi dikejar sepupunya dan dipaksa turun dari bus. Adik kadung Desi (Yansri) melaporkan hal tersebut ke orang tua.

Keluarganya takut kalau ayah dari bayi tersebut diambil dari Desi. Desi sudah mencoba meyakinkan keluarganya kalau tidak mungkin pacarnya akan mengambil bayinya. Pacar Desi tidak terlalu memikirkan sikap keluarganya yang membenci dirinya, pacarnya bilang, "Terserah kalian kalau memang tidak mau saya bertanggung jawab atas anak itu. Asal kalian urus anak saya baik-baik," kata Desi menirukan perkataan suaminya.

Suaminya bilang ke Desi kalau dia sudah bertanggung jawab hingga bayi itu lahir. Tapi, Desi masih kecewa karena suaminya tidak mau membawa keluarganya saling bertemu supaya bisa diurus. Desi ingin menjadi pasangan suami istri yang sah, tetapi pacarnya belum bersedia.

Sistem Dukungan

Desi tidak pernah merasa terancam. Hanya saja saat hamil dia sering dibentak dan dimarahi oleh Nana dan suaminya. Mendapat perkataan-perkataan yang menyakitkan hati. Desi punya beban kerja yang berat. Desi menceritakan selama hamil mendapat dukungan dari Bunda Mery, teman organisasinya. Bunda Mery yang menasehatinya harus minum obat penambah darah. Saat hamil Desi tidak berani terlalu banyak mengeluh karena hidup menumpang dan bekerja di rumah orang.

Desi lebih memilih menyimpan perasaannya karena tidak mudah percaya dengan orang lain. Orang yang selalu memberikan dukungan dan membantu mengambil keputusan adalah pacar dan sahabatnya Lena. Dukungan yang diberikan suami berupa

kenyamanan, bantu menjaga bayi, memberikan uang buat keperluan anak dan dirinya. Lena juga bantu menasehati, membelikan alat pemeriksaan kehamilan, mengantar periksa ke dokter, membantu saat bekerja.

Sosial

Lena adalah sahabat karib Desi. Lena jadi tempat curhat dan teman berbagi saat suka dan duka. Lena jadi orang yang paling tahu kapan Desi senang dan sedih. Lena pernah berencana suatu saat nanti akan menyewa kamar kost sendiri supaya bisa tinggal sama Desi. Lena sendiri yang akan kerja dan mengurusi Desi supaya bisa tinggal bersama dengan bebas. Lena tidak mau pisah dengan Desi. Berat dan ringan selalu dihadapi bersama. Lena tidak pernah menghakimi apapun yang Desi lakukan. Lena selalu mendukung apapun keputusan Desi.

Deskripsi Dita, Disabilitas Netra (Kupang)

Pada tanggal 27 Februari 2021, pukul 17.00, Berti dan Elmi berangkat menuju kos Dita (bukan nama sebenarnya). Setelah tiba di kos Dita, ternyata orang lumayan ramai. Kamar Dita berukuran kecil dan di sebelah kamarnya tinggal tiga orang difabel Netra.

Setelah suami Dita meninggal 3 tahun lalu, Dita tinggal sendiri dengan anaknya yang berumur 8 tahun. Karena kondisi rumah Dita sedang ramai, kami mengajak Dita ke warung makan yang tidak jauh dari kosnya. Setelah keliling mencari akhirnya kami menemukan sebuah warung yang sepi. Hanya ada 2 orang penjaga warung yang ada di warung tersebut. Tempatnya cukup nyaman untuk bercerita.

Wawancara dimulai dari jam 18:00 sampai jam 19:30 WITA. Setelah selesai bercerita, Berti dan Elmi memberikan uang saku sebesar Rp150.000 kepada Dita. Total biaya makan malam kami bertiga sebesar Rp.95.000. Selesai makan, Berti dan Elmi mengantar Dita pulang ke rumahnya. Dita tiba di kamar kosnya pukul 19:45.

Identitas Informan

Dita adalah seorang perempuan yang lahir di Kabupaten Sabu. Perempuan berusia 32 tahun ini memiliki rambut hitam lurus dengan panjang sebahu. Dia bentuk wajah oval dan hidung mancung. Dita sapaannya memiliki tinggi tubuh 140 cm, dia pernah mengenyam pendidikan formal sampai kelas 3 SD. Dulunya Dita bisa melihat, namun akhirnya mengalami low vision dan lama-kelamaan tidak bisa melihat sama sekali. Dita melanjutkan pendidikannya di Panti Tuna Netra Hitbia, Kupang. Dia sudah menikah namun suaminya meninggal dua tahun lalu karena sakit. Kini Dita tinggal di kamar kos yang dihuninya sejak 2 tahun lalu. Sebelumnya dia menyewa kos di dekat gereja, tetapi tempat itu menyimpan banyak kenangan terhadap suaminya sehingga dia tidak nyaman dan memutuskan mencari kos baru. Setelah ditinggal suaminya, kini dia menjadi orang tua tunggal yang membesarkan anaknya.

Demi menyambung hidup, sehari-hari Dita bekerja membuat kemoceng. Dalam sehari dia mampu memproduksi 12 buah kemoceng. Dita membeli sendiri bahan-bahan yang dibutuhkan. Kemoceng buatannya ia titipkan di depan Toko Swamitra Swalayan Oebobo untuk dijual.

Selain membuat kemoceng, Dita juga berprofesi sebagai tukang pijat panggilan, baik laki-laki maupun perempuan. Untuk pasien laki-laki dia mensyaratkan harus sudah menikah. Dita tidak pernah mematok tarif pijat pada pelanggannya. Tapi rata-rata pelanggannya membayar minimal Rp250.000 untuk satu jam.

Dalam memasarkan kemocengnya Dita meminjam lapak temannya, namun Dita harus menunggu temannya selesai berjualan dulu baru dia tempati. Dulu sebelum suaminya meninggal Dita punya lapak sendiri, namun sejak suaminya sakit mereka pulang kampung ke Lembata. Setelah kembali lapaknya sudah ditempati oleh orang lain.

Dalam melakukan aktivitas sehari-hari Dita tidak memiliki hambatan, namun kondisi Covid-19 membuatnya kesulitan untuk mendapatkan pekerjaan. Dita mengatakan kondisi penglihatannya membuatnya kesulitan mencari pekerjaan untuk bertahan hidup. Terlebih dia harus menyesuaikan ketika berada di lingkungan baru.

Pemaknaan Terhadap Diri

Dita adalah seorang difabel sensorik yang tidak bisa melihat sama sekali. Meski begitu, dia tetap semangat dan merasa tidak punya perbedaan dalam hidupnya. Dia sangat percaya diri dan bisa berbaur dengan tetangga, teman organisasi dan masyarakat. Dia bisa berjalan kaki, mengurus anak dan bekerja.

Selama ini belum pernah ada yang mengejek Dita. “Orang yang mengejek saya di belakang mungkin ada tetapi tidak ada yang di depan saya langsung. Teman-temannya selama ini baik kepadanya. Namun Dita sedikit merasa minder karena kondisi penglihatannya. Dia merasa malu karena tidak memiliki pekerjaan lain selain menjual kemoceng dan tukang pijat.

Situasi pandemi Covid-19 berdampak besar kepada Dita. Dia takut jika terpapar virus Covid-19 dan tidak ada yang akan mengurus anaknya. Dita juga sangat khawatir jika penghasilanya tidak lagi cukup memenuhi kebutuhan hidupnya dan anaknya. Selama pandemi Dita jarang keluar. Sementara dia harus membayar sewa kos Rp250.000 per bulan. Sebelum pandemi, hasil jualan kemoceng Dita lumayan laku. Untuk membayar sewa kos Dita dibantu adiknya yang ada di Rote. Adiknya mengirimkan Rp500.000 untuk membayar sewa kos selama dua bulan.

Meskipun dalam situasi Covid, pelanggan pijat Dita dalam sebulan sekisar 3 sampai 4 orang. “Ya mungkin mereka merasa kasihan sama saya atau mungkin merasa senang dan kadang mereka kasih itu Rp.250.000, Rp.300.000 bahkan kadang sampai Rp.500.000. Tapi itu mereka sendiri yang kasih, saya tidak minta segitu”. Pada umumnya tarif pijat selama satu jam sekitar Rp.150.000.

Dita mewajibkan yang datang pijat bagi yang sudah berkeluarga harus datang dengan pasangannya. Dita tidak mau melayani pelanggan yang datang seorang diri. Dia tidak mau dituduh macam-macam oleh orang di sekitarnya. Dita sadar bahwa diri, tubuh, pikiran dan suaranya sangat berharga.

Selama hidupnya Dita pernah beberapa kali mengalami diskriminasi atau direndahkan. Pertama, ketika dia memijat pelanggan di Hotel Orsip. Setelah Dita memijat pelangganya, tiba-tiba ada dua laki-laki datang meminta jasanya dengan nada menggoda, namun Dita tolak. Dita tidak mau diperlakukan oleh pelanggan seperti itu. Kedua, dia pernah dipukul oleh suaminya karena merahasiakan kehamilannya yang sudah berusia 4 bulan. Suaminya berpikir bayi yang dikandungnya akibat selingkuh dengan pria lain. Ketiga, banyak perempuan di sekitarnya mengatakan kepadanya kalau perempuan difabel itu aseksual. Mereka mengatakan bagaimana bisa difabel kawin dengan difabel. Dita langsung menjawab kalau tubuh difabel dan non difabel itu sama saja. Letak payudara dan organ reproduksi juga sama. Dita telah membuktikan kepada banyak orang bahwa perempuan bisa punya anak dan mampu merawatnya dengan baik.

Seksualitas dan Reproduksi

Dita merasakan jatuh cinta pertama kali pada 2006, waktu itu umurnya baru 19 tahun. Dia Dengan pacar pertamanya menjalani hubunga 1 tahun 4 bulan. Pacar pertamanya adalah sesama netra asal Belu dan pernah sama-sama tinggal di Panti Hitbia. Dia putuskan pacar pertamanya pada tanggal 8 April 2007 karena alasan cemburu. Setelah putus Dita memutuskan untuk berdiam diri dan tidak mau untuk diganggu. Beberapa bulan kemudian dia mendapatkan kekasih lalu menikah pada Agustus 2007.

Dita tidak paham tentang seks, aktivitas seksual dan seksualitas. Saat pacaran dengan pacar pertamanya mereka tidak pernah melakukan hubungan apapun. “Dipanti kami tidak diberi kebebasan, kalau sampai ketahuan berhubungan, itu sudah tanda merah.” Di panti dibolehkan pacaran tetapi tidak boleh melebihi batas.”Pacaran yang sampai berciuman, meraba di susu atau di kemaluan itu tidak di perbolehkan” terang Dita. Di Panti tidak punya waktu banyak untuk pacaran. Pasangan diberikan waktu pacaran jam 19.00-20.00.

Dita pertama kali bertemu suaminya di Panti Tuna Netra. Semasa pacaran mereka tidak pernah berciuman karena mereka sudah membuat kesepakatan bersama. “Kalau kamu cinta saya, kamu tunggu saya, kamu jaga saya punya perasaan karena kita sama-sama tidak lihat jangan sampai saat kita berciuman ada orang dibelakang kita ada intip nanti kita yang malu,” pesan Dita pada suaminya dulu.

Dita melakukan hubungan seksual pertama kali suaminya pada 12 januari 2012 ketika mereka sudah keluar dari panti dan tinggal bersama di kos-kosan. Mulanya mereka kencan di kos. Suaminya berinisiatif melakukan aktivitas seksual dengan mencium. Dita merasa geli dan senang saat pertama kali dicium oleh suaminya. Senang karena sudah bisa tinggal berdua meskipun belum menikah resmi. Mereka tinggal berdua bukan karena paksaan tetapi karena mereka saling suka.

Saat pertama kali melakukan hubungan seksual Dita menangis. Dia merasa kesakitan dan menendang suaminya. Dia kemudian ingat perkataan Ibunya bahwa berhubungan seksual itu awalnya sakit. “Karena kata ibu saya, kalau berhubungan itu sakit katanya jadi saya takut, menangis dan saya tendang dia’’.

Satu minggu kemudian baru mereka melanjutkan lagi hubungan seksual. Sebelumnya setiap hari suami meminta untuk melakukan aktivitas seksual tetapi dia tidak mau. Dita mau berhubungan lagi karena takut kehilangan. “Karena saya sudah tidur dengan dia satu kali jadi kalau saya tidak mau lagi berarti nanti dia sudah berpindah dengan perempuan lain lagi”. Karena takut kehilangan Dita rela melanjutkan hubungan seksual sampai hamil. “Kalau saya tidak melayaninya nanti dia bisa berpaling, pergi meninggalkan dan pergi dengan perempuan lain.”katanya.

Saat pertama kali berhubungan dan terasa sangat sakit, saat itu Dita tidak mau lagi untuk melanjutkan hubungan. Tapi suaminya selalu meminta, dan merayu. Dita tetap menolak. Suami tetap membujuk. Mereka kemudian melanjutkan hubungan seksual dua kali dalam seminggu “Sebagai suami kita harus layani, tetapi kalu terus menerus kalau dia minta tiap malam juga saya tidak mau”.

Berhubungan seksual bisa mengakibatkan kehamilan. Dita mendengar dari orangtuanya. Orang tuanya juga bilang kalau sering berhubungan seksual dengan ganti-ganti pasangan bisa menyebabkan penyakit. Dita sadar dengan akibat dari berhubungan seksual dengan suaminya. Dia sudah terlanjur berhubungan dengan suami maka dia harus siap hamil. Suaminya juga siap untuk tanggung jawab.

Dita selalu bilang ke suaminya jika ingin berhubungan seksual. Dia tidak memendam hasratnya. Dia mengajak suaminya berhubungan seksual. Kadang Dita kecewa ketika suaminya tidak ingin melakukan hubungan seksual karena suaminya capek, namun itu hanya sekali saja terjadi. Hal yang paling dia suka dari suami saat berhubungan seks adalah dicium di bagian pipi. “Suka cium di pipi karena dia punya jenggot kena di pipi,” kata Dita. Dari setiap hubungan seksual Dita selalu menikmati.

Reproduksi

Dita mengetahui dirinya hamil pada 12 Februari 2020 setelah satu bulan tidak menstruasi. Dia terakhir menstruasi pada 12 Januari 2020. Dita bersama dengan temannya seorang difabel netra pergi periksa ke dokter, saat di USG dia terbukti hamil. Setelah kembali ke kos, ia belum memberitahukan suamin kalau dia hamil. Dia pun masih berhubungan seksual dengan suaminya sampai usia kandungannya 5 bulan.

Suaminya tahu Dita hamil saat usia kehamilan 4 bulan 15 hari. Suaminya marah setelah tahu Dita hamil dan tidak memberitahu. "Saat itu saya dipukul, dimarahi, dikatakan perempuan sundal, perempuan tidak baik karena saya tidak cerita ke dia. Saat itu saya takut karena dia tuna netra tidak melihat, jangan sampai dia pukul saya di perut. Dia pukul di lengan pakai gagang sapu karena dia netra, dia tidak lihat saya jadi tabrak saya." Kata Dita.

Setelah perkelahian itu mereka 2 minggu tidak saling bicara. Ketika tidur pun tidak pernah bersentuhan. Mereka berdamai kembali saat suami minta maaf. Setelah itu suami mulai menyayangi dia. Dita tidak diperbolehkan untuk cuci piring, cuci pakaian, membersihkan rumah dan semua aktivitas berat lainnya. Suaminya yang melakukan semua aktivitas di rumah bahkan mencari nafkah juga suami yang melakukan.

Saat memeriksa kehamilan ke puskesmas Dita selalu bersama temannya yang difabel. Dita tidak bisa ditemani periksa suaminya karena suaminya difabel netra. Jadi suaminya tinggal di kos.

Saat melahirkan Dita mengalami kesulitan. Penyebabnya karena beberapa minggu sebelum melahirkan dia melakukan banyak aktivitas berat. Dia mengankat air yang jaraknya sekitar 100 meter. Saat itu ia merasa kesakitan seperti ada bola di pahanya. Setelah seharian beraktivitas, malam harinya baru dia merasa sakit, rasa seperti mau buang air kecil dan air besar. Setelah sampai di kamar mandi yang darah ternyata darah. Dokter sebelumnya juga sudah bilang bahwa kandungan Dita lemah dan tidak boleh banyak beraktivitas fisik.

Dita kebingungan setelah tahu yang bahwa cairan yang keluar ternyata darah. Bayi yang dikandungnya bergerak-gerak dan seperti memukul dari dalam. Malam itu Dita merasakan sakit dan dia tahan sakit itu sampai jam 5 pagi.

Paginya teman Dita yang seorang difabel yang mengantar Dita ke Puskesmas bersama suami. Mereka sampai di Puskesmas jam 06.30 pagi. Dokter belum ada yang datang. Satu-satunya yang ada hanyalah petugas kebersihan.

Setelah hampir dua jam menunggu barulah Dita diperiksa kandungannya pada jam 8 pagi. Pemeriksaan selanjutnya dilakukan pada jam 11 siang. Pada siang itu juga air ketuban Dita pecah. Selang beberapa jam kemudian janin yang dikandungnya lahir dengan kondisi tidak menangis. Mengetahui hal itu dokter berinisiatif menyiram bayi dengan air baru bayi tersebut menangis. Setelah menangis dokter menidurkan bayinya ke badan Dita untuk menyusui. Ditaknya lahir dengan bobot 3,2 kg.

Dita memilih memakai KB saat usia anaknya 9 bulan 14 hari. Dia memakai KB susuk atas persetujuan suami. Suaminya menyetujui karena didesak oleh Dita dan tidak mau suaminya selingkuh karena tidak bisa berhubungan seksual.

Sistem Dukungan

Dita selalu merahasiakan setiap masalah yang menimpa keluarganya. Dia tidak pernah cerita apapun kepada teman-temannya jika terjadi suatu masalah. Menurut Dita perkara dalam rumah tangga tidak boleh ada orang lain yang tahu. Sebelumnya suami adalah support system utama yang dimiliki Dita. Tapi setelah suaminya tiada, teman-temannya yang selalu hadir setiap Dita butuh bantuan atau dukungan.

Sosial

Dita punya banyak sahabat. Sahabatnya itulah yang membantu di kala suka dan duka. Sahabatnya yang selalu ada membantu adalah perempuan difabel yang mendampinginya sejak dia hamil, melahirkan bahkan sampai sekarang saat anaknya sudah berusia delapan tahun.

Deskripsi Tania, Disabilitas Tuli (Kupang)

Pada tanggal 16 Maret 2021, jam 08.30, Elmi berangkat dari Kupang ke Balai Rehabilitasi Sosial Penyandang Disabilitas Sensorik Rungu Wicara (BRSPDSRW) yang berlokasi di Kabupaten Kupang. Seharian udara sangat cerah. Jarak dari rumah ke Panti Efata jauh sehingga Elmi memutuskan untuk pergi ke Panti Efata dengan menggunakan GrabCar. Awalnya, Elmi janjian akan bertemu dengan Bapak Lukas Patipeilohy, Koordinator Fungsional Pekerjaan Sosial dan Penyuluhan Sosial, tetapi ternyata dalam perjalanan ke Naibonat, Bapak Lukas dan Kepala Panti sedang perjalanan dinas. Setelah tiba di Panti Efata, Elmi harus izin terlebih dahulu kepada Kepala Substansi bagian TU, kedua Elmi harus izin lagi kepada Bapak Sem Kasse sebagai penyuluh sosial, dan Bapak Maksen Babnesi sebagai pekerjaan sosial untuk menyampaikan maksud dan tujuan kedatangannya di panti. Akhirnya, Elmi mendapat izin wawancara dengan salah satu difabel Tuli yang ada di panti.

Bapak Maksen dan Bapak Sem Kasse mengantar Elmi dan Ibu Yori, pendamping di asrama sekaligus yang akan membantu Elmi untuk menjadi juru bahasa isyarat. Mereka kemudian berjalan ke asrama perempuan. Sambil menunggu kedatangan Tania (bukan nama Sebenarnya), difabel Tuli, yang sedang belajar keterampilan menjahit di kelasnya, Elmi dan Ibu Yori mendiskusikan cara permasalahan Tania dengan menggunakan bahasa yang sangat sederhana. Setelah beberapa menit kemudian, akhirnya Tania datang menemui Elmi dan Ibu Yori. Elmi menjelaskan maksud dan tujuan kedatangannya kepada Tania, dengan dibantu oleh Ibu Yori menggunakan bahasa isyarat.

Kami membuat Tania merasa nyaman untuk menceritakan pengalaman hidupnya kepada kami. Setelah 15 menit kami bertiga bercerita di ruang tamu, akhirnya kami pergi ke satu kamar yang sepi. Hanya kami bertiga yang berada di dalam ruangan itu, tempat yang nyaman dan aman untuk kami.

Wawancara dimulai dari jam 10:36 sampai 13:25 WITA dibantu oleh Berti melalui telepon seluler. Responden sangat terbuka dengan hidupnya dan mempraktikkan aktivitas-aktivitas yang dia ingat dalam memorinya. Elmi juga menggali lagi informasi dengan menghubungi keluarga Tania di kampung via telepon.

Setelah selesai bercerita, Elmi memberikan uang Rp150.000 kepada Tania. Elmi juga memberikan uang Rp300.000 kepada Ibu Yori untuk upah menjadi juru bahasa isyarat. dari Yayasan SIGAB Tania dan Ibu Yori mengantar Elmi pulang ke kantor untuk mengucapkan terima kasih kepada Pak Maksen dan Pak Sem yang sudah mengizinkan Elmi untuk wawancara dengan Tania. Tania kembali ke kelas untuk melanjutkan aktivitas menjahitnya, sedangkan pukul 13:35 Elmi naik Grab untuk kembali ke Kupang.

Identitas Informan

Tania adalah seorang perempuan muda putih dan cantik, lahir pada 11 November 1986 di Sabu, Kabupaten Sabu. Perempuan berusia 34 tahun ini memiliki rambut hitam lurus yang panjangnya sampai di bawah bahu. Bentuk wajahnya bulat dan hidungnya mancung. Tania sapaannya, memiliki tinggi badan sekitar 143 cm. Perempuan cantik ini tidak pernah mengenyam pendidikan di bangku sekolah. Tania merupakan anak pertama dari 9 bersaudara, di antaranya 4 laki-laki dan 5 perempuan. Tania mengalami disabilitas Tuli dari kecil, saat masih bayi, sehingga setiap hari aktivitasnya hanya membantu ibunya di rumah seperti menyapu dan mencuci piring. Pada 21 Februari 2021, Tania dibawa oleh petugas Panti Efata untuk belajar keterampilan di sana. Dari semua keterampilan yang ada di panti, Tania lebih menyukai keterampilan menjahit.

Saat bercerita dengan Tania, Elmi sangat terbantu dengan keberadaan Ibu Maria Yorita Usfinit, perempuan kelahiran 32 tahun. Selain menjadi JBI (juru bahasa isyarat), Ibu Yori juga merupakan ibu pengasuh asrama bagi anak-anak difabel Tuli di asrama perempuan.

Setiap hari, aktivitas Tania dan teman-teman yang ada di panti adalah belajar keterampilan sesuai dengan minat masing-masing. Tania menekuni keterampilan menjahit, dan saat ini ia sedang belajar menjahit baju.

Tania memiliki sedikit hambatan dalam beraktivitas sehari-hari karena susah berkomunikasi dengan orang lain. Dia sangat cerita dengan teman-temannya yang ada di asrama. Jika ada tugas, dia sering bertanya kepada teman-temannya. Namun, Tania sangat tertutup ketika menceritakan masalah hidupnya. Ia juga harus menyesuaikan ketika berada di lingkungan atau ketika berada di tempat yang baru. Tania memiliki orientasi mobilisasi yang baik.

Pemaknaan terhadap Diri

Tania, difabel sensorik wicara yang memiliki kelainan pada saat berbicara. Dia sangat semangat ketika berbicara. Dia merasa tidak berbeda dalam menjalani kehidupan sehari-hari. Dia sangat percaya diri dan bisa berbaur dengan tetangga, teman organisasi, dan masyarakat. Selain itu, ketika masih di Sabu, Tania membantu ibunya mengurus rumah tangga dan mengurus anak.

Pada tahun 2006, teman-temannya malu dan tidak mau berteman dekat dengan Tania karena ia hamil. Ia merasa sedih karena laki-laki yang ia cintai pergi meninggalkannya. Dia tidak tahu harus mencari laki-laki tersebut di mana. Tania berkata, “Saya susah karena laki-laki itu jalan, meninggalkan saya, dan tidak tahu mau cari laki-laki itu di mana.” Tania juga malu saat mandi, ia tidak mau teman-temannya melihat bekas melahirkan di perutnya.

Laki-laki pertama yang menghamili Tania adalah tetangganya, yang jarak rumahnya tidak begitu jauh, hanya berjarak 3 rumah dari rumahnya Tania. Mereka tinggal di dusun yang sama. Saat hamil, orang tua dan keluarga Tania tidak mau mencari masalah, mereka justru bersyukur bahwa kehamilan Tania adalah berkat.

Adik Tania mengatakan, “Waktu hamil anak pertama, Bapak tidak mau untuk cari masalah dengan laki-laki itu, tetapi Bapak menganggap itu adalah berkat dalam rumah.” Saat hamil sampai melahirkan, laki-laki tersebut masih sering ke rumah Tania, dan selama Tania hamil ia masih mendapat perhatian dari laki-laki tersebut. Anak pertama dari Tania diangkat oleh keluarga bapak kecil yang tinggal di Lembata.

Tanial hamil anak kedua dengan laki-laki yang berbeda. Laki-laki tersebut sangat dekat dengan Ayahnya Tania karena sering datang ke rumah Tania untuk makan, minum, dan bermain. Mereka tinggal di kampung yang sama, tetapi beda dusun. Tania tinggal di Dusun 1, sedangkan laki-laki tersebut tingal di Dusun 3. Saat berhubungan sampai Tania Hamil, laki-laki tersebut tidak pernah lagi datang di rumah Tania. Adik Tania mengatakan, “Saat hamil, laki-laki itu tidak pernah lagi datang di rumah, sama sekali *Andide* (tidak) perhatian dan *katong* (kita) juga *Andide* (tidak) anggap dia.” Anak kedua dari Tania diangkat oleh keluarga Bapak Kecilnya yang berada di Kabupaten Timor Tengah Utara karena mereka tidak memiliki anak.

Tania hamil ketiga dengan laki-laki yang berbeda, mereka sesama difabel Tuli. Laki-laki itu adalah orang yang Tania cintai, tetapi tidak mendapatkan restu dari orang tuanya, meskipun sudah memiliki seorang anak dari laki-laki tersebut. Tania menyadari bahwa diri, tubuh, organ tubuh, pikiran, dan suaranya berharga dan cantik. Dia mengatakan, “Saya berarti dan berharga karena cantik.”

Seksualitas dan Reproduksi

Seumur hidupnya, Tania baru pertama kali ke salon pada saat masuk di Panti Efata tahun 2021. Saat itu, Tania pergi untuk meluruskan rambutnya di salon yang ada di panti. Setelah selesai dari salon, dia mendapat pujian dari instruktur salon bahwa dirinya cantik. Ia juga mendapat pujian dari teman-temannya, “Bagus”.

Tania tidak mengerti tentang seks, aktivitas seksual, dan seksualitas. Saat berhubungan dengan laki-laki petama, itu bukan atas dasar pacaran, tetapi Tania sedang menyapu di depan halaman rumah. Saat itu, laki-laki bernama Andi (bukan nama sebenarnya) sedang lewat depan rumahnya dan memberikan simbol isyarat *love* kepada Tania. Tania juga ternyata suka pada Andi. Saat itu, Andi kemudian mengajak Tania

untuk pergi, tetapi Tania tidak tahu ke mana Andi mengajaknya pergi. Ternyata, mereka pergi ke sebuah rumah yang tidak berpenghuni. Saat mengajak ke rumah itu, Andi menggunakan motor, sedangkan Tania berjalan kaki. Andi yang menunjukkan rumah kosong itu kepada Tania. Tania mengatakan, "Andi suruh jalan lurus terus ke rumah kosong untuk tidur jam 3 sore."

Sebelum mereka tidur, Andi mencium pipi, mata, dahi, bibir, dan berlanjut ke berhubungan badan. Andi memaksa membuka pakaian Tania. Saat itu, Tania menolak, tetapi Andi memaksa untuk berhubungan badan dengan Tania. Ia mengatakan, "Saat itu saya tolak untuk berhubungan badan, tetapi Andi yang tarik kembali tangan Tania untuk melanjutkan hubungan tersebut dengan paksaan sampai semua badan sakit". Saat berhubungan pertama kali Tania merasa sakit dan takut, sampai keluar darah dari kemaluannya. Usai berhubungan badan secara paksa, Andi mengantar Tania pulang kembali ke rumah. Tania juga menceritakan kejadian tersebut kepada adiknya.

Bukan hanya sekali, Tania dan Andi sering melakukan hubungan badan. Hal ini terjadi bukan karena mereka saling suka, tetapi Andi yang memaksa untuk berhubungan badan sebanyak 4 kali di rumah kosong hingga akhirnya Tania hamil. Saat Tania telah hamil 1 bulan, mereka putus. Tania mengetahui kehamilannya dari oma dan opanya. Saat itu, ia muntah dan orang tuanya merasa curiga. Tania mengatakan "Ayah tanya, lu kenapa, sampai marah-marah baru Tania memberitahukan kepada orang tuanya kalau ia sedang hamil, tidur dengan Andi." Saat mengetahui kehamilannya, ia sangat takut.

Saat hamil, ayah Tania tidak mau membawanya ke puskesmas untuk memeriksa kandungan. Tania melahirkan anak pertamanya di rumah dan tidak pernah dibawa ke puskesmas.

Hingga saat ini, Tania tidak mengalami masalah saat menstruasi. Saat berhubungan dengan laki-laki kedua juga karena paksaan. Laki–laki tersebut bernama Rizal (bukan nama sebenarnya). Rizal memaksanya untuk berhubungan. Rizal mencakar tangan Tania dan menggigit bahunya. Tania mengatakan laki-laki kedua memaksanya untuk berhubungan. Saat itu secara paksaan sampai bekas luka tersebut masih ada pada bagian tangan kiri Tania. Mereka melakukannya pada malam hari, saat

Tania sedang mandi malam di kamar mandi. Orang tua Tania mengetahui hal tersebut, mereka kemudian mengusir Rizal untuk pulang. Namun, setelah itu Rizal tetap memberanikan diri untuk datang ke Rumah Tania.

Malam saat semua keluarga Tania tidur, sekitar pukul 01:00 atau pukul 02:00, laki-laki tersebut datang. Kamar tidur Tania tidak memiliki pintu. Saat Rizal membangunkan Tania, Rizal menutup mulutnya supaya tidak berteriak. Rizal lalu mencakar dan menarik tangan Tania, membawanya keluar kamar dan pergi ke samping kamar mandi lalu mulai berhubungan badan dalam posisi tidur di lantai yang kotor.

Mereka berhubungan sebanyak 2 kali, Tania akhirnya hamil anak kedua. Saat hamil anak kedua, kedua orang tuanya membawa Tania ke Puskesmas untuk melakukan tes urine dengan menggunakan alat tes kehamilan. Di sana, Tania tidak mengalami diskriminasi, dia justru mendapatkan pelayanan yang sangat baik. Keluarga juga mengetahui kehamilan kedua pada saat ia muntah-muntah.

Tania merasakan jatuh cinta tahun 2014 sejak umur 28 tahun. Dia menjalani hubungan dengan pacar ketiganya yang sesama teman Tuli. Temannya berasal dari Sabu. Mereka tinggal di desa yang sama. Saat itu, mereka saling suka. Saat berhubungan dengan Jen, gaya yang paling disukai Tania dari Jen adalah tidur. Tania sangat menyukai Jen saat mereka tidur bersama karena mereka saling menyukai satu sama lain. Mereka melakukan hubungan tersebut sampai Tania hamil. Sampai saat ini Tania tidak mengetahui bentuk alat kontrasepsi. Saat berhubungan dengan pacarnya, mereka tidak menggunakan pengaman apa pun hingga Tania hamil anak ketiga.

Saat hamil sampai melahirkan, Jen masih sering datang ke rumah Tania. Namun, orang tua Tania tidak menyetujui hubungan mereka sampai tahap selanjutnya. Sampai sekarang, Tania dan Jen masih saling mencintai satu sama lain.

Saat Tania hamil anak ketiga dengan laki-laki yang juga merupakan difabel Tuli, adik Tania mengatakan, “Waktu hamil anak ketiga, laki-laki (masih) keluarga jauh dan rumah juga berjauhan. Mereka sama-sama berkebutuhan khusus juga, Tuli bisu.” Mereka suka sama suka, laki-laki tersebut siap untuk bertanggung jawab dan ingin untuk membawa anak tersebut ke rumahnya. Namun, belum ada pertemuan keluarga,

dari keluarga laki-laki dan keluarga perempuan. Adik Tania mengatakan, “Hamil sampai melahirkan itu dia ada, karena anak laki-laki, dan dia mau ambil, tapi belum ada pertemuan keluarga dari kedua pihak, masa mau ambil orang *pung* (punya) anak sembarangan. Keluarga juga tidak setuju karena dianggap tidak menghargai orang.” Anak ketiga dari Tania kini berusia 5 tahun dan tinggal bersama dengan orang tua Tania di Sabu.

Sistem Dukungan

Tania terancam, tetapi tidak mengetahui cara menolong diri atau mencari pertolongan karena keterbatasan berkomunikasi. Tania mencoba menceritakan kejadian buruk yang dia alami, tetapi keluarga tidak membela Tania dan membiarkan pemerkosa melakukan berulang kali. Keluarga hanya menerima keadaan Tania dan membiarkan Tania melahirkan anaknya. Ketika ada masalah, Tania juga bercerita kepada kedua orang tua dan adik-adiknya. Tania mengatakan saat selesai berhubungan dengan laki-laki yang mengajaknya, Tania menceritakannya kepada ayah atau adik-adiknya. Selama ini yang mendukung Tania adalah kedua orang tua dan adik-adiknya. Ayah adalah pengambil keputusan dalam hidup Tania.

Sosial

Tania memiliki beberapa sahabat di panti. Salah satu teman dekat Tania adalah Rika. Menurut Tania, manfaat dari sahabat adalah sebagai teman cerita dan teman untuk saling membantu. Namun, Tania sangat membenci teman laki-laki karena suka mencium dan berbuat hal yang tidak menyenangkan. Alasan lain Tania membenci laki-laki adalah karena dia pernah mengalami trauma di masa lalu seperti dipaksa untuk berhubungan seksual.

Deskripsi Maria, Disabilitas Mental (Kupang)

Pada tanggal 25 Maret 2021, pukul 11:15, Berti dan Elmi berangkat dari rumah ke rumahnya Maria (bukan nama sebenarnya) di Kota Kupang. Saat itu, masih pagi dan cuaca juga cerah sehingga Berti dan Elmi memutuskan untuk pergi ke rumah Novi dengan menggunakan motor. Pada tanggal 24 Maret malam, Elmi menghubungi salah satu temannya, Kaka Nila Kulata, perawat yang bekerja di Rumah Sakit Jiwa Naimata via telepon untuk meminta rekomendasi perempuan orang dengan gangguan jiwa yang sudah sembuh dan pernah dirawat di rumah sakit jiwa.

Saat dihubungi, Kaka Nila (bukan nama sebenarnya) dengan senang hati bersedia dan mau membantu. Namun, Kaka Nila mengatakan bahwa difabel mental perempuan mayoritas telah berusia 40 tahun ke atas. Memang ada perempuan difabel mental berusia di bawah 40 tahun, tetapi mereka semua tinggal di Kabupaten Kupang. Sehingga, Kaka Nila merekomendasikan kepada perempuan difabel mental yang tinggal di Kota Kupang. Sebelum Elmi menelepon saudara Maria yang bernama Pak Santo (bukan nama sebenarnya), Kaka Nila sudah menghubungi Pak Santo terlebih dahulu. Kaka Nila telah meminta persetujuan apakah saudara Pak Santo, Maria, yang merupakan difabel mental bersedia untuk diwawancara atau tidak. Lima menit kemudian, Elmi mendapat telepon dari Kaka Nila bahwa Maria bersedia untuk diwawancarai oleh Berti dan Elmi. Kaka Nila juga meminta izin kepada Pak Santo untuk memberikan nomor teleponnya kepada Elmi.

Elmi kemudian menghubungi Pak Santo. Dia menjelaskan maksud dan tujuan mewawancarai Maria. Mereka kemudian menyepakati waktu untuk bertemu. Di pagi hari, Elmi menghubungi Pak Santo untuk meminta alamat rumah dan meminta agar pendamping Maria adalah perempuan. Hal ini karena pada awal berkomunikasi, Pak Santo ingin menjadi pendamping Maria. Saat Elmi dan Pak Santo berkomunikasi melalui telepon seluler, Pak Santo meminta agar upah narasumber ditambah lagi menjadi Rp200.000.

Saat itu, Elmi menjelaskan bahwa dari narasumber pertama hingga narasumber keempat, biasanya akan mendapatkan hak sebesar Rp150.000. Nominal tersebut telah menjadi ketentuan dari Yayasan Sapda Yogyakarta. Elmi juga mengatakan bahwa mereka hanya membantu teman dari Sapda untuk melakukan penelitian Ini. Namun, Pak Santo menanyakan bahwa bagaimana akan mendapatkan banyak informasi dari narasumber jika upah untuk narasumber hanyalah Rp150.000.

Elmi lalu menghubungi Kaka Nila untuk memberitahukan hal tersebut. Setelah berkomunikasi, Elmi dan Kaka Nila sepakat untuk mencari narasumber difabel pengganti. Hal ini dikarenakan difabel mental yang telah berusia 47 tahun, dan juga karena keluarganya meminta upah narasumber yang melebihi ketentuan.

Namun, Kaka Nila meminta kepada Elmi untuk memberikan alasan pembatalan kepada keluarga difabel. Saat Elmi menghubungi Pak Santo untuk tujuan pembatalan, Pak Santo mengatakan, "Karmana adik mau kasih batal, dari pagi kami sudah batal semua kegiatan kami untuk tunggu diwawancara adik saya. Adik saya juga tidak jualan (karena) hanya mau menunggu untuk diwawancara. Bagaimana mau dapat informasi banyak tapi bayaran sedikit? Saya yang kaka kandungnya, tapi kenapa bukan saya yang menjadi pendampingnya? Kenapa sekarang batal dan tidak mau wawancara? Pokoknya, kami tunggu untuk wawancara dengan adik saya." Pak Santo juga mengatakan bahwa jika saudaranya tidak diwawancarai, maka telepon selulernya langsung akan dimatikan.

Elmi kembali menghubungi Pak Santo. Namun, bukan Elmi yang berbicara, melainkan Berti. Setelah Berti memberi penjelasan ulang kepada Pak Santo, akhirnya mereka mendapat persetujuan untuk wawancara dengan difabel mental, dan fee untuk narasumber tetap Rp150.000. Mereka juga tetap meminta agar pendamping narasumber adalah perempuan.

Mereka pun datang ke rumah Maria. Setiba di sana, Maria ternyata sudah menunggu Elmi dan Berti. Mereka disambut dengan baik oleh Maria, dan diizinkan untuk masuk ke rumahnya. Mereka duduk di ruang tamu, dan ruang tamu adalah tempat ternyaman untuk wawancara karena hanya empat orang di ruangan itu. Sebelum wawancara dimulai, Berti memberi penjelasan ulang tentang maksud dan tujuan

kedatangan mereka kepada Maria. Setelah mendapat persetujuan dari Maria, akhirnya Berti meminta agar ada perwakilan perempuan dari keluarga Maria. Tujuannya adalah jika ada jawaban dari narasumber yang belum jelas, maka pendamping yang akan membantu meluruskan dengan jawaban yang benar.

Wawancara dimulai dari pukul 11:50–12:40. Setelah selesai wawancara, Elmi dan Berti memberikan uang Rp150.000 kepada Maria dan Rp150.000 kepada Ibu Sarlin Pella sebagai pendamping. Setelah itu, Berti dan Elmi pulang ke rumah dengan menggunakan motor.

Identitas Informan

Maria Susana Pella adalah seorang perempuan single yang cantik. Dia lahir pada 21 Februari 1974. Perempuan berusia 47 tahun ini memiliki rambut pendek lurus sebahu. Maria mengenyam pendidikan terkahir di bangku SMP di Jawa. Saat wawancara, kami dibantu oleh pendampingnya yang bernama Ibu Tata (bukan nama sebenarnya) (52 tahun) yang merupakan kakak ipar dari Maria.

Saat ini, Maria tinggal di Kupang. Ini tahun keempat dia tinggal di sana bersama dengan kakak kandungnya. Sebelumnya, Maria tinggal bersama keluarganya di Jawa. Kedua orang tua Maria sudah meninggal, sedangkan kakak dan adik Maria yang lain, tinggal di Jakarta, Balikpapan, dan Salatiga. Maria mengalami disabilitas mental usai tamat dari bangku SMP. Penyebabnya adalah didikan ayahnya yang begitu keras. Maria sering dipukul, dan saat itu kepalanya sudah mulai terganggu. Maria mengatakan, “Kan, dulu Papi orangnya keras, suka pukul kena kepala, tapi kurang tahu karena beta (saya) masih kecil. Kata Mami, sih, kena benturan, tapi, ya, puji Tuhan sekarang sudah bisa beraktivitas.”

Pendampingnya juga mengatakan bahwa terkadang jiwa Maria bisa menjadi dua, terkadang baik dan terkadang jahat. Dari tamat SMP, ia tidak melanjutkan sekolah karena sudah sakit dan penyakitnya sering kumat. Walaupun saat ini sudah sembuh, tetapi Ia masih rutin minum obat. Jika obatnya habis, ia harus mengambil obat lagi di Rumah Sakit Jiwa Naimata Kupang.

Setiap hari aktivitas Maria sebagai penjual masker. Ia juga selalu membantu bekerja di rumah, seperti membuang sampah, menyapu, memberi makan kepada ayam dan bebek, dan mengambil air dari sumur. Setiap hari, Maria bangun tidur pukul 04:00. Maria mengatakan, "Di kamar ada radio kecil, biasanya bangun tidur jam 4, lalu dengar lagu-lagu rohani, renungan rohani di radio SK (Suara Kupang), karena di radio SK biasanya putar lagu rohani dari jam 4 sampai jam 6 pagi, jadi tiap pagi dengar itu. Setelah itu baru mulai kasih makan ayam, bebek, buang sampah, tarik air di sumur, dan lain-lain."

Dalam beraktivitas sehari-hari, Maria tidak memiliki hambatan ketika berkomunikasi dengan orang lain. Maria mengatakan, "Saya biasa sa (saja) dengan anak-anak kos dan lainnya biasa sa." Pendampingnya juga mengatakan bahwa perbedaan Maria dengan yang lain hanyalah, Maria bujang, sedangkan yang lain telah menikah. Maria juga memiliki orientasi mobilisasi yang baik.

Pemaknaan terhadap Diri

Maria adalah difabel mental yang sangat bersemangat ketika berbicara. Dia merasa tidak berbeda dengan orang lain dalam menjalani kehidupan sehari-hari. Dia sangat percaya diri dan bisa berbaur dengan tetangga indekos dan lingkungan sekitarnya.

Maria mengatakan bahwa di tempat menjual masker, ia biasa mendapat olok-olok dari orang-orang di sekitarnya. Namun, ia menanggapinya dengan cuek dan tertawa. Maria mengatakan, "Biasa di stadiun merdeka tempat jualan sering itu (diolok), tapi tanggapinya dengan bercanda-bercanda, orang sinikan begitu." Pendampingnya juga menambahkan bahwa, "Biasa orang muda, biasa nona-nona begitu (yang mengejek)." Maria mengatakan dengan tertawa kepada kami, "Biasa dong (mereka) panggil beta (saya) Lola atau loading lama, tapi beta biasa sa (saja) sampai sekarang ma ee beta cuek saja, ngapain tanggapi malah menambah penyakit, biasa yang mengganggu laki-laki dengan perempuan sama sa, di stadiun merdeka, kan, ada yang sudah berkeluarga.'' Ia juga mengatakan bahwa nama sebenarnya buka Lola, sedari kecil orang-orang di sekitarnya tidak bisa memanggilnya Maria sehingga mereka

memanggilnya dengan nama Lola. Lola adalah nama panggilan di rumah. Maria mengatakan "Tapi, Mami, almarhumah, kan, orang Manado jadi biasa panggil dengan nama panggilan Loke."

Dia menyadari bahwa diri, tubuh, organ tubuh, pikiran, dan suaranya sangat berharga. Maria mengatakan, "Ya ialah berharga untuk membantu to, biasanya pagi-pagi itu paling lama setengah lima mulai kegiatan menyapu halaman, kalau lihat sampah sudah penuh saya buang, terus habis kasih makan binatang, terus mandi siap ke sana (tempat) jual masker, pagi-pagi jam 6 itu sudah jalan jualan masker."

Seksualitas dan Reproduksi

Maria biasanya pergi ke salon, tapi jarang. Biasanya, dia pergi ke salon untuk menggunting rambut. Biasanya, dia menyemir rambutnya sendiri. Maria bercerita sambil menunjuk rambutnya, bahwa dia menyemir rambut karena rambutnya telah berwarna putih. "Semir rambut supaya awet muda, masa mau kelihatan tua? Kalau semir rambut orang kira (akan berpikir saya) 27 tahun," katanya.

Biasanya, setelah menggunting dan menyemir rambut, dia juga mendapat pujian dari teman-temannya yang sama-sama menjual masker. Maria mengatakan, "Wi (wow) kayak anak muda e, hoo e beta mau semir rambut dengan warna cokelat dan be (saya) bilang kalau ada 100 ribu beta kasih sambil bercanda. Jadi dong bilang, awii satu pujian 100 ribu, be bilang ho ee," sambil tertawa. Terkadang juga anak indekos di daerah tempat tinggalnya yang menggunting rambutnya. Maria mengatakan, "Kadang anak kos yang potong, kalau ada gunting tajam be minta tolong dong potong, potong rata." Ia merasa ke salon juga penting untuk kecantikan dan merawat tubuh.

Sejak dulu, ia suka memakai lipstik. Maria juga pernah bekerja di salon. "Karena memang dari dulu suka begitu, beta pung (punya) mami, kan, dulu suka dandan," kata Maria sambil mengambil foto kedua orang tuanya dan menaruhnya kembali di atas meja. Maria mengatakan bahwa dulu di Jakarta, ia pernah bekerja di salon sebagai perias pengantin.

Pertama kali jatuh cinta pada umur 25 tahun. Saat masih bekerja di Bekasi, Maria bertemu pria tersebut saat makan di warung makan tempatnya bekerja. Maria mengatakan, "Bukan jatuh cinta, biasa-biasa saja, sama seperti sahabat yang suka curhat." Saat itu, belum ada ponsel sehingga mereka berkomunikasi melalui surat. "Aduh beta ni dulu kena tipu dari laki-laki banyak jadi pamalas (malas), laki dong itu cuman mau doi (uang) saja, kalau kotong (kita) ada gaji dong mulai dekat-dekat, habis itu jauh sudah, jadi sekarang beta pamalas pacaran, lebih baik sendiri dan sehat-sehat."

Sejak dulu, banyak laki-laki yang sering membuatnya kecewa. Mereka hanya mengajak Maria untuk makan bakso, jalan-jalan, dan bercerita. Mereka hanya butuh uang Maria, bukan Maria. Saat ditanya apakah saat pacaran ia pernah bergandeng tangan atau berciuman, Maria menjawab sambil tertawa, "Awii ini masih remaja ini ma, ini su (sudah) mau umur 50 tahun, rambut su uban, su umur rambut putih ini."

Ia juga mengatakan bahwa di tempat jualan masker, ia pernah diganggu laki-laki yang berusia di bawahnya. Maria mengatakan, "Di tempat jual be sering dapat ganggu, tapi be bilang basong umur berapa, tapi ada yang jawab umur 25, ada yang 35 tahun, tapi u (kamu) tahu be umur berapa? 47 tahun, ee u umur sama besar dengan be pung ponakan."

Maria pernah berciuman dan berpelukan dengan pacarnya. Ia bertemu dengan pacarnya yang masih menjalin hubungan hingga saat ini. Ketika mereka bersama-sama berada di Rumah Sakit Jiwa Naimata, Maria mengatakan, "Dulu sakit pertama, kan, berobat di UKSW Setia Wacana. Itu, kan, ada psikolog di situ, terus tiap hari, kan, beta ke situ. Beta pegang buku, dong bilang wee Maria jurusan apa, be bilang hukum. Padahal, memang di atas ruang psikolog ada Fakultas Hukum. Be dalam hati bae suh basong anggap beta hukum," ceritanya sambil tertawa. Maria juga mengatakan saat berkonsultasi dengan psikolog, ia bisa sembuh tanpa mengonsumsi obat. "Tapi puji Tuhan, saat be di psikolog itu be sembuh tanpa obat, dulu berbincang-bincang begitu sembuh, psikolog Pak Endro."

Pacarnya saat ini, bernama Roflen (37 tahun) yang sama-sama difabel mental, yang saat ini sedang mengerjakan proyek di Manggarai, Kabupaten Flores. Mereka baru berpisah 4 hari yang lalu. Saat bertemu, biasanya mereka hanya berpelukan dan berciuman di pipi dan di mulut. Aktivitas seksual yang paling dia sukai dengan kekasihnya adalah ciuman di bibir. Mereka jarang bertemu. Setiap kali kekasihnya mengajak Maria untuk keluar dan pergi ke pantai atau jalan-jalan, Maria selalu beralasan bahwa dia tidak memiliki uang. Biasanya, mereka berciuman di rumah kekasihnya. Kekasihnya yang memulai ciuman di bibir terlebih dahulu. Maria merasa senang. Maria juga mengatakan bahwa Roflen adalah laki-laki yang ia cintai.

Ia juga tidak pernah berpikir untuk melakukan hubungan yang lebih dari itu. Maria mengatakan, "Tidak ada dia pung orang tua di situ." Saat berkunjung ke rumah Roflen, ia biasa bercerita dengan Ibu pacarnya di ruang tamu saja. Sampai saai ini, ia masih berkomunikasi baik dengan Roflen melalui SMS. Maria memiliki impian untuk menikah. Dia mengatakan bahwa kekasihnya pergi bekerja di Manggarai supaya bisa menabung untuk menikah. "Kalau Tuhan berkehendak, ya, berumah tangga to, karena beta juga sudah umur dan ingin untuk berumah tangga juga."

Mereka pernah keluar bersama sekali, duduk di pinggir laut di Ketapang Satu. Hal yang disukai Maria dari kekasihnya adalah suaranya. "Dia pung suara be suka. Dulu di rumah sakit jiwa itu, dong kasih karaoke, nyanyi-nyanyi lagi segala macam, be suka menyanyi lagu rohani Bapak Surgawi ajarku mengenal, dia bilang wii sapa (siapa) yang menyanyi tuh, dong bilang tuh Maria," kata Maria. Dia juga menceritakan bahwa mereka saling jatuh cinta pertama kalinya saat masih berada di Rumah Sakit Naimata, dan saat itu mereka sedang karaoke.

Maria mengetahui alat untuk KB ketika menonton televisi. "Alat kontrasepsi itu (untuk) KB, ada yang kasih masuk di dalam vagina dan ada yang suntik," ujarnya. Hal yang ia ketahui mengenai KB adalah pil dan suntik. "Ada pil, ada suntik, dan ada satu lagi yang kasih masuk di dubur atau apa itu," kata Maria. Ia juga mengatakan bahwa kondom adalah alat pelindung untuk laki-laki.

Hingga saat ini, ia tidak bermasalah dalam menstruasi, tetapi biasanya waktunya hanya 3 hari. Sebelumnya, ia menstruasi sampai 5 hari. Saat hari pertama menstruasi, ia merasakan kesakitan di bagian perutnya, tapi ia sering minum jamu beras kencur.

Saat menikah nanti, Maria ingin memiliki anak. “Kalau lihat orang melahirkan sering, beta pernah lihat langsung kaka nomor satu yang (di) Jakarta melahirkan, batareak (berteriak) setengah mati, beta lihat beta yang takut, kan, dia pung anak nomor dua agak susah to jadi agak setengah mati, kalau (anak) yang nomor tiga operasi,” sambil mengecek ponselnya karena ada SMS masuk. Jika Tuhan mengizinkan, Maria ingin mempunyai anak.

Sistem Dukungan

Maria mengatakan bahwa selama ini ia tidak pernah mendapat ancaman. Ketika ia merasa ketakutan, pendampingnya mengatakan Maria biasanya karena mendapat gangguan dari orang. Maria biasanya bercerita kepada kakak laki-laki yang tinggal bersama dengannya saat ini. Maria merasa kaka laki-lakinya itu sama seperti orang tua kandung. Selain curhat kepada kakaknya, ia juga biasa cerita ke pacarnya. kekasihnya selalu menguatkannya untuk tenang, berdoa, dan membaca firman Tuhan. “Biasa SMS kasih tahu, tapi dia jawab, ee sudah sa, tenang, doa dan membaca firman Tuhan,” kata Maria.

Maria selalu bangun jam 4 pagi dan mendengarkan radio rohani sampai jam 6 pagi. Kakak-kakaknya selalu berpesan supaya banyak berdoa agar tidak ada gangguan. Mendengarkan radio membuat hati Maria tenang.

Pendamping Maria mengatakan bahwa Maria setiap hari selalu berkomunikasi dengan kakak-kakaknya melalui SMS dan telepon. Keluarganya terkadang memproteksi Maria secara berlebihan, dan kadang Maria marah akan hal ini. Namun, menurut pendampingnya, keluarga Maria tidak ingin ada orang yang menyakiti atau memanfaatkan Maria jika mengetahui kelemahannya.

Sosial

Bagi Maria, keluarga adalah sahabat. Arti sahabat menurutnya adalah tempat untuk curhat. “Ya, supaya (kalau) kita punya unek-unek, emosi, apa semua bisa tersalur, kalau diam terus di kamar bisa stres sendiri,” ujar Maria. Sahabat terdekat dalam hidupnya adalah anak-anak indekos, tetapi sahabat yang paling dekat dengan Maria adalah Tuhan Yesus. Maria mengatakan, “Yang paling dekat adalah Tuhan Yesus, kotong mau menangis atau apa Tuhan yang tahu.” Sahabat terdekatnya juga adalah kucing, bebek, dan ayam. Maria biasanya curhat ke kucing kesayangannya yang bernama Bleket.

Ketika sakit, Maria biasanya memeriksakan diri di Puskesmas Oepoi. Kalau di rumah sakit jiwa, ia biasa kontrol sebulan sekali untuk mengambil obat. Namun, obat yang ia konsumsi sekarang hanya 2 macam, yaitu obat trehekzi dan nama obat yang satunya ia lupa. Maria mengonsumsi obat tersebut 2 kali sehari, yaitu pagi dan malam. Namun, biasanya ia mengonsumsi obat pada malam hari sebelum tidur karena pagi sampai sore dia harus berjualan masker. Obat yang diminum selalu buat mengantuk sehingga dia tidak mau ngantuk sambil berjualan.

Maria mulai menjual masker secara mandiri sejak Februari 2021. Sebelumnya, ia bekerja sebagai penjual makser dengan orang lain selama 7 bulan, tetapi ia dipecat. Setelah mendapat modal dari kakaknya di Jakarta, Maria mulai berjualan sendiri. Pendampingnya mengatakan bahwa Maria mendapat masker dari obral masker dengan harga murah, tetapi kalau masker kain ia membeli dari penjahit masker bernama Sri, sedangkan masker medis ia biasa membeli di Apotek Kristal.

Rani, Disabilitas Intelektual (Kupang)

Pada tanggal 9 Maret 2021, jam 18:30 Berti dan Elmi berangkat menuju rumah Rani (bukan nama sebenarnya) di Kota Kupang. Karena sudah malam dan cuaca mendung, Berti dan Elmi memutuskan pergi dengan menggunakan mobil transportasi online. Sebelum Elmi menelpon Opanya Rani untuk meminta karena Opa Rani tidak pernah mengijinkan cucunya keluar malam. Elmi berusaha meyakinkan dan meminta mewawancara cucunya sekitar satu jam dan menjamin Rani pulang dengan aman. Setelah mendapat restu kami mengajak Rani ke rumah makan yang tidak jauh dari rumahnya.

Setibanya di rumah makan, kami bertiga mencari tempat duduk yang aman dan nyaman untuk wawancara. Berti dan Elmi menyampaikan maksud dan tujuan wawancara. Wawancara dimulai pada jam 19:30–20:30, setelah selesai bercerita, Elmi memberikan uang Rp150.000 kepada Rani. Berti juga membayar makan malam kami sebesar Rp72.000. Setelah selesai wawancara, Berti dan Elmi mengantar pulang Rani kerumahnya, Rani tiba dirumah Jam 20:45. Setelah itu Berti dan Elmi langsung pulang ke rumah.

Identitas Informan

Rani adalah seorang perempuan muda, lahir di Kabupaten Timor Tengah Utara. Perempuan berusia 21 tahun ini memiliki rambut keriting pendek sebahu, bentuk wajahnya bulat. Rani biasa ia disapa, memiliki ukuran tubuh 140 cm. Saat ini Rani kelas 3 di salah satu SMALB di Kupang.

Rani tinggal bersama Opa dan Oma serta bapaknya di Kupang, sedangkan ibu kandung Rani tinggal kampung. Rani mengalami disabilitas Intelektual sejak masih di bangku sekolah dasar. Selain sekolah Rani menekuni hobinya sebagai atlet lari dari tahun 2018 sampai sekarang. Di rumah, Rani selalu membantu Oma dan Opanya memasak dan mencuci piring.

Rani lebih suka olahraga lari daripada sekolah. Rani tidak suka belajar dan berpikir. Di sekolah, mata pelajaran yang Rani tidak suka adalah matematika, sedangkan pelajaran yang paling ia sukai adalah mata pelajaran Penjaskes. “Sonde suka belajar, pemalas sekolah,” kata Rani.

Dalam beraktivitas Rani tidak memiliki hambatan termasuk ketika berkomunikasi dengan orang lain. Rani jarang beraktivitas di luar rumah kecuali untuk pergi ke sekolah dan berolahraga.

Pemaknaan Terhadap Diri

Rani adalah seorang difabel intelektual yang memiliki hambatan berpikir terutama soal angka. Dia sangat semangat ketika berbicara. Dia merasa tidak berbeda dalam menjalani kehidupan sehari-hari. Dia sangat percaya diri dan mudah berbaur dengan teman sekolah, teman sesama atlit dan orang-orang di sekitar tempat tinggalnya.

Tahun 2016, waktu pindah dari kampungnya ke Kota Kupang Rani mendapat ejekan dari anak-anak di sekitar rumah Opanya karena beda sekolah. Mereka sering memanggil Rani gila Perasaan Rani saat itu sangat sedih. “Sangat sedih, karena baru pertama masuk kota trus dong panggil begitu,” katanya.

Teman-temannya di atlet lari juga ada yang memanggil Rani dengan “Rani anak SLB”. Rani bilang bahwa ada beberapa temannya yang sama seperti dirinya. Rani mengatakan bahwa dia punya banyak teman yang berbeda dengan dirinya, teman difabel juga, tapi mereka saling menghargai, tidak saling mengejek.

Di tempat olahraga, saat pelatih memberikan peringatan atau aba-aba kadang Rani tidak paham. Kadang Rani harus bertanya ulang kepada pelatihnya. Rani sering bingung saat latihan karena pelatihnya bicara terlalu cepat. Jika tidak paham Rani selalu bertanya ulang. “Kalau pelatih bilang lari 100-200 meter, kadang belum mengerti 100meter, 200meter. Saya tanya supaya dikasih tahu start-nya dimana, finish-nya dimana.

Dia menyadari bahwa diri, tubuh, pikiran dan suaranya berharga baik untuk dirinya sendiri dan kedua orangtuanya. Rani mengatakan "Saya merasa diri saya berharga. Untuk orang lain mungkin saya tidak berharga, tapi saya merasa berharga di hadapan bapak dan mama."

Seksualitas dan Reproduksi

Seumur hidupnya, Rani tidak pernah pergi ke salon. Untuk urusan potong rambut, Opanya yang selalu menggunting rambutnya. Soal dandan juga tidak pernah, biasanya ia hanya memakai lisptik dan bedak, itu pun bedak bayi. Rani paling suka pakai lipstik karena membuat bibirnya lebih cerah.

Rani pertama kali jatuh cinta pada umur 17 tahun. Dia jatuh cinta sama teman kelasnya. Selama pacaran Rani tidak pernah bergandengan tangan, hanya saling suka saja. "Dari awal tidak pernah pegangan tangan, hanya saling suka saja," katanya. Tapi sekarang Rani sudah punya pacar baru yang sesama atlet dan seorang difabel intelektual (19 tahun) asal Soe Kabupaten Timor Tengah Selatan. Mereka bertemu saat ikut lomba pada tahun 2019.

Rani jarang ketemu dengan pacarnya. Mereka hanya punya kesempatan bertemu ketika ada kegiatan atau latihan. "Pacaran beberapa tahun tapi ketemu palingan pas di hotel saja saat ada kegiatan, itu pun dia di lantai atas, saya di lantai bawah. Ketemu paling pas makan, terus pergi ke stadion dia bantu bawa tas saya dan duduk dekat saya pas di bus".

Mereka jalan bersama saat pulang latihan dan makan kelapa muda bersama, karena ketika ia keluar juga opanya sudah menghafal jadwal keluar dan kembali di rumah. Ia juga pernah menghayal untuk jalan bersama dan bergandengan tangan. "Pernah berpikir untuk berciuman tapi saya rasa geli, be pikir-pikir ais itu be rasa ke karmana e, b pung otak geli dengan itu barang," kata Rani.

Rani belum pernah berpikir menikah. Opanya pernah bilang tujuan dia datang ke kota untuk sekolah, jadi tidak boleh pacaran. Kalau mau pacaran terpaksa harus sembunyi. Rani pernah punya banyak pacar di facebook. Selama pacaran mereka pernah video call. Hal yang paling dia sukai dari pacarnya adalah mendapat kejutan saat

dijemput di sekolah. Waktu jemput, pacarnya tidak bilang lebih dulu sama Rani. Saat dibonceng naik motor Rani tidak berani memeluk karena takut dilihat kakanya di jalan.

Reproduksi

Selama pacaran Rani belum pernah ciuman. Saat teman-temannya di sekolah menceritakan pacarnya, dia merasa tidak suka dan tidak enak didengar. Rani bilang kadang bingung dengan teman-temannya karena mereka pacarannya aneh. Dia pernah melihat temannya pakai KB, padahal menurutnya KB itu untuk ibu-ibu.

Sistem Dukungan

Rani pernah merasa terancam dari ana-anak tetangganya karena sering diolok. Orang yang paling mengerti Rani dan paling besar berperan dalam pengambil keputusan dalam hidupnya adalah Opanya. Ketika ada masalah, dia juga cerita kepada ketiga sahabatnya yang sama-sama satu sekolah dan satu kelas. Selama ini yang mendukung Rani adalah kedua orangtua, oma, opa dan ketiga sahabatnya.

Sosial

Rani punya tiga sahabat sejak awal masuk di SMALB. Sahabatnya itu masing-masing sudah punya pacar. Salah satu sahabat Rani sudah punya pacar pernah cerita tentang ngapain saja mereka kalau pacaran, tapi Rani tidak suka mendengarnya dan memilih pergi. Sahabatnya yang lain suka sekali film Korea dan selalu cerita tentang film Korea. Satunya lagi selalu memberikan dukungan kepada Rani. Ketiga sahabat Rani selalu mendukung dan memberikan solusi saat ia memiliki masalah. Arti sahabat menurut Rani adalah teman untuk cerita dan teman untuk curhat.

Deskripsi Jasmin, Disabilitas Fisik (Yogyakarta)

Hidup sebagai perempuan penyandang disabilitas bukan sebuah pilihan, tetapi kenyataan yang memang harus dijalani sebagai takdir dari Tuhan. Tidak mudah, tetapi selalu ada kekuatan untuk tetap melanjutkan kehidupan sebagai perempuan-perempuan "terpilih". Salah satunya, Jasmin (nama samaran), perempuan tuna daksa yang tinggal di Yogyakarta.

Salah satu responden untuk penelitian Sentra Advokasi Perempuan Difabel dan Anak (Sapda) ini, awalnya kami temui di sebuah kios berukuran 3x3 meter yang ia sewa sejak beberapa tahun terakhir. Sekitar pukul 14.00 WIB, perempuan dua anak ini datang dengan mengendarai sepeda motornya, serta menenteng kruk sebagai alat bantu untuk menopang kaki kirinya yang mengalami kelumpuhan.

Meski mengalami keterbatasan fisik, Jasmin adalah perempuan yang enerjik di usianya yang kini sudah 40-an tahun. Ia juga ramah, murah senyum, dan termasuk *open minded*.

Jasmin menceritakan, kios yang ia sewa itu selama ini dikelola oleh suaminya, bersama anak sulungnya, gadis kecil yang kini duduk di bangku sekolah dasar (SD). Sementara Jasmin sehari-harinya bekerja sebagai karyawan di salah satu yayasan di Yogyakarta.

Awalnya, kami merencanakan untuk ngobrol panjang lebar tentang kehidupan pribadinya di dalam kios tersebut. Namun, karena situasinya yang kurang kondusif untuk membicarakan hal yang sifatnya sangat privat, akhirnya kami memutuskan untuk mencari tempat lain yang lebih nyaman untuk berbagi cerita tentang pengalaman hidup, cinta, dan seksualitas yang ia jalani bersama pasangannya.

Setelah sekitar 30 menit menempuh perjalanan dengan sepeda motor, kami tiba di salah tempat bernuansa tradisional Jawa. Meski ruang publik, tapi ada satu tempat yang bagi kami lebih nyaman untuk membicarakan banyak hal, termasuk mendengarkan cerita Jasmin.

Ia mulai bercerita tentang masa lalunya yang terasa sangat berat hingga sempat membuat mentalnya *down* selama beberapa tahun. Jasmin menyadari bahwa ada yang berbeda dari fisiknya, ketika dia tumbuh menjadi gadis kecil. Penyakit polio menyebabkan salah satu kakinya tidak bisa menjadi penopang tubuhnya dengan sempurna sehingga cukup kesulitan saat berjalan, karena tidak bisa tegak.

Meski begitu, Jasmin mengaku masih bisa mengendarai sepeda kayuh dan ketika beranjak remaja juga terbiasa mengendarai sepeda motor. Pada suatu ketika, Jasmin mengalami peristiwa nahas saat pulang sekolah. Jasmin mengalami kecelakaan di jalan raya sehingga tubuhnya tertimpa sepeda motornya. Kecelakaan tersebut memperparah kondisi kaki kirinya. Bahkan, pasca-kecelakaan, ia lumpuh total sekitar 6 bulan.

Terpuruk dan Direndahkan karena Fisik Berbeda

Sejak kecelakaan itu, Jasmin merasa berada di titik terendah dalam hidupnya. Rasa percaya dirinya kian luntur saat menyadari kondisinya lumpuh. Meskipun pada akhirnya bisa berjalan lagi dengan tongkat, Jasmin tidak serta merta bisa bangkit dari keterpurukannya.

“Dulu saya merasa ada yang salah dan menyalahkan diri sendiri kenapa saya yang harus mengalami seperti ini? Seperti menyesali kondisi karena sebelumnya saya bisa berjalan tanpa tongkat (kruk) ini,” tutur Jasmin.

Ia sempat enggan untuk melanjutkan sekolahnya karena takut kondisi fisiknya akan menjadi bahan cemoohan. Namun, usaha ibunya yang luar biasa untuk membangkitkan kembali semangat hidupnya, mampu meluluhkan hati Jasmin hingga dia bisa melanjutkan sekolahnya kembali.

Jasmin mengaku kondisi kaki kirinya yang tak berfungsi dengan baik cukup menghambat mobilitasnya. Contohnya, ketika menaiki tangga dengan membawa barang bawaan, Jasmin merasa kesulitan. Hal itu lantaran tangan kirinya harus memegang tongkat, dan tangan kanannya juga harus berpegangan saat naik turun tangga.

Menurutnya, hambatan aktivitas karena keterbatasan fisik masih belum seberapa, jika dibandingkan dengan stigma yang sering kali dilekatkan pada dirinya sebagai penyandang disabilitas. Jasmin merasa bahwa dengan kondisi fisiknya yang berbeda itu tak jarang dia mendapatkan perlakuan tak menyenangkan, seperti dilecehkan, direndahkan, dan diejek orang-orang di lingkungannya.

Jasmin mengaku, salah satu ucapan paling menyakitkan yang pernah ia dengar adalah ketika dirinya akan menikah dengan sesama penyandang disabilitas.

"*Lah uwong ngono kae kok, mlakune podo rekoso wae kok yo arep mbojo* (orang-orang itu berjalan saja sulit, kok, akan menikah)," ungkapnya.

Ucapan yang tak mengenakkan kembali ia dengar, saat dirinya hamil sekitar 8 bulan dan kembali ke kampung halamannya.

"Ada yang bilang lagi, *mlakune rekoso kok yo meteng* (berjalan saja kesulitan, kok, ya, hamil)," katanya.

Jika sudah begitu, Jasmin mengaku tak segan lagi untuk membalas ucapan mereka. Menurutnya, itu menjadi pilihan untuk melepaskan rasa tidak nyamannya, sekaligus menghindarkan dirinya dari unek-unek yang justru akan berdampak buruk bagi dirinya, saat hanya dipendam dalam hati.

Di satu sisi, Jasmin menyadari bahwa secara fisik memang berbeda dengan orang-orang normal. Namun di sisi lain, secara kemampuan, Jasmin merasa tak berbeda dengan orang lain pada umumnya. Baginya, perbedaan hanya terletak pada penggunaan alat bantu saat berjalan, dan aktivitas fisik yang berhubungan dengan gerak kaki. Selebihnya, dia bisa lakukan sebagaimana orang-orang tanpa disabilitas tertentu.

Oleh karena itu, Jasmin menganggap bahwa tubuhnya adalah bagian yang paling berharga sehingga harus tetap dijaga dengan baik dan dilindungi. Setidaknya untuk diri sendiri, suami, anak-anak, dan juga orang tuanya. Salah satu bentuk penghargaan terhadap tubuhnya adalah dengan mengenakan jilbab untuk menutup aurat, setelah lulus SMK hingga sekarang. "Tidak ada yang menyuruh, apalagi memaksa," tegasnya.

Kandasnya Cinta Pertama hingga Takut Dosa

Sebagai manusia, perempuan penyandang disabilitas juga memiliki rasa ingin tampil cantik dan terlihat sempurna, khususnya di depan lawan jenis juga menjadi hal yang sangat lumrah terjadi. Apalagi di usia-usia remaja hingga beranjak dewasa.

Jasmin mengaku selama ini memang tidak pernah melakukan perawatan ke salon-salon kecantikan. Namun, dia mempunyai cara untuk merawat diri di rumah. Hal ini karena selain merasa tak nyaman ketika harus membuka hijab saat berada di tempat umum, ia juga memiliki kemampuan dasar merias wajah yang didapat dari kursus kecantikan selama 6 bulan di Yogyakarta. Tak jarang, keterampilannya merias wajah itu ia terapkan pada anak-anaknya yang akan pentas menari.

Dalam urusan percintaan, sebelum menikah atau sekitar usia 18 tahun, Jasmin menjalin hubungan dengan laki-laki yang ketika itu sedang bekerja di Malaysia. Mereka pacaran jarak jauh (*long distance relationship*) selama kurang lebih 2 tahun. Namun, Tuhan berkehendak lain. Setelah mengalami kecelakaan dan dirinya harus menggunakan tongkat sebagai alat bantu jalan, perasaan Jasmin hancur lebur.

Jasmin pun memilih untuk memupus perasaan cintanya pada laki-laki tersebut, karena merasa tak pantas lagi menjalani hubungan pada saat ia sedang merasa tidak baik-baik saja. Hal ini diperparah dengan cibiran salah satu adik kelas, yang tak lain juga adik dari kekasihnya. Si adik kekasihnya itu terlihat tidak setuju dengan hubungan mereka berdua karena alasan disabilitas.

Pada tahun 2007, Jasmin menemukan belahan jiwa yang bersedia menikahinya dan membina rumah tangga hingga sekarang. Mereka dikaruniai dua anak. Pada saat menikah, Jasmin berusia sekitar 25 tahun.

Jasmin mengatakan bahwa di usianya yang telah dewasa tersebut, ia belum mengenal istilah seks, seksualitas, dan aktivitas seksual. Pengalaman pertama menjalani aktivitas seksual adalah ketika dirinya sudah menikah. Itu pun awalnya ia menjalani hubungan seksual dengan pasangannya karena takut berdosa.

"Suami itu kalau saya menolak, selalu menggunakan kata-kata dosa *loh* kalau kami tidak mau (berhubungan intim). Jadi, ketakutannya sama dosa, karena saya sebagai istri punya kewajiban melayani, tetap saya justru selalu menolak," anggapnya.

Minimnya pemahaman tentang seksualitas dan kesehatan reproduksi (Kespro) membuat Jasmin tak menyadari bahwa dirinya tengah dalam keadaan hamil, tepatnya 3 bulan sejak pernikahan.

"Sekarang saya baru mengerti bahwa ternyata kesehatan reproduksi itu seharusnya dikenalkan kepada anak sejak dini," ucapnya.

Menurut Jasmin, jika pemahaman kesehatan reproduksi terus dianggap sebagai sesuatu yang tabu, maka ketika beranjak remaja atau dewasa, anak-anak tidak mendapatkan sumber informasi tentang Kespro yang benar.

Alhasil, Jasmin hanya mendapatkan cerita dari temannya bahwa berhubungan seksual dengan pasangan itu cukup menakutkan karena terasa sakit dan bisa berdarah-darah. Namun pada kenyataannya, ia tak sampai berdarah-darah, meskipun tetap ada rasa sakit usai melakukan hubungan seksual.

Sebagai pelaku seksual aktif, Jasmin dan pasangan terkadang juga mengalami hambatan, ketika salah satu dari mereka tidak menginginkan untuk berhubungan intim pada saat-saat tertentu. Dalam situasi seperti itu, komunikasi dengan pasangan menjadi sangat penting untuk dilakukan. Hal ini termasuk membicarakan tentang hal yang mereka sukai atau tidak sukai saat melakukan hubungan seksual.

"Saya paling suka ketika kedinginan terus dipeluk," ucapnya tersipu. Sementara, hal yang paling tidak disukai adalah ketika waktunya tidak tepat atau salah satu dari mereka tidak siap, tetapi memaksakan diri.

KB, Pilihan Menjaga Kespro

Saat masa kehamilan anak pertama dan kedua relatif tidak mengalami masalah. Jasmin rutin melakukan konsultasi dengan dokter kandungan. Sementara pada saat melahirkan, ia harus menjalani operasi sesar karena janinnya terlalu besar, sedangkan panggulnya kecil sehingga cukup berisiko untuk proses persalinan normal.

Bagi Jasmin, keluarga berencana (KB) menjadi salah satu pilihan untuk mencegah terjadinya kehamilan tak diinginkan. Dengan menggunakan KB suntik, ia tak pernah lagi mengalami haid selama kurang lebih 2 tahun. Baru setelah KB tersebut dihentikan, datang bulannya kembali normal.

Mandiri dan Bebas Menentukan

Sebagai perempuan pekerja yang aktif di ranah publik, Jasmin merasa bersyukur karena memiliki *support system* yang baik. Suaminya yang sehari-hari bekerja mengelola usaha di kios yang mereka sewa rela melakukan pekerjaan rumah saat istrinya sedang bekerja di luar rumah, mulai dari memasak hingga mengasuh anak.

Dalam pengambilan keputusan, Jasmin juga memiliki kebebasan untuk menentukan pilihan yang menurutnya baik untuk dijalani. Sebagai seorang perempuan pekerja sekaligus ibu rumah tangga, lingkaran pertemanan Jasmin relatif terbatas. Orang-orang di lingkungan kerjanya, ia anggap sebagai teman yang bisa menjadi tempat berbagi, serta memberikan pertimbangan dalam pengambilan keputusan. Selain itu, ada juga pertimbangan dari keluarga inti. Sedangkan terkait dengan aktivitas seksualnya, Jasmin menganggap teman-temannya memberikan respons yang wajar terhadap dirinya.

Deskripsi Disa, Disabilitas Netra (Yogyakarta)

Di rumah sederhana bercat hijau, yang tepatnya berada di belakang warung bakso, tidak jauh dari jalan raya di Yogyakarta, Disa (bukan nama sebenarnya) tinggal bersama suami dan keluarga kecilnya. Perempuan 39 tahun ini menyewa rumah yang sekaligus ia jadikan sebagai tempat buka praktik pijat tuna netra, sejak 5 tahun terakhir.

Disa adalah perempuan penyandang disabilitas netra, khususnya *low vision*. Sejak lahir pada 3 Mei 1981, Disa sudah mengalami gangguan penglihatan dengan jarak pandang maksimal 3 meter. Ia menikah dengan seorang laki-laki yang juga penyandang disabilitas *low vision* pada tahun 2004. Kini, Disa dan suaminya dikarunia seorang putra yang telah berusia sekitar 16 tahun, dan putri kecil berusia 9 tahun.

Sehari-hari, perempuan berhijab ini membuka praktik pijat tuna netra. Keahlian memijat ia peroleh ketika mengikuti pelatihan di Panti Sosial Bina Netra (PSBN) Bantul, setelah lulus SMA tahun 2000. Dari balik pintu rumah kontrakannya, terlihat dua bilik yang disekat dengan gorden berwarna *pink*. Satu bilik menjadi tempat praktik suaminya, dan satu bilik di sebelahnya biasa digunakan Disa untuk melayani para pelanggannya yang tak jarang datang dari luar Kota Yogyakarta.

Ketika saya (Tria) datang ke rumahnya pada hari Sabtu, 6 Maret 2021, sekitar pukul 17.00 WIB, Disa sudah menunggu di kursi bambu teras rumah. Tampak sebuah sepeda motor *matic* milik pelanggan terparkir di teras. Sementara suaminya berada di dalam sedang memijat tamu tersebut. Di sela-sela obrolan kami, Disa juga sempat menyisir rambut panjang putri kecilnya yang datang menghampirinya. Setelah sekitar 15 menit kami perkenalan, kami pun memulai wawancara hingga azan magrib berkumandang.

Pemaknaan atas Diri dan Tubuh

Disa mulai menyadari ada yang berbeda dengan penglihatannya sejak usianya sekitar 6–7 tahun. Ia hanya bisa melihat dengan cukup jelas ketika objek yang dituju berada di depannya dengan jarak pandang maksimal 3 meter. “Kalau dari jauh, terlihat kabur. Saya tahu ada orang, tapi tidak jelas wajahnya,” ucap Disa.

Ia bercerita bahwa ketika kecil sering kali jatuh saat berjalan karena tidak bisa melihat dengan jelas. Termasuk ketika ia sedang belajar naik sepeda, Disa tak menyadari telah berada di kebun orang ketika dirinya terjatuh. Sejak itu, ia tak berani lagi belajar bersepeda.

Meskipun memiliki keterbatasan dalam penglihatan, Disa mengaku aktivitasnya sehari-hari dapat ia kerjakan dengan baik. Bahkan, dalam mengurus anak-anaknya, "Sejak lahir, mereka tidak saya titipkan pada orang lain," kata Disa. Namun, Disa tak memungkiri bahwa ada rasa minder ketika dia berkumpul dengan orang-orang. Mengingat, ketika kecil dulu, dirinya sering diejek teman-temannya karena tidak dapat melihat.

Ia juga mengalami kendala ketika sedang pergi ke sebuah hajatan yang mengharuskan ia menulis nama di buku tamu. "Orang mengiranya saya bisa melihat dengan baik," ungkapnya. Selain itu, dulu ketika belum marak ojek *online* seperti sekarang, mobilitasnya juga terbatas karena ketika akan naik kendaraan umum tidak bisa sendiri. Begitu juga ketika hendak menyeberang jalan. "Ketika ada tetangga yang sedang menggelar hajatan, sebenarnya saya ingin membantu, tapi membantu apa dengan kondisi saya seperti ini?"

Meski begitu, Disa merasa bersyukur karena sejak dulu ia merasa lebih diterima di lingkungannya dengan baik. "Mereka tidak mengucilkan saya," ujarnya. Ia juga aktif di acara-acara pengajian di kampungnya, dan tak jarang menghadiri undangan-undangan pertemuan di sekolah anaknya. Sehingga, dia merasa dirinya tidak jauh berbeda dengan orang tua pada umumnya.

Oleh karena itu, Disa juga mensyukuri apa pun kondisi fisiknya. Salah satunya dengan mengenakan jilbab untuk melindungi diri dan tubuhnya dari perbuatan-perbuatan tak diinginkan. Mengingat, dirinya sebagai tukang pijat, kini tak hanya melayani pasien perempuan, tetapi kadang juga laki-laki.

Seksualitas dan Reproduksi

Sejak dulu, Disa mengaku hampir tidak pernah pergi ke salon kecantikan. Kalau pun dulu sesekali datang, hanya sekadar memotong rambutnya. Ia merasa sayang jika harus mengeluarkan uang cukup yang banyak untuk melakukan perawatan tubuh di salon.

Ia mengaku pertama kali merasakan jatuh cinta ketika duduk di bangku SMA. Ketika itu, ia bahkan sempat menjalin hubungan asmara dengan kakak kelasnya yang juga penyandang disabilitas netra. Layaknya orang-orang pada umumnya, Disa mengaku merasa bahagia dan nyaman ketika bersama pasangannya. Terlebih, ia merasa menemukan sosok pengganti ayahnya yang telah meninggal sejak dirinya masih kelas 5 SD. "Saya merasa lebih nyaman menjalin hubungan dengan sesama tuna netra, karena kalau dengan orang normal takutnya saya justru akan direndahkan," ucapnya. Namun, hubungan keduanya pada akhirnya kandas tanpa ada alasan yang jelas.

Suami Disa sekarang adalah laki-laki yang ia kenal ketika sama-sama berada di pusat rehabilitasi bagi penyandang disabilitas YAKKUM Yogyakarta, kemudian bertemu kembali di PSBN Bantul. Karena merasa ada kecocokan, keduanya pun sepakat untuk membina rumah tangga, dan mendapatkan restu dari keluarga kedua belah pihak.

Dalam pemahaman Disa, tidak ada perbedaan tentang makna seks, seksualitas, dan aktivitas seksual. Baginya, semua itu adalah aktivitas seksual antara suami-istri, seperti bercumbu. Sebelum menikah, ia tak pernah membayangkan rasanya dicium, berhubungan intim dengan orang yang ia cintai, maupun masturbasi untuk melampiaskan hasrat seksualnya.

Saat pertama kali melakukan hubungan seksual dengan suaminya, Disa mengaku sempat merasakan sakit pada alat kelaminnya, dan mengeluarkan darah meskipun tidak banyak. Demi tanggung jawabnya sebagai istri yang melayani suami, ia selalu berusaha menikmati saat dirinya berhubungan intim dengan pasangannya.

Bercumbu adalah hal yang paling ia sukai ketika melakukan aktivitas seksual. Sedangkan, hal yang paling tak disukai adalah saat dia diminta berhubungan dengan gaya yang aneh-aneh, seperti berdiri. Disa mengaku, selama ini ia dan pasangannya selalu mengomunikasikan hal tersebut dengan baik.

Reproduksi

Dalam hal menstruasi, Disa tak mengalami masalah. Hanya saja, ketika menggunakan alat kontrasepsi, tubuhnya terasa tidak nyaman, dan darah yang keluar saat menstruasi cenderung lebih banyak jika dibandingkan saat kondisi normal.

Sewaktu dirinya hamil, baik anak pertama maupun kedua relatif tidak mengalami masalah. Ia rutin memeriksakan diri ke puskesmas terdekat. Saat melahirkan kedua anaknya juga normal. “Sejak melahirkan anak pertama, kami langsung disarankan untuk KB,” ucap Disa. Kemudian, Disa memilih menggunakan alat kontrasepsi IUD karena menurutnya itu lebih aman dibandingkan jenis alat kontrasepsi lainnya.

Awalnya, ia dan pasangan sepakat hanya akan memiliki satu anak. Namun, setelah putranya berusia 6 tahun, keduanya memutuskan untuk menambah momongan supaya ketika nanti mereka sudah menua, dan anaknya dewasa, mereka tidak sendiri. Lahirlah seorang anak perempuan. Setelah kelahiran anak kedua itu, Disa berganti alat kontrasepsi dari IUD ke suntik. Namun, ia merasa ada yang tidak beres dengan tubuhnya. Hal ini karena setiap kali berhubungan intim terasa sakit dan tubuhnya sering merasa tidak nyaman. Ia pun memutuskan untuk menghentikan suntik KB dan hingga sekarang tidak memasang alat kontrasepsi lagi. Walaupun aktivitas seksualnya masih aktif, Disa dan suami sepakat untuk saling “menjaga” agar tidak mengalami kehamilan tak diinginkan.

Sistem Dukungan

Disa merasa bersyukur karena selama ini dia memiliki kebebasan dalam menentukan pilihan dan mengambil keputusan dalam hidupnya, termasuk dalam hal perlindungan tubuh dan seksualitasnya. Oleh karena itu, ia hampir tak pernah merasa terancam saat hendak menentukan pilihannya. Suaminya pun memberikan dukungan penuh. Termasuk saat keduanya memutuskan untuk mengontrak rumah sendiri, daripada tinggal di rumah orang tua yang juga ditempati oleh saudara mereka.

Sosial

Disa termasuk perempuan yang tidak suka membicarakan aktivitas seksualnya kepada orang lain, meskipun pada sahabatnya. Ia mengaku memiliki seorang sahabat, sesama perempuan. Hanya saja, karena masing-masing sudah berkeluarga sehingga intensitas pertemuan mereka sangat jarang.

Deskripsi Wulan, Disabilitas Tuli (Yogyakarta)

Hari Senin, 1 Maret 2021, saya (Tria) bertemu dengan Wulan (bukan nama sebenarnya), dengan temannya, Lusi di salah satu warung di Yogyakarta. Sekitar pukul 13.30 WIB, saya tiba di lokasi dan langsung menyapa mereka yang sudah berada di lokasi lebih dulu. Di antara beberapa tamu di warung tersebut, tak sulit menemukan mereka, meskipun kami belum pernah saling bertemu sebelumnya. Itu karena keduanya berkomunikasi dengan bahasa isyarat. Kami pun saling menyapa. Dengan bantuan Lusi sebagai juru bahasa isyarat (JBI), saya dan Wulan dapat berkomunikasi dengan baik. Suasana percakapan kami terasa sangat cair.

Sebelum wawancara dimulai, saya sodorkan *hardcopy* dari draf pertanyaan kepada Lusi. Kemudian, diteruskan kepada Wulan yang duduk berhadapan dengan kami berdua. Pertimbangan saya adalah demi kenyamanan bersama, karena sebagian pertanyaan bersifat sangat privasi sementara kami berada di ruang publik. Setelah membaca sekilas, dan memberikan sedikit penjelasan tentang beberapa istilah seperti *petting* kepada Lusi agar lebih mudah disampaikan kepada Wulan, mereka pun sepakat tak keberatan untuk membicarakan hal tersebut di tempat kami bertemu.

Identitas Informan dan Pendamping

Wulan adalah perempuan penyandang disabilitas rungu yang kini telah berusia 25 tahun. Dia lulusan S-1 Jurusan Seni Rupa, dan masih lajang. Wulan tak bisa mendengar sejak lahir. Waktu itu, ibunya sempat tidak menyadari kalau Wulan Tuli sejak lahir. Ketika mengetahui kondisi tersebut, keduanya hanya bisa berkomunikasi melalui bahasa tubuh sampai kemudian Wulan menggunakan alat bantu dengar. Namun, setelah besar dan dewasa, dia memilih untuk melepasnya. Menurutnya, memakai alat bantu dengar justru terasa bising sehingga sering membuat pusing. Apalagi ketika terdengar suara keras, seperti orang tertawa. Meski tak dapat mendengar, Wulan masih bisa sedikit berkomunikasi secara oral.

Sementara, Lusi adalah JBI yang sudah mengenal Wulan sejak 2017. Awalnya karena dirinya belajar bahasa isyarat di Deaf Art Community (DAC). Sejak itu, ia sering diajak Wulan menjadi JBI untuk berbagai kegiatan. Kebetulan, keduanya juga seumuran.

Pemaknaan terhadap Diri dan Tubuh

Wulan mulai menyadari ada masalah dengan pendengarannya sejak berusia sekitar 4 tahun. Kondisi pendengarannya semakin parah setelah ia terjatuh dari tangga dan kepalanya terbentur. “Saya tidak bisa mendengar suara panggilan ibu saya sama sekali,” kenang Wulan. Ia merasa minder dan enggan bersekolah. Apalagi, ada yang pernah mengatakan dirinya jelek karena tidak bisa bicara. Ada juga yang justru mengasihaninya. Saat sekolah di sekolah luar biasa (SLB), Wulan dan gurunya tidak bisa berkomunikasi dengan baik karena sama-sama tak memahami bahasa isyarat.

Ibunya terus mendorong agar Wulan tetap bersekolah supaya memiliki pendidikan yang setara dengan anak-anak pada umumnya. Lalu, Wulan dimasukkan ke sekolah umum. Saat masuk ke SMK, Wulan kembali menemui hambatan karena tidak bisa mendapatkan informasi sama sekali, dan tidak ada teman berdiskusi. Kemudian, dia mencoba melakukan advokasi diri ke pihak sekolah sehingga mendapatkan sedikit akses, melalui penyediaan layar monitor, dan pelajaran dalam bentuk tulisan. Itu pun yang tersedia baru di jurusannya, sementara untuk jurusan lain belum ada.

Wulan juga masih ingat saat pertama kali dirinya masuk ke sekolah tersebut, ada teman laki-laki yang mengejek dan menjadikannya sebagai bahan guyonan, dengan mengatakan “Hei, kamu dicari!”, tapi maksudnya untuk mengejek kalau Tuli itu jelek. Wulan kemudian melaporkan hal tersebut kepada guru. Akhirnya teman-temannya dinasihati agar tidak mengejeknya lagi. Di kelasnya, ada dua siswa yang juga disabilitas rungu. Namun, mereka lebih memilih untuk diam dan sering menyendiri. Wulan berusaha memberikan pemahaman kepada temannya tersebut, agar berani membela diri. “Ketika Tuli diam, maka dianggap dia polos,” ucapnya.

Wulan merasa berbeda dengan orang lain hanya dalam hal berkomunikasi saja. Oleh karena itu, dia sering membutuhkan pendamping (JBI) ketika menghadiri atau mengikuti kegiatan dengan masyarakat pada umumnya. Namun, ketika berkumpul sesama disabilitas rungu dan wicara, dia tak mengalami hambatan. Bahkan, Wulan juga bisa melakukan mobilitas sendiri dengan mengendarai sepeda motor.

Oleh karena itu, Wulan merasa bahwa tubuhnya sangat berharga, dan dia mencintai dirinya. "Aku sangat mencintai tubuhku, dengan isyaratku, aku bisa berjalan-jalan dengan leluasa. Bahkan, ketika ke luar negeri (Australia) dengan berbahasa isyarat, mereka sangat menghormati orang Tuli," ujar Wulan.

Di sisi lain, dia juga menyadari bahwa masih ada orang-orang yang memandangnya sebelah mata. Ketika mendengar ada orang membicarakan keterbatasan fisiknya, maka Wulan selalu memberikan pemahaman kepada mereka bahwa pada dasarnya semua orang sama sehingga tidak perlu merasa seperti bos hanya karena bisa mendengar.

Seksualitas dan Reproduksi

Dalam urusan perawatan tubuh, Wulan mengaku sering pergi ke salon kecantikan bersama ibunya. Namun terkadang, dia juga datang sendiri untuk sekadar memotong rambut. Dia merasa nyaman karena mendapatkan sambutan hangat dari pihak salon yang menurutnya sangat menghormati semua pelanggan, termasuk dirinya.

Wulan mengaku pernah merasakan jatuh cinta, dan menjalin hubungan dengan seorang laki-laki yang juga penyandang disabilitas rungu. Ketika itu, dia masih duduk di bangku sekolah. Namun, hubungan mereka kandas karena pasangannya sering memaksanya untuk melakukan aktivitas seksual. "Aku tahu, dia sering nonton film-film dewasa (porno)," tutur Wulan. Suatu ketika, Wulan pernah memukul laki-laki tersebut ketika hendak mencium pipi Wulan tanpa izin. Saat itu juga Wulan memutuskan hubungan mereka.

Wulan kemudian menjalin hubungan dengan teman laki-laki lainnya, yang sudah lama mereka hilang kontak. Dia merasa menemukan pasangan yang baik, lucu, suka ngobrol, dan saling suka. "Aku melihat dari tatapan matanya. Aku merasa jatuh cinta," ucapnya dengan wajah berseri-seri.

Bagi Wulan, menjalin hubungan kasih sayang dengan lawan jenis bukan berarti rela menyerahkan tubuh untuk pasangan. Justru, dia sangat protektif dengan tubuhnya. Salah satunya, dia langsung memukul mantan pacarnya karena hendak mencium pipinya. Selain itu, Wulan juga sering mendapatkan nasihat dari ibunya agar pandai menjaga diri, jangan sampai hamil di luar nikah. "Kalau kamu sampai hamil (di luar nikah), tanggung sendiri," kata Wulan menirukan ucapan ibunya. Wulan juga selalu diingatkan oleh ibunya agar tidak menikah sebelum selesai kuliah dan bekerja.

Terkait seks, seksualitas, dan aktivitas seksual, dalam pemahaman Wulan, seks berhubungan dengan alat kelamin, laki-laki berupa penis, dan pada perempuan namanya vagina. Sedangkan seksualitas, Wulan mengaku tak memahami definisinya, meskipun dia sempat mendapatkan informasi tersebut dari sebuah pertemuan. Sementara aktivitas seksual, ia mencontohkan seperti berciuman pipi dan bagian tubuh lainnya.

Reproduksi

Selama ini, Wulan tak mengalami masalah dengan menstruasi, dan selalu lancar setiap bulan. Sebagai perempuan, Wulan juga membayangkan sebuah pernikahan dan memiliki anak. Bahkan, ia sudah dilamar oleh kekasihnya yang sejak 7 tahun terakhir menjalin hubungan asmara dengannya. "Kemungkinan kami akan menikah tahun ini," ujar Wulan. Ia merasa menemukan pasangan yang baik dan bisa menghargainya. Selama pacaran pun mereka hanya sebatas berciuman tangan, dan lebih banyak membicarakan tentang masa depan, dan jalan-jalan sambil bergandengan tangan.

Meski belum pernah melakukan hubungan seksual, maupun menggunakan alat kontrasepsi, Wulan mengaku mengetahui tentang kondom yang bisa menjadi alat untuk mencegah kehamilan. Ia mendapatkan informasi tersebut dari pertemuan yang pernah ia ikuti, dan *sharing* dari teman-temannya yang telah menikah.

Sistem Dukungan

Saat ini, Wulan merasa sangat nyaman menjalani hubungan dengan tunangannya. Dia tak merasa terancam. Namun, dalam hubungan dengan mantan pacar sebelumnya, dia merasa terancam ketika pasangannya ingin mengajaknya melakukan aktivitas seksual, dan dia merasa risih. Puncaknya, dia memukul sang mantan karena tak terima akan dicium pipinya.

Dalam setiap pengambilan keputusan, Wulan kerap kali mendapatkan pertimbangan dari keluarga, tunangan, dan juga teman-temannya. Pada intinya, mereka memberikan masukan dan saran terkait keputusan yang akan diambil Wulan.

Kehidupan Sosial

Wulan mengaku memiliki sahabat untuk saling berbagi tentang banyak hal, saling menghibur, dan saling berdiskusi, termasuk dalam hal seksualitas. Kalau sudah begitu, biasanya mereka saling kepo.

Deskripsi Marlina, Disabilitas Mental (Yogyakarta)

Pertemuan saya (Tria) dengan Ibu Sinta diawali dengan menemui Mbak Marlina, yang merupakan pendamping dari Ibu Sinta (51 tahun), sejak 2 tahun terakhir. Ibu Sinta memang bukan perempuan yang bisa dengan mudah "nyambung" saat berkomunikasi dengan orang lain. Sepanjang perjalanan kami menuju rumahnya, Mbak Marlina menceritakan bahwa perempuan yang akan kami temui adalah orang dengan gangguan jiwa (ODGJ) dan memiliki seorang anak gadis.

Mbak Marlina juga mengatakan, ibu satu anak tersebut mengalami depresi berat sejak suaminya meninggal dunia, dan tidak mendapatkan support system yang baik dari keluarganya. Sementara itu, dia juga memiliki tanggungan seorang anak perempuan penyandang disabilitas. Bahkan, ketika putrinya sakit, tidak ada yang mengurusnya sehingga Sentra Advokasi Perempuan Disabilitas dan Anak (Sapda) Yogyakarta berinisiatif membawanya ke rumah sakit (RS) agar mendapatkan perawatan secara intensif. Setelah sembuh hingga kini, anak perempuan Ibu Sinta tinggal di Pusat Rehabilitasi Terpadu Penyandang Cacat (PRTPC) Bantul.

Ketika tiba di rumah sederhana milik Ibu Sinta di Jowahan, beliau sedang duduk di kursi kayu di teras rumah. Pakaian lusuh dan tatapan kosong, itu kesan pertama yang saya tangkap ketika menghampirinya. Saat kami sapa, dia bisa menjawab dengan baik, meskipun agak lama karena melamun. Setelah memperkenalkan diri, saya meminta tolong Mbak Marlina untuk menyampaikan poin-poin pertanyaan dengan "bahasa" yang dimengerti oleh Ibu Sinta. Namun, karena keterbatasan ingatan dan kendala komunikasi, tidak banyak informasi yang bisa kami dapatkan dari Ibu Sinta. "Kalau berkomunikasi dengan ODGJ memang sulit untuk bisa mendapatkan jawaban sesuai yang kita harapkan," kata Mbak Marlina.

Pemaknaan atas Diri dan Tubuh

Sepeninggal suaminya, Ibu Sinta menanggung beban yang sangat berat sehingga mengalami depresi dan gangguan jiwa. Sejak ia mengalami gangguan jiwa, hidupnya sering menggelandang tak terurus hingga akhirnya mendapatkan pendampingan dari SAPDA.

Ia pernah dibawa berobat ke Rumah Sakit Jiwa (RSJ) Ghrasia di Pakem, Sleman, DIY sekitar tahun 2019. Saat itu, Ibu Sinta menjalani perawatan intensif di bangsal RSJ 1 bulan dan dipulangkan dalam keadaan yang lebih baik. Harapannya, keluarga bisa menerima kehadirannya dengan baik. Namun, yang terjadi adalah Ibu Sinta justru sempat dipasung, dengan dimasukkan ke dalam rumah dengan pintu digembok dari luar. Tujuannya agar tidak merepotkan keluarga. Setelah mendapatkan ancaman akan dipolisikan jika tak dibebaskan, keluarga kemudian membuka gembok di pintu rumah Ibu Sinta.

Saat ditanya tentang hambatan yang dihadapi dalam kehidupan sehari-hari dan saat berinteraksi sosial; apakah ada yang salah dengan tubuhnya; apakah merasa pernah disalahkan atas keadaannya tersebut; apakah merasa berbeda dengan orang lain; apakah tubuhnya berharga; jawabannya selalu mboten (tidak).

Ketika disinggung tentang perlakuan bulik yang tak menyenangkan terhadap dirinya, Ibu Sinta mengatakan, “Mboten disalahke, mboten ngerti (tidak disalahkan, tidak tahu).” Lalu, kami bertanya lebih lanjut, apa yang biasanya ia lakukan ketika menghadapi situasi tersebut. Ia menjawab, “Mendel mawon (diam saja).”

Seksualitas dan Reproduksi

Ibu Sinta mengaku tak pernah ke salon kecantikan. Bahkan, ia juga tak paham apa yang dimaksud dengan salon kecantikan.

Ia mengaku jatuh cinta pada suaminya. Dulu ketika belum menikah, Ibu Sinta sering dikunjungi kekasih yang ia sebut namanya Kuswanto. Ada perasaan senang saat bertemu dengan sang pujaan hati. Namun, Ibu Sinta tak memahami istilah seks, seksualitas, maupun aktivitas seksual. Ia pun terlihat sungkan untuk menjawab sejumlah pertanyaan yang bersifat intim. Dia hanya mengatakan bahwa amor (berhubungan badan) dengan suami bisa menyebabkan dirinya hamil dan memiliki seorang anak perempuan.

Saking sayangnya pada suaminya, hingga kini Ibu Sinta belum bisa menerima kenyataan bahwa suaminya telah meninggal sejak beberapa tahun lalu. “Tiyang e kih loro maag. Wonten Ngijon, mboten purun wangsul (orangnya sakit maag. Sekarang di Dusun Ngijon dan tidak mau pulang),” kata Sinta setiap kali disinggung tentang almarhum suaminya. Dengan nada suara yang agak tinggi seolah menunjukkan adanya perasaan emosional dalam batinnya.

Melihat kondisi Ibu Sinta yang mulai tidak nyambung dengan pertanyaan-pertanyaan kami, akhirnya kami memutuskan untuk beralih ke pertanyaan lain.

Reproduksi

Di usianya yang telah memasuki 51 tahun, Ibu Sinta mengaku sudah tidak lagi mengalami menstruasi. Ia pernah menikah dengan seorang pria dan dikaruniai seorang anak perempuan penyandang disabilitas cerebral palsy yang sekarang berusia sekitar 23 tahun. Selama masa kehamilannya dulu, ia juga rutin melakukan konsultasi di puskesmas setempat hingga proses kelahirannya berjalan normal, meskipun bayinya terlahir prematur. Sebelumnya, Ibu Sinta tidak pernah mengalami kehamilan tak diinginkan, keguguran, maupun aborsi. Kala itu, dia mendapatkan dukungan penuh dari suaminya. Sayangnya, setelah suaminya meninggal, dia tidak lagi memiliki orang yang bisa memberinya dukungan, bahkan dari keluarga dekatnya. Setelah menikah dan memiliki anak pertama, Ibu Sinta tidak menggunakan alat kontrasepsi apa pun.

Sistem Dukungan

Depresi berat yang dialami Ibu Sinta menunjukkan dia mengalami tekanan kejiwaan yang salah satunya dikarenakan tidak adanya dukungan dari keluarga. Terutama setelah suaminya meninggal dunia. Perlakuan tidak menyenangkan, seperti pemasungan di dalam rumah dengan digembok dari luar merupakan bentuk tidak adanya kebebasan baginya dalam menentukan keputusan untuk hidupnya sendiri. Hal ini termasuk tidak adanya perlindungan atas tubuh dan seksualitasnya.

Hanya saja (berdasarkan penjelasan Mbak Marlina), kondisinya kini sudah terlihat membaik dibandingkan sebelumnya. Ibu Sinta sudah tidak lagi dikunci dari luar, dan bisa mandi sendiri serta sesekali memasak. Hal tersebut tidak lepas dari dukungan Sapda yang memberikan pendampingan untuknya.

Sosial

Dalam kehidupan sosialnya, Ibu Sinta menyebut Mbak Fita sebagai tetangga yang cukup baik padanya. Dia mengaku sering bermain ke tempat Mbak Fita.

Deskripsi Ani, Disabilitas Intelektual (Yogyakarta)

Siang itu, dengan waktu yang sudah disepakati kami bertemu dengan seorang ibu usianya sekitar 35 tahun. Saya mengenal perempuan ini sejak dia masih sekolah di SLB setingkat SMP, di sebuah acara kawan disabilitas. Dia berbeda dari perempuan disabilitas lainnya sehingga menarik perhatian banyak orang yang hadir di sana, termasuk saya. Selain cantik, pembawaannya juga sangat ceria.

Setelah sekian tahun tidak bertemu, akhirnya kami dipertemukan lagi beberapa tahun yang lalu dengan kondisi yang jauh berbeda dari sisi penampilan fisiknya. Namun, dia tetap cantik dan menggunakan make up di wajahnya.

Dia adalah Mbak Ani (bukan nama sebenarnya), seorang disabilitas mental intelektual. Pada masa muda, Mbak Ani adalah seorang atlet tolak peluru dan pelari. Kemampuan bicaranya masih bisa dipahami, meskipun kadang pembicaraannya melebar ke mana-mana dan tidak fokus. Hingga saat ini, dia masih rajin konsultasi ke dokter syaraf dan mengonsumsi obat.

Tidak begitu banyak yang dia ceritakan karena setiap menjawab pertanyaan, jawabannya selalu tidak fokus, dan jika sudah capek dia akan mengeh-mengeh. Maka, kami pun tidak memaksa dia untuk banyak bicara karena pasti akan mengulangi jawaban sebelumnya.

Pemaknaan Diri

Mbak Ani mengalami disabilitas mental intelektual tidak sejak lahir. Dia menjadi disabilitas karena kecelakaan yang menyebabkan benturan di kepala bagian belakangnya. Mbak Ani ditinggal meninggal Ibunya sejak dia kecil, setelah 2 tahun ayahnya menikah lagi dengan perempuan yang galak terhadap Ani. Sejak ayahnya menikah, Ani sering ditampar dan dimarahi oleh ayah dan ibunya.

Ayahnya adalah seorang PNS yang mempunyai penghasilan yang cukup dan jaminan kesehatan. Sehingga, beliau mampu untuk memberikan pengobatan kepada Ani dengan melakukan operasi mengeluarkan cairan di kepala bagian belakangnya. Setelah dioperasi, kondisi Ani mulai membaik, tidak pusing dan bisa berkomunikasi dengan lancar.

Ani merasa sangat pusing ketika ada banyak masalah yang dia pikirkan. Jika ayahnya marah, beliau akan mengatakan bahwa Ani pethuk, goblok. Selain itu, ayahnya juga memukul Ani hingga kepalanya pusing.

Tetangganya juga sering mengatakan bahwa Ani adalah bocah pethuk. Namun, dia tidak mau memedulikan dan memikirkannya karena jika dipikirkan kepalanya akan pusing. Ani mengenyam pendidikan SD sampai SMA di SLB dan pernah tinggal di Asrama Yakum. Di Asrama Yakum, Ani banyak mengenal teman dan terbebas dari ayahnya karena tidak pernah dimarahi lagi.

Seksualitas dan Reproduksi

Ani sadar bahwa dia adalah seorang perempuan yang cantik. Dulu, dia sering menjadi model untuk teman-teman disabilitasnya yang kursus kecantikan. Dari situ, Ani belajar merias diri. Dia kemudian sering meminta imbalan dari teman-temannya yang menggunakan jasanya sebagai model, imbalan berupa lipstik atau alat make up yang dia inginkan. Teman-temannya pun memberikannya imbalan berupa make up. Ani sangat ingin kursus memotong rambut, tapi tidak diizinkan ayahnya. Akhirnya, dia belajar di Youtube. Saat ini, dia sedang senang belajar menyanyi melalui Youtube, dan sering menyanyi bersama teman-temannya.

Selama sekolah, Ani belum pernah pacaran. Dia pernah jatuh cinta dengan laki-laki non-disabilitas yang merupaka seorang atle. Namun, Ani pergi dari Jogja dan mereka tidak pernah bertemu lagi. Ani selalu didekati laki-laki yang baik, dari disablitas maupun yang non-disabilitas. Banyak di antara mereka yang menyatakan cinta. Ani selalu senang kalau ada yang mengatakan dirinya cantik, dia akan tersipu-sipu (senyum-senyum). Saat masih SMP, ada laki-laki disabilitas yang menyatakan senang dengan Ani dan akan menikahinya. Namun, ditolak oleh ayahnya Ani. Ayahnya selalu marah

jika ada laki-laki disabilitas yang mendekati atau senang dengan Ani. Setiap hari, Ani dimarahi. Dia tidak diizinkan pergi dan tidak boleh bergaul dengan laki-laki disabilitas. Ani mengatakan, dia tidak pernah mau kalau ada laki-laki yang akan mencium dirinya atau meraba payudaranya. Dia akan melawan. Kata Ani, perempuan harus berani melawan. Dia juga takut jikalau hamil dan memiliki anak. Dia bingung menghadapi kondisi tersebut.

Ani pertama kali merasakan berhubungan badan (tidur bersama dengan tanda tangannya menunjuk ke alat kelaminnya) bersama 5 orang disabilitas. Mereka mengajak Ani pergi ke hotel. Namun, Ani menolak. Akhirnya mereka pergi ke rumah salah satu dari 5 orang disabilitas tersebut. Sesampainya di rumah tersebut, payudara Ani diraba. Dia disuruh tiduran, kemudian satu-satu dari mereka menindih tubuh Ani. Dia merasa sakit dan mengeluarkan darah. Namun, Ani tidak tahu apa yang terjadi dengan dirinya dan apa yang dilakukan oleh 5 laki-laki tersebut. Dia tidak sadar apa yang terjadi, tetapi merasakan "enak" setelah ditindih dan alat kelaminnya dimasuki alat kelamin laki-laki (dia menyebut nama laki–laki).

Ani setiap hari jalan-jalan dan mendatangi teman-temannya, termasuk teman laki-laki. Ketika Ani datang ke laki-laki yang bernama Tomo (bukan nama sebenarnya), dia sering disuruh tiduran dan payudaranya diremas–rema, tubuhnya juga ditindih. Sampai suatu ketika, badannya bertambah gemuk dan sering mual-mual. Banyak temannya yang mengatakan bahwa dia hamil. Namun, Ani tidak paham dan merasa kalau hanya sakit maag. Meski demikian, ayahnya mengajaknya pergi ke puskesmas, dan ternyata Ani telah hamil 5 bulan. Sejak saat saat itu, dia sering memeriksakan kandungannya sendiri. Dan, dari kelima orang itu, ada satu yang bersedia menikahi Ani. Namun, orang tua Ani tidak menyukai laki-laki itu karena disabilitas. Setelah Ani tinggal di rumah suaminya, dia selalu dicereweti oleh ibu mertuanya. Kata mertuanya, "Bocah kok raiso ngopo-ngopo." Setiap hari Ani dimarahi oleh mertuanya. Hari kedua setelah melahirkan, Ani naik motor untuk datang ke dokter. Dia ingin dipasangkan alat kontrasepsi spriral oleh dokter. Sejak saat itu, Ani memakai alat kontrasepsi.

Di rumah mertuanya, Ani selalu bertengkar dengan mertuanya. Akhirnya, Ani pulang ke rumah ayahnya dengan membawa anaknya. Dia mengurus semua kebutuhan anaknya sendiri, dari berjualan baju, membantu lembaga-lembaga untuk mengantar surat, dia lakukan untuk memenuhi kebutuhan dirinya dan anaknya. Ani selalu membawa anaknya ke mana-mana. Ada seorang disabilitas yang kemudian membantu Ani untuk menitipkan anaknya di pondok pesantren hingga saat ini. Setelah anaknya dititipkan, Ani merasa bebas untuk bermain ke rumah teman-temannya, terutama yang laki-laki.

Jika sedang ingin berhubungan seksual, Ani akan datang ke suaminya. Namun, suaminya kadang marah dan cemburu kalau diberi tahu kalau Ani sering jalan dengan lelaki lain. Kalau sudah cemburu, suaminya akan galak dan Ani akan pusing.

Oleh karena itu, Ani meminta teman-temannya agar tidak memberi tahu suaminya. Ani mengalami seks aktif sehingga dia sering mempunyai keinginan berhubungan badan. Jika dia sangat ingin, dia akan datang ke suaminya. Namun, kadang ada juga yang mengajak jalan dan makan-makan, kemudian diajak tidur bersama (bercinta). Ani mengaku bahwa dia senang. Laki-laki yang mengajaknya yang selalu membayar biaya makan saat jalan-jalan. Menurut Ani, perempuan jangan mau mengeluarkan uang untuk membayar makan.

Ani melakukan hubungan badan tidak hanya dengan disabilitas, tetapi juga dengan non-disabilitas. Biasanya, para lelaki menghubungi Ani melalui WhatsApp untuk meminta bertemu. Ani akan malu-malu dan menolak, tetapi kadang dia justru yang akan datang sendiri.

Kadang, ketika ada laki-laki yang memintanya untuk tidur bersama, dan Ani tidak suka, dia pasti akan menolak dan mendorong laki-laki tersebut. Dia tahu bahwa kalau sering melakukan hubungan seksual, maka perutnya akan sakit.

Reproduksi

Ani mengalami menstruasi pada saat SMP. Dia bisa menggunakan pembalut dan memiliki pengetahuan seputar menstruasi pada saat tinggal di Asrama Yakum.

Setelah mengalami pemerkosaan, Ani menjadi seks aktif hingga dia tidak tahu bahwa usia kandungannya telah 5 bulan. Ani tidak memahami cara merawat dan menjaga kehamilannya sehingga dia tetap aktif ke mana-mana meskipun sedang hamil.

Belakang, Ani memeriksakan alat kontrasepsi yang dia gunakan. Namun, kata dokter alat tersebut tidak ada di rahimnya. Kata dokter, spiralnya hilang. Ani sering mengalami sakit di perut sebelah kiri, tetapi dia selalu berdoa agar sakitnya hilang dan spiralnya tidak mengganggu. Sekarang dia tidak merasa sakit lagi di perutnya.

Dalam urusan kebutuhan seksual, Ani berhubungan seksual dengan suaminya 3 minggu sekali. Namun sejak ada virus corona, dia tidak mau tidur dengan suaminya. Ani justru berhubungan seksual dengan orang lain, asalkan suaminya tidak tahu. Sampai saat ini, menstruasi Ani lancar dan tidak ada rasa sakit.

Sistem Dukungan

Dalam kehidupannya, Ani mempunyai banyak teman yang dijadikan tempat untuk bercerita, termasuk menceritakan hal yang dialaminya pada saat diperkosa oleh 5 disabilitas. Namun, untuk kejadian saat dia berhubungan seksual dengan beberapa teman disabilitas dan non-disabilitas dia tidak mau menceritakan kepada orang lain karena takut suaminya akan tahu. Ani baru menceritakannya saat ini karena untuk membantu teman–teman disabilitas yang tidak tahu apa-apa (menurut Ani).

Ani banyak mendapatkan dukungan dari kawan-kawan sesama disabilitas dalam banyak hal karena sifatnya yang riang dan banyak juga yang merasa kasihan padanya. Dia pernah merasa takut dengan istri dari laki-laki disabilitas yang mengajaknya tidur bersama. Ani takut dengan istri temannya yang sering dia datangi.

Sosial

Ani hidup bersama ayah, ibu tiri, serta adik-adik tirinya. Mereka baik kepadanya, kecuali ibu dan ayahnya yang selalu galak. Ani merasa sebagai disabilitas yang cantik dan pandai. Dia sering diajak Tomo (orang yang sering mengajaknya tidur bersama) untuk mendatangi disabilitas dan memberikan bantuan, serta memberitahukan banyak hal karena dia merasa lebih pintar. Ani sering berkeliling ke teman-teman disabilitas.

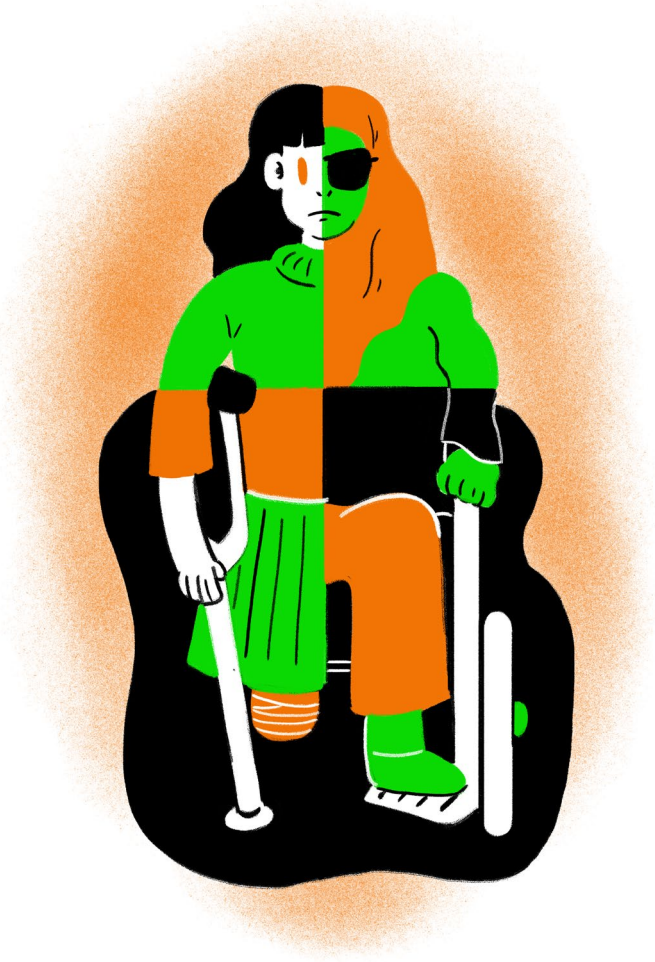
ENGLISH VERSION

Women's Fund Asia

Sapda
Sentra Advokasi Perempuan, Difabel dan Anak

Report Research

ADVOCACY FOCUSED ON BODY AUTONOMY AND SEXUAL RIGHTS OF WOMEN WITH DISABILITIES IN INDONESIA



CONTENT LIST

CHAPTER I

CONTEXT & BACKGROUND

1.1. Background

Life as a woman with a disability has various challenges and obstacles. This does not only happen in the education or work sector, but also comes from the immediate environment such as the nuclear family, spouse, and the children they are born with. Positive family acceptance of the existence and conditions of disabilities is a fundamental need for women with disabilities, from childhood to adulthood to grow and have a positive social role. Choosing a partner is a struggle in itself for women with disabilities in the midst of the stigma surrounding kitchens, mattresses and wells. A domestic responsibility that positions women with disabilities is considered different and less valuable than women without disabilities. It is important to start a discussion showing that women with disabilities have normal lives together with their disabilities that have been neglected so far.

Sexuality among women with disabilities is still considered taboo to discuss. This is caused by the stigma and myths that develop in society which tend to consider women with disabilities as asexual beings who do not have the desire to have sexual and emotional relationships. Although they are also not considered hypersexual, in many cases their sexual arousal is controlled so as not to surpass male sexual power. Control over women's sexuality, for example, through female circumcision and the inculcation of values in girls that sex is the right of men and women only have to serve. The impact of this perspective has consequences for multiple barriers compared to men with disabilities. She not only experiences obstacles because of the disability she carries, but also experiences discrimination and stereotypes as a woman. This results in women with disabilities not only vulnerable to the stigma described above, but also prone to sexual violence.

This research will show how a woman with a disability interprets her life in this case in the body of a woman with a disability who is often considered "abnormal and different from other women" and manages her sexuality among those who think that women with disabilities are asexual or hypersexual individuals from the perspective of women with disabilities.

1.2. Research Objectives

This research has several specific objectives:

1) Describe the situation of women with disabilities in terms of body and sexuality from the perspective of women with disabilities as independent and dignified individuals, which are translated into 5 key points:
    a. Individual meaning of women with disabilities about their bodies and sexuality.
    b. Sexual activity, choice of partner and sexual orientation and consequences for themselves and their bodies.
    c. Choice and who and what influence on personal choice of body and sexuality.
    d. The strategy of a woman with a disability in overcoming obstacles and challenges to her bodily autonomy and sexuality.
    e. Support for women with disabilities can make choices about their bodies and sexuality.
2) Finding support needs for women with disabilities to be able to make independent choices about their bodies and sexuality, as well as special protection needs.

1.3. Research Questions

1) What is the autonomy situation over the body and sexuality of women with disabilities as dignified individuals based on cultural diversity and disabilities?

2) How to map the needs for disability support as a form of special protection and more for women with disabilities and the potential for its fulfillment?

1.4. Research Method & Data Analysis

1.4.1. Research Subject

The study involved 10 resource persons or informants with disabilities who represented every type of disability with calendar ages from 20 to 40 years; women with active disabilities (have/have had a partner, either active or married); able to communicate well (with or without a companion/Sign Language Interpreter). The resource persons/informants are distinguished in a variety of blind, intellectual, mental, physical and speech-impaired disabilities.

1.4.2. Ressearch Location

The research took place in 2 areas with different cultural bases, namely Yogyakarta with a Javanese cultural background and Kupang. Each region received 5 speakers.

1.4.3. Research Approach and Data Analysis

- This research is a qualitative study with sources / informants with predetermined criteria.
- The approach taken in this research is gender and disability perspective, by prioritizing the personal views of female speakers with disabilities who have the awareness to express their opinions and experiences.

- Resource persons receive accessibility support through companions and sign language interpreters as needed to facilitate communication and capture detailed information provided.
- Observations are made to understand the environmental situation of the resource person living and doing activities.
- Data analysis was carried out in depth based on the theory of gender and disability.

CHAPTER II

POLICY & LITERATURE REVIEW

2.1 Existing Policies in Indonesia in Protecting the Body Autonomy and Sexuality of Women with Disabilities.

The policy that becomes a reference regarding the protection of the body autonomy and sexuality of women with disabilities cannot be separated from several international conventions and regulations in Indonesia relating to persons with disabilities, women and reproductive health-sexuality.

Instruments for protecting women with disabilities are actually available at the global, national and local levels. At the global level, the United Nations General Assembly adopted the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities in resolution 48/96 of 20 December 1993. in December 2001, the General Assembly The United Nations adopts a resolution on a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities. Post-adoption, various conferences and formulation of international policies are developed for the advancement, fulfillment and protection of human rights of persons with disabilities.

In 2006, the UN General Assembly adopted the Convention on the Right of People with Disability (CRPD) and opened for signature by member states on March 30, 2007.[1] Indonesia ratified this convention in 2011 with Law Number 19 of 2011 concerning the Ratification of the Convention on the Rights of People with Disabilities. The UNCRPD principles are inherent dignity, non-discrimination, effective inclusion, respect for differences, equal opportunities, accessibility, gender equality, and respect for capacity building of children with disabilities (Wapling & Downie, 2012, pp. 18-19; Schulze, 2010, pp. 44-49).

[1] UNCRPD is the cornerstone for the recognition and implementation of the Rights of Persons with Disabilities worldwide. To date, 160 countries have signed and ratified, 92 signed and 88 countries ratified the optional protocol; an important milestone for the realization of the rights of persons with disabilities.

In 1979 the United Nation General Assembly adopted The Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW). A total of 189 countries ratified the convention in 1981. CEDAW adopts a substantive/corrective equality approach namely ensuring an equal start, ensuring environmental readiness and ensuring equality in outcomes. The scope of this substantive equity includes access, participation, control and benefits.

The general recommendation on women's access to justice issued by the CEDAW Committee in July 2015, in the introduction, clearly states that the scope of discrimination against women is an intersection of various things including disabilities that are worn by women.

> *"Discrimination may be directed against women on the basis of their sex and gender. Gender refers to socially constructed identities, attributes and roles for women and men and the cultural meaning imposed by society on biological differences, which are constantly reproduced amongst the justice system and its institutions. Under article 5 (a) of the Convention, States parties have an obligation to expose and remove the underlying social and cultural barriers, including gender stereotypes, that prevent women from exercising and claiming their rights and impede their access to effective remedies. 8. Discrimination against women, based on gender stereotypes, stigma, harmful and patriarchal cultural norms, and gender-based violence, which particularly affect women, have an adverse impact on the ability of women to gain access to justice on an equal basis with men. In addition, discrimination against women is compounded by intersecting factors that affect some women to a different degree or in different ways than men and other women. Grounds for intersectional or compounded discrimination may include ethnicity/race, indigenous or minority status, colour, socio-economic status and/or caste, language, religion or belief, political opinion, national origin, marital and/or maternal status, age, urban/rural location, health status, disability, property ownership, and being lesbian, bisexual, transgender women or intersex persons. These intersecting factors make it more difficult for women from those groups to gain access to justice"*

The Indonesian government has passed Law Number 7 of 1984 concerning the Ratification of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW).

The issuance of Law Number 8 of 2016 is the basis of legality and the Regional Government must follow up by issuing Regional Regulations (Perda) and operational policies to realize equal services (equality) to persons with disabilities related to the right to life; free from stigma; privacy; justice and legal protection; education; employment, entrepreneurship, and cooperatives; health; political; religious; sports; culture and tourism; social welfare; accessibility; public service; protection from disasters; habilitation and rehabilitation; concession; data collection; data collection; live independently and be involved in society; express, communicate, and obtain information; change place and nationality; and free from acts of discrimination, neglect, torture and exploitation (chapter 5 paragraph 1).

This law places women with disabilities specifically for the following protections; women with disabilities have the right to reproductive health; accept or reject the use of contraceptives; get more protection from layered discrimination treatment; and to get more protection from acts of violence, including violence and sexual exploitation (article 5 paragraph 2 c).

This protection is also inseparable from the articles which contain the right to have a family for persons with disabilities, the right to make decisions and get support to make such choices or decisions. To provide protection to women with disabilities as individuals with dignity as contained in the principles contained in the UNCRPD.

2.2 The Concept of Universal Protection for the Body Autonomy and Sexuality of Women with Disabilities.

Protection of autonomy over the body and sexuality of women with disabilities universally cannot be separated from the theories of feminism and the dignity of a woman with a disability as seen from her body, voice, sexuality and politics/life choices.

2.2.1 Sexuality

The statement that sexuality is a right and sexual orientation which is the choice of persons with disabilities is quite a complicated choice. This complexity is related to their social attachment to the community, family, and people who have supported their lives as persons with disabilities who cannot accept their sexual orientation which is still seen as deviant behavior because it is considered a disease and must be abandoned. or recover. So that most of them choose to keep their sexual orientation a secret because they are not ready for the social risks they have to accept.

Meanwhile, there were not enough people with disabilities who were open to sexuality or their choice of sexual relations, because it was related to their understanding of sexuality as an individual right, and they had options for that. This is inseparable from their role in the family or society, as well as the level of socio-economic independence and interaction with the outside world.

Sexuality is not only related to biology and psychology but also experience and subjective meaning in it. It is in line with Abraham's explanation that the concept of sexuality includes not only sexual identity, sexual orientation, sexual norms, sexual practices, and sexual habits, but also human feelings, desires, fantasies and experiences related to sexual awareness, stimulation and sexual acts. included in heterosexual relationships and homosexual relationships. This includes subjective experiences and the meaning inherent in them. The concept of sexuality includes not only biological and psychological, but also social and cultural dimensions of sexual identity and habits.[2]

[2] Lena Abraham, "Introduction" in "Understanding Youth Sexuality: A Study of College Student in Mumbai", Unit for Research in Sociology of Education, Tata Institute of Social Sciences, (Deonar: Mumbai, India, 2000), page 1

The definition of sexuality based on the social, cultural, sexual identity and sexual habits of persons with disabilities can be seen from the above story, both individually because it is formed by family or culture.

The limitation of the social environment of persons with disabilities is a problem in itself, if there is a question why they are so afraid of losing their group or family and prefer to hide their sexual orientation and even their partners, the answer is the problem of social acceptance of people with disabilities. They need to make sacrifices and strive for recognition and support from social groups and their families.

In reality, persons with disabilities experience social, cultural, political and economic oppression. Oppression no longer looks at the causes of disability: congenital, war and violence, malnutrition, viruses, accidents, child labor, and natural disasters. In theory and practice, people with disabilities continue to experience oppression from the world of medicine, science, and the control of professionals in almost all sides of life, both from the public, private and even very private sectors, namely sexuality which often occurs due to disablism, racism or sexism that is running together.[3]

So it is only natural that a person with a disability is hesitant to join a homosexual group which they consider exclusive and closed or even related to the lifestyle of certain groups, but people with disabilities with the same orientation will still have difficulty getting recognition. of groups with individual and social constraints. They even hesitate to convey that they will be a single woman/single mom with sexually active as a choice for their sexuality.

The challenge of some parties to position persons with disabilities as whole human beings is that persons with disabilities as individuals with dignity who must be recognized regardless of conditions and types of disabilities have autonomy over the body, have the right to refuse medical

[3] MD Mukhotib dkk, Kesehatan Reproduksi dan Seksual bagi Remaja Penyandang Disabilitas, Lembaga SAPDA, Yogyakarta, first Print, 2015

treatment against themselves, including refusing contraception or sterilization of reproductive organs. They have the right to reject acts of violence against the body and coercion/control over their sexuality. This includes forcing both men and women with disabilities to be heterosexual or homosexual, including by the LGBTQ community itself. Married or not married, giving birth or not giving birth to their children and when to have sexual relations, as well as control over their reproductive organs.

2.2.2 Feminism, Gender and Disability

Discussing sexuality and women with disabilities cannot be separated from the concept of feminism and especially the feminism of persons with disabilities. In a feminist movement with disabilities, Rose Marry, a woman with disabilities, said that: "Women and girls with disabilities come from all ages, all races, ethnicities, religions and socio-economic backgrounds, and sexual orientations; they live in rural communities, urban, suburban. Women and girls with disabilities live in the corner of disability and femininity - with two minority identities at once, discrimination and multiple stereotypes and layered barriers to achieving their life goals. Even so, many women with disabilities find strength, the strength, and immense creativity of their multi-layered identities, they always face the consequences of discrimination.

Women with disabilities have a need to define themselves, but they are still on the fringes of the social justice movement, even from movements on behalf of themselves -the women's movement, the rights movement for people with disabilities and the civil rights movement - leaving women and girls behind a disability from all backgrounds are basically invisible." (Rosemarie Garland-Thomson and Barbara Faye Waxman Fiduccia).[4] Regarding issues of reproductive health and sexuality,

[4] Rosemary Garland Thomson, Integrating Disability, Transforming on Feminist Theory, Source: NWSA Journal, Vol. 14, No. 3, Feminist Disability Studies (Autumn, 2002), pp. 1-32 Published by: The Johns Hopkins University Press, URL: http://www.jstor.org/stable/4316922

there are very basic differences between women with disabilities and women without disabilities. Currently most women with disabilities are still trying hard to get married, proving their ability to serve their partners (read: husbands) in sexual relations and being able to get pregnant and have children.

By getting married they can have sexual relations and satisfy their husbands, and childbirth is the ideal condition for most women with disabilities. However, not all women with disabilities can live it, so it is considered as a fundamental issue and a privilege for women with disabilities who can get it. This is not really necessary when they have a homosexual partner as either lesbian or gay. Strengthens Rose Mary's theory that "The third area of feminist theory communicated by disability analysis is identity. Feminist theory has been productively and rigorously criticized by the category of female identity, on which all feminist endeavors seem to rest. Feminism increasingly recognizes that women occupy a variety of subject positions and claimed by several categories of cultural identity (Spelman 1988). It is the focus of men to women to look more fully at the exclusionary, essentialist, oppressive, and binary aspects of the category of women themselves. It is one of those identities that disrupts the reality of women's classification and challenges gender superiority as a monolithic category.[5] It could be that the fulfillment of sexual needs that do not risk getting pregnant, or the fear of giving birth to a child with a disability makes them choose to have a relationship, not as an option when they are in a good bargaining position.

In its development, this feminist theory then moves into a gender concept that not only sees women but sees this situation as a social construction/formation. Whereas the existence of social and cultural constructions causes a fundamental shift in the definition of gender, from

[5] Ibid

what is originally considered natural to become cultural. Awareness of the different definitions of masculinity and femininity in every society brings awareness to the existence of forms of sexual division of labor (Saptari and Holzner 1997: 21).[6] As a consequence, the sexual division of labor, namely the roles of men and women is determined because their sexuality in society and even the smallest environment, namely the family, is typical by looking at the customs/culture of the local community so that it is local, which may differ between regions/ethnicities/nations. and also have differences between those who live in the mountains and the coast, those who live in rural and urban areas, and will change/develop in accordance with developments in technology or knowledge.

Like gender, disability is also a social construction/formation, related to the perspectives, habits, typical, or knowledge of the community which greatly affects how they see, treat, position/place persons with disabilities in a family and society. This includes positioning/placing people in a relationship with their partner and recognition in decisions about sexuality and reproduction as an autonomous and dignified individual.

This will be influenced by the local cultural system, knowledge and social interaction between groups of people with disabilities and those who are not persons with disabilities, of course policies/regulations have a role as a social engineering that affects the situation and conditions in society. Where the situation of women with disabilities in eastern Indonesia can be different from women with disabilities in western or central Indonesia, because the diversity of ethnic, cultural and religious groups will certainly affect the construction of disability and gender itself in a society.

[6] Titi Surti Nastiti, Perempuan Jawa, Pustaka Jaya, 2016, page 11

CHAPTER III

FILED FINDINGS ANALYSIS

3.1 Description of the Situation of Women with Disabilities Regarding Body and Sexuality from the Perspective of Women with Disabilities as Individuals who are Independent and with Dignity.

3.1.1 Meaning of women with disabilities about their bodies and sexuality.

It can be said that literacy on the issue of women with disabilities is still too little, so that quite a number of parents who have children with disabilities or society in general are still missing the knowledge of how to protect those with special needs.[7]

10 respondents indicated that women with disabilities as a whole are able to recognize their bodies and sexuality the same as women in general, only 1 woman with disabilities is unable to recognize themselves and does not have the desire to take care of themselves and the confidence to understand their body and sexuality, this happens because she developed an intellectual disability after adulthood because her husband died, so it is more difficult for her to regain her confidence and rise to life with the full support of her family and companions. Meanwhile, 9 women with other disabilities did not have problems with self-meaning.

1) Women with physical disabilities

Women with physical disabilities have problems related to the meaning of their bodies that are relatively bigger and felt until they reach adulthood this happens because they directly see and feel that there are physical differences, the injuries inflicted on women with physical disabilities are due to bad treatment. in society, it will carry over to adulthood, this will have an impact on some women with physical disabilities that will show others that they are capable of being the same

[7] Ariani, Soekanwo, et al. 2011. Seksualitas dan Kesehatan Reproduksi Perempuan dengan Disabilitas Jurnal Perempuan. Jakarta

as women without disabilities, however this does not happen to women with physical disabilities who get full support from their families.

Women with physical disabilities who get support and attention from their families will be able to survive quickly adapt to society. Women with physical disabilities often experience violence from fellow women with disabilities because of the urge to show leadership skills, feel like role models/seniors in their community.

2) Women with blind disabilities

In the group of women with blind disabilities, they have very high self-confidence, they tend to be ignorant of the environment, they also experience violence both during childhood and after adulthood. quickly adapt to new environments.

3) Women with deaf disabilities

In the group of deaf women with disabilities, tend to take a long time to understand the condition of their bodies, this happens because not all parents are ready for children with deaf disabilities, so they do not prepare themselves to become parents with disabilities, for example not all families are able to use sign language, all they do is oral until children enter special schools and acquire skills about sign language, this situation affects their knowledge and recognition of themselves. Even though the process of self-recognition and the environment is late, women with deafness have a strong sense of brotherhood among deaf peers.

4) Women with intellectual disabilities

For women who have experienced intellectual disabilities from a young age, they tend to be able to interpret themselves and recognize themselves better than women with intellectual disabilities who are adults or even married.

Women with intellectual disabilities from a young age are able to interpret themselves and their bodies, they are able to socialize and interact with society in general, are able to carry out positive activities such as sports and school. Because they experienced discrimination from the surrounding community since they were young, so that they had a better survival power, she realized that her body was very valuable. They also get more attention from their family. Families will tend to be protective of children with intellectual disabilities, so that they are able to adapt and get along with the environment.

Meanwhile, for women with mental disabilities that they experience as adults, many are treated more severely, some have to live on the streets and some are shackled by their families, this is done because families do not want to be blamed by residents when women with intellectual disabilities run amok. and commit violence against society. The decision to lock down is usually made based on shame and pressure from the community. Due to their disability condition they tend to ignore their body condition, this happens because of a feeling of more despair and a loss of enthusiasm for life.

5) Women with mental disabilities

In the group of women with mental disabilities, their self-meaning and self-confidence were very good. They are very confident in associating and interacting with the community. They don't feel that there is anything different from other women. They get along with everyone and are able to work like everyone else, even though they have to take medication to keep them focused. Women with mental disabilities face discrimination from society to adulthood. Even when they work, they still experience insults in the form of calling people “crazy”.

Women with mental disabilities generally pursue one of the sports fields, they will focus on that activity, it happens in many women and in many areas, so she has high self-confidence.

3.1.2 Activity, choice of partner and sexual orientation and consequences for themselves and their bodies.

In some areas in Indonesia there is an opinion that persons with disabilities are a curse or disgrace that has been committed by their parents and is considered asexual. This assumption makes parents with children with disabilities tend to limit their access to the outside community. The sad thing is that people let that happen. As a result, information on reproductive and sexual health and rights is difficult to access. Even parents lack knowledge of sexual and reproductive health and rights.[8]

This is clearly illustrated in research conducted on 10 women with disabilities in 5 different types of disabilities: limited information on reproductive health and sexual education, women with disabilities do not know about sexual activities, so they are very vulnerable to sexual violence, as the description shows.

1) Women with pyshical disabilities.

Based on the results of interviews with two women who have different cultural backgrounds, geographic conditions, and locations, it generally shows that women with physical disabilities recognize sexuality at an adult age, even though they know the opposite sex on average at 17 years of age, they do not do so. sexual activity.

[8] National Women Commision. Findings: culture-based Women with Disabilities in thematic studies and studies of violence against women. 2012; Komnas Perempuan's SRHR Team. 2015. Proceedings of the Workshop on Preparation for the Development of the SRHR Berief Policy. Komnas Perempuan. Jakarta; Komnas Perempuan's SRHR Team. 2015. Results of Field Visits in Yogyakarta, Bandung and Balikpapan. Komnas Perempuan. Jakarta

Women with disabilities in Yogyakarta recognize sexuality activities after marriage. This occurs because the limited information on sexuality of women with disabilities tends not to understand sexual activities even though they are married.

Different things happen in NTT with different cultural backgrounds, women with disabilities in NTT choose to have relationships with men with disabilities without official ties. This happened because in NTT, when a man was getting married, he had to provide a very large dowry, while most of the poor with disabilities were unable to pay a dowry for marriage. So, so choose to have sex without marital status.

2) Women with blind disabilities.

In interviews conducted with women with visual disabilities, they engage in sexual activities after they are legally married. This breaks the assumption of society that people with disabilities are asexual. Women with disabilities can also get pregnant like women in general. Sometimes people's prejudice that people with disabilities are asexual makes them marginalized. The community also considers women with disabilities to be unable to marry and care for children. Even though women with disabilities can also have children, they only need support during pregnancy and more medical attention.[9] This is experienced by women with visual disabilities, they are often considered unable to care for children, so that many women with disabilities when having children are taken by their families. However, not a few women with disabilities are able to care for their children to adulthood.

[9] www.betterhealth.vic.gov.au. Domestic Violence and Women with Dissabilities. The Better Health Channel, Australia

3) Women with deaf disabilities.

Deaf women with disabilities are prone to sexual violence, this happens because of barriers to speech that make perpetrators of violence feel safe in carrying out their actions. From the interviews conducted, deaf women with disabilities have been subjected to violence more than once and the perpetrator is their closest person. This means that the family knows and knows the perpetrator of the rapist, but they are unable to do anything, because they cannot prove and feel ashamed of having a child with a disability that makes them tend to hide, including when pregnancy occurs, they are ashamed to bring them to Puskesmas. Another thing that happens to families with deaf disabilities, they will carry out strict supervision of their children, by accompanying all their activities. so that on average, deaf disabilities will be late in getting education and understanding the outside world, including knowing and understanding reproductive education.

4) Women with mental disabilities.

Women with mental disabilities are also vulnerable to sexual violence. Based on the interviews conducted, families have a very important role in looking after women with mental disabilities. Women with mental disabilities who experience disabilities in adulthood. Because one event certainly will not understand sexuality. This makes them vulnerable because they don't know what people are doing with their bodies. Meanwhile, women with mental disabilities experienced from childhood will be better able to understand sexuality activities, but with the right information and family support, women with disabilities are able to carry out activities in the public sphere well.

5) Women with intellectual disabilities.

Women with intellectual disabilities on average have a very cheerful and expressive nature, they have more self-confidence. They know beauty and understand how to care for the body. Mental disabilities are also very vulnerable to sexual violence, because they do not understand what people are doing to their bodies. This is what makes them often get violence because they will still look cheerful (like enjoying) and are done more than once so that in cases of sexual violence in mental disabilities it is difficult to get justice because the perspective of law enforcers is not yet responsive to disabilities. For example, women with disabilities were raped more than once. The assumption is that law enforcement is raped more than once and they are still happy. This resulted in many cases that did not proceed to legal proceedings, even though they were often raped. The understanding of the needs of disabilities in conflict with the law is very complex, starting from understanding from their families, at the level of investigation, at trials that need intensive assistance to women with intellectual disabilities. Because they experience sexual violence not only once but many times, some even get violence every week. Limited information about sexuality makes them unaware that they have had sexual intercourse, even if they are pregnant, they do not understand.

3.1.3 Determination of choice and who and what affects personal choice of body and sexuality.

In terms of making choices, women with disabilities are often unable to negotiate with their partners, feelings of submission and fear of being abandoned by their partners make them silent and follow their partners. Including getting violence from their partners. Some women with disabilities are often unable to enjoy sexual activities such as women with spinal cord injuries, some of them cannot feel their sexual activities, although some are still able to enjoy them. When they are unable to enjoy

sexual intercourse, they feel pain, as well as for women with mental disabilities who do not understand what is happening to their bodies. They can only feel pleasure without being able to know the impact. From this condition, women with disabilities need access to information on contraceptives that are in accordance with their body condition, not forcing contraception to be installed. Usually, this contraceptive is also given by his family and even by coercion, especially for people with mental and intellectual disabilities. For people with certain disabilities, it may be difficult for them to put on and take off the condom. To consume hormones due to other drugs being consumed and so on, it is necessary to provide information, skills and support. Contraceptives for women with disabilities are often given by their families, even forced sterilization is often found in persons with mental (psychosocial) and intellectual disabilities. this can be seen from the interviews conducted with.

1) Women with physical disabilities.

The decision to marry or live together with a partner without being married is a decision that must be accepted by women with physical disabilities. There is a fundamental difference between being married or not. Getting married has little risk, while living together without being married risks being ostracized for cultural reasons, the consequences for women are heavier, ranging from being ridiculed by society to having to be abandoned by their partners. Likewise, when they are pregnant, support from their partners is expected. In interviews conducted, couples with official marriages received support from both their spouses and their families. Meanwhile, for couples without ties, the support women receive is very limited. Likewise, when they decide to use contraceptives, with physical disabilities they can make choices about the contraception they want.

2) Women with blind disabilities.

In terms of the decision to do marriage, women with visual disabilities are often paired with blind people and work as masseurs. When pregnancy occurs, women with visual disabilities receive support from their partners, but because of their fear of becoming pregnant and having children, respondents in Kupang did not tell their husbands about their pregnancy. This is because she is not ready to get pregnant and have children, limited information makes her afraid and anxious when she has children, but thanks to the support of her partner, she is finally able to accept her pregnancy and diligently check her womb at the nearest health clinic.

Women with visual disabilities in deciding to use contraception, on average, use family planning implants, but a lot of bleeding occurs so they decide to change contraception after getting the right information from the doctor. Couples have a very and very expected role in making decisions to use contraceptives.

3) Women with deaf disabilities.

Many women with deaf disabilities experience sexual violence, this is clearly illustrated by respondents in Kupang. She got repeated sexual violence and even had 3 children from different boys. Limited information about sexual education and contraceptives makes recurrent pregnancies violent. These respondents do not have authority over their bodies. Until her third pregnancy she still did not have access to contraceptives. Meanwhile, respondents in Yogyakarta experienced violence in the form of prohibiting their husbands from using contraceptives. Meanwhile, her mother continued to force her to use contraceptives. This conflict made him confused in making choices. The choice to use contraception without careful consideration made her choose the wrong contraceptive and caused bleeding for 6 months.

When pregnancy occurs, women desperately need support from their partners, however this was not obtained from respondents in Kupang. She did not get health access to the puskesmas until she gave birth, only in pregnancy the 3 respondents had their womb checked at the puskesmas.

4) Women with mental disabilities.

Women with mental disabilities do not know information about contraceptives, usually their families will represent them to agree to use contraceptives. Not a few of them experience coercion. Sterilization is the choice of many families for family members with mental disabilities. In fact, women with mental disabilities still have the right and authority to choose the contraceptive device they want.

5) Women with intellectual disabilities.

From respondents who already have children, it is known that she only realized that she was pregnant when she was 5 months pregnant. She was a victim of rape by more than one man. The parent who brought it to the puskesmas. She eventually married the perpetrator who raped her and her parents accepted the child she had given birth to. However, her husband's family did not accept verbal abuse and so she chose to leave her husband's house. In the decision to use contraception she did not know, suddenly one day after giving birth she was put on a spiral contraceptive device, but strangely enough when she wanted to remove/replace her spirals it was not in her uterus.

3.1.4 The strategy of a woman with a disability in overcoming obstacles and challenges to her bodily autonomy and sexuality.

Discrimination on sexual and reproductive rights among women with disabilities still occurs. Women with disabilities are often considered asexual and sexually unattractive and unable to engage in sexual activity. Even though some think they are capable of sexual activity, they are

considered monsters who cannot control their sex drive and feelings. Cannot be responsible or take care of children.[10] This occurs because of cultural understandings, myths and stigma that affect sexual experiences of persons with disabilities. A woman with a disability experiences a multitude of burdens, on the one hand she has to compromise her body condition, on the other hand she has to be able to overcome discrimination from society. In research conducted on women with disabilities with different disabilities, there are different strategies.

1) Women with physical disabilities.

A respondent in Yogyakarta experienced disabilities and discrimination since childhood. Even when she decided to get married she was still discriminated against by being ridiculed by the community, being considered unable to carry out sexual activities and let alone getting pregnant and taking care of children. However, with family support and strong determination, these respondents were able to prove that disabilities can have children and are able to care for children properly. While the respondent in Kupang chose not to marry for reasons of poverty, she lived her pregnancy with a lot of struggle. She is against all discrimination against her for getting pregnant outside of wedlock. To overcome the difficulties, respondents in Kupang entrust their children to their families so that they can work and earn money to support their children.

2) Women with blind disabilities.

Barriers to women's disabilities in terms of sexual activity are almost non-existent. They are able to perform normal sexual activity. Discrimination appears precisely from the community, they question the care of their children. Women with visual disabilities are considered

[10] Penchan Sherer, PhD, dari Department of Society and Health Faculty of Social Sciences and Humanities Mahidol University, Thailand dalam acara the 6th Asia Pacific Conference on Reproductive and Sexual Health and Right di Grha Sabha Pramana UGM

unable to care for children, but they prove that they are capable, including being able to overcome the stigma of society by continuing to work and support from partners which greatly affects their strength and self-confidence.

3) **Women with deaf disabilities.**

Deaf women are prone to sexual violence, even from their closest relatives. They do not have barriers in sexual activity, but vulnerability to acts of violence is very real among deaf women, according to respondents in Yogyakarta, the way she does this is by organizing and making friends with deaf friends and having discussions with each other regarding sexual activities. The role of the family is important to ensure women with disabilities seek sexual references in the right place. While respondents were in Kupang, due to very limited access to information, as well as family poverty, respondents became victims of sexual violence many times.

4) **Women with mental disabilities.**

Respondents in Yogyakarta how to overcome obstacles by diligently taking medication. Family support are needed for respondents experiencing disabilities in adulthood. While respondents in Kupang were done to overcome barriers by becoming athletes and socializing with many people.

5) **Women with intellectual disabilities.**

A respondent in Yogyakarta experienced repeated sexual violence. To overcome this she uses contraceptives and avoids meeting people she doesn't like, she will refuse when asked by men she doesn't like. She realized that having sexual activity would result in pregnancy, her experience of being pregnant made her remember. Meanwhile, respondents in Kupang kept their distance from their girlfriends so they would not engage in sexual activity.

3.1.5 Support for women with disabilities can make choices about their bodies and sexuality.

In living life, women with disabilities experience discrimination from birth, when their families are poor and are not ready for the presence of children with disabilities, what will happen will be discrimination from the family, but it is different from women with disabilities who are born in well-off families. He will get support even if it is too late, but in general he will be able to get through life better. Family is still the main factor in providing support to women with disabilities and especially mothers of women with disabilities. Support from friends is needed partly when the family is unable to provide support to overcome existing obstacles. Finally, support from a partner is important because not all women get a partner who understands their body condition and sexuality.

3.2 Map of Support Needs for Women with Disabilities to be Able to Make Independent Choices About Their Body and Sexuality, as well as Special Protection Needs.

Based on the conditions and situations of women with disabilities in terms of the need for freedom to determine their choice of body and sexuality as well as the need for special protection, this support is needed:

a. Ensure access to information for women with disabilities on the importance of reproductive health.
b. Intensively conduct special sexuality education for persons with disabilities according to their types and needs.
c. Involving families and parents with children with disabilities in educational activities for disabilities.

d. There is access to clear information about contraceptives.
e. The availability of accessible services related to services / counseling related to contraceptives.
f. There is a special clinic for families with children with disabilities.

Attachment:

RESPONDENTS DESCRIPTION

Description of Desi, Physical Disability (Kupang)

On February 20, 2021, at 18.00 WIB, Berti and Elmi went to Desi's house (not her real name). We picked her up to dinner. However, that day none of the restaurants allowed their customers to eat on the premises. Desi's house is crowded. We then decided to go to my house (Berti). Interviews started at 19.00-20.30 WIB. After we finished, the three of us had dinner.

Elmi and I called the car that took us to take Desi back to her house. Desi leaves at 21.10 and arrives at her house at 21-30. Me and Elmi gave Rp150,000 to Desi and paid for car transportation Rp100,000.

Respondent Identity

Desi is a woman with a disability who was born in Timor Tengah Selatan Regency. This 33-year-old girl has straight, waist-length black hair. Desi has a body size of about 55 cm. Desi has a deformity in the shape of her legs that makes her unable to walk fast. Desi often has difficulty when riding a vehicle.

Desi is not married but has had children. However, her son died when he was 10 months old. Desi never went to school so she couldn't read and write. She sells betel nut every day in a small shop near the Kupang City terminal. Desi has a disabled sister who recently graduated from high school. Her sister's posture is the same as Desi.

Meaning of self

Desi, a disabled person with a mini body, has an abnormality in both legs that makes it difficult for her to walk. She is confident and can blend in with neighbors and society in her daily life. In addition to selling, Desi also helps take care of and take care of her sister's children who are only a few days old.

Desi has been discriminated against. It is not uncommon for children to call her a child. Near the place where she was selling, there was once a man who was bullied. Seeing this, Desi ventured to encourage the person. "What do you see me like? Just the same. It's not that you're perfect, you're great. You have hands, I have hands. It's just the posture that's different," said Desi.

Not only that, there were also people who looked cynically at Desi. Desi's sister who saw this was immediately angry. "Why look long at my sister like that?". Desi was just silent seeing her sister angry. Desi no longer cares about what people think of her. "Many people make it uncomfortable but I just ignore it." he said.

Desi has made peace with himself. She didn't feel anything strange about her physique. She was actually disappointed with her parents who treated her and her younger sister with a disability. Since childhood, Desi lived with her aunt. She was sad because she felt abandoned by her parents. When she lived with her aunt, Desi didn't go to school because it was too far away. "I'm very disappointed why I don't go to school like other siblings who can go to school," she said. "Other people can read, I can't read," added Desi. Desi never thought and felt different because her circle of friends did not distinguish one another. She is grateful for her body condition.

She realized that her self, body, mind, and voice were precious. Desi says that there is nothing lacking in her. "I have legs, full arms, eyes too." Desi is sure that God has a reason to give her a body like that.

When riding public transportation or at the terminal, people often stare at her for a long time. Seeing this, Desi immediately reacted and asked, "What's wrong? There was also a man who looked at her with a look she didn't like. "Maybe they've never seen anyone like me," she said. Desi's cousin once snapped at people who looked at her for a long time. Desi herself chose to be silent at that time because she didn't want to add to the problem.

Sexuality and Reproduction

Desi fell in love for the first time when she was 17 years old. She once dated a man named Andre. They met and got to know each other at the shop. Desi also said that she had dated more than 5 men she recognized through her cellphone.

About sex all I know is having sex. Desi is attracted to men. With her first boyfriend, Desi only met at a shop. "I'm scared and don't want to go out, I'm more careful because I don't know the nature of men," said Desi.

At the age of 25 years (in 2011), Desi began to know about sexual activity when she met her boyfriend. Her boyfriend is also disabled. At first they were just nose kisses. Her boyfriend then asked Desi to have sex. Desi feels happy when having sex like husband and wife because they like each other. Desi is happy and willing to talk to each other every time. But there is a desire from herself to stop for fear of getting pregnant. The reason is because her parents don't know about her relationship, so she's afraid that she might get pregnant.

Although happy but Desi is afraid because there is no clarity about the relationship. Desi knows the impact of having sex, namely getting pregnant. Therefore, when it comes to using contraception.

Desi is familiar with a Posyandu cadre and the cadre collects data so that implants can be inserted. Her boyfriend allowed Desi to put implants. Desi several times came to her boyfriend's house which is 1 hour from his house. Her boyfriend's family knew when Desi came. Desi is provided with her own room.

When dating, Desi loves to be hugged by her boyfriend. Desi never said that she wanted to have a relationship. She only hooked up when hier girlfriend asked. Desi uses the code "want to be pampered" if she wants to be hugged by her boyfriend. The boyfriend will then hug her. There is no sexual activity that Desi doesn't like because she likes it and her boyfriend always does sexual positions that Desi likes.

Reproduction

Currently, Desi's menstrual period is not smooth. This month she only had one day of menstruation. Though usually two to three days. Desi once had a desire to have children after marriage. However, she actually experienced an unwanted pregnancy (KTD) in 2012. The incident occurred when she started working as a babysitter and household assistant at the head of the disability organization in NTT, namely Nana (not her real name).

In that house, Desi lives with her best friend, Lena (not her real name). Sis Nana, lives with her husband and one of her adopted daughters who are about 5 years old and adopts a baby boy who was raped.

Desi's job was not only to take care of the baby but also to do other household chores. She works and lives in the house from Monday to Saturday and is paid IDR 250,000 per month. She bought daily necessities from the money. If there are organizational activities, the money will be deducted. Every working day Desi is allowed to go home. Desi used the opportunity to get in touch with her boyfriend. After 6 months of work (2012), Desi got pregnant. She realized her pregnancy was the result of having sex with her boyfriend who was not using contraception. Her boyfriend found out about the pregnancy news and wanted to take care of the child in her womb.

Desi only dared to tell her pregnancy after she was three months pregnant. She told her best friend, Lena. Lena couldn't believe it. Finally, Lena told Sis Nana. Lena was then asked to go to the pharmacy to buy a pregnancy test kit. The next day Desi did a test and the result was positive. Sis Nana is shocked and says bad things to Desi and blames her for being pregnant. In addition, Desi also continues to do strenuous activities, take care of the baby, clean the house, wash clothes and lack of rest.

Desi was desperate and even tried to abort her pregnancy for fear that her parents would find out. Desi had consumed Bodrex and drank Sprite as an attempt to abort the womb. Because her parents have not approved her relationship with her boyfriend. Her aunt also only found out when she was 6 months pregnant. During pregnancy her family only thought Desi was fat.

Her friend Lena advised her to take care of the fetus. Her boyfriend also supports that the fetus is well cared for. Finally, Desi decided to continue caring for the baby. When she was 8 months pregnant, Desi stopped working for Sis Nana. During her pregnancy, Desi is sometimes accompanied by Lena to the health center to check the womb. Desi's boyfriend never accompanied her to the doctor. She only gives a little money when she meets.

When she was nine months pregnant, Desi decided to go to the General Hospital. Desi forced her boyfriend to take her for control and preparation for childbirth. The doctor recommended surgery because Desi's body did not allow her to give birth normally. All delivery costs are assisted with the BPJS card. The other expenses were borne by her girlfriend. The delivery process went smoothly, the mother and baby were safe. However, the baby died at the age of 10 months.

After giving birth, Desi returned to her aunt's house and took care of the baby. Desi provides exclusive breastfeeding for 3 months. When the baby was 3 months old, her boyfriend asked for sex. As a couple Desi complied. Desi doesn't want to fight and make him angry. Desi chooses to keep her partner's feelings.

When her son was 40 days, her girlfriend returned to Oesao to work. Desi decides to return to her parents' house. At home, Desi's brother is angry that her girlfriend didn't send her money or food. Desi finally decided to leave the baby at her parents' house. Desi chooses to return to work selling betel nut in Kupang and leaves her baby for 3 months.

Whenever there is money, Desi always visits her son. Desi often fights with her father and mother when they want to return to work in Kupang. Her mother is angry with Desi's boyfriend. Desi's younger brother also threatens her girlfriend not to meet Desi and her baby. Her family thought her girlfriend was gone. Finally Desi decided to go back to Kupang and live with her aunt.

Desi comes home to see her baby once every two weeks when there is money. Desi once tried to take her child away when her parents weren't home. However, Desi is chased by her cousin and forced to get off the bus. Desi's older sister reported this to her parents.

The family is afraid that the baby's father will be taken from Desi. Desi had tried to convince her family that it was impossible for her boyfriend to take the baby. Desi's boyfriend doesn't really think about Desi's family's attitude that hates him, her boyfriend said, "It's up to you if you don't want me to be responsible for the child. As long as you take good care of my child," said Desi imitating her husband's words.

Her husband told Desi that he was responsible until the baby was born. However, Desi is still disappointed because her husband doesn't want to bring his family to see each other so they can be taken care of. Desi wants to be a legal husband and wife, but her boyfriend is not ready yet.

Support System

Desi never felt threatened. It's just that when she was pregnant she was often yelled at and scolded by Nana and her husband. Get hurtful words. Desi has a heavy workload. Desi said that during her pregnancy she received support from Mother Mery, a friend of her organization. Mother Mery who advised her to take blood-boosting medicine. When she was pregnant, Desi didn't dare to complain too much because she lived and worked at other people's homes.

Desi prefers to keep her feelings because she doesn't trust other people easily. The person who always provides support and helps make decisions is her boyfriend and best friend Lena. The support given by the husband is in the form of comfort, helping to take care of the baby, giving money for the needs of the child and herself. Lena also helps with advice, buys pregnancy test kits, takes check-ups to the doctor, helps with work.

Social

Lena is Desi's best friend. Lena became a place to vent and friends to share the joys and sorrows. Lena is the one who knows best when Desi is happy and sad. Lena once planned that one day she would rent her own boarding house so she could live with Desi. Lena herself will work and take care of Desi so they can live together freely. Lena does not want to part with Desi. Heavy and light are always faced together. Lena never judges anything Desi does. Lena always supports Desi's decision. keputusan Desi.

Desciption of Dita, Blind Disability (Kupang)

On February 27, 2021, at 17.00, Berti and Elmi left for Dita's boarding house (not her real name). After arriving at Dita's boarding house, it turned out that there were quite a lot of people. Dita's room is small and next to her room lives three people with blind disabilities.

After Dita's husband died 3 years ago, Dita lives alone with her 8 year old son. Because Dita's house was busy, we took Dita to a restaurant not far from her boarding house. After searching around we finally found a quiet restaurant. There were only 2 waiters in the restaurant. The place is quite comfortable to talk.

Interviews started from 18:00 to 19:30 WITA. After they finished telling the story, Berti and Elmi gave Dita an allowance of IDR 150,000. The total cost of dinner for the three of us was IDR 95,000. After eating, Berti and Elmi took Dita home. Dita arrived at her boarding room at 19:45.

Respondent Identity

Dita is a woman who was born in Sabu Regency. This 32-year-old woman has straight, shoulder-length black hair. She has an oval face shape and a sharp nose. Dita as she is called has a height of 140 cm, she had formal education up to grade 3 elementary school. In the past, Dita could see, but eventually she had low vision and over time she couldn't see at all. Dita continued her education at the Hitbia Blind Home, Kupang. She was married but her husband died two years ago due to illness. Now Dita lives in the boarding room where she has lived since 2 years ago. Previously she rented a boarding house near the church, but the place held so many memories of her husband that she was uncomfortable and decided to find a new boarding house. After being left by her husband, now she is a single parent who raises her child.

In order to survive, Dita works daily making dusters. In a day he is able to produce 12 dusters. Dita bought herself the materials needed. She left the duster she made in front of the Oebobo Supermarket for sale.

Apart from making dusters, Dita also works as a massage therapist on call, both male and female. For male patients she requires that he is married. Dita never fixes massage rates on her customers. But the average customer pays a minimum of IDR 250,000 for one hour.

In marketing her duster, Dita borrowed a friend's stand, but Dita had to wait for her friend to finish selling before she occupied it. Before her husband died, Dita had her own stand, but since her husband was sick they returned to their village to Lembata. After returning the stand is already occupied by someone else.

In carrying out her daily activities, Dita has no obstacles, but the Covid-19 condition has made it difficult for her to find work. Dita said her visual condition made it difficult for her to find work to survive. Moreover, he has to adjust when he is in a new environment.

Meaning of Self

Dita is a sensory disabled person who can't see at all. Even so, she is still enthusiastic and feels that she has no difference in her life. She is very confident and can blend in with neighbors, organizational friends and the community. She can walk, take care of children and work.

So far, no one has mocked Dita. “People who mock me behind but no one in front of me directly. Her friends have always been good to her. However, Dita feels a little inferior because of the condition of her eyesight. She feels ashamed because she has no other job besides selling dusters and masseurs.

The Covid-19 pandemic situation has had a major impact on Dita. She is afraid that if she is exposed to the Covid-19 virus and no one will take care of her child. Dita is also very worried if her income is no longer enough to meet the needs of her life and that of her child. During the pandemic Dita rarely went out. Meanwhile, she has to pay the rent of Rp. 250,000 per month. Before the pandemic, the results of selling Dita's duster were pretty good. To pay the rent, Dita is assisted by her sister who is in Rote. His sister sent IDR 500,000 to pay the rent for two months.

Even though in the Covid situation, Dita's massage customers in a month are around 3 to 4 people. “Yes, maybe they feel sorry for me or maybe they feel happy and sometimes they give Rp. 250,000, Rp. 300,000 and sometimes up to Rp. 500,000. But it was they themselves who gave it, I didn't ask for that.” In general, the price for an hour massage is around Rp. 150,000.

Dita requires that those who come for massages who are married must come with their partners. Dita does not want to serve customers who come alone. He didn't want to be accused by the people around him. Dita realizes that her self, body, mind and voice are very precious.

During her life, Dita has experienced discrimination or humiliation several times. First, when she massaged a customer at the Orsip Hotel. After Dita massaged her customers, suddenly two men came asking for her services in a seductive tone, but Dita refused. Dita does not want to be treated by customers like that. Second, she was once beaten by her husband for keeping her 4-month-old pregnancy a secret. Her husband thought the baby she was carrying was the result of having an affair with another man. Third, many women around her told that disabled women were asexual. They say how can the disabled marry with the disabled. Dita immediately replied that disabled and non-disabled bodies were the same. The location of the breasts and reproductive organs is also the same. Dita has proven to many people that women can have children and are able to take good care of them.

Sexuality and Reproduction

Dita fell in love for the first time in 2006, when she was only 19 years old. She and her first boyfriend were in a relationship of 1 year and 4 months. Her first boyfriend was a blind fellow from Belu and had lived together at the Hitbia Panti. He broke up with her first boyfriend on April 8, 2007 due to jealousy. After breaking up, Dita decided to keep quiet and didn't want to be disturbed. A few months later he got a boyfriend and got married in August 2007.

Dita does not understand about sex, sexual activity and sexuality. When going out with their first boyfriend they never had any relationship. "Our home is not given freedom, if we are caught having sex, that is a red sign." In the orphanage it is allowed to date but not to exceed the limit. "Dating that involves kissing, touching breasts or genitals is not allowed," explained Dita. At the orphanage did not have much time to date. Couples are given courtship time at 19.00-20.00.

Dita first met her husband at the orphanage for the Blind. During their courtship they never kissed because they had made a mutual agreement. "If you love me, you wait for me, you take care, I have feelings because we both don't see it, don't let it be when we kiss someone behind us, there's a peek, we'll be embarrassed," Dita said to her husband first.

Dita had her husband's first sexual intercourse on January 12, 2012 when they were out of the orphanage and living together in a boarding house. At first they were dating at the boarding house. Her husband initiated sexual activity by kissing. Dita was amused and happy when her husband kissed her for the first time. Glad to be able to live together even though they are not officially married. They live alone not because of coercion but because they like each other.

When she had sex for the first time, Dita cried. She felt pain and kicked her husband. She then remembered her mother's words that making love was painful at first. "Because my mother said, if it hurts to have sex, she said so I was scared, cried and I kicked her".

One week later they resumed sexual relations. Previously every day the husband asked for sexual activity but she did not want to. Dita wants to be in touch again for fear of losing. "Because I've slept with her once, so if I don't want to, it means that later he's moved with another woman." For fear of losing, Dita was willing to continue sexual relations until she became pregnant. "If I don't serve him later he can turn away, leave and go with another woman," she said.

When she first had sex and it hurt so much, at that time Dita didn't want to continue the relationship. But her husband is always asking, and begging. Dita still refuses. Husband still persuading. They then continued sexual intercourse twice a week. "As husbands, we have to serve, but if he keeps asking every night, I don't want to".

Having sex can lead to pregnancy. Dita heard from her parents. Her parents also said that frequent sexual intercourse with multiple partners can cause illness. Dita is aware of the consequences of having sex with her husband. She is already in a relationship with her husband so she must be ready to get pregnant. Her husband is also ready for responsibility.

Dita always told her husband if she wanted to have sex. He couldn't contain his desire. She invites her husband to have sex. Sometimes Dita is disappointed when her husband doesn't want to have sex because his husband is tired, but that only happened once. The thing she likes most about her husband during sex is being kissed on the cheek. "He likes to kiss on the cheek because he has a beard on his cheek," said Dita. From every sexual relationship Dita always enjoys.

Reproduction

Dita found out that she was pregnant on February 12, 2020 after a month without menstruation. She last had her period on January 12, 2020. Dita and her friend, a blind person, went to see a doctor, when on ultrasound it was proven that she was pregnant. After returning to the boarding house, she has not told her husband that she is pregnant. She was still having sex with her husband until she was 5 months pregnant.

Her husband found out that Dita was pregnant when she was 4 months and 15 days pregnant. Her husband was angry when he found out that Dita was pregnant and didn't tell him. "At that time I was beaten, scolded, said to be a prostitute, women are not good because I didn't tell her. At that time I was afraid because he was blind and couldn't see, lest he hit me in the stomach. He hit him on the arm with a broom because he was blind, he didn't see me so he hit me." Dita said.

After that fight they didn't talk to each other for 2 weeks. When sleeping they never touch. They reconcile when the husband apologizes. After that her husband started to love her. Dita is not allowed to wash dishes, wash clothes, clean the house and all other strenuous activities. Her husband who does all the activities at home and even makes a living is also the husband who does.

When checking her pregnancy at the health center, Dita is always with her friend with a disability. Dita cannot be accompanied to check on her husband because her husband is blind. So her husband stayed in the boarding house.

When giving birth, Dita had difficulties. The reason is because a few weeks before giving birth she did a lot of strenuous activities. She lifted the water which was about 100 meters away. At that time she felt pain like a ball in her thigh. After a day of activities, at night she just felt sick, felt like she wanted to urinate and defecate. After arriving in the bathroom the blood turned out to be blood. The doctor previously also said that Dita's womb was weak and shouldn't do much physical activity.

Dita was confused after knowing that the liquid that came out was blood. The baby she was carrying was moving and was like hitting her from the inside. That night Dita felt pain and she endured the pain until 5 am.

In the morning, Dita's friend, who is a disabled person, took Dita to the health center with her husband. They arrived at the health center at 06.30 in the morning. The doctor hasn't come yet. The only ones there are the cleaners.

After almost two hours of waiting, Dita checked her womb at 8 am. The next inspection was conducted at 11 am. That afternoon, Dita's water broke. A few hours later, the fetus she was carrying was born without crying. Knowing this, the doctor took the initiative to splash the baby with water and the baby started crying. After crying, the doctor put the baby on Dita's body to breastfeed. his son was born with a weight of 3.2 kg.

Dita chose to use family planning when her child was 9 months and 14 days old. She uses implants with the approval of her husband. Her husband agreed because Dita urged him and didn't want him to cheat because he couldn't have sex.

Support System

Dita always keeps every problem that befalls her family a secret. She never told anything to her friends if something happened. According to Dita, no one else should know about domestic matters. Previously, her husband was Dita's main support system. But after her husband passed away, her friends who were always there whenever Dita needed help or support.

Social

Dita has many friends. Her friends are the ones who help in times of joy and sorrow. Her best friend who is always there to help is a woman with a disability who has accompanied her since she was pregnant, gave birth and even now when her child is eight years old. tahun.

Description of Tania, Deaf Disability (Kupang)

On March 16, 2021, at 08.30, Elmi departed from Kupang for the Social Rehabilitation Center for People with Sensory Deaf and Speech Disabilities (BRSPDSRW) located in Kupang Regency. The distance from the house to the Efata orphanage is far so Elmi decides to go to the Panti Efata using GrabCar. Initially, Elmi made an appointment to meet with Mr. Lukas Patipeilohy, the Functional Coordinator of Social Work and Social Counseling, but apparently on their way to Naibonat, Mr. Lukas and the Head of the Panti were on an official trip. After arriving at the Efata orphanage, Elmi must first obtain permission from the Head of Substance of the TU section, the two Elmi must again obtain permission from Mr. Sem Kasse as a social instructor, and Mr. Maksen Babnesi as a social worker to convey the intent and purpose of his arrival at the orphanage. Finally, Elmi got permission to interview one of the Deaf disabled in the orphanage.

Mr. Maksen and Mr. Sem Kasse escorted Elmi and Mrs. Yori, assistants in the dormitory who will also help Elmi to become sign language interpreters. They then walked to the girls' dormitory. While waiting for the arrival of Tania (not her real name), disabled Deaf, who is learning sewing skills in her class, Elmi and Ibu Yori discuss how to solve Tania's problems using very simple language. After a few minutes later, Tania finally came to meet Elmi and Ibu Yori. Elmi explained the purpose and purpose of her arrival to Tania, assisted by Mrs. Yori using sign language.

We made Tania feel comfortable sharing her life experiences with us. After 15 minutes the three of us talked in the living room, we finally went to a quiet room. Only the three of us were in the room, a comfortable and safe place for us.

The interview started from 10:36 to 13:25 WITA assisted by Berti via cell phone. The respondent is very open with his life and practices activities that he remembers in his memory. Elmi also digs up more information by contacting Tania's family in the village via telephone.

After finishing the story, Elmi gave Rp150,000 to Tania. Elmi also gave Rp. 300,000 to Mrs. Yori for wages to become a sign language interpreter. from the SIGAB Foundation, Tania and Mrs. Yori took Elmi back to the office to thank Mr. Maksen and Mr. Sem for allowing Elmi to interview Tania. Tania returns to class to continue her sewing activities, while at 13:35 Elmi takes a Grab to return to Kupang.

Respondent Identity

Tania is a white and beautiful young woman, born in Sabu Regency. This 34-year-old woman has straight black hair that reaches below the shoulders. Her face is round and her nose is pointed. Tania as she is called, has a height of about 143 cm. This beautiful woman has never received a formal education. Tania is the eldest of 9 children, of whom 4 are boys and 5 are girls. Tania has been deaf since childhood, when she was a baby, so every day her activities only help her mother at home such as sweeping and washing dishes. On February 21, 2021, Tania was taken by Efata orphanage officials to learn skills there. Of all the skills in the orphanage, Tania prefers sewing skills.

When talking to Tania, Elmi was greatly helped by the presence of Mrs. Maria Yorita Usfinit, a woman who was born 32 years old. In addition to being a JBI (sign language interpreter), Mrs. Yori is also a boarding nurse for children with disabilities in Deaf in the girls' dormitory..

Every day, the activity of Tania and her friends at the orphanage is learning skills according to their respective interests. Tania is pursuing sewing skills, and currently she is learning to sew clothes.

Tania has a few obstacles in her daily activities because it is difficult to communicate with other people. He is very talkative with his friends in the dormitory. If there is an assignment, she often asks her friends. However, Tania is very secretive when it comes to her life problems. She also has to adjust when in the environment or when in a new place. Tania has a good mobilization orientation.

Meaning of Self

Tania, a speech sensory disability who has a speech disorder. She was very excited when she spoke. He felt no different in living her daily life. She is very confident and can blend in with neighbors, organizational friends, and the community. In addition, while still on Sabu, Tania helped her mother take care of the household and take care of the children.

In 2006, her friends were embarrassed and didn't want to be friends with Tania because she was pregnant. She felt sad because the man she loved left her. She didn't know where to look for the man. Tania said, "I'm having a hard time because the man walked away, left me, and didn't know where to look for the man." Tania is also shy when she takes a bath, she doesn't want her friends to see the marks of giving birth on her stomach.

The first man who impregnated Tania was her neighbor, whose house was not that far away, only 3 houses away from Tania's house. They live in the same village. When pregnant, Tania's parents and family did not want to get into trouble, they were grateful that Tania's pregnancy was a blessing. Tania's sister said, "When you were pregnant with your first child, you didn't want to get into trouble with the man, but you thought it was a blessing at home." When she was pregnant until she gave birth, the man still often went to Tania's house, and while Tania was pregnant she still received attention from the man. Tania's first child was adopted by her uncle who lives in Lembata.

Tania is pregnant with her second child with a different man. The man is very close to Tania's father because he often comes to Tania's house to eat, drink, and play. They live in the same village. When they had sex until Tania was pregnant, the man never came to Tania's house again. Tania's sister said, "When she was pregnant, the man never came home again, didn't care at all and we didn't think of him either." Tania's second child was adopted by her uncle in North Central Timor Regency because they have no children.

Tania is pregnant for the third time with a different man, they are both deaf and disabled. The man is the person who Tania loves, but does not get approval from her parents, even though she already has a child from this man.

Tania realizes that her self, body, organs, mind, and voice are precious and beautiful. She said, “I am meaningful and valuable because I am beautiful.”

Sexuality and Reproduction

In all her life, Tania had been to a salon for the first time when she entered the Efata orphanage in 2021. At that time, Tania went to straighten her hair at the salon in the orphanage. After she finished from the salon, she got compliments from the salon instructor that she was beautiful. She also received praise from his friends.

Tania does not understand about sex, sexual activity, and sexuality. Tania had sex with the first man named Andi (not his real name), at that time Andi passed by his house and gave Tania a love symbol. Tania also turns out to like Andi. At that time, Andi then asked Tania to go, but Tania did not know where Andi had asked her to go. As it turned out, they went to an uninhabited house. When invited to the house, Andi uses a motorbike, while Tania walks. Andi shows the empty house to Tania. Tania said, "Andi told him to go straight to an empty house to sleep at 3 pm.”

Before they sleep, Andi kisses the cheeks, eyes, forehead, lips, and continues to have sex. Andi forces Tania to undress. At that time, Tania refused, but Andi insisted on having sex with Tania. He said, "At that time I refused to have sex, but it was Andi who pulled back Tania's hand to have sex by force until all bodies hurt". When having sex for the first time, Tania felt pain and fear, until blood came out of her genitals. After forcibly having sex, Andi takes Tania back home. Tania also told the incident to her sister.

Not just once, Tania and Andi often have sex. This happened not because they liked each other, but it was Andi who forced him to have sex 4 times in an empty house until Tania became pregnant. When Tania was 1 month pregnant, they broke up. Tania found out about her pregnancy from her grandma and grandpa. At that time, she vomited and her parents were suspicious. Tania said, "Father asked, why are you so

angry, then Tania told her parents that she was pregnant, slept with Andi." When she found out she was pregnant, she was very scared. When she was pregnant, Tania's father did not want to take her to the health center to check the womb. Tania gave birth to her first child at home and was never taken to the puskesmas.

Until now, Tania has not experienced any problems during menstruation. When having sex with the second man is also due to coercion. The man's name is Rizal (not his real name). Rizal forced her to get in touch. Rizal clawed at Tania's hand and bit her shoulder. Tania said the second man forced her to have sex. At that time, by force, the scar was still on Tania's left hand. They did it at night, when Tania was taking a night bath in the bathroom. Tania's parents found out about this, they then kicked Rizal to go home. However, after that Rizal still ventured to come to Tania's house.

The night when all of Tania's family was sleeping, around 01:00 or 02:00, the man came. Tania's bedroom has no door. When Rizal wakes up Tania, Rizal covers her mouth so she doesn't scream. Rizal then clawed and grabbed Tania's hand, took her out of the room and went to the side of the bathroom and started having sex in a sleeping position on the dirty floor.

They had sex twice, Tania finally became pregnant with their second child. When she was pregnant with her second child, her parents took Tania to the health center to do a urine test using a pregnancy test kit. There, Tania did not experience discrimination, she actually got very good service. The family also found out about her second pregnancy when she was vomiting.

Tania fell in love in 2014 since she was 28 years old. She is in a relationship with her third boyfriend who is deaf person. Her friend is from Sabu. They live in the same village. At that time, they liked each other. When having sex, Tania's favorite style is lying down. Tania really likes it when they sleep together because they like each other. They had this relationship until Tania became pregnant. Until now, Tania does not know the form of contraception. When having sex with her boyfriend, they don't use any protection until Tania is pregnant with their third child.

When she was pregnant until she gave birth, Jen still often came to Tania's house. However, Tania's parents did not approve of their relationship until the next stage. Until now, Tania and Jen still love each other.

When Tania was pregnant with her third child with a man who is also a deaf person, Tania's sister said, “When she was pregnant with her third child, the man (still) had distant families and his house was also far apart. They both have special needs too, deaf mute.” They are consensual, the man is ready to take responsibility and wants to take the child to his home. However, there has been no family gathering, from male and female families. Tania's sister said, “He was pregnant until he gave birth, because it was a boy, and he wanted to take it, but there was no family meeting from both parties. The family also doesn't agree because they don't respect people." Tania's third child is now 5 years old and lives with Tania's parents in Sabu.

Support System

Tania is threatened, but does not know how to help herself or seek help due to communication limitations. Tania tries to tell the bad incident that she experienced, but the family does not defend Tania and allows the rapist to do it again and again. The family only accepted Tania's condition and let Tania give birth to her child. When there is a problem, Tania also tells her parents and siblings. Tania said that when she finished dealing with the man who invited her, Tania told her father or siblings. So far, Tania's parents and siblings have supported her. Father is the decision maker in Tania's life.

Social

Tania has several friends at the orphanage. One of Tania's close friends is Rika. According to Tania, the benefits of friends are as storytellers and friends to help each other. However, Tania really hates male friends because she likes to kiss and do unpleasant things. Another reason Tania hates men is because she has experienced trauma in the past such as being forced to be raped.

Description of Nila, Mental Disability (Kupang)

On March 25, 2021, at 11:15 am, Berti and Elmi departed from Maria's house (not her real name) in Kupang City. At that time, it was still morning and the weather was sunny, so Berti and Elmi decided to go to Novi's house by motorbike. On the evening of March 24, Elmi contacted one of her friends, Nila Kulata, a nurse who works at the Naimata Mental Hospital via telephone to ask for recommendations for women with mental disorders who have recovered and have been treated in mental hospitals.

When contacted, Nila (not her real name) was happy and willing to help. However, Nila said that the majority of women with mental disabilities were aged over 40. Indeed, there are mentally disabled women under the age of 40, but they all live in Kupang Regency. So, Nila recommends women with mental disabilities living in Kupang City. Before Elmi called Maria's brother named Pak Santo (not his real name), Nila had already contacted Mr. Santo first. Nila has asked for approval whether Mr. Santo's brother, Maria, who is mentally disabled is willing to be interviewed or not. Five minutes later, Elmi got a call from Nila that Maria was willing to be interviewed by Berti and Elmi. Nila also asked Mr. Santo's permission to give his phone number to Elmi.

Elmi then contacted Santo. He explained the intent and purpose of interviewing Maria. They then agreed on a time to meet. In the morning, Elmi contacted Santo to ask for his home address and asked that Maria's companion be a woman. This is because at the beginning of the communication, Santo wanted to be Maria's companion. When Elmi and Santo communicated via cell phone, Santo asked that the informant's salary be increased to Rp. 200,000.

At that time, Elmi explained that from the first to the fourth interviewee, usually they would get a right of Rp. 150,000. This nominal has become a provision from the Yogyakarta SAPDA Foundation. Elmi also said that they were only helping a friend from SAPDA to do this research. However, Santo asked that how will he get a lot of information from the informants if the salary for the informants is only Rp. 150,000.

Elmi then contacted Nila to inform her of this. After communicating, Elmi and Nila agreed to find substitute sources with disabilities. This is due to a mental disability who is 47 years old, and also because his family asks for wages from sources that exceed the provisions.

However, Nila asked Elmi to give reasons for the cancellation to the disabled families. When Elmi contacted Santo for the purpose of canceling, Santo said, “Why do you want to cancel, since this morning we have canceled all our activities to wait for my sister to be interviewed. My sister also doesn't sell because she just wants to wait to be interviewed. How do you want to get a lot of information but pay a little? I'm her biological brother, but why can't I be her companion? Why now cancel and do not want to interview? Anyway, we are waiting for an interview with my sister.” Santo also said that if her sister was not interviewed, then his cell phone would immediately be turned off.

Elmi again contacted Mr. Santo. However, it wasn't Elmi who spoke, but Berti. After Berti re-explained to Santo, they finally got approval for interviews with people with mental disabilities, and the fee for the resource persons remained Rp150,000. They also continue to request that the resource persons accompanying them are women.

They came to Maria's house. Arriving there, Maria was already waiting for Elmi and Berti. They were warmly welcomed by Maria, and allowed to enter her house. They sat in the living room, and the living room was the most comfortable place for interviews because there were only four people in the room. Before the interview started, Berti gave Maria a re-explanation of the purpose and purpose of their arrival. After getting approval from Maria, Berti finally asked for a female representative from Maria's family. The goal is that if there is an answer from the informant that is not clear, then the assistant will help straighten it out with the correct answer.

Interviews were from 11:50–12:40. After finishing the interview, Elmi and Berti gave Rp150,000 to Maria and Rp150,000 to Mrs. Sarlin Pella as a companion. After that, Berti and Elmi went home by motorbike.

Informant Identity

Maria Susana Pella is a beautiful single woman. She was born on February 21, 1974. This 47-year-old woman has short, shoulder-length hair. Maria received her last education at junior high school in Java. During the interview, we were assisted by her companion named Mrs. Tata (not her real name) who is Maria's sister-in-law.

Currently, Maria lives in Kupang. This is the fourth year he lives there with his older brother. Previously, Maria lived with her family in Java. Both of Maria's parents have died, while Maria's other brothers and sisters live in Jakarta, Balikpapan and Salatiga. Maria experienced a mental disability after graduating from junior high school. The reason is her father's upbringing is so strict. Maria was often beaten, and by that time her head was starting to get irritated. Maria said, “Well, Papa used to be tough, he liked to be hit on the head, but I didn't know because I was a kid. Mami said, I was hit by a collision, but, yes, thank God I can now do activities.”

Her companion also said that sometimes Maria's soul can be in two, sometimes good and sometimes evil. After graduating from junior high school, he did not continue his education because he was sick and his illness often recurred. Even though she is now recovering, she is still taking medicine regularly. If the medicine runs out, she has to take another medicine at the Naimata Mental Hospital Kupang.

Every day Maria's activity as a mask seller. She also always helps with household chores, such as taking out the trash, sweeping, feeding the chickens and ducks, and fetching water from the well. Every day, Maria wakes up at 04:00. Maria said, “In the room there is a small radio, usually I wake up at 4 o'clock, then listen to spiritual songs, spiritual reflections on the SK radio (Suara Kupang), because on SK radio usually play spiritual songs from 4 to 6 am, so hear it every morning. After that, just start feeding chickens, ducks, taking out the garbage, pulling water from the well, and so on.”

In her daily activities, Maria does not have any obstacles when communicating with other people. Maria said, "I'm used to (just) with the boarding children and the others are normal." Her companion also said that the only difference between Maria and the others was that Maria was single, while the others were married. Maria also has a good mobilization orientation.

Meaning of Self

Maria is a mentally disabled person who is very excited when she speaks. She felt no different from other people in living her daily life. She is very confident and can blend in with the neighboring boarding house and the surrounding environment.

Maria said that at a place selling masks, she used to get ridicule from people around her. However, she responded indifferently and laughed. Maria said, "Usually at the Merdeka Stadium where salespeople are often bullied, but the response is by joking, people make fun of it." Her companion also added that, "It's normal for young people, ladies and gentlemen are like that." Maria said laughingly to us, "They usually call me Slow Respond, but I don't care, why do I respond instead it adds to the disease, usually it bothers men and women alike, in the Merdeka stadium, right, some are already married."

He realized that his self, body, organs, mind, and voice were very precious. Maria said, "Yes, it's valuable to help, usually in the morning at least half past five to start sweeping the yard, if I see the garbage is full I throw it away, then I finish feeding the animals, then take a bath ready to go there (where) sell masks, early in the morning at 6 it was already selling masks."

Sexuality and Reproduction

Maria usually goes to the salon, but rarely. Usually, she goes to the salon to get her hair cut. Usually, she dyes his own hair. Maria told me that she dyed her hair because it was already white. "Shine hair to stay young, do you want to look old? If people dye their hair, people think (will think I am) 27 years old," she said.

Usually, after cutting and shining her hair, she also gets compliments from her friends who both sell masks. Sometimes it is also the boarding house children in the area where they live who cut their hair. Maria said, "Sometimes it's a boarding house child who cuts it, if there are sharp scissors, ask for help, cut it, cut it evenly." she feels that going to the salon is also important for beauty and body care.

Since the first, she likes to wear lipstick. Maria has also worked in a salon. "Because she always liked it that way, my mother used to like makeup," said Maria, taking a photo of her parents and placing it on the table. Maria said that back in Jakarta, she had worked in a salon as a bridal makeup artist.

I fell in love for the first time at the age of 25. While still working in Bekasi, Maria met the man while eating at the food stall where she worked. Maria said, "Not in love, just ordinary, just like a friend who likes to talk." At that time, there were no cell phones so they communicated by mail. “I used to be tricked by lazy men. He looked for me when I got a salary, if I wasn't there they left. Now I do not want to date, better to be alone.”

In the past, many men often disappointed her. They only invited Maria to eat meatballs, go for walks, and tell stories. They only need Maria's money, not Maria. When asked if during courtship she had held hands or kissed, Maria replied with a laugh, "I am 50 years old, my hair is gray, haha.".”

She also said that at a mask selling place, she was once harassed by a man who was younger than her. Maria said, "They are often harassed at the shop, but I told them how old they were, some said they were 25, some were 35," she said.”

Maria once kissed and hugged her boyfriend. She met her boyfirends who is still in a relationship to this day. When they were together at the Naimata Mental Hospital, Maria said, “Before the first illness, right, for treatment at SWCU Setia Wacana. That's right, there's a psychologist there, so every day, right, I go there. I held the book, she asked Maria what major, I said law. In fact, above the psychologist's room there is a Faculty of Law,” She recalls laughing.

Maria also said that when she consulted a psychologist, she could recover without taking medication. "But thank God, when he was at the psychologist he recovered without medicine, used to talk when he was healed, psychologist Mr. Endro."

Her current boyfriend, named Roflen (37 years old) who is both mentally disabled, is currently working on a project in Manggarai, Flores Regency. They just separated 4 days ago. When they meet, they usually just hug and kiss on the cheek and on the mouth. The sexual activity she likes the most with her lover is kissing on the lips. They rarely see each other. Whenever her lover asks Maria to go out and go to the beach or go for a walk, Maria always makes excuses that she doesn't have any money. Usually, they kiss at her lover's house. It was her lover who started the kiss on the lips first. Maria is feeling happy. Maria also said that Roflen was the man she loved.

She also never thought of having a relationship more than that. Maria said, "There were no parents there." When she visited Roflen's house, she used to talk to her girlfriend's mother in the living room. Until now, she still communicates well with Roflen via SMS. Maria has a dream to get married. She said that her boyfriend went to work in Manggarai so he could save money for marriage. "If God wills, yes, you can get married, because I am getting old and wants to have a family too."

They had been out together once, sitting by the sea in Ketapang Satu. The thing that Maria liked about her lover was his voice. "I like his voice. In the mental hospital, we used to do karaoke, we sang all kinds of songs. I like to sing spiritual songs," said Maria. He also shared that they fell in love with each other for the first time when they were at Naimata Hospital, and that they were karaoke.

Maria found out about using family planning while watching television. "Contraception is (for) family planning, some are inserted into the vagina and some are injected," she said. All she knows about family planning is pills and injections. "There are pills, there are injections, and there is another one that goes into the rectum or something," said Maria. She also said that condoms were a protective device for men.

So far, she hasn't had any problems with her period, but usually it's only 3 days. Previously, she had her period for up to 5 days. On the first day of menstruation, she felt pain in her stomach, but she often drank herbal recipe.

If married, Maria wants to have children. "I often see people giving birth, I've seen my sister in Jakarta give birth, screaming half to death, I'm afraid to see her," he said. If God permits, Maria wants to have children.

Support System

Maria said that so far, she had never received any threats. Maria usually told her older brother who lived with her. Maria felt that her brother was the same as her real parent. In addition to confiding to his brother, she also used to tell his boyfirend. her lover always encouraged her to calm down, pray, and read God's word.

Maria always wakes up at 4 am and listens to the spiritual radio until 6 am. Her brothers always told her to pray a lot so that there would be no disturbance. Listening to the radio calmed Maria's heart.

Maria's companion said that Maria communicated with her brother every day via SMS and telephone. Her family sometimes overprotected Maria, and sometimes Maria was angry about this. However, according to her consort, Maria's family doesn't want anyone to hurt or take advantage of Maria if they know her weakness.

Social

For Maria, family is friends. The meaning of friends according to her is a place to vent. "Yes, so that if we have problems, emotions, can everything be channeled, if we stay in the room we can stress ourselves out," said Maria. The closest friends in her life are boarding house children, but the closest friend to Mary is the Lord Jesus. Maria said, "The closest is the Lord Jesus, don't you want to cry or what God knows." Her closest friends are also cats, ducks, and chickens. Maria usually confides in her favorite cat named Bleket.

When she is sick, Maria usually checks herself at the Oepoi Health Center. If she is in a mental hospital, she usually checks once a month to take medicine. However, the medicine she is currently taking is only 2 kinds, namely trehekzi medicine and the name of the other medicine she forgot. Maria took the drug 2 times a day, morning and night. However, she usually takes medicine at night before going to bed because from morning to evening she has to sell masks. The medicine she takes always makes her sleepy so she doesn't want to sleep while selling.

Maria started selling masks independently since February 2021. Previously, she worked as a mask seller with other people for 7 months, but she was fired. After getting capital from her sister in Jakarta, Maria started selling on her own. Her companion said that Maria got a mask from a mask sale at a cheap price, but for cloth masks she bought from a mask tailor named Sri, while medical masks she used to buy at the Pharmacy.

Desciption of Rani, Intellectual Disability (Kupang)

On March 9, 2021, at 18:30 Berti and Elmi left for Rani's house (not her real name) in Kupang City. Because it was night and the weather was cloudy, Berti and Elmi decided to go by using an online transportation car. Before Elmi called Rani's grandmother to ask because Rani's grandmother never allowed her granddaughter to go out at night. Elmi tried to convince her and asked to interview her grandson for about an hour and ensure that Rani came home safely. After getting approval, we took Rani to a restaurant not far from her house.

Arriving at the restaurant, the three of us looked for a safe and comfortable seat for the interview. Berti and Elmi conveyed the intent and purpose of the interview. The interview started at 19:30–20:30, after finishing the story, Elmi gave Rp150,000 to Rani. Berti also paid for our dinner Rp72,000. After finishing the interview, Berti and Elmi took Rani home, Rani arrived home at 20:45. After that Berti and Elmi went straight home.

Informan Identity

Rani is a young woman, born in North Central Timor Regency. This 21-year-old woman has shoulder-length short curly hair, round face shape. Rani she is usually called, has a body size of 140 cm. Currently Rani is in 3rd grade at one of the special high schools in Kupang.

Rani lives with her grandmother and father in Kupang, while Rani's biological mother lives in the village. Rani has been intellectually disabled since she was in elementary school. Apart from school, Rani has been pursuing her hobby as a running athlete from 2018 until now. At home, Rani always helps her grandmother cook and wash the dishes.

Rani prefers running to school. Rani doesn't like studying and thinking. At school, the subject that Rani dislikes is mathematics, while the subject she likes the most is Physical Education. "I don't like studying, I'm lazy to go to school," said Rani.

In her activities, Rani has no obstacles, including when communicating with other people. Rani rarely does activities outside the house except for going to school and exercising.

Meaning of Self

Rani is an intellectually disabled person who has difficulty thinking, especially about numbers. She was very excited when she spoke. She felt no different in living her daily life. She is very confident and easily mingles with his schoolmates, fellow athletes and the people around him.

In 2016, when she moved from her village to Kupang City, Rani received ridicule from the children around her grandparents' house because of the different schools. They often call Rani crazy. Rani's feelings at that time were very sad. "Very sad, because this is the first time I live in the city, so please call me that," she said.

Some of her friends in running athletes also call Rani "Rani is an extraordinary schoolgirl". Rani says that there are some of her friends who are just like her. Rani says that she has many friends who are different from her, friends with disabilities too, but they respect each other, don't make fun of each other.

At the gym, when the coach gave a warning or a signal, sometimes Rani did not understand. Sometimes Rani has to ask her coach again. Rani is often confused during practice because her coach talks too fast. If you don't understand, Rani always asks again. "If the coach says to run 100-200 meters, sometimes they don't understand 100 meters, 200 meters. I asked to let you know where it starts and where it finishes.

She realized that her body, mind and voice were precious both to herself and to her parents. Rani says “I feel myself valuable. For others, I may not be worthy, but I feel valuable in front of your father and mother.”

Sexuality and Reproduction

In all her life, Rani has never gone to a salon. When it comes to haircuts, it's her grandpa who always cuts her hair. No matter about make-up either, usually she only uses lipstick and powder, that's even baby powder. Rani likes wearing lipstick the most because it makes her lips brighter.

Rani first fell in love at the age of 17 years. She fell in love with her classmate. During courtship Rani never held hands, only liked each other. "From the start, they never held hands, they just liked each other," she said. But now Rani has a new boyfriend who is a fellow athlete and an intellectual disability (19 years old) from South Central Timor Regency. They met while participating in a competition in 2019.

Rani rarely met her boyfriend. They only have the opportunity to meet when there are activities or exercises. "Dating for several years but meeting at the most right at the hotel when there are activities, and even then he is upstairs, I am downstairs. Met the best time to eat, then went to the stadium he helped carry my bag and sat next to me right on the bus".

They walked together when they came home from practice and drink coconuts together, because when he came out, her grandpa had memorized the schedule for going out and returning home. She also dreamed of traveling together and holding hands. "Ever thought about kissing but I feel ticklish, when I think about ice it feels like karma, my brain is tickled by that stuff," said Rani.

Rani had never thought of getting married. Her uncle once said that she came to the city for school, so she couldn't date. If you want to date you have to hide. Rani once had many boyfriends on facebook. During their courtship they had video calls. The thing she likes most about her boyfriend is getting a surprise when she gets picked up at school. When she picked him up, her boyfriend didn't tell to Rani first. When riding a motorbike, Rani doesn't dare hug her for fear of being seen by her sister on the street.

Reproduction

During courtship Rani has never kissed. When her friends at school tell about his girlfriend, she feels uncomfortable and unpleasant to hear. Rani says she sometimes gets confused with her friends because they have a strange relationship. She has seen her friends use family planning, even though she thinks it's for mothers.

Support System

Rani once felt threatened from her neighbor's children because she was often made fun of. The person who understands Rani the most and plays the biggest role in making decisions in her life is her grandmother. When there is a problem, she also tells hier three friends who are both in the same school and the same class. So far, Rani has supported her parents, grandma, grandpa and her three best friends.

Social

Rani has three friends since the beginning of entering the extraordinary school. Each of her friends already has a boyfriend. One of Rani's best friends, who already has a boyfriend, once told her about what they were doing when they were dating, but Rani didn't like hearing it and chose to leave. Her other friends love Korean films and always talk about Korean films. The other always gives support to Rani. Rani's three friends always support and provide solutions when she has problems. The meaning of friend according to Rani is a friend for stories and friends to confide in.

Description of Jasmin, Physical Disability (Yogyakarta)

Life as a woman with a disability is not an option, but a reality that must be lived as a destiny from God. It is not easy, but there is always the strength to continue living as “chosen” women. One of them, Jasmin (not her real name), is a physically disabled woman who lives in Yogyakarta.

One of the research respondents of the Advocacy Center for Women with Disabilities and Children (SAPDA), we initially met at a shop that she had been renting for the past few years. At around 14.00 WIB, this woman with two children came riding her motorbike, and was carrying crutches as a tool to support her left leg which was paralyzed.

Despite having physical limitations, Jasmin is an energetic woman in her 40s. He is also friendly, smiling, and including open minded.

Jasmin recounted that the shop she had rented had been managed by her husband, along with their eldest child, a little girl who is currently in elementary school (SD). Meanwhile, Jasmin works as an employee at a foundation in Yogyakarta.

Initially, we planned to have a long chat about his personal life. However, because the situation was not conducive to discussing very private matters, we finally decided to find another more comfortable place to share stories about the experiences of life, love, and sexuality that he lived with his partner.

After about 30 minutes of traveling by motorbike, we arrived at a place with a traditional Javanese nuance. Even though it is a public space, there is one place where we are more comfortable to talk about many things, including listening to Jasmin's story.

She began to talk about her past that was so heavy that it had made her mentally down for several years. Jasmin realized that there was something different about her physique, when she grew up to be a little girl. Polio disease caused one of her legs to be paralyzed making it difficult to walk.

Even so, Jasmin admits that she can still ride a bicycle and when she was a teenager she was also used to riding a motorcycle. Once upon a time, Jasmin had an incident while back from school. Jasmin had an accident on the highway so that her motorbike hit her body. The accident worsened the condition of her left leg. In fact, post-accident, she was completely paralyzed for about 6 months.

Down and Degraded because of Different Physical

Since the accident, Jasmin feels at the lowest point in her life. Her confidence waned when she realized her condition was paralyzed. Although in the end she was able to walk again with a cane, Jasmin could not immediately get up from her slump.

"I used to feel that something was wrong and blamed myself why did I have to experience this? Like regretting the condition because previously I was able to walk without this cane (crutches)," said Jasmin.

He did not want to continue his education because he was afraid that his physical condition would be ridiculed. However, her mother's extraordinary efforts to revive her spirit of life were able to convince Jasmin to return to school

Jasmin admitted that the condition of her left leg which was not functioning properly had hampered her mobility. For example, when climbing stairs with luggage, Jasmin finds it difficult. That's because her left hand must hold the stick, and her right hand must also hold on when going up and down stairs.

According to her, the obstacles to activities due to physical limitations are still not much, when compared to the stigma that is often attached to her as a person with a disability. Jasmin feels that with her different physical condition, she often gets unpleasant treatment, such as being harassed, humiliated, and ridiculed by people in her environment.

Jasmin admitted that one of the most painful words she had ever heard was when she was about to marry another person with a disability.

“It's difficult for people to walk, really, will get married)," they said.

The unpleasant words she heard again, when she was about 8 months pregnant and returned to her village.

"Some say again, walking is difficult, but you can get pregnant," she said.

In that condition, Jasmin admitted that she would no longer hesitate to reply to their words. According to her, it was an option to relieve discomfort, as well as to prevent her from doing things that would have a bad impact, when she only kept it in her heart.

On the one hand, Jasmin realized that physically she was different from other people. But on the other hand, in terms of ability, Jasmin feels no different from other people in general. For her, the only difference is using assistive devices to walk, and physical activity related to footwork. The rest, she can do as people without certain disabilities.

Therefore, Jasmin considers that her body is the most valuable part so that it must be maintained properly and protected. At least for myself, husband, children, and also their parents. One form of appreciation for her body is to wear a hijab to cover her aurat, after graduating from vocational school until now. "No one ordered, let alone forced," she said.

The Loss of First Love to Fear of Sin

As humans, women with disabilities also have a desire to look beautiful and look perfect, especially in front of the opposite sex. Especially in the ages of teenagers to adults.

Jasmin admitted that so far she had never been to beauty salons. However, she has ways of taking care of herself at home. She feels uncomfortable having to take off her hijab in public. Besides that, she also has basic makeup skills which she got from a beauty course for 6 months in Yogyakarta. Not infrequently, she applies his makeup skills to his children who are going to dance performances.

In matters of love, before marriage or around the age of 18, Jasmin had a relationship with a man who was working in Malaysia at that time. They dated long distance (long distance relationship) for approximately 2 years. However, God had other plans. After an accident and she had to use a cane as a walking aid, Jasmin's feelings were broken.

Jasmin also chose to erase her feelings for the man, because she felt that she no longer deserved to be in a relationship when she was not feeling well. This is exacerbated by the sneer of one of the underclassmen, who is none other than the younger brother of his girlfriend. The sister of her lover looks disapproving of their relationship because of disability reasons.

In 2007, Jasmin found a soulmate who was willing to marry her and build a household until now. They have two children. At the time of marriage, Jasmin was about 25 years old.

Jasmin said that at that age, she was not familiar with the terms sex, sexuality, and sexual activity. The first experience of sexual activity was when she was married. Even then, she initially had sexual relations with her partner for fear of sin.

“The husband, when I refuse, always uses the words sin if we don't want to (have sex). So, the fear is the same as sin, because as a wife I have an obligation to serve, but I always refuse, "he thought.

The lack of understanding about sexuality and reproductive health (Kespro) made Jasmin not realize that she was pregnant, exactly 3 months since the wedding.

"Now I just understand that it turns out that reproductive health should be introduced to children from an early age," she said.

According to Jasmin, if the understanding of reproductive health continues to be considered taboo, then when they grow up to be teenagers or adults, children will not get the correct source of information about reproductive health. As a result, Jasmin only got a story from a friend that having sex with a partner is quite scary because it hurts and can bleed. But in reality, she didn't bleed, even though there was still pain after sexual intercourse.

As active sex offenders, Jasmin and her partner sometimes also experience obstacles, when one of them does not want to have sex at certain times. In such situations, communication with your partner becomes very important. This includes talking about what they like or don't like about having sex.

“I like it the most when it's cold to be hugged," she said, blushing. Meanwhile, the most disliked thing is when the time is not right or one of them is not ready, but pushes himself.

Family Planning, Options for Maintaining Health

During pregnancy, the first and second children were relatively free of problems. Jasmine regularly consults with a gynecologist. At the time of delivery, she had to undergo a cesarean section because the fetus was too large, while the pelvis was small so it was quite risky for a normal delivery process.

For Jasmin, family planning (KB) is an option to prevent unwanted pregnancies. By using injectable contraception, she has never had her period again for about 2 years. Only after the KB is stopped, the menstruation returns to normal.

Independent and Free to Determine

As a career woman who is active in the public sphere, Jasmin feels grateful for having a good support system. Her husband, who works daily in managing the business in the shop they rent, is willing to do housework while his wife is working outside the home, from cooking to taking care of children.

In making decisions, Jasmine also has the freedom to make choices. As a working woman and a housewife, Jasmin's circle of friends is relatively limited. The people in her work environment, she considers as friends who can be a place to share, and give consideration in making decisions. In addition, there are also considerations from the nuclear family. As for her sexual activity, Jasmin considers her friends to give a reasonable response to her.

Description of Disa, Blind Disability (Yogyakarta)

In a simple green house, which is behind a meatball shop, not far from the main street in Yogyakarta, Disa (not her real name) lives with her husband and small family. This 39-year-old woman has been renting a house which is also a place to open a massage practice for the blind, since the last 5 years.

Disa is a woman with a visual disability, especially low vision. Since birth, Disa has experienced visual impairment with a maximum visibility of 3 meters. She married a man with low vision disability in 2004. Now, Disa and her husband have a son who is around 16 years old, and a small daughter who is 9 years old.

Everyday, this hijab-wearing woman opens a massage practice for the blind. She acquired her massage skills when she attended training at the Blind Orphanage (PSBN) in Bantul, after graduating from high school in 2000. In her rented house, Disa divides the room into two parts. One room became her husband's practice area, and the one next to it was used by Disa to serve her customers who often came from outside the city of Yogyakarta.

When I (Tria) came to her house on Saturday, March 6, 2021, at around 17.00 WIB, Disa was already waiting. A customer's automatic motorbike was parked on the terrace. While her husband was inside massaging the guest. On the sidelines of our conversation, Disa also had time to comb the long hair of her little daughter who came to her. After about 15 minutes of introductions, we started the interview until the evening call to prayer sounded.

Meaning of Self and Body

Disa began to notice something different with her eyesight since she was around 6-7 years old. The maximum viewing distance is 3 meters. "From a distance, it looks blurry. I know there are people, but their faces are not clear," said Disa.

He told me that when he was little he often fell while walking because he couldn't see clearly. Including when he was learning to ride a bicycle. Since then, he did not dare to learn to ride a bicycle.

Despite having limited vision, Disa admits that she can do her daily activities well. In fact, in taking care of her children, "Since my child was born, I have never entrusted it to someone else," said Disa. However, Disa does not deny that there is a sense of inferiority when she gathers with people. Disa remembers that when she was little she was often bullied by her friends because she couldn't see.

She also had a problem when he attended an event and was asked to write his name in the guest book. "People think I can see well," she said. In addition, before when there were no online motorcycle taxis like now, her mobility was also limited because she couldn't ride public transportation . The same goes for crossing the road. "When a neighbor is having a party, actually I want to help, but what can I do with my condition?"

Even so, Disa feels grateful because she has always felt accepted in her environment well. "They don't hate me," she said. She is also active in recitation events in her village, and often attends invitations to meetings at her son's school. So, she felt was not much different from other parents.

Therefore, Disa is also grateful for whatever her physical condition is. She tries to protect herself by wearing a headscarf. Considering that she is a masseur, now he does not only serve female patients, but sometimes also men.

Sexuality and Reproduction

Since childhood Disa never went to a beauty salon. I've been to Copy but only for a haircut. She feels wasteful if she has to spend quite a lot of money to do body treatments at the salon.

She admitted that she first fell in love when she was in high school. At that time, she even had a romantic relationship with her classmate who is also a blind person. Like people in general, Disa admits that she feels happy and comfortable when she is with

her partner. Moreover, she felt she had found a replacement for her father who had died since she was in 5th grade. "I feel more comfortable in having relationships with fellow blind people, because with normal people I'm afraid that I will be humiliated," she said. However, their relationship ended in the end for no apparent reason.

Disa married a man she knew when she was at the YAKKUM rehabilitation center for people with disabilities, Yogyakarta. In Disa's understanding, there is no difference about the meaning of sex, sexuality, and sexual activity. For her, all of that is sexual activity between husband and wife, like making love. Before marriage, he had never imagined what it felt like to be kissed, have sex with the person she loved, or masturbate to vent his sexual desires.

When she first had sexual intercourse with her husband, Disa admitted that she felt pain in her genitals, and even though not much blood was bleeding. For the sake of her responsibility as a wife who serves her husband, she always tries to enjoy being intimate with her partner. Having sex is the thing he likes most. Meanwhile, the thing she disliked was when her husband asked to deal with strange styles, such as standing. Disa admitted that so far she and her partner always communicated this well.

Reproduction

In terms of menstruation, Disa has no problems. However, when using contraceptives, the body feels uncomfortable, and the blood that comes out during menstruation tends to be more than during normal conditions.

When she was pregnant, both the first and second children were relatively no problem. She regularly checks herself at the nearest health center. When giving birth to her two children was also normal. "Since we gave birth to our first child, we were immediately advised for family planning," said Disa. Then, Disa chose to use the IUD because she thought it was safer than other types of contraception.

Initially, she and his partner agreed that they would only have one child. However, after their son was 6 years old, both of them decided to have more children so that when they were old, and their children grew up, they were not alone. After giving birth to her second child, Disa changed her contraception from an IUD to an injection.

However, she felt something strange about her body. This is because every time she has sex it hurts and her body often feels uncomfortable. she also decided to stop the birth control injection. Even though her sexual activity is still active, Disa and her husband agreed to "take care" of each other so they don't have an unwanted pregnancy.

Support System

Disa feels grateful because so far she has had the freedom to make choices and make decisions in her life, including in terms of protecting her body and sexuality. Therefore, she almost never feels threatened when she is about to make her choice. Her husband also gave full support. Including when the two decided to rent their own house, rather than living in their parents' house which was also occupied by their sibling.

Social

Disa doesn't like to talk about her sexual activities to other people, even to her best friend. He has a friend, a fellow woman. It's just that, because each of them is already married, the intensity of their meeting is very rare.

Wulan, Deaf Disability (Yogyakarta)

On Monday, March 1, 2021, I (Tria) met Wulan (not her real name), and her friend, Lusi, at one of the stalls in Yogyakarta. At around 13.30 WIB, I arrived and immediately said hi to them. Among the few guests at the stall, it wasn't hard to find them, even though we had never met each other before. That's because both of them communicate by sign language. With the help of Lusi as a sign language interpreter (JBI), Wulan and I were able to communicate well. Our conversation was very comfortable.

Before the interview started, I handed Lusi a hardcopy of the draft question. Then, forwarded to Wulan who sat opposite the two of us. My consideration is for the sake of mutual convenience, because some questions are very private while we are in a public space. After skimming through, and giving a little explanation of some terms such as petting to Lusi to make it easier to convey to Wulan, they agreed that they wouldn't mind discussing it at the place where we met.

Identity of Informants and Companions

Wulan is a woman with a deaf disability who is now 25 years old. He graduated from S-1 Department of Fine Arts, and is still single. Wulan couldn't hear since she was born. At that time, his mother did not realize that Wulan was deaf since birth. When her mother realized Wulan was deaf, the two could only communicate through body language until Wulan used a hearing aid. However, after growing up and growing up, she chose to let it go. According to her, wearing hearing aids actually makes you feel dizzy. Especially when there is a loud sound, like people laughing. Even though she can't hear, Wulan can still communicate a little orally.

Meanwhile, Lusi is a JBI who has known Wulan since 2017. Initially, she learned sign language at the Deaf Art Community (DAC). Since then, Wulan has often invited him to become JBI for various activities. Coincidentally, the two of them were also the same age.

Meaning of Self and Body

Wulan began to notice problems with her hearing when she was about 4 years old. His hearing condition worsened after he fell down the stairs and hit his head. "I couldn't hear my mother calling at all," Wulan recalled. He felt ashamed and refused to go to school. Moreover, someone once said he was ugly because he couldn't talk. There are also those who actually feel sorry for her. When he was at an extraordinary school (SLB), Wulan and her teacher could not communicate well because they both did not understand sign language.

Her mother continues to encourage Wulan to stay in school so that she has an education that is equal to children in general. Then, Wulan was put into a public school. When entering senior high school, Wulan again encountered obstacles because she could not get any information at all, and there were no friends to discuss. Then, he tried to do self-advocacy to the school so that he got a little access, through the provision of monitor screens, and lessons in written form. Even that is only available in the department, while for other majors there is no such thing.

Wulan also still remembers the first time she entered the school, a male friend mocked her and made her a joke, saying "Hey, you're wanted!", but meant to mock that Deaf is ugly. Wulan then reported this to the teacher. Finally, her friends were advised not to make fun of him again. In her class, there are two students who are also deaf. However, they prefer to be quiet and often alone. Wulan tried to give understanding to her friend, so she dared to defend herself. "When a deaf person is silent, they are considered innocent," she said.

Wulan felt different from other people only in terms of communicating. Therefore, she often needs a companion (JBI) when attending or participating in activities with the community in general. However, when people with hearing and speech disabilities gather, she does not experience any obstacles. In fact, Wulan can also do her own mobility by riding a motorcycle.

Therefore, Wulan felt that her body was very precious, and she loved herself. “I love my body so much, with my gesture, I can walk around freely. In fact, when they go abroad (Australia) using sign language, they really respect Deaf people," said Wulan.

On the other hand, she also realized that there were still people who looked down on him. When she hears people talking about her physical limitations, Wulan always gives them an understanding that basically everyone is the same, so there's no need to feel like a boss just because you can hear.

Sexuality and Reproduction

In body care, Wulan often goes to a beauty salon with her mother. But sometimes, she also comes alone to just cut her hair. She felt comfortable because she got a warm welcome from the salon, which she said was very respectful of all customers, including himself.

Wulan admitted that she had fallen in love, and had a relationship with a man who is also a deaf person. At that time, she was still in school. However, their relationship foundered because her partner often forced him to have sexual activity. "I know, she often watches adult films (porn)," said Wulan. One time, Wulan hit the man when she wanted to kiss Wulan on the cheek without permission. At that time Wulan broke their relationship.

Wulan then formed a relationship with another male friend, whom they had lost touch with for a long time. She felt she found a good partner, funny, like to chat, and like each other. "I like the way he look at me. I feel in love,” she said with a beaming face.

For Wulan, having a relationship with a lover does not mean being willing to have sex. Instead, she was very protective of her body. One of them, she immediately hit her ex-girlfriend for wanting to kiss her on the cheek. In addition, Wulan also often gets advice from her mother to be good at taking care of herself, not to get pregnant before marriage. "If you get pregnant (before marriage), bear it yourself," said Wulan imitating her mother's words. Wulan is also always reminded by her mother not to get married before finishing college and have a job.

Regarding sex, sexuality, and sexual activity, in Wulan's understanding, sex is related to the genitals, for men it is a penis, and for women it is called the vagina. As for sexuality, Wulan admitted that she did not understand the definition, even though she had gotten the information from a training. While sexual activity, she gave an example such as kissing cheeks and other body parts.

Reproduction

So far, Wulan has not had problems with menstruation. As a woman, Wulan also envisions marriage and having children. In fact, she has been proposed by her girlfriend who for the last 7 years has a love affair with her. "We will probably get married this year," said Wulan. She feels she found a good partner and can appreciate it. During their courtship they were only limited to kissing hands, and talking more about the future, and walking hand in hand.

Although she has never had sexual intercourse or used contraceptives, Wulan admitted that she knew about condoms, which can be used as a tool to prevent pregnancy. She got this information from training she had attended, and sharing from friends who were married.

Support System

Currently, Wulan feels very comfortable in a relationship with her fiancé. She didn't feel threatened. However, in a relationship with a previous ex-boyfriend, she felt threatened when her partner wanted to engage her in sexual activity, and she felt uncomfortable. The climax, she hit his ex because she did not accept being kissed.

In every decision making, Wulan often gets consideration from her family, fiancé, and also her friends. In essence, they provide input and advice regarding the decisions that Wulan will take.

Social

Wulan claimed to have friends to share with each other about many things, entertain each other, and discuss with each other, including in terms of sexuality. If that's the case, they usually get mad at each other.

Description of Marlina, Mental Disability (Yogyakarta)

My meeting with Mrs. Sinta was started by meeting Ms. Marlina, who is the companion of Mrs. Sinta (51 years old), since the last 2 years. Mrs. Sinta is not a woman who can easily "connect" when communicating with other people. Along our way to her house, Mbak Marlina told us that the woman we were going to meet was a person with a mental disorder who had a daughter.

Marlina also said that the mother of one child had suffered from severe depression since her husband died, and did not get a good support system from her family. Meanwhile, she also has a dependent daughter with a disability. In fact, when her daughter was sick, there was no one to take care of her so the Yogyakarta Advocacy Center for Women with Disabilities (Sapda) took the initiative to take her to a hospital (RS) for intensive treatment. After recovering until now, Mrs. Sinta's daughter lives in the Integrated Rehabilitation Center for Persons with Disabilities (PRTPC) Bantul.

When he arrived at Mrs. Sinta's modest house, she was sitting on a wooden chair on the terrace of the house. Shabby clothes and blank stares, that's the first impression I caught when I approached him. When we greeted him, he could answer well, although it took a while because of daydreaming. After introducing myself, I asked Ms. Marlina to ask questions in a "language" understood by Mrs. Sinta. However, due to memory limitations and communication problems, we could not get much information from Mrs. Sinta. "When it comes to communicating with people with mental disabilities, it is difficult to get the answers we expect," said Marlina.

Meaning of Self and Body

After the death of her husband, Mrs. Sinta bears such a heavy burden that she suffers from depression and mental disorders. Since he had a mental disorder, his life was often neglected until he finally got assistance from Women, Disabled and Children Advocacy Center Foundation (SAPDA).

She was taken to the Ghrasia Mental Hospital (RSJ) in Pakem, Sleman, DIY around 2019. At that time, Mrs. Sinta underwent intensive treatment in the RSJ ward for 1 month and was sent home in a better condition. The hope, the family can accept his presence well. However, what happened was that Sinta was put in pasung by being put into the house with the door locked from the outside. The goal is not to bother the family. After receiving a threat to the police if not released, the family then opened the lock on the door of Mrs. Sinta's house.

When asked about the obstacles faced in daily life and when interacting socially; is there something wrong with her body; do you feel that you have ever been blamed for the situation; whether to feel different from other people; is his body valuable; the answer is always "no."

When asked about her aunt's unpleasant treatment of her, Ibu Sinta said, "Don't get me wrong, she doesn't understand." Then, we further asked what she usually does when faced with this situation. He replied, "just shut up".”

Sexuality and Reproduction

Mrs. Sinta admitted that she had never been to a beauty salon. In fact, she doesn't even know what a beauty salon is.

She confessed that she fell in love with her husband. Before, when she was not married, Mrs. Sinta was often visited by a lover whom she called Kuswanto. There is a feeling of pleasure when meeting with the idol of the heart. However, Sinta does not understand the terms sex, sexuality, or sexual activity. She also seemed reluctant to answer a number of intimate questions. She only said that having sex with her husband could cause her to become pregnant and have a daughter.

So sad for her husband, until now Mrs. Sinta has not been able to accept the fact that her husband has died several years ago. "The person has an ulcer and doesn't want to go home," said Sinta every time she was mentioned about her late husband. With a slightly high tone of voice as if to indicate an emotional feeling in her heart.

Seeing Mrs. Sinta's condition, which began to disconnect with our questions, we finally decided to move on to other questions.

Reproduction

At the age of 51, Mrs. Sinta admitted that she no longer had menstruation. She was once married to a man and has a daughter with cerebral palsy who is now 23 years old. During her first pregnancy, she also regularly consulted at the local health center until the birth process went normally, even though the baby was born prematurely. Previously, Mrs. Sinta had never experienced an unwanted pregnancy, miscarriage, or abortion. At that time, she had the full support of her husband. Unfortunately, after her husband died, she no longer had anyone to support her, even from her immediate family. After getting married and having their first child, Ibu Sinta does not use any contraception.

Support System

Mrs. Sinta's severe depression shows that she is experiencing mental stress, one of which is due to the lack of support from her family. Especially after her husband died. Unpleasant treatment, such as shackled inside the house with a padlock from the outside is a form of lack of freedom for him to make decisions for his own life. This includes the lack of protection over his body and sexuality.

It's just that (based on Marlina's explanation), his condition now looks better than before. Mrs. Sinta is no longer locked from the outside, and can bathe by herself and occasionally cook. This cannot be separated from the support of SAPDA who provides assistance for him.

Social

In her social life, Sinta calls Marlina a pretty good neighbor to her. He admitted that he often played at Marlina's place.

Description of Ani, Intellectual Disability (Yogyakarta)

That afternoon, at the agreed time, we met a mother who was about 35 years old. I have known this woman since she was still studying at an SLB at the junior high school level, at an event for friends with disabilities. She is different from other disabled women so that it attracts the attention of many people, including me. Besides being beautiful, she is also very cheerful.

After a long time no see, we finally met again a few years ago with conditions that were much different in terms of physical appearance. However, she's still pretty and puts on make-up on her face.

She is Ani (not her real name), an intellectual mental disability. When she was young, Ani was an athlete and runner. The ability to speak is still understandable, although sometimes the speech is scattered and unfocused. Until now, she still diligently consults a neurologist and takes medicine.

He didn't say much because every time she answered a question, the answer was always unfocused, and when she was tired she would whine. So, we don't force her to talk too much because she will definitely repeat her previous answer.

Self Meaning

Ani has not had intellectual mental disability since birth. He became disabled due to an accident that caused a blow to the back of his head. Ani's mother died when she was little, after 2 years her father remarried to a woman who was fierce towards Ani. Since her father married, Ani was often slapped and scolded by her father and stepmother.

Her father is a civil servant who has sufficient income and health insurance. So, she was able to provide treatment to Ani by performing surgery to remove fluid from the back of her head. After the operation, Ani getting well, she was not dizzy and could communicate smoothly.

Ani feels very dizzy when there are many problems she thinks about. If her father is angry, he will say that Ani is an idiot. In addition, his father also hit Ani until her head was dizzy.

Her neighbors also often say that Ani is an idiot. However, she didn't want to care and think about it because if she thought about it her head would get dizzy. Ani was educated from elementary to high school at SLB and had lived in the Yakum Dormitory. In Yakum Dormitory, Ani knows a lot of friends and is free from her father because she is never scolded again.

Sexuality and Reproduction

Ani realized that she was a beautiful woman. In the past, she often became a model for her disabled friends who were taking beauty courses. From there, Ani learned to apply makeup. He then often asks for compensation from his friends who use his services as a model, in return for lipstick or makeup tools that he wants. His friends also gave him a reward in the form of make up. Ani really wanted to take a hair cutting course, but her father didn't allow it. Finally, he studied on Youtube. Currently, he is happy to learn to sing through Youtube, and often sings with his friends.

During school, Ani had never been in a relationship. She once fell in love with a non-disabled man who was an athlete. However, Ani left Jogja and they never saw each other again. Ani is always approached by good men, both disabled and non-disabled. Many of them expressed love. Ani is always happy when someone says she is beautiful, she will blush (smiles). When he was still in junior high school, there was a man with a disability who said he was happy with Ani and would marry her. However, Ani's father refused. Her father is always angry when a disabled man approaches or likes Ani. Every day, Ani was scolded. She is not allowed to go and is not allowed to hang out with disabled men. Ani said she never wanted a man to kiss her or touch her breasts. He will fight. Ani said, women must be brave to fight. She is also afraid of getting pregnant and having children.

Ani experienced sexual intercourse for the first time with 5 people with disabilities. They took Ani to the hotel. However, Ani refused. Finally they went to the house of one of the 5 people with disabilities. Arriving at the house, Ani's breasts were touched. He was told to lie down, then one of them pressed Ani's body. He felt sick and was bleeding. However, Ani did not know what had happened to her and what the 5 men were doing. She was not aware of what was happening, but felt "good" after being crushed and the penis penetrated into her vagina (she mentioned a boy's name).

Ani goes out every day and visits her friends, including male friends. When Ani came to a man whose name was Tomo (not his real name), he was often told to lie down and squeezed his breasts, and his body was also crushed. Until one day, his body grew fat and often nauseous. Many of her friends said that she was pregnant. However, Ani did not understand and felt that it was just an ulcer. However, her father took her to the health center, and it turned out that Ani was 5 months pregnant. Since then, he has often checked his own womb. And, of the five people, there is one who is willing to marry Ani. However, Ani's parents did not like the boy because of his disability. After Ani stayed at her husband's house, she was always scolded by her mother-in-law. His mother-in-law said, "You can't do anything." Every day Ani is scolded by her in-laws.

The second day after giving birth, Ani rode a motorbike to come to the doctor. She wants to be put on a spiral contraception by a doctor. Since then, Ani has been using contraceptives.

At her mother-in-law's house, Ani always fights with her in-laws. Finally, Ani returned to her father's house with her son. She takes care of all the needs of her own children, from selling clothes, sending letters. Everything he did to meet the needs of himself and his children. Ani always takes her child everywhere. There is a person with a disability who later helps Ani send her child to a boarding school until now. After her son went to school, Ani felt free to go to her friends' houses.

If want to have sex, Ani will come to her husband. However, her husband sometimes gets angry and jealous when he is told that Ani often goes out with other men. If he is jealous, his husband will scold Ani.

Therefore, Ani asked her friends not to tell her husband. Ani experiences active sex so she often has sexual desires. If she is in lust, she goes to her husband. However, sometimes there are also those who take them for a walk and have a meal, then are invited to make love. Ani said she was happy. The man who invited her who always pays for meals when traveling. According to Ani, women don't want to spend money to pay for food.

Ani has sex not only with disabilities, but also with non-disabled people. Usually, the men contact Ani via WhatsApp to ask to meet. Ani will be shy and refuse, but sometimes he will come alone.

Sometimes, when a man asks her to make love, and Ani doesn't like it, she will definitely refuse and push him. She knows that if she has sex often, her stomach will hurt.

Reproduction

Ani had her period when she was in junior high school. She can use sanitary pads and has knowledge about menstruation while living in Yakkum Dormitory.

After being raped, Ani became sexually active until she did not know that she was already 5 months pregnant. Ani does not understand how to care for and maintain her pregnancy so she keeps traveling even though she is pregnant.

Later, Ani checked the contraceptive she was using. However, the doctor said the device was not in her womb. The doctor said the spiral was gone. Ani often has pain in the left side of her stomach, but she always prays that the pain will go away and the spiral won't bother her. Now she doesn't feel any pain in her stomach anymore. So far, Ani's periods are smooth and painless.

In terms of sexual needs, Ani has sex with her husband once every 3 weeks. But since there was the corona virus, she didn't want to make love to her husband. Ani actually has sex with other people, as long as her husband doesn't know.

Support System

In her life, Ani has many friends who she uses as a place to tell stories, including telling what happened when she was raped by 5 disabilities. However, for the incident when she had sexual relations with several disabled and non-disabled friends she did not want to tell others for fear that her husband would find out. Ani only told this now because it was to help disabled friends who didn't know anything (according to Ani).

Ani gets a lot of support from fellow disabled friends in many ways because of her cheerful nature and many feel sorry for her. He was once afraid of the wife of a disabled man who asked him to sleep with her. Ani is afraid of her friend's wife who she often goes to.

Social

Ani lives with her father, stepmother, and step-sisters. Her stepmother and father are always fierce to Ani. Ani feels that she is a beautiful and intelligent disabled person. He is often invited by Tomo (the person who often invites him to sleep with him) to visit the disabled and provide assistance, and tell him many things because he feels that he is smarter. Ani often goes around to friends with disabilities.d isabilitas.