Kirghizistan : prise en charge de l’autisme

Renseignement de l’analyse-pays de l’OSAR

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Sommaire

1 Introduction ... 4

2 Situation des enfants en situation de handicap ... 4
2.1 Institutionnalisation excessive, discrimination et négligence ... 4
2.2 Accès à l'éducation ... 5
2.3 Accès aux soins de santé ... 6
2.4 Accès à des soins de réhabilitation ... 7
2.5 Accès à une protection sociale ... 7

3 Prise en charge de l'autisme ... 8

4 Sources: ... 10

Ce rapport repose sur des renseignements d'expert-e-s et sur les propres recherches de l'Organisation suisse d'aide aux réfugiés (OSAR). Conformément aux standards COI, l'OSAR fonde ses recherches sur des sources accessibles publiquement. Lorsque les informations obtenues dans le temps imparti sont insuffisantes, elle fait appel à des expert-e-s. L'OSAR documente ses sources de manière transparente et traçable, mais peut toutefois décider de les anonymiser, afin de garantir la protection de ses contacts.

1 Introduction

Les questions suivantes sont tirées d'une demande adressée à l'analyse-pays de l'OSAR :

1. Quelle est la situation des enfants présentant des retards de développement au Kirghizistan ?
2. Quelles sont les possibilités de prise en charge de l'autisme dans la ville de Tokmok, au Kirghizistan ?
3. Les enfants en situation de handicap, y compris celles et ceux atteints d'autisme, ont-ils droits à des soins de santé et de réhabilitation gratuits ?
4. Les enfants autistes peuvent-ils bénéficier d'un accompagnement scolaire ?
5. Peuvent-ils également bénéficier d'une forme de protection sociale ?

L'analyse-pays de l'OSAR observe les développements au Kirghizistan depuis plusieurs années.[1] Sur la base de ses propres recherches ainsi que de renseignements transmis par des expert-e-s externes, elle apporte les réponses suivantes aux questions ci-dessus.

2 Situation des enfants en situation de handicap

2.1 Institutionnalisation excessive, discrimination et négligence

Au moins 29 000 enfants en situation de handicap. Beaucoup vivent en situation de vulnérabilité. *Eurasianet* rapporte qu'en 2015, le nombre total de personnes souffrant d'un handicap au Kirghizistan était estimé à 160 000. La plupart sont confinées dans leur maison reflétant la croyance très répandue que ces personnes ne sont pas capables de vivre de manière indépendante (*Eurasianet*, 15 septembre 2015). Selon un rapport du *Conseil des droits de l'homme* (UN HRC), au Kirghizistan, les enfants atteint-e-s d'un handicap sont en situation de vulnérabilité. Il y a au moins 29 000 enfants en situation de handicap dans le pays, toutefois, ce nombre ne comprend que les enfants officiellement enregistré-e-s comme invalides et bénéficiant de prestations sociales mensuelles. Il y aurait également un nombre important d'enfants « invisibles » souffrant de troubles du développement (UN HRC, 8 mai 2019).

L'institutionnalisation des enfants en situation de handicap reste la norme. Les enfants souffrant d'un retard mental sont particulièrement défavorisé-e-s. Risque de discrimination, de négligence et de maltraitance. Selon l'UNICEF, l'institutionnalisation des enfants

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[1] www.osar.ch/publications/rapports-sur-les-pays-dorigine

en situation de handicap est très répandue au Kirghizistan. Celles-ceux-ci n'ont qu'un accès limité à des services abordables. La situation est particulièrement défavorable pour les enfants souffrant d'un retard mental. Les efforts de désinstitutionalisation sont entravés par un manque de spécialistes et de services sociaux qualifiés et par un manque de services de soins alternatifs adéquats, tels que le placement familial spécialisé (UNICEF, 2021). Dans un rapport de décembre 2020, *Human Rights Watch* (HRW) indique qu'au moins 3000 enfants en situation de handicap vivent dans des institutions résidentielles où elles/ils courent le risque d'être victimes de négligence, de traitements médicaux inappropriés et de discrimination. Souvent les institutions ne disposent pas d'un personnel suffisant pour s'occuper de ces enfants, ce qui entraîne une négligence ou un manque d'attention individualisée. HRW rapporte également que le personnel des institutions a régulièrement recours à des psychotropes ou à une hospitalisation psychiatrique forcée pour contrôler le comportement des enfants et les punir. Sans accès à des systèmes de plainte confidentiels, ces enfants ne peuvent pas signaler les cas de maltraitance ou de négligence (HRW, 10 décembre 2020). Pour *Danuta Penkala-Gawecka*, spécialiste d'anthropologie médicale, au Kirghizistan, la réponse aux problèmes de santé mentale repose essentiellement sur les grands établissements hospitaliers qui fonctionnent de manière inefficace. Selon elle, la plupart des actrices-teurs du domaine de la santé mentale estiment que l'institutionnalisation excessive est le problème le plus important du système de santé mentale au Kirghizistan (*Danuta Penkala-Gawecka*, 2019).

La détection d'un potentiel d'handicap ou de retard de développement est entravée par le manque de connaissances et de formation du personnel médical. Un pot-de-vin est souvent exigé pour la reconnaissance d'une déficience. Processus long et bureaucratique pour obtenir le statut d'invalide. Selon l'UNICEF, parmi les principaux obstacles rapportés par les parents d'enfants en situation de handicap figurent le fait qu'au niveau local les professionnel-le-s de la santé qui détectent un potentiel de retard ou d'handicap sont réticent-e-s à en informer les parents le plus tôt possible. Ces professionnel-le-s ne sont souvent pas assez formé-e-s et n'ont pas les connaissances techniques. Il est également courant qu'ils ou elles exigent un pot-de-vin avant d'accepter d'identifier une déficience qui pourrait donner lieu à un certificat d'invalidité. Par ailleurs, le processus d'examen qui conduit à la reconnaissance d'un handicap est compliqué et bureaucratique. A partir du moment où un-e enfant est identifié-e comme ayant un handicap, les parents doivent souvent s'engager dans un processus coûteux et émotionnellement difficile, souvent sans soutien. Les informations sur leurs droits ne leur sont pas fournies au niveau médical ou de l'aide sociale, et ils sont confrontés à l'absence de diagnostic ou à un diagnostic incorrect, à des demandes de pots-de-vin de la part des professionnel-le-s et à des procédures administratives lourdes (UNICEF, 2021).

2.2 Accès à l'éducation

Accès très limité à l'éducation inclusive pour les enfants en situation de handicap, notamment en raison d'un manque de soutien et d'accompagnement. Pas d'éducation pour les enfants qui vivent dans des institutions. Au moins 27 000 enfants en situation de handicap sont exclu-e-s de l'enseignement. Même si l'enfant est officiellement reconnu-e comme invalide, cela ne garantit pas son accès à l'éducation. Des pots-de-vin doivent souvent être payés. Pour HRW, malgré les engagements pris par le gouvernement, les enfants en situation de handicap sont souvent privé-e-s d'une éducation inclusive de qualité, dans laquelle les enfants avec et sans handicap étudient ensemble dans des écoles ordinaires. Ces écoles sont souvent physiquement inaccessibles ou ne fournissent pas le soutien ou l'accompagnement nécessaire. Les enfants en situation de handicap sont soumis-e-s à des évaluations gouvernementales discriminatoires qui conduisent souvent à une ségrégation dans des écoles spéciales ou à la maison. Celles-ceux qui sont placé-e-s dans des institutions ou des écoles spéciales ne reçoivent souvent aucune éducation ou alors une éducation médiocre (HRW, 10 décembre 2020). Selon l'UNICEF, pour avoir accès à une éducation, les parents d'un-e enfant en situation de handicap doivent remplir un formulaire et espérer que le personnel veuille bien accepter l'enfant. Pour obtenir une éducation spécialisée, adaptée au handicap de l'enfant, les parents doivent obtenir une carte qui certifie que celle-ci/celui-ci est invalide. Sans cette carte, une école spécialisée n'acceptera pas l'enfant. Toutefois, la possession de cette carte ne garantit pas non plus que l'enfant sera accepté. Les parents qui souhaitent que leur enfant soit inclus-e dans une école ordinaire dépendent du bon vouloir de la directrice/du directeur de l'école ou des enseignant-e-s. En général, cela nécessite le paiement d'un pot-de-vin. Par ailleurs, la transition école-travail n'est pas adaptée aux adolescent-e-s en situation de handicap qui rencontrent d'importantes difficultés pour accéder à un emploi après leur formation, même dans le service public (UNICEF, 2021). En 2015, *Eurasianet* indiquait, sur la base d'informations fournies par des spécialistes, qu'un nombre important d'enfants en situation de handicap, estimé à 27 000, étaient régulièrement exclu-e-s de l'enseignement ordinaire (*Eurasianet*, 15 septembre 2015).

