

1 **Opinion Paper for Trends in Parasitology**

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4 **Neglected tropical diseases (NTDs) and mental health: Progress,**
5 **partnerships, and integration**

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22

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29

30 **Abstract** (120/120 words)

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33 Neglected tropical diseases (NTDs) are increasingly recognised as major drivers of
34 psychosocial morbidity in affected individuals and their caregivers. Nevertheless, there
35 has remained a lack of prioritisation at the policy level of some of the most stigmatising
36 and chronic NTDs, with subsequent under-representation within NTD programmes. In
37 response, the Neglected Tropical Disease / Non-Governmental Organization / Network
38 (NNN) has established a Mental Wellbeing and Stigma Task Group (MWS) in order to
39 address these issues through a comprehensive research agenda. In our article, we
40 highlight the progress in understanding the scope of the mental health impact of NTDs
41 and the innovative practice emerging in this area. Finally, we examine opportunities for
42 integration of mental and physical health for individuals with NTDs.

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64 **Glossary**

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66 **Anxiety Disorder:** The second most prevalent group of mental disorders; characterised
67 by feelings of anxiety and fear; the extended duration of symptoms makes anxiety
68 disorders more chronic than episodic disorders. The most prevalent anxiety disorder is
69 Generalised Anxiety Disorder (GAD), commonly termed “anxiety”; however, anxiety
70 disorders also include phobia disorders and obsessive-compulsive disorder (OCD).

71

72 **Coalition for Operational Research on NTDs (COR-NTD):** An international group of
73 researchers, program managers, and in-country partners, with a shared goal of optimising
74 NTD control and elimination.

75

76 **Depressive Disorders:** The most prevalent group of mental disorders; characterised by
77 sadness, loss of pleasure, guilt, low self-worth, disturbed sleep or appetite, fatigue, and
78 poor concentration. Made up of Major Depressive Disorder (an often relapsing and
79 remitting condition of varying intensity, commonly termed “depression”), and Dysthymia
80 (a more persistent condition of lower intensity than MDD).

81

82 **Disease burden:** A concept to describe the impact of a condition on the affected
83 population, and comprised of a disability (YLD) and a mortality (YLL) component.
84 Estimates of disease burden are used to compare and rank the impact of different
85 conditions.

86

87 **Global Burden of Disease (GBD) Study:** GBD studies aim to rank conditions/diseases
88 according to their disease burden, using the Disability-Adjusted Life Year (DALY) metric.
89 Formerly these studies were conducted by WHO, though GBD studies are now carried
90 out at regular intervals by the Institute of Health Metrics and Evaluation at the University
91 of Washington.

92

93 **Global Mental Health:** A growing international movement aimed at improving recognition
94 of mental illness as well as strengthening mental healthcare provision for affected
95 individuals worldwide.

96

97 **InfoNTD:** An online platform and repository for cross-cutting research, tools, and other

98 information on Neglected Tropical Diseases, including disability, inclusion, stigma, and
99 psychological co-morbidity.

100

101 **Mental Health Innovation Network (MHIN):** An online network for the global mental
102 health community to share knowledge and resources in order to improve the quality and
103 coverage of mental healthcare.

104

105 **Neglected Tropical Disease (NTD):** A diverse group of ~20 communicable diseases
106 recognised by WHO as being underfunded relative to other conditions of equal
107 prevalence; NTDs affect predominantly the World's poorest populations, and many have
108 chronic course, are physically disabling, and/or are associated with stigmatisation.

109

110 **Non-Communicable Disease (NCD):** Non-infectious diseases characterised by a
111 chronic and slowly progressive course. Common examples include cardiovascular
112 diseases, cancers, chronic respiratory diseases, and diabetes. In recent years mental
113 health disorders have been more clearly defined within the NCD category, sharing many
114 characteristics and potential common treatment platforms as other NCDs.

115

116 **NTD-NGO-Network (NNN):** A global platform for NGOs to work together to tackle
117 important issues in NTD control and development. A cross-cutting task force on Disease
118 Management Disability and Inclusion (DMDI) has recently developed a mental health
119 research agenda through its Mental Wellbeing and Stigma (MWS) task group.

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130 **NTDs and mental health: A growing evidence base**

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132 The scale of psychological co-morbidity in the 1 billion affected worldwide with **Neglected**
133 **Tropical Diseases (NTDs)** (see Glossary) has become increasingly recognised by the
134 NTD community after being highlighted in 2012 [1]. As of October 2018, over 3,000 studies
135 have been added to an online repository for cross-cutting NTDs research – **InfoNTD** – a
136 significant proportion of which are related to the psychosocial impact of NTDs
137 [https://www.infontd.org/biblio_search/search]. In this time, along with an increased depth
138 of research for a number of well-studied NTDs (leprosy; lymphatic filariasis; and
139 cutaneous leishmaniasis), there has also been a large growth in the evidence base for a
140 growing number of lesser studied NTDs (see Table 1). Per InfoNTDs, a holistic study
141 (quality of life, stigma, psychological distress, or physical disability) now exists for the large
142 majority of NTDs (17/23), including eight additional NTD populations since 2012 – Buruli
143 ulcer (BU) [2]; Chagas disease [3]; chikungunya [4]; mycetoma [5]; podoconiosis [6];
144 schistosomiasis [7]; soil-transmitted helminths [7]; and visceral leishmaniasis [74].
145 Meanwhile, there has also been an increase in the number of studies quantifying the
146 prevalence of common mental health conditions (**anxiety and depressive disorders**)
147 associated with NTDs, including three additional NTD populations since 2012 – BU [8];
148 LF [9]; and podoconiosis [10].

149

150 Overall, control studies have consistently shown a significantly increased rate of
151 depressive disorders in populations affected by NTDs, including patients [10-14] and
152 caregivers [15-17], as well as affected communities [18]. For NTDs with a predominantly
153 acute course, psychological co-morbidity may normalise with full resolution of both primary
154 [4; 19-21] and secondary symptoms (including pain, fatigue, and itch) [22;23]. This effect
155 is likely due to the positive psychological impact of physical and surgical treatment [24-
156 28]. However, a key finding is that the psychological impact of NTDs is not restricted to
157 active infection but extends to those NTDs with chronic sequelae [8; 11; 14; 29; 30]. This
158 is important for two reasons: 1) many NTDs are chronic conditions that extend well beyond
159 the active infection [1]; 2) chronic diseases are recognised risk factors for the development
160 and maintenance of common mental health disorders [31]. Indeed, systematic reviews of
161 several stigmatising chronic NTDs (CL [32]; leprosy [33]; and LF [34]) show that NTDs are
162 associated with higher rates of common mental health conditions than other chronic
163 diseases [35]. Because the psychosocial impact of chronic NTDs is lasting, it follows that

164 physical intervention alone is insufficient to address these larger holistic aspects of
165 disease on the lives of affected individuals and their caregivers.

166

167 Nevertheless, given the primary focus of NTD policy on disease elimination, it is
168 unsurprising that chronic NTDs and their associated psychological impact has only
169 recently been recognised [36]. For example, most chronic NTDs (e.g. Leprosy; CL; and
170 BU) have among the lowest **disability burdens** as estimated by **Global Burden of
171 Disease (GBD) studies** [37], which is due to the underrepresentation of chronic sequelae
172 and their impact in both prevalence and disability estimates. Furthermore, integrated
173 chronic and psychological care is not a focus of NTDs programmes at present. This is
174 also partly due to the fact that, despite recent progress in this space, there remains a
175 significant lack of psychological interventions in the NTD literature. To date, psychological
176 intervention studies have been conducted for just three NTD populations (CL [38]; leprosy
177 [39]; and snake bite [40]), with social intervention studies having been assessed in a
178 further three NTD populations (BU [41]; leprosy [42]; and mycetoma [5]). Equally, there
179 have been no intervention studies targeting chronic NTD sequelae, representing a clear
180 area for future work.

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183 **The NTD NGO Network (NNN): Progress in partnership development**

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185 The network representing civil society organisations working in NTDs (**the Neglected
186 Tropical Disease (NTD)/ Non-Governmental Organization (NGO)/ Network, NNN**) has
187 expanded in membership, influence, and scope significantly over recent years. The cross-
188 cutting task force addressing issues of Disease Management, Disability and Inclusion
189 (DMDI) has established a Mental Wellbeing and Stigma Task Group to focus on NTD-
190 related stigma and the mental wellbeing of those affected by NTDs alongside their
191 physical needs [<https://www.infontd.org/keytopic/stigma-and-mental-health>]. The aims of
192 the group are: 1) to support and develop resources for advocacy of affected individuals
193 and to promote their empowerment; 2) to ensure NTD programmes include interventions
194 which promote positive attitudes and behaviour of communities to those affected and
195 address structural discrimination; 3) to promote self-advocacy and expression of the
196 needs of those affected; and 4) to increase the awareness of the rights and responsibilities
197 of those affected and those who provide services to them, including their care-givers. At

198 a recent DMDI meeting, a person affected by lymphatic filariasis described his
199 experiences and priorities (see Box 1 below).

200
201 Critical to these aims are the needs to engage in a structured programme of research to
202 further clarify key conceptual questions and explore practical implementation issues. This
203 will require resources for field studies to demonstrate proof of concept that interventions
204 can reduce the burden of mental health and stigma associated with NTDs. Increasing
205 awareness of the stigma and mental health dimensions of NTDs with organisations and
206 programmes involved in NTD work is essential to this goal, as well as developing and
207 sharing resources for advocacy and evidence-based interventions. A major achievement
208 of the Mental Wellbeing and Stigma (MWS) task force to date has been to engage the
209 World Health Organization (WHO) Department of Mental Health and Substance Abuse in
210 developing a joint mental health intervention manual for NTDs, which is due to be
211 published in 2019.

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214 **Integration of mental and physical health for NTDs**

215
216 The **non-communicable diseases (NCD)** community has recently emphasised the
217 benefits of integrating mental and physical healthcare services for individuals living with
218 chronic conditions [31]. Similarly, individuals with chronic NTDs have emphasised the
219 inclusion of psychological care as a key to improving patient care [43]. It is therefore
220 important to consider how integration of mental healthcare might be incorporated into
221 health systems for individuals with NTDs. Several general and specific considerations for
222 integration are highlighted below, combining recent innovation in mental health and NTDs
223 with recommendations for integration from the NCD community, and recent advances in
224 **global mental health**.

225

226 **General considerations**

227
228 A range of existing integration strategies are applicable to all NTDs, each of which are
229 dependent upon a given country's capacity. As the majority of NTDs are found in low-

230 resource settings, these would practically involve integration of mental health into either
231 NTD programmes (service delivery integration), primary care, or community-based
232 activities; a stepped care approach has been shown to be effective [31], with increasing
233 resources afforded to those at the highest risk of significant psychological impact. Indeed,
234 for individuals with acute NTDs in low resource settings, it may be most appropriate to
235 continue to focus on physical intervention given the positive psychological benefits of
236 physical treatment discussed above and the tendency for improvement in psychological
237 co-morbidity with full clinical recovery. In such settings, it may be more suitable to focus
238 resources instead on NTDs with chronic sequelae and or high levels of stigmatisation.

239

240 Given the challenges of specialist mental health service provision [44], a further important
241 consideration is the need for culturally-sensitive psychological measurement tools that are
242 practical for large-scale and non-expert administration. The recent development of a
243 holistic toolkit for NTDs is promising and has been validated in different NTD populations
244 [3], but its use relies upon time and expertise that is currently not available in the many
245 settings where NTDs are most prevalent. Nevertheless, research into leprosy has
246 demonstrated the effectiveness of several stigma and group counselling interventions
247 suitable for administration by non-specialists [45; 46], supporting similar research findings
248 in the global mental health community [47].

249

250 Importantly, a grassroots approach can be an effective way of providing continuity of care
251 for individuals affected by chronic NTDs. A good example of this approach is the
252 BasicNeeds approach, centred upon peer support and economic empowerment groups
253 for current and former mental health service users [48; 49]. This community-led approach
254 has developed advocacy and empowerment to affected individuals and should be further
255 explored for those affected by NTDs. Elsewhere, the mass uptake of social media allows
256 that community-led solutions need not be geographically restricted. For example, the
257 recent use of a social media app has helped connect and empower Brazilian families
258 affected by congenital Zika syndrome, leading to the development of a successful
259 grassroots NGO [50].

260

261 **Specific considerations for PC-NTDs**

262
263 NTD programmes are varied in their approach to the control and elimination of specific
264 NTDs, however some programmes have a common basic infrastructure that could be
265 adapted for integration. For example, mass drug administration (MDA) programmes are
266 specialised NTD programmes that deliver high quality, cost-effective prophylactic
267 treatment to communities at risk of 5 Preventative Chemotherapy NTDs (PC-NTDs) - LF;
268 STH; schistosomiasis; onchocerciasis; and trachoma. Such programmes have a direct
269 physical health benefit to at risk communities for PC-NTDs, but have also been shown to
270 confer a psychosocial benefit [25].

271
272 Following a successful pilot physical disability study in Ghana using the Washington
273 Group Short Set of Disability Questions, the international NGO Sightsavers are now
274 investigating if the MDA programme could also be used as a platform to identify suspect
275 new and chronic cases of LF and Onchocerciasis with mental health problems through
276 use of non-specialist trained health volunteers. The benefits of such an integration
277 strategy would be to reinforce weaker aspects of the MDA process such as the registration
278 of community members during which time psychological screening could take place, as
279 well as to improve overall compliance [51] and therefore improve MDA coverage. As the
280 MDA programme targets at risk populations at the pre-diagnostic level, this represents an
281 interesting service delivery integration opportunity to address the larger socio-economic
282 impact of NTDs on affected communities [18].

283

284 **Specific considerations for skin NTDs**

285
286 NTDs with a predominant skin manifestation have recently been aligned in integrated
287 control efforts [52; 53], although the morbidity management component of these proposed
288 activities has not explicitly included psychological assessment and care. This is significant
289 because, among the NTDs, skin NTDs are the best-defined group for psychosocial impact.
290 It is therefore important to determine how mental healthcare could be better included in
291 this framework. The best example of a holistic approach to a group of skin NTDs is
292 currently being tested for LF, podoconiosis, and leprosy – The EnDPoINT (Excellence in
293 Disability Prevention Integrated across NTDs) programme
294 [[https://www.bsms.ac.uk/research/global-health-and-infection/nihr-global-health-](https://www.bsms.ac.uk/research/global-health-and-infection/nihr-global-health-research-unit-for-ntds/nihr-work-packages.aspx)
295 [research-unit-for-ntds/nihr-work-packages.aspx](https://www.bsms.ac.uk/research/global-health-and-infection/nihr-global-health-research-unit-for-ntds/nihr-work-packages.aspx)] - and is based upon previous successful

296 research for populations with podoconiosis in Northern Ethiopia [10]. Differing from the
297 MDA approach, the EnDPoINT approach is targeted to those with an existing diagnosis
298 (acute and chronic) and is in this case delivered by specialists.

299

300 Considering the approach to individual skin NTDs, the international leprosy NGO, Lepira,
301 has been successful in translating the findings of a large evidence base for leprosy stigma
302 research [42] into its activities to date. Nevertheless, despite being the best studied NTD
303 for psychological impact, there remain sizeable opportunities within national programs and
304 international NGOs [54; 55] to apply this research into integrated care for affected
305 individuals. In the case of another well studied NTD, CL, these opportunities extend to
306 refugee and displaced populations in the Middle East [56; 57]. Interestingly, however, the
307 holistic management of lesser studied skin NTDs such as BU [41] and mycetoma [5] have
308 found their way into local healthcare settings through a combination of specialist and
309 community measures.

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311

312 **Concluding remarks**

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314 Progress in research and partnership in the past 6 years has seen mental health emerge
315 as a key cross-cutting area of NTDs research. Currently, an increasing evidence base
316 points to a disproportionately high prevalence of co-morbid mental illness among
317 individuals affected by NTDs, in particular, chronic NTDs. Indeed, it is increasingly
318 recognised that, in order to eliminate NTDs “as public health problems” [60], we must not
319 only focus our efforts on the elimination of active NTD infection, but also tackle the residual
320 impairment and associated social and psychological impact of chronic NTD sequelae.
321 Given the unique stigma and socioeconomic impact of NTDs [58], as well as their links to
322 poverty [59], individuals and communities affected by NTDs may well represent one of the
323 highest risk populations for mental disorder. Importantly, these more neglected aspects of
324 NTDs need to be championed first by the NTD community in order that more widespread
325 recognition can occur.

326

327 As such, we have highlighted a growing number of effective psychosocial interventions
328 which have been demonstrated in a number of NTD populations and discussed future

329 opportunities to scale up and practically integrate this growing evidence base into existing
330 NTD programme activities. Success in this process is dependent upon the input of
331 affected communities and those living with the lasting sequelae of NTD. Further
332 engagement and knowledge sharing outside of the NTD community is also critical to drive
333 future collaboration and innovation in this process. For example, the NTD community can
334 gain valuable insights from the global mental health community in terms of community-led
335 mental health assessment and delivery of care. Equally, the scale of mental health and
336 NTDs, the unique aspects of NTD programmes, and the opportunities outlined above for
337 integration of mental and physical healthcare all serve as important contributions to the
338 global mental health community and should be shared. The finding that NTDs research is
339 not currently featured in the global mental health online research repository, **Mental**
340 **Health Innovation Network (MHIN)** [<http://www.mhinnovation.net/resources>], suggests
341 that further links can and should be made.

342
343 It is in the context of aforementioned challenges that the Mental Wellbeing and Stigma
344 (MWS) task force of the NNN has been established and currently convenes on an annual
345 basis. At the time of writing, significant progress has been made on a key intervention
346 manual created in collaboration with WHO, which is due to be published in 2019.
347 Furthermore, a session at the **Coalition for Operational Research on Neglected**
348 **Tropical Diseases (COR-NTD)** meeting in Baltimore in November 2017 was focused on
349 the identification of a research agenda for the task force. A list of research priorities was
350 created in the session and were refined by key actors in the field (see Outstanding
351 Questions), paving the way for further progress and partnerships to come.

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627 **Table 1: Evidence base for mental health and NTDs.** Holistic,
 628 psychological, and intervention studies. As per InfoNTDs, October 2018.

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NTD	Holistic (QoL; stigma; physical disability)	Psychological (Anxiety; Depression)	Holistic/Psychological Intervention
Buruli ulcer	Ackumey MM et al, 2012 [2]; Klis S et al, 2014 [20]	Kpadonou TG et al, 2013 [8]	Amoussouhoui AS et al, 2016 [41]
Chagas	van 't Noordende AT et al, 2016 [3]; Sousa GR et al, 2018 [61]	Ozaki Y et al, 2011 [62]	-
Chikungunya	Soumahoro M-K et al, 2010 [22]; Courturier E et al, 2012 [4]	-	-
Cutaneous/ mucocutaneous leishmaniasis	Reithinger R et al, 2005 [63]; Honório IM et al, 2016 [64]; Al-Kamel, 2017 [65]	Yanik M et al, 2004 [11]; Simsek Z et al, 2005 [13]; Torkashvand F et al, 2016 [29]	Nilforoushzadeh MA et al, 2010 [38]
Dengue	Lum LC, et al 2008 [66]	Bhatia MS et al, 2017 [21]; Gunathilaka N et al, 2018 [30]	-
Echinococcosis	Torgerson PR et al, 2001 [67]	-	-
Foodborne trematodiasis	-	-	-
Guinea-worm disease	-	-	-
Human African Trypanosomiasis	-	-	-

Leprosy	Tsutsumi A et al, 2007 [12]; van Brakel WH et al, 2012 [68]; van 't Noordende AT et al, 2016 [3];	Tsutsumi A et al, 2007 [12];	Floyd-Richards M et al, 2000 [39]; Sermrittirong S et al, 2014 [42]; Peters RMH et al, 2015 [45]; Lusli M et al, 2016 [46];
Lymphatic Filariasis	Perera M et al, 2007 [69]; Abdulmalik J et al, 2018 [70]	Obindo J et al, 2017 [9]	-
Mycetoma	Bakhiet SM et al, 2018 [5]	-	Bakhiet SM et al, 2018 [5]
Onchocerciasis	Hagan M, 1998 [71]; Okoye IC et al, 2007 [72]; Mbanefo EC et al, 2010 [73];	-	-
Podoconiosis	Mousley E et al, 2013 [6]	Bartlett J et al, 2016 [10]	-
Rabies	-	-	-
Scabies	Jin-gang A et al, 2010 [19]	-	-
Schistosomiasis	van 't Noordende AT et al, 2016 [3]; Fürst T et al, 2012 [7]	-	-
Snake Bite	Williams SS et al, 2011 [14]	Williams SS et al, 2011 [14]	Wijesinghe CA et al, 2015 [40]
Soil-Transmitted Helminths	Fürst T et al, 2012 [7]	-	-
Taeniasis	-	-	-
Trachoma	Dhaliwal U et al, 2006 [24]; Habtamu E et al, 2015 [23]; Habtamu E et al, 2016 [27]	-	-

Visceral leishmaniasis	van 't Noordende AT et al, 2016 [3]; Pal B et al, 2017 [74]	-	-
Yaws	-	-	-

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Box 1. The experience of a person affected by a Neglected Tropical Disease

Experience of Muhammad Jidda, Nigeria

Mr Muhammad Jidda was born in Borno State in 1959 in northern Nigeria to a family of nomadic cattle rearers – a member of the Shuwa Arab tribe. He started school in Maiduguri before moving to Kano for post-primary schooling. After graduating in Public Administration and Rural and Community Development (postgraduate diploma), he joined the Nigeria Customs Service, rising through the ranks until he reached the senior rank of Superintendent of Customs.

In 1990, he went to see a doctor in Port Harcourt as he had a swelling of his buttocks, and was diagnosed as having TB and given a long course of antibiotics. This was ineffective, and he noted that his right leg was also swelling. This was eventually diagnosed as lymphatic filariasis by visiting international doctors working with Doctors Without Borders. After being diagnosed, he was told that there was nothing that could be done for him as there was no effective treatment available.

His leg continued to swell – a process commonly called elephantiasis. Many of his friends told him that this was a spiritual problem, and that medicine could not help him. People thought that he was cursed by someone who was not happy with him because of his job as a customs officer. Despite seeking treatment from both traditional healers ('babalao'), and through Islamic healers, he saw no benefit, and it was a very expensive process.

When his leg became very large, he travelled long distances to specialist hospitals, was given repeated skin graft surgery to reduce the size of the swelling. Mr Jidda estimates that he spent more money traveling to Abuja, the capital of Nigeria, trying to get help, than he gained for his efforts.

The situation made him feel hopeless, and he felt very low, not finding any reason to live, and he gradually withdrew from the world. He rarely left the house, because when he went out, people would run away from him. People did not want to be near him, fearing infection. He has been married 5 times, and on four occasions, his wives left him because of his disability. His wife now is supportive, and they have two children.

He never spoke to anyone about his low mood and hopelessness, and he did not consider seeking psychiatric help, as this would label him as 'mad', something that was even worse than the situation he was already in.

Although the disease caused occasional periods of fever, and he found difficulty with walking, he was still able to carry out his work. Despite this, the Customs Service decided that he should retire early, a decision that he did not agree with. This has had a severe impact on his ability to have a sustainable income. In addition, the treatment that he must pay for costs more than his small pension, and he is now reliant on friends and family.

Mr Jidda was invited to participate in a process of identifying research priorities, and shared what he considered to be the changes that would make the most difference to his life, and to promoting better outcomes for others affected by NTDs.

Key messages:

- The delays in getting help due to lack of good local medical expertise and care caused undue suffering and expense. Obtaining good treatment and support is still a major challenge. **Better and early access to medical treatment is essential, thereby reducing the potential for inappropriate expenditures which may be catastrophic to a family.**
- There are still many people with conditions who don't seek medical help. This is partly due to lack of local services, partly due to their belief that these are spiritual problems and their fear of diagnosis and the resulting stigma. **There is a need to raise awareness. Affected people are well placed to take these messages to communities around them.**
- There is frequently no available support for emotional distress throughout this period of disability. **Emotional support should be accessible for affected individuals, but needs to be offered in a non-stigmatising way and not associated with the 'psychiatry or mental illness' label, otherwise people will be reluctant to use it.**

- Difficulty with employment and high costs of managing the physical effects of NTDs make finding sufficient money to support a family very challenging. **Support for