2.3 Accès aux soins de santé

Les enfants en situation de handicap n'ont pas véritablement accès aux services de santé, surtout pas gratuitement. La mauvaise qualité des soins peut causer la mort prématurée de ces enfants. L'assurance maladie ne couvre que les interventions biomédicales. Selon l'UNICEF, l'accès à la santé est basé sur un modèle d'assurance à trois niveaux et les citoyen-ne-s ont accès à l'assurance maladie publique de base garantie par l'État. Des dispositions existent pour des populations spécifiques, notamment les enfants en situation de handicap. Le système de santé garantit l'accès à une gamme de services gratuits qui se focalisent sur les soins hospitaliers et curatifs, mais qui souffrent d'importants déséquilibres régionaux en termes d'accessibilité et de qualité. En termes de soins de santé pour les enfants, les principaux défis incluent, selon l'UNICEF, « *le surtraitement et l'hospitalisation des enfants, le sous-développement et la centralisation du domaine de la santé mentale des enfants et des adolescents, le manque de professionnels de la santé dans les zones rurales éloignées, le faible niveau de qualification du personnel et des équipements médicaux, et la lourdeur de la charge de travail combinée à la faiblesse des salaires, à l'exode des prestataires de santé et à la faible coopération gouvernementale*. ». En principe, les personnes handicapées ont droit à deux hospitalisations par an, mais également à des services médicaux gratuits et à des prestations pharmaceutiques. Toutefois, au vu des défis énoncés plus haut, l'UNICEF estime que dans la pratique, les enfants en situation de handicap n'ont souvent pas accès aux services de santé et surtout pas gratuitement comme le prévoit la loi. Il n'est ainsi pas rare que les parents doivent payer ces services. L'UNICEF affirme par ailleurs que des recherches ont montré que la mauvaise qualité des soins de santé dispensés aux personnes en situation de handicap au Kirghizistan peut entraîner leur mort prématurée (UNICEF, 2021). Selon UNHRC, les enfants en situation de handicap souffrent toutes et tous d'un accès limité à des services de soins de qualité répondant à leurs besoins. Un autre problème est que comme les soins de santé sont toujours basés sur un modèle biomédical étroit et dépassé, l'assurance-maladie ne couvre principalement que les interventions biomédicales (UNHRC, 8 mai 2019).

Les soins de santé mentale pour enfants sont inexistants. Seuls six pédopsychiatres exercent dans le pays. Selon UNHRC, le domaine de la santé mentale des enfants et des adolescent-e-s est particulièrement sous-développé, avec seulement quelques spécialistes travaillant dans ce domaine dans les deux plus grandes villes du pays (UNHRC, 8 mai 2019). Selon l'agence de presse *24kg*, en mai 2018, le rapporteur spécial des Nations-Unies sur le droit à la santé physique et mentale, Dainius Puras, a affirmé qu'au Kirghizistan, les soins psychiatriques pour enfants n'existaient pas (*24kg*, 31 mai 2018). Pour *Danuta Penkala-Gawecka,* il n'y a pas assez de psychiatres dans le pays. Leur nombre est passé de 250 en 2001 à 53 en 2015, dont seulement six sont pédopsychiatres. Cette baisse drastique est notamment dû à l'émigration massive de docteurs et de psychiatres, mais également au fait que la profession de psychiatre est peu prestigieuse et n'attire pas beaucoup de médecins. Par ailleurs, dans les hôpitaux psychiatriques, seuls les traitements à l'ancienne sont disponibles (*Danuta Penkala-Gawecka*, 2019).

2.4 Accès à des soins de réhabilitation

Le programme étatique de réhabilitation est sous-développé et de médiocre qualité. Les spécialistes font défaut. Les personnes en situation de handicap ignorent souvent leurs droits en la matière. L'accent est généralement mis sur la réhabilitation médicale au détriment des services de réhabilitation psychologique ou sociale. Les ONG doivent se substituer à l'État. Selon le rapport d'UNICEF, le programme étatique de réhabilitation des personnes en situation de handicap ne dispose pas des connaissances et des services de haute qualité nécessaires sur le terrain et les personnes en situation de handicap elles-mêmes ignorent en grande partie qu'elles ont droit à un plan de réhabilitation. La réhabilitation sociale, psychologique ou éducative ne sont pas réalisées en raison du manque de spécialistes, d'équipements et de méthodes. La grande majorité des centres de réhabilitation sont privés et exigent le paiement de frais. Des centres publics gratuits existent à Bishkek et Ak-Suu et un nouveau centre est en cours de développement à Jalal-Abad. Alors qu'ils sont en principe garantit par la loi, de nombreux services de réhabilitation ne sont pas disponibles en raison du manque de spécialistes, tels que des ergothérapeutes, des orthophonistes, des spécialistes de la réadaptation professionnelle ou des enseignant-e-s spécialisé-e-s. Lorsqu'ils sont disponibles, les services se focalisent sur la réhabilitation médicale, fournie par le système de santé et ceci au détriment d'une réhabilitation psychologique ou sociale. Cette réhabilitation médicale n'est également fournie que partiellement en raison d'un manque de moyens médicaux et techniques. En conséquence, il existe un important déficit de services de réhabilitation et de fourniture de technologies d'assistance. Celles et ceux qui peuvent se le permettre vont se faire traiter à Osh, Bishkek ou même à l'étranger. D'autres vont simplement arrêter le traitement en raison de moyens financiers insuffisants ou d'un manque d'infrastructure. C'est le secteur non-gouvernemental qui fournit une bonne part des prestations de services aux personnes handicapées, y compris des soins de réhabilitation. Il y a plus de 50 centres de réhabilitation privés dans le pays qui offrent des services aux enfants et adultes en situation de handicap. Les parents qui peuvent se le permettre font souvent appel au secteur privé de la réhabilitation (UNICEF, 2021).

2.5 Accès à une protection sociale

L'allocation mensuelle pour enfant invalide a doublé entre 2018 et 2022. Une protection sociale toutefois insuffisante pour soutenir les familles avec des enfants en situation

de handicap. Selon l'UNICEF, des régimes de protection sociale existent pour les enfants en situation de handicap, toutefois il existe des obstacles à l'accès, les niveaux de prestations ne reflètent pas les besoins différenciés et sont considérés comme inadéquats. L'allocation mensuelle moyenne pour un enfant invalide, quel que soit son handicap, était de 4000 som (environ 43 francs suisses[2]) en 2018 (UNICEF, 2021). Selon le *Central Asian Bureau for Analytical Reporting* (CABAR), en 2021, cette allocation était montée à 6000 som et à partir de 1er janvier 2022, elle atteindrait 8000 som, soit l'équivalent de 86,75 francs suisses. A noter que depuis 2018, les parents qui s'occupent à plein temps de leurs enfants invalides peuvent également toucher une allocation mensuelle de 4900 som, ou 53 francs suisses, au titre du service social « Assistant personnel » (CABAR, 24 janvier 2022). Selon l'UNICEF, le système de protection sociale n'est pas capable de fournir un soutien complet aux plus pauvres. Il a un impact insignifiant sur les niveaux de vie, n'offre qu'une faible couverture des personnes dans le besoin et ne fournit pas de services sociaux suffisamment qualifiés. Les montants des prestations d'invalidité n'atteignent pas le minimum vital considéré comme un revenu minimum de base nécessaire à une vie décente. En principe, les personnes identifiées comme ayant un handicap ont droit à une prestation liée au handicap. Toutefois, selon l'UNICEF, le processus d'enregistrement est lourd et peu clair et la plupart des parents d'enfants en situation de handicap ne savent pas comment y accéder. Par ailleurs, comme le fait d'être enregistré ne donne pas le droit à des services gratuits et inclusifs et peut même conduire à la séparation d'avec son enfant, de nombreux parents ne cherchent même pas à obtenir ce statut officiel d'invalide (UNICE, 2021).

3 Prise en charge de l'autisme

L'autisme est mal diagnostiqué et mal compris. Les personnes atteintes d'autisme n'ont pas accès à des services appropriés. Important risque d'exclusion et de discrimination. Manque de spécialistes et de connaissances de la maladie. Selon CABAR, qui cite des chiffres du *Republican Medical and Social Assessment Board*, en 2021 il avait 630 enfants autistes au Kirghizistan. Le système de formation médicale nationale ne forme pas encore de spécialistes pour traiter et accompagner ces enfants. Nazgul Mirzamatova, chef du département des enfants du Centre républicain de santé mentale, interrogé par CABAR, admet que le pays compte peu de médecins capables de travailler avec des enfants autistes. Les neuf spécialistes que compte le pays travaillent tous à Bichkek (CABAR, 24 janvier 2022). D'après le rapport du UNHRC, au Kirghizistan, les enfants et adultes atteint-e-s d'autisme font face à des obstacles et n'ont pas accès à des services appropriés. Rares sont les enfants qui bénéficient d'un soutien adéquat dès leur plus jeune âge par le biais d'un dépistage précoce et de mesures de soutien familial ciblées. Ces enfants sont exposé-e-s à un risque important d'exclusion et de discrimination (UNHRC, 8 mai 2019). Le *Global Fund for Children*, une organisation qui octroie des subventions aux ONG pour améliorer la vie des enfants les plus vulnérables, indique qu'au Kirghizistan l'autisme est souvent mal diagnostiqué et mal compris (*Global Fund for Children*, 21 octobre 2019). Selon le rapport alternatif soumis en 2014 par une coalition d'organisations impliquées dans la promotion des droits socio-économiques des enfants et des femmes, au Kirghizistan, les enfants autistes se retrouvent souvent en hôpital psychiatrique et passent parfois le reste de leur vie dans des internats neuropsychiatriques (*Coalition of NGOs on promotion of socio-economic rights of children and* women, 2014).

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[2] Selon le taux de change du 2 février 2022.

Accès très limité à l'éducation. L'école conventionnelle ne tient pas compte des besoins spécifiques des enfants autistes et les enseignant-e-s ne sont pas formé-e-s pour répondre à leurs besoins. Selon le *Global Fund for Children*, sous l'impulsion d'ONG, telles que l'association *Hand in Hand*, le gouvernement a adopté en 2019 un programme d'éducation inclusive (*Global Fund for Children*, 21 octobre 2019). HRW relevait en décembre 2020 que le gouvernement n'avait pas encore respecté ses engagements en la matière et que les enfants en situation de handicap restaient largement exclu-e-s de l'école ordinaire (HRW, 10 décembre 2020). CABAR indique que selon Mme Sadykova, qui a fondé l'association *Hand in Hand* pour aider les enfants autistes, les mesures promises dans le cadre du programme d'éducation inclusive adopté par le gouvernement en 2019 ont été reportées en raison de la pandémie Covid-19 et de changements politiques. Selon la mère d'un enfant autiste, interrogée par CABAR, l'un des principaux problèmes au Kirghizistan est effectivement que les enfants autistes n'ont pas accès à l'éducation. Selon cette mère, le système éducatif conventionnel ne tient pas compte des besoins des enfants autistes qui ont souvent besoin d'une approche individuelle et d'un-e tutrice-teur personnel-le. Les écoles n'offrent pas cette approche personnalisée et ne donnent pas leur accord à la présence d'un-e tutrice-teur (CABAR, 24 janvier 2022). Selon la coalition d'organisations impliquées dans la promotion des droits socio-économiques des enfants et des femmes, au Kirghizistan, les enfants autistes n'ont pas accès à une prise en charge et à une éducation spécialisée. Ces enfants restent souvent à la maison, sans contacts avec la société avec souvent comme conséquence que leur santé se dégrade. L'État n'est pas en mesure d'offrir une éducation spécialisée à ces enfants, notamment parce que les enseignant-e-s des établissements préscolaires et scolaires n'ont pas les connaissances requises en termes de pédagogie et de thérapies correctionnelles ou n'ont pas la volonté de travailler avec ces enfants (*Coalition of NGOs on promotion of socio-economic rights of children and* women, 2014). Selon *Eurasianet* qui cite une ONG, les efforts du gouvernement en matière de soutien scolaire sont limités, notamment en raison de problèmes budgétaires (*Eurasianet*, 15 septembre 2015).

Les enfants peuvent être pris-es en charge dans ces centres de réhabilitation privés, mais les prix sont élevés et hors de portée de la plupart des familles. D'après CABAR, le pays ne dispose pas d'établissements publics pour prendre en charge les enfants autistes et permettre de soulager les parents. Des centres privés existent, mais ils sont très chers et la plupart des parents n'ont pas les moyens d'y envoyer leurs enfants. Gulzada Akunova, du département des services sociaux pour les personnes handicapées et les personnes âgées, a ainsi confirmé à CABAR que presque tous les centres de réhabilitation du pays appartiennent à des entités commerciales et les enfants y sont traité-e-s uniquement sur une base payante (CABAR, 24 janvier 2022).

Des ONG, comme l'association *Hand in Hand*, soutiennent les enfants autistes et leurs parents. Le rapport alternatif de la coalition d'ONG indique que certains projets pour améliorer la prise en charge des enfants autistes ont pu être mis en place grâce aux efforts des parents, des ONG et des fondations internationales (*Coalition of NGOs on promotion of socio-economic rights of children and* women, 2014). *Eurasianet* cite l'exemple de l'association *Hand in Hand* qui soutient les enfants autistes et leurs familles. En plus d'offrir un accompagnement thérapeutique à ces enfants pour traiter des problèmes de comportement, l'association organise également des séminaires de sensibilisation avec des médecins, des enseignant-e-s et des travailleuses et travailleurs sociaux. En 2014, une classe accueillant six enfants souffrant d'autisme a ouvert à Bishkek, ouvrant la voie à la mise en place d'un modèle éducatif plus inclusif (*Eurasianet*, 15 septembre 2015). Le *Global Fund for Children* ajoute que l’association *Hand in Hand* éduque les parents sur cette maladie et forme les professionnels de la santé à identifier l’autisme à orienter les enfants vers les soins appropriés. L'organisation a mis en place le premier centre du pays entièrement consacré à l'aide aux enfants autistes. En plus de ses activités éducatives, qui visent à l’aide de spécialistes à donner aux enfants autistes les moyens de satisfaire leurs besoins et leurs objectifs personnels, l’association influence également la manière dont les enfants autistes sont diagnostiqué-e-s et pris-es en charge dans le pays. L’association, qui emploie 40 spécialistes, possède trois centres à Bishkek et a ouvert une branche dans la ville de Karakol (*Global Fund for Children*, 21 octobre 2019).

4 Sources:

24 kg, 31 mai 2018:

> « ***There is no children’s psychiatric care in Kyrgyzstan. Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health of the Office of the United Nations High Commissioner for Human Rights, Dainius Puras, told journalists.***
>
> ***According to him, it is necessary to develop these services for children and adults with mental and psychosocial disorders, taking into account that such people need mainly other treatment based on a non-biomedical model.***
>
> *He added that an integrated long-term health strategy should be developed to close isolated institutions, including psychiatric hospitals and nursing homes for children.*
>
> *Dainius Puras stressed that in general, Kyrgyzstan demonstrates effective implementation in the field of realizing the rights to physical and mental health.* » Source: 24 kg, Kyrgyzstan lacks children’s psychiatric care, 31 mai 2018: https://24.kg/english/86309_Kyrgyzstan_lacks_childrens_psychiatric_care_/.

CABAR, 24 janvier 2022:

> « ***Kyrgyzstan, according to the Republican Medical and Social Assessment Board, has nearly 630 autistic children as of 2021.***
>
> ***According to the law "On state benefits in the Kyrgyz Republic", autistic children in Kyrgyzstan are entitled to monthly benefits. According to the president's decree, the benefit amounts to 6 thousand som (70.75 dollars) from October 2021, and will be 8 thousand som (94.33 dollars) from January 1, 2022. Moreover, a new kind of social service "Personal Assistant" was introduced in 2018 to support parents with children with disabilities. It provides for monthly payment of 4,900 som (57.79 dollars).*** *[…]*
>
> *Last year, according to Zhyldyz, the republican medical and social assessment board (MSEK) paid much attention to children with mental disorders and made some exemptions for them. In particular, previously parents had to gather documents every year, undergo assessment and get confirmation of autism in their child. This is necessary to get the disability status and to*

receive benefits. Many parents refused to pass all these procedures even if they needed money. […]

Moreover, ***according to Sadykova, medical universities of Kyrgyzstan do not train specialists needed for autistic children. "However, the inclusive education concept was adopted two years ago. It requires that universities train necessary specialists," Zhyldyz said. "Unfortunately, because of Covid, political tempests and changes in structures, state agencies postponed many issues. I'd like to believe that this country will have everything gradually, step by step.****" […]*

According to Nazgul Mirzamatova, head of children's department of the Republican Centre for Mental Health, Kyrgyzstan has few doctors who can work with autistic children. There are only nine specialists in Bishkek, and none in the regions.

"Children with autism spectrum disorders are recommended to work with speech pathologists," Mirzamatova said. "However, not everyone wants to study this area deeply because working with such children is very difficult." […]

One of the biggest problems in Kyrgyzstan, Indira said, is that autistic children have no access to education.

"There are specialised schools for children with special needs, but they have a conventional system of education that does not take into account the needs of children with special needs," she said. "An autistic child can hardly take any information, they need individual training, individual approach, assistance of a personal tutor. But not all schools take tutors or give consent to their presence."

Indira cannot come to work now as she has to commit herself to the child in full.

"The benefits we receive are not enough. You can see the food prices now," she said. "Moreover, autistic children need to undergo preventive treatment twice a year. It is not cheap – one small drug costs 1,200 som (14.15 dollars). Semetei needs to take drugs not to have problems with behaviour and health in the future."

Indira is dreaming of going to work to be able to maintain her children independently. But first, Kyrgyzstan must have some public facilities for autistic children where they can spend time. However, the country does not have such facilities. *[…]*

Unfortunately, the relatives did not tolerate the boy's problem behaviour. According to Aidai, she has been blamed for the fact that Tynai was born like that.

"In general, the society in general have a bad attitude to such children," she said. "For example, previously we had lived on the fourth floor, and our neighbours from downstairs often complained that Tynai was running, stomping his feet, or jumping. We explained to them that the child was disabled and he didn't understand that someone was living downstairs. The neighbours did not want to listen to us and told us to move. Also, the boy could shout unexpectedly in public transport. Some passengers would just turn their faces away, but most of them watched him with deprecatingly."

> ***"Services provided by private centres for children with special needs are very expensive. Taking into account hard times today, many parents cannot afford paying for such services every month. Therefore, most children with disabilities cannot get help on time just because they don't have money."***
>
> ***Gulzada Akunova, chief specialist of the department of social services for people with disabilities and the elderly, said to CABAR.asia that the republic has a range of rehabilitation centres where children can obtain various services. However, almost all of them belong to commercial entities and children are treated there on a paid basis.***
>
> *Much money is needed to open public centres, but now there are problems with financing, so construction of such facilities is not even discussed. »* Source: Central Asian Bureau for Analytical Reporting (CABAR), Autistic Children. Kyrgyzstan Lags Behind, 24 janvier 2022: https://longreads.cabar.asia/kyrgyz_autsim_eng.

Coalition of NGOs on promotion of socio-economic rights of children and women, 2014:

> *« 8.3.* ***In Kyrgyzstan, children with autism spectrum disorders (ASD) do not have access to treatment and education, they have to stay at home for years, being isolated from the society that leads to a health aggravation of the child: speaking abilities do not develop and behavioral problems deteriorated, as well as socially important skills not obtained. A low detection rate of children with ASD takes place in the country due to the lack of specialists, who are able to make a diagnosis. The state has no abilities to offer any of existing forms of education for children with ASD, because teachers at preschool and school institutions do not have the knowledge about features of development and perception of children with ASD; teachers do not know the modern techniques of correctional pedagogy (ABA therapy, PEKS, TEACH, and others) and they have no capabilities and willingness to work with such children. The state does not pay attention to numerous proposals of non-governmental sector representatives to organize the education, to establish correctional groups / classes in preschool and school institutions, to solve the issue of accompanying (tutors) children with ASD in educational institutions. None of the departmental documents of government agencies for 2013-2014 mentioned about the problem of children with ASD****. [...]*
>
> *8.8. All attempts to introduce "inclusive education" have a failure. Donors and international development partners work in the education sector in a fragmented and scattered manner. Therefore,* ***children with special features of intelligence and autism do not have access to education, and often they turn to be in psychiatric hospital or spend the rest of their life in neuropsychiatric boarding schools.*** *Implementation of some projects aimed at integration of children with special intelligence and autism into the community performed due to the efforts of parents, NGOs and international foundations. »* Source: Coalition of NGOs on promotion socio-economic rights of children and women, Alternative Report on the Kyrgyz Republic's implementation of the International Convention on Economic, Social and Cultural Rights, 2014, p.20,22: https://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/KGZ/INT_CESCR_ICO_KGZ_18502_E.doc.

Eurasianet, 15 septembre 2015:

« There are some 160,000 disabled individuals living in Kyrgyzstan — that accounts for about 2.75 percent of the population. ***Many are confined to their homes as there is a widely held belief in Kyrgyzstan that disabled people are unable to live independently.***

"We are here to say that we can live a normal life, but we need many barriers to be removed", Jaladin, a trainer working for the organization Empowering Blind People, said at the Bishkek march.

Jaladin illustrated his point with a story about one of his students, a blind woman with underdeveloped muscles. "Her family ignored the fact that blind people can live independently if they are trained to use a cane," he said. For 40 years, the woman sat cooped up indoors and was fed by her family.

"With the collapse of the Soviet Union, the belief that disabled people need help for everything and can't live independently has increased," Jalaldin said.

Many organizations are now working to raise awareness about various disabilities. ***Hand in Hand is a public association that supports children with autism and their families. In addition to offering therapy for children with autism to address behavioral issues, the organization also conducts aware-raising seminars with doctors, teachers and social workers.***

"Usually parents come to us when their child is two or three years old and doesn't speak. They ask, 'What is wrong with my child?' said Galya Gaas, an applied behavioral therapist at Hand in Hand.

Nazgul Irisova, also a specialist at Hand in Hand, said that some progress is being registered.

"Some parents used to think that they had made a mistake [when raising their child] and considered it shameful to have a child with autism, but this is changing slowly," Irisova said.

Gaas and Irisova recognize the government has made efforts to help people with autism, but the potential scope for action is limited by budgetary issues, which leaves the voluntary sector doing the specifically targeted work. "Nongovernmental organizations should just work on very specific missions, such as teaching children after school," Gaas said.

In 2014, a class opened in Bishkek for six children with autism. The results appear promising and are setting the standard for a more inclusive model of education. Around 27,000 disabled children in Kyrgyzstan are routinely excluded from mainstream education, according to specialists in the sector. Kazakunova argued that must change.

UNICEF has recently started to work on a project of inclusive programs in kindergartens. "Working with children is essential if we want to change mentalities and give them a future," said Yukie Mokuo, UNICEF's representative in Kyrgyzstan.

> *Speaking at the Kyrgyz State University, Kazakunova told of how a handful of children from a special education center began attending regular schools in the town of Karakol a few years ago. "It is a first step, the integration process is beginning," she said.* » Source: Eurasianet, Kyrgyzstan: Disabled Battle for Acceptance and Access, 24 septembre 2015: https://eurasianet.org/kyrgyzstan-disabled-battle-for-acceptance-and-access.

Global Fund for Children, 21 octobre 2019:

> *« **In a country where autism is widely misdiagnosed and misunderstood, Hand in Hand educates parents about the condition and trains healthcare professionals to identify autism and refer children for proper care. The organization established the first center in the country that is devoted entirely to assisting children with autism.***
>
> ***At the center, children take part in daily and weekly treatment, testing, and educational sessions. Each child works with a team of specialists who together empower the child to meet their personal needs and goals. The organization also works extensively with parents and caregivers, helping them to better understand their children's abilities and challenges.***
>
> ***Over the years, while providing these services to hundreds of children and families, Hand in Hand also worked to grow stronger as an organization and systemically influence the way children with autism are diagnosed and cared for.***
>
> *"After our trainings of health care workers and a lot of information work through mass media, we were able to reduce the age of children who get their diagnosis from 6-8 years to 3-4 years. Last year children under age 2 started to come to the Center for help," Zhyldyz said. "This is a great victory because the chances of catching up with their peers in development are higher if the right teaching approach for young children is used."*
>
> ***Hand in Hand has also helped develop and advocate for laws advancing the rights of children with disabilities. The organization played a key role in establishing a clinical protocol for children with autism, and in expanding their educational opportunities. In 2019, the national government approved an official concept for the development of inclusive education – an initiative spearheaded by Zhyldyz, among others.***
>
> *Once operating out of a shared, temporary space, **Hand in Hand has since acquired its own buildings, where it now employs more than 40 different specialists. It has opened a branch in the city of Karakol and has trained numerous specialists, who have opened three additional centers for children with autism in Bishkek.*** » Source: Global Fund for Children, For Kyrgyz children with autism, a local NGO paves the way to better care, 21 octobre 2019: https://globalfundforchildren.org/story/hand-in-hand/.

HRW, 10 décembre 2020:

> *« **Thousands of children with disabilities in Kyrgyzstan are segregated in residential institutions where they can experience neglect, inappropriate medical treatment, and discrimination**, Human Rights Watch said in a report published today, on International Human Rights Day.*

The 74-page report, “Insisting on Inclusion: Institutionalization and Barriers to Education for Children with Disabilities in Kyrgyzstan,” documents how ***children are frequently denied quality, inclusive education, in which children with and without disabilities study together in mainstream schools. Children with disabilities are subject to discriminatory government evaluations that often lead to segregation in special schools or at home,*** *Human Rights Watch found. Kyrgyzstan ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2019.*

“The Kyrgyz government has committed to guaranteeing access to inclusive education, meaning that children with disabilities should be able to study in mainstream schools in the communities where they live,” said Laura Mills, researcher at Human Rights Watch and the report’s author. “However, the government still needs to turn this pledge into a reality for children across the country.”

Human Rights Watch interviewed 111 people between October 2019 and July 2020, including children and young adults with disabilities, teachers and staff at residential institutions and special schools, parents, and disability rights activists. Human Rights Watch also visited six residential institutions and schools for children with disabilities in four regions.

Human Rights Watch found that the institutions had insufficient personnel to care for children with disabilities, resulting in neglect or lack of individualized attention. Children were segregated according to disability, which is discriminatory.

Human Rights Watch also documented that ***institution staff regularly use psychotropic drugs or forced psychiatric hospitalization to control children’s behavior and punish them.***

A doctor at an institution for children with disabilities described sending a boy to a psychiatric hospital because the institution staff were unhappy with the boy’s behavior. The doctor recognized the dangerous use of medications on children, saying, “There they can even overdose on sedatives, but [the hospital] has an intensive care unit so they can resuscitate them.”

None of the six institutions visited had accessible and confidential complaint systems, meaning that children there cannot report abuse or neglect.

Since 2012, the Kyrgyz government has pledged to close 17 residential institutions for children, including three for children with disabilities. But 3,000 children with disabilities remain in institutions, and the government has closed only one residential special school.

Two bodies evaluate children and can make recommendations based on a child’s disability that block their access to mainstream education, or to any education at all. The Psycho-Medical-Pedagogical Consultations (PMPC), made up of doctors and education specialists, often recommends that children with disabilities study in special schools or receive home education. Another body, made up only of doctors, can make similar recommendations, including that some children should not receive any education.

> *While evaluations by these two bodies are formally recommendations only, Human Rights Watch found that* ***mainstream schools often deny enrollment to children who were recommended for special school or home education.***
>
> ***Human Rights Watch found that children who live at home, including those whose parents have taken them out of an institution, encounter significant, discriminatory obstacles to their education in mainstream schools.***
>
> ***A major barrier to inclusive education is that mainstream schools are physically inaccessible or do not provide necessary support to children with disabilities. Due to the absence of support or accommodations, many parents may feel compelled to accompany their children to school to help them move between floors of the school, use the bathroom, or read the blackboard.***
>
> *While many children with disabilities receive education at home, parents said teachers come for very few hours and are often not trained in teaching a child with a disability.*
>
> ***Children in residential institutions and special schools receive either a poor education or no education at all.***
>
> *The limited access for children with disabilities to mainstream schools is discriminatory and violates Kyrgyz and international law, Human Rights Watch said. State agencies should stop segregating children and identify and provide individualized supports, known as reasonable accommodations, to ensure a child's education. Under Kyrgyzstan's international human rights obligations, children with disabilities have the right to live in the community and to grow up in a family. […]* » Source: Human Rights Watch (HRW), Kyrgyzstan: Barriers to Education for Children with Disabilities, 10 décembre 2020: www.hrw.org/news/2020/12/10/kyrgyzstan-barriers-education-children-disabilities.

Danuta Penkala-Gawecka, 2019:

> *« As Eugene Raikhel and Dörte Bemme (2016, 161) note, mental healthcare has remained highly institutionalised in most of the former Soviet states. With regard to Kyrgyzstan, Ainura Ibraimova et al. (2011a, 93) point to* ***an overemphasis on large inpatient facilities, which work inefficiently. This issue is also discussed by local psychiatrists who likewise notice deficiencies of the inherited system.*** *For example, Molchanova et al. (2015, 13) write that it is "overly centralised (…) and still resembles the mental health care system in the Soviet Union", and complain about the lack of adequate financing for improving its structure. Krassimir Kanev, the author of one of the reports, maintains that the opinion on* ***excessive institutionalisation as the most significant problem of mental healthcare system*** *in Kyrgyzstan was shared "almost unanimously by government representatives, users and the progressive professional community", whom he interviewed (Kanev 2012, 6).*
>
> ***The inadequate number of psychiatrists poses another challenge to the functioning of mental healthcare. According to the data reported by Molchanova et al. the number of psychiatrists in the Kyrgyz Republic decreased from 250 in 2001 to 53 in 2015, and among them there were only six child psychiatrists (down from 33 in 2001). Such a dramatic decrease is mainly due to the mass emigration of medical doctors, including psychiatrists, and the low popularity of this specialty among medical students (Molchanova et***

> ***al. 2015, 13). The WHO report on mental healthcare in Kyrgyzstan also noted that “psychiatry lost a majority of qualified specialists (migration to other countries, leaving for other structures)”, while the demand for psychiatric aids increases (****WHO-AIMS Report… 2008, 30, 31). What is striking is that* ***local psychiatrists often lament the very low prestige of their profession. In Molchanova’s words “mental health care specialists in KR [Kyrgyz Republic] are stigmatized even more than patients with mental disorders”*** *(2014a, 26). Supposedly, this is the result of the political abuse of psychiatry in the Soviet times, as Reikhel and Bemme argue, claiming that its “aftereffects for the profession’s reputation in Russia – and elsewhere in the post-socialist world – have been longstanding and profound” (Reikhel and Bemme 2016, 159).[…]*
>
> *One often addressed problem is the use of outdated treatment schemes, which is mainly caused by the lack of adequate funding. Although the psychiatrists working at the departments of psychiatry at the Kyrgyz State Medical Academy and the Slavonic University in Bishkek have developed clinical protocols recommending innovative models of treatment,* ***only old-fashioned treatment programmes are available in mental health hospitals*** *(Molchanova et al. 2015, 16). However, according to Ibraimova et al. (2011a, 93–94), the availability of psychotropic medicines has improved, largely because in 2006 the Additional Drug Package of the Mandatory Health Insurance Fund was introduced for insured citizens.»* Source: Danuta Penkala-Gawecka, “New psychiatry” and traditional healing in Kyrgyzstan: attempts to develop culturally sensitive and community-based treatment, 2019, p.193-195: https://rcin.org.pl/Content/98636/Ethnologia-Polona-vol-40-2019_11-DANUTA-PENKALA-GAW%C4%98CKA.pdf.

UN HRC, 8 mai 2019:

> *« 42.* ***The low salaries of health-care personnel have a negative impact on the quality of services and provide incentives for informal payments. They also contribute to the brain drain of medical personnel, not only to other countries but from the public to the private sector, including the pharmaceutical industry.*** *[…]*
>
> *54.* ***Children with disabilities are another group in a vulnerable situation. According to the most recently available data provided by the Ministry of Labour and Social Development, there were 29,000 registered children with disabilities in 2017. However, this number only includes those children who have been registered by the Ministry as eligible for monthly social benefits, and not the “invisible” children with developmental disabilities. All children with disabilities, whether registered by the Ministry or not, have poor access to quality care services that meet their needs. The current care system in Kyrgyzstan continues to focus on the medical model of disability, which rarely provides for appropriate support at a young age through early identification and targeted family support measures, putting children with disabilities at a significant risk of exclusion and discrimination****. […]*
>
> *57****. Health-care services in Kyrgyzstan are still based on a narrow and outdated biomedical model, which is why health insurance coverage includes mainly biomedical interventions****. It is important to recall that, globally, modern health care has incorporated new priorities with a holistic approach, such as mental health services for children and adults with disabilities, services for older persons, medical and psychosocial rehabilitation and palliative care.* ***Kyrgyzstan should modify its health-care system so that resources are used not only for medication and hospital treatment, but also for other types of health-related***

> ***intervention, which may not necessarily be only biomedical. This is particularly important when planning and developing policies and services to address mental health, an area increasingly becoming a global priority**. […]*
>
> *59. If the right to mental health is to be fully realized, strategic changes must be made to the entire system**. Primary care should take mental health as seriously as it does physical health. To be effective, primary care must be supported by mental health specialists working as consultants at the outpatient and day-care levels. However, these services, with some exceptions in larger cities, are not available to the majority of persons who need them. The field of child and adolescent mental health is particularly underdeveloped, with only a few specialists working in this important field in the two largest cities.** […]*
>
> *61. The Special Rapporteur emphasizes that child and adolescent psychiatry is an established medical specialty and that it should be developed in Kyrgyzstan to address adolescent suicide and other child and adolescent mental health issues. Furthermore**, services for children and adults with intellectual and psychosocial disabilities, which mainly require non-biomedical interventions, should be developed at the community level. Autism is an excellent example of a condition that cannot be effectively addressed through the biomedical model. Children and adults with autism face barriers that should be removed through a broader approach, which involves health, education and social services and a good level of cooperation between those three sectors**. »* Source: Human Rights Council (UN HRC), Visit to Kyrgyzstan. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 8 mai 2019, p.9, 10-12: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G19/132/99/PDF/G1913299.pdf?OpenElement.

UNICEF, 2021:

> *« **The process of early identification and early intervention – when it exists - is fragmented between departments, lacks specific expertise, and does not count on the participation of parents, caretakers, and their environment. Having a child identified as having a disability often requires that parents navigate through a costly and emotionally difficult process, often without support. Information about their rights is not provided at the medical or welfare levels, and they are faced with a lack of/incorrect diagnosis, requests for bribes from professionals, and cumbersome administrative procedures.** The health care system is committed to ensuring the quality of its services considering the needs of people. However, **persons with disabilities are not viewed as a group of service users of the health care system similar to the rest of the population. Rather, health care professionals relate to persons with disabilities as impersonal carriers of a disease, which is needed to qualify them according to regulation, and do not take into consideration the emotional or social charges of experiencing a disability.***
>
> ***The rehabilitation programme for persons with disabilities, developed by the Medical and Social Expert Commission, is not provided with the necessary high-quality habilitation and rehabilitation knowledge and services needed in the field and persons with disabilities themselves largely do not know they have the right to a rehabilitation plan. Outdated***

medical rehabilitation services are not readily available to everyone and social, psychological, educational, and other types of rehabilitation are not carried out due to the lack of specialists, equipment, and methods.

Age-appropriate assistive devices of acceptable quality – that might aid in enhancing participation - are difficult to obtain, particularly in rural and remote areas due to the lack of person-centred approaches, absence of choice and long waiting periods.

In policy and in practice, mainstream and special education are considered separately, preserving the segregation of children with disabilities. Access to education by children with disabilities is dependent upon a disability registration form and the whim of school personnel. Parents who want their children to access segregate settings (and reportedly receive specialized education adequate to the type of disability) must pursue a disability registration card. A special school will not enrol a child without it but may refuse enrolment even if a child has it. Likewise, parents who do not want to send their children to segregated settings (often away from home) will not pursue a disability registration, unless they need the monthly benefit to purchase medicine or services. In this case, children can only enrol in a mainstream school if the school director and/or the teacher agree to it, which often requires the payment of a bribe. Adolescents and young adults with disabilities face significant difficulties in accessing employment as school-to-work transition is not adapted to persons with disabilities, opportunities in vocational training and rehabilitation are scarce, the public employment service is generally not sensitive to the specific needs, and the quota system of reserved workspaces is not reinforced.

Social protection schemes do exist, specifically in the monthly social benefit which targets children with disabilities, as well as others. However, there are access barriers, the benefit levels do not reflect the differentiated needs and are considered inadequate. *Personalized social services have been promoted with the introductions of “personal assistants” and a contractual opening for third-sector providers of public services. Coverage and adequacy of these services, however, remains below the perceived needs.*

Study participants reported on the ***persistence of negative attitudes towards disability in Kyrgyz society. Service providers have low awareness on the issue of disability or are guided by traditional and medical models of disability.*** *Civil society organizations promote information about different types of disabilities but remain restricted to promoting the rights of persons with a particular impairment.* ***Families do not receive enough information to be able to make informed decisions and are vulnerable to potentially biased support of the non-governmental sector’s group communication and education, the family’s place of residence, social status, etc.*** *Data collected for this Situation Analysis indicates that children and adolescents with disabilities in the justice system, either as victims of crime or alleged perpetrators, are not provided with sufficient safeguards to protect them against victimisation and manipulation.*

There is widespread institutionalisation of children with disabilities, lack of support to families, financial discrimination, lack of access to accessible and affordable services, with a particular disadvantaged situation for children with mental disabilities*. *The national deinstitutionalization programme has been developed and is being implemented almost exclusively by civil society. Reportedly, state bodies are not actively involved or

are reluctant to engage. *Thus,* ***deinstitutionalization is hampered by a lack of intergovernmental interaction, a lack of qualified specialists and social services, indifferent or negative attitude of society towards children with disabilities, lack of systematic and complex support for children leaving residential institutions and lack of adequate alternative care services, such as specialised fostering, respite services,*** *etc. […]*

Several commissions and consultations are responsible for determining disability and formulating development plans, some of which are further detailed in a separate analysis of the EIEI practice elaborated in the context of this study. […]

Resolution. 68 of the Government of the Kyrgyz Republic ***regulates the determination and assessment of disability ("person with limited opportunities of health" in the original) is the responsibility of one of the 27 Medical Social Expert Commissions (MSEC) under the Ministry of Labour and Social Protection****. Two of them are specialized, working in the South and North of the country, and four of them are specific to psychiatric, ophthalmic and physiatrists (tuberculosis). People apply to the examination by the commission after treatment in primary health care organizations or based on referral from secondary health care organizations.* ***The MSECs are then responsible for establishing the "structure and extent of restriction of activity of the citizen, and also determination of measures of rehabilitation and social protection" (Art 1.1).***

*However, as extensively reported by parents of children with disabilities who participated in this study****, the only MSECs that seem to function adequately are those in large cities (Bishkek and Osh), which are quick to respond to parents and doctors' concerns, and do not require out-of-pocket payment. Local MSECs either do not exist, do not reach the rural areas, do not have adequate human or technical expertise or simply refer parents to another MSEC in Bishkek or Osh. More importantly, parents in every small town FGD reported instances of bribery when applying for a determination of disability. While this is supposed to be a procedure free of charge, parents have been asked to contribute with anything from money (cash, "first 3 pensions"), to goods (honey, sheep).*** *When advised – by an NGO or the MSEC in Bishkek – to follow up with an official complaint, parents are reluctant to do so due to fear of retaliation.*

For a person to be recognized as having a disability, several conditions must be met: (1) the person must have a permanent disorder of the body functions or systems, caused by a disease, or a consequence of illness or defect, in accordance to the International Classification of Diseases-10,30 (2) the disorder must result in activity restrictions (either complete or partial loss of the ability to self-care, move independently, "communicate, to control the behaviour, to study or be engaged in labour (sic) activity" (1.2.a), and (3) require measures related to social protection, including rehabilitation. As described above, adults with disabilities will be further categorized under groups I, II or II depending on the severity of the impairment, and persons up to 18 years old will be categorized as "child with limited opportunities of health".

According to Order n.675, the assessment procedure is described as follows:

1. A person undergoes a complete physical examination by a physician who determines the disease, injury or defect that cause the permanent restrictions;
2. The person presents the health expert of the MSEC the documentation provided by the attending physician (step 1 above);

3. The person enters a comprehensive health assessment (hospitalization);
4. The person is assigned (or not) a disability status;
5. In case of recognition of disability, the MSEC develops the Individual Programme of Rehabilitation.

*However, a report given in interview by the chairperson of an NGO indicates that a simplified assessment procedure has been implemented for children, a procedure that indicates children can be assessed without the required hospitalization. In addition, the initial requirement that all children with disabilities be re-assessed yearly has been revised**. In some cases (e.g. autism) the first assessment is valid for 5 years and, if confirmed, it is then provided indefinitely.***

As confirmed by the participants in this study, and reported by United Nations Development Programme (UNDP) in 2016, ***various obstacles exist in assessing and determining disability.***

Lack of coordination and monitoring of the process of assessment across ministries, and between ministries and OPDs, and issues related to accessibility, assistive technology, and provision of services as anticipated in the law continue to be barriers. However, ***parents and NGOs indicated that the greatest barriers to assessment and determination of disability status are:***

1. lack of technical capacity of doctors and frontline workers combined with the lack of a mechanism of Early Identification and Early Intervention;
2. lack of knowledge – by professionals and the general population - with regards to delays and disabilities which prevents them from seeking or retaining help;
3. lack of transparency and professionalism within most responsible structures at Oblast and local levels. *[…]*

Once a child of age 3 and above has been identified as having a disability, the legislation envisages that an education plan be devised by the Republican, Bishkek city or any of the 24 regional Psychological Medical Pedagogical Commissions/Consultations (PMPC) under the Ministry of Education and Science (MoES). Their responsibility is to recommend the form of education that a child with a disability should receive (special or mainstream), based on a complex diagnostic. Two commissions are stationary (Bishkek city and Republican) and work permanently throughout the year and the regional consultations provide their services – for one week - before the start of the academic year (August) and at the end of the academic year (May). According to a Republican PMPC representative, the Regional PMPCs are composed of doctors, teachers, special school professionals, auxiliaries, etc. and operate upon parental request.

The PMPC assessment is based on guidelines for enrolment of children with disabilities in education developed by the MoES in 2008. According to these guidelines, the enrolment of a child in school is based upon a list of diseases that is used to determine whether the child can enrol in a mainstream school or, alternatively, be provided home-schooling. Likewise, the guidelines determine placement in special schools. The educational assessment is based on a medical diagnosis, parent and doctor's information, and tests conducted by the PMPCs, as needed. A child may be sent to a clinic to establish a diagnosis, or to a specialized institution in the decision-making process.

While a UNDP study indicated that assessment of children is difficult due to the regulation of the PMPCs, our research indicates that there is no common understanding of the role and the actual procedures undertaken by PMPCs. While PMPC representatives are adamant that they follow established procedures with changes made to account for local contexts, parents of children with disabilities reported no contact with PMPC except in the instances where they are actively seeking that their child be placed in a special school. Otherwise, ***parents whose children with disabilities attend their local school indicated that the decision to enrol was taken by the school director and the teachers, often involving the payment of a bribe****. The predominantly exclusionary effect of the action of the PMPCs has recently been reconfirmed in a research, that called for an abolition of the very institution of the PMPC, if inclusive education was to be promoted.[...]*

The Kyrgyzstan Republic's constitution guarantees the universal right to health protection, with free medical services provided by, and under the responsibility of, the State (article 47) and to a healthy environment (article 48), with minimum levels of health and labour protection being set for citizens in socially vulnerable situations (article 9). In addition, it prohibits medical, biological or psychological experiments without a person's expressed and verified voluntary consent, legislating the provision of informed consent (article 22). This centralized healthcare system guarantees access to a range of free services, prioritizing hospital and curative care (rather than preventative), with significant regional imbalances in accessibility and quality. Access to health is based on a 3-level model of insurance and all citizens have access to the Basic Public Health insurance, that is State-guaranteed and includes provisions for specific populations, including children with disabilities.

The Kyrgyz health system has received praise for the promotion of family medicine and by the priority given to its funding. However, ***challenges remain, such as the overtreatment and hospitalization of children, the underdevelopment and centralization of the field of child and adolescent mental health, the lack of medical professionals in remote rural areas, the low level of qualification of medical personnel and equipment, and heavy workload combined with low wages, high outflow of the health providers, and poor governmental cooperation.***

Health policy towards disability

*Since 1996, a number of strategic programs have tried to increase the efficiency of healthcare facilities and attention to patients' needs, with particular emphasis on health protection of mother and child, primary health care and cardiovascular disease****. In 1997, a new system of compulsory health insurance started to be implemented and the compulsory health insurance fund was created. This was followed by the development of clinical protocols and an increase in the quality of primary health care, especially to the most vulnerable groups of the population, exempted from co-payment. The range of medical services provided free of charge at the outpatient level for persons with disabilities was expanded.*** *However, the validity of the treatment and diagnostic measures and their compliance with the very few clinical protocols developed by the Ministry of Health (with support from UNICEF) and introduced into clinical practice was limited.*

Persons with disabilities are entitled to two hospitalizations per year, free medical services, and drug benefits*. The goal of promoting evidence-based medicine that helps to develop and provide quality health services for persons with disabilities was set in The National Programme of Reforming Health Care System in Kyrgyz Republic 2006-2010. It provided the development of clinical protocols, such as a clinical protocol for the treatment of child cerebral palsy, in which the ICF principles were applied. The National Health Care Reform Programme of Kyrgyz Republic 2011–2016 (extended until 2018) aimed at orientating the health care system to the needs of people and some diagnoses related to the assignment of disability status and congenital malformation monitoring system were developed, patient registers established, qualifications and skills of personnel drafted, and the training of medical workers done according to approved clinical protocols in the field.*

The new Programme of the Government of the Kyrgyz Republic for the Protection of Public Health and Development of the Health Care System for 2019-2030 was signed on December 20, 2018. Its main goal is to strengthen people-centred systems that ensure public health and provide quality services throughout the lifecycle, and aims to reduce rates of disability (primary, secondary), of preventable diseases and of morbidity and disability (primary, secondary), with a focus on socially significant diseases.

Access to services by persons with disabilities

As reported by professionals and indicated in the literature, at the primary level, persons with disabilities are entitled to receive health care services provided by a group of family doctors, family medicine centres and a limited number of general practitioners' centres. In small villages with a population of 500-2000 people, primary services are provided by feldsherobstetric services, often by middle level health professionals only. With regards to the provision of health services to children with disabilities it is reported that, regardless of registration, access to quality care services is poor, as the current system (with weak cross-sectorial coordination at central and community levels) remains focused on treating illness or disorders. This poses difficulties for early identification and targeted family support measures.

In general, when asked question related to their health, children and adolescents with disabilities who participated in FGDs did not understand the physiological origins of their impairments. None could explain why they had a disability registration, and some did not see themselves as "disabled". Some of the children reported going to other cities to receive medical treatment but could not explain what it was. In a city in the urban south the youth reported receiving a massage at home, going to a rehabilitation centre because "there we get treatment", or spending half a year at the hospital for treatment. One hospital in Bishkek seems to be the preferred treatment location, although there are reports that parents must pay for it. ***Overall, health services are not available to children with disabilities, and certainly not available for free as legislated. Almost all parents involved in the study indicated that:***

1. Local health professionals who recognize the potential for a delay or disability are reluctant to inform parents as soon as possible. […]
2. When local health professionals refer parents to another hospital (Osh or Bishkek) for further observation/treatment they cannot/will not explain why that was needed. There is a lack of technical knowledge by medical professionals. […]
3. local health professionals expected a bribe in order to identify an impairment (which must be completed to adequately pursue a disability certificate). […]

4. Children with disabilities are not seen as general health care rights-holders, only as persons who require specialized care. […]

In addition, many parents report that the ***process of examination in Kyrgyzstan is complicated and bureaucratic.*** *On the one hand there is a lack of specialized medical workers in rural and remote areas, limited set of diagnostic services, clinical standards and protocols, tools, long distance to secondary medical services, indifferent and negative attitudes of medical doctors. Research on access to services provided by the health care system to persons with disabilities identified the lack of specialised medical workers - outflow of qualified personnel from rural to urban regions and abroad. On the other hand, parents are often are not aware of the right to health and stereotypical or negative attitudes of medical workers towards persons with disabilities are barriers to access to health. In particular, there are reported indifferent and indulgent treatments and specialists looking at patients with disabilities as outcasts or with disdain, providing unequal treatment.*

Research has shown that poor quality health care given to persons with disabilities in Kyrgyzstan can lead to their premature death*. […]*

In Kyrgyzstan, the rules on providing citizens with the technical devices for social rehabilitation do not depart from the CRPD core principle of person-centeredness and choice – but, ***most rehabilitation centres were, in 2018, reported to be private and dependent upon the payment of fees, with public (free-of-charge) centres in Bishkek and Ak-Suu and a new one being established in Jalal-Abad (to assist a residential institution for children, in the development of personal independence skills).*** *[…]*

As of 2019, occupational therapy and physiotherapy (requiring higher education qualifications), as well as social assistant, personal assistant, and occupational therapy assistant, are part of the national classification of occupations, as well as defectologists and oligophrenopedagogy (pedagogy used in teaching children with intellectual disabilities). However, most rehabilitation workload is still reliant on doctors who may not have the necessary training, knowledge, or skills, with a single fully qualified occupational therapist in the country. […]

A 2008 monitoring report on the rights of persons with disabilities as patients in the IssykKul region confirmed that 94% of persons with disabilities surveyed were not aware about their entitlement to an IPR; this is corroborated by more recent personal experiences of parents of children with disabilities in the Kyrgyz Republic, as well as interviews with professionals. ***Many rehabilitation services, guaranteed by the state law, are not available because, at present, there are no (re)habilitation specialists such as occupational therapists, speech therapists, vocational rehabilitation specialists or special teachers. Thus, the services that should otherwise be provided are not even included in the IPRs.***

When available, the focus is on medical rehabilitation, which is provided by the health care system, in detriment to other types of rehabilitation such as professional, psychological and social rehabilitation. Even with this focus, medical rehabilitation is not carried out fully, due to a lack of medical and technical means of rehabilitation. Reportedly, the result is a total deficit of rehabilitation services and provision of assistive technologies.

Parents who can afford it will pursue treatment in Osh, Bishkek, or even in other countries (Russian Federation, Uzbekistan and Kazakhstan). Others will stop treatment due to lack of financial resources or because they cannot access the health services due to lack of infrastructure. *Moreover, children with disabilities and parents reported that rehabilitation services that were provided when the children were young and were discontinued when the children grew older. […]*

One parent reported paying 8000 soms per month for speech therapy, an amount that most parents cannot afford. Doctors in the Russian Federation recommended that she stop the therapy and work with her child at home. She did not report this to her local doctor. In Kyzyl Kia some children temporarily received services from a speech therapist. Parents paid between 50-100 soms per session to a therapist from a special school. However, the therapist stopped coming to the village and now works in the school full time, as private sessions are not profitable. […]

Non-governmental involvement in service provision

Perhaps due to a lack of state engagement, the non-governmental sector has become increasingly engaged in service provision and many NGOs in Kyrgyzstan provide services to persons with disabilities and even established rehabilitation centres. There are currently more than 50 private rehabilitation centres in Kyrgyzstan that provide different services for children and adults with disabilities. Their development is viewed as an essential step in providing the necessary educational, social and (re)habilitation services that the state does not provide to families with children with disabilities. Parents who have a good financial situation often hire private (re)habilitation professionals and these services have – reportedly - become very popular in the last few years. *The appropriateness and safety of private interventions for the child are not always objectively measured and adverse effects are a real risk.*
[…]

Personal Assistants

According to state policy, the main responsibility in supporting children with disabilities is given to parents, but this has been done without adequate supports being available. Organisations of parents of children with disabilities have been raising the issue of personal assistants since 1996 but only in January of 2019 as the Kyrgyz Government, created the position of personal assistant. According to Decree No. 556, a personal assistant can be assigned to a child with a disability by the local department of social protection, based on a need expressed in the MSEC report. One of the parents, guardians or close relatives of the child can become a personal assistant and is paid an allowance. Also, a person who becomes a personal assistant is considered an employee and accumulates years of work that will count for their social security benefits. Thus, the care work is credited as seniority with regards to pensions entitlement in the social security. […]

In the last decade, the Government of the Kyrgyz Republic has seen a dynamic period in policy formulation in social protection and has adopted and implemented several state programmes to support persons with disabilities. A major paradigm shift towards a system of universal child grants, elaborated in 2017 by Government and authorized in 2018 by Parliament, had been *stopped and reversed during implementation. Currently the government plans to create a National Model of Social Protection and a Long-Term Concept of Social Protection Development Plan until the Year 2030, which would incorporate international best practices. In general, disability has not yet been considered systematically in the domestic social policy debate. […]*

Non-contributory assistance is principally provided mainly via two benefits: Monthly Benefit for Poor Families with children (MBPF) and Monthly Social Benefit (MSB). Whilst MBPF is directed to poor families and can be accessed by passing a significant administrative hurdle of means testing, the MSB, as a "categorical programme", is directed to beneficiaries with certain objective conditions as certified by the social administration, amongst which are persons with disabilities, including children, as well as orphans and mothers of large families (7 children). The average disability benefit for children with disabilities (end of the year, in som) was 3000 (around 37 USD) for all disability categories, in 2014-2017, with an increase to 4000 som (around 50 USD), in 2018. There is also a lump sum birth grant, as one-off payment. In view of the heavy procedure of means-testing to access social assistance, the targeting towards the poorest quintiles is rather unsuccessful.

The social protection system cannot fully provide support for the poor and faces several challenges, among them an insignificant impact of living standards, low coverage of those in need and, particularly important with regards to children with disabilities, the insufficient development of qualified social services. In general, the social protection system for children with disabilities has access barriers, the benefit levels are inflexible to differentiated needs and are considered as inadequate. *The design rather promotes retraction from employment, as opposed to fostering active inclusion.* ***The amounts of the disability benefits do not reach the subsistence minimum considered as a basic minimum income needed for decent life.***

For the most part, parents of children with disabilities did not report knowing about and/or accessing social services except for applying for a disability benefit in order to be able to afford medicine and care. *Some parents were told by the doctors in Osh and Bishkek how to apply for a disability certificate, and some were provided with the necessary documents to apply at the local level. However, as reported above, the process is not clear, and a bribery payment is expected at various steps in the process. Parents who have a good economic situation do not apply, and some parents reported being pressured by their own families to not apply, due to the stigma associated with having a child with a disability in the family. […]*

*As documented extensively****, the Kyrgyz government approach to children with disabilities in education, ECEC, health and rehabilitation, transportation, communication and accessibility is not CRPD compliant. The few services available to children and adolescent with disabilities are either not free, not accessible, or not inclusive****. Thus, not compliant with the CRPD. […]*

There is no EI/EI system in place in Kyrgyzstan. There are a series of unrelated and uncoordinated services that do not yet constitute a mechanism. As previously mentioned, most of the services available to children and adolescent with disabilities are either not free, not accessible, or not inclusive. Thus, not compliant with the CRPD. […]

The barriers to full or partial participation are extensive, from attitudinal to environmental. Not only is the legislative/policy landscape non-inclusive, but services needed to support and promote the rights of persons with disabilities do not exist. Families feel isolated from their extended families and communities, and children and adolescents with disabilities do not have access to the same rights as other children, even in rural communities.
[…]
Existing services are not disability-inclusive. The main gaps are likely due to 1) a lack of general knowledge about diversity (in all its forms), and 2) lack of knowledge about disability that is not steeped in stereotypes and misconceptions.

1) The legislative landscape does not provide for umbrella policies that enforce the rights of all citizens, including those with disabilities and/or including children with and without disabilities.

2) Not only is the legislation mostly silent with regards to the rights of persons with disabilities but professionals are not knowledgeable about issues related to disability and/or inclusion. Even health professionals who should be the ones prepared to identify, assess and refer children at risk of a delay or disability are misinformed, and reportedly lack professional empathy and ethical guidelines. […]

Persons who are identified has having a disability are entitled to a disability-related benefit. However, the process is cumbersome, unclear and most parents who have children with disabilities are unfamiliar with the identification/registration process. In addition, because being registered as a person with a disability does not entitle them to free and inclusive services and might, on the contrary, lead to separation of children from families – as is the case with an implied relationship rehabilitation and special schools – many families of children with disabilities do not pursue an official disability registration or status*. […]*

All parents of children with disabilities and children and adolescents with disabilities themselves reported that Kyrgyzstan is not an accessible country, at the legislative and environmental (physical, communication and information) levels. […]

Children and adolescents with disabilities and their families are not heard or taken seriously. Children and adolescents are not viewed as holders of rights and, while their parents do take them seriously, they often decide what is best for them. Fortunately, many of the parents of children with disabilities who participated in this research have a very strong sense of family and unity that translates in their refusal to place their children in institutional care. This is particularly important, because it points to institutionalization as a governmental practice, rather than a family practice (as alluded to by some professionals). In addition, refusing to place children with disabilities in institutional care is increasingly difficult to the societal pressure - parents of children with disabilities reported not having any social networks to lean on, and being berated by the professionals whose job it is to educate and support them.

NGOs and OPDs who work to promote the CRPD are supportive of children with disabilities and their families and have often intervened with government, to promote and advocate for needed legislation and services. ***They have also developed services for children with dis-***

abilities due to a lack of government intervention but are limited in capacity, both financial and human. » Source: UNICEF, Situation analysis: Children and Adolescents with Disabilities in Kyrgyzstanp, 2021, p.9-10, 22-24, 36-45, 60-61: www.unicef.org/kyrgyzstan/media/7256/file/Situation%20Analysis%20of%20Children%20and%20Adolescents%20with%20Disabilities%20in%20Kyrgyzstan.pdf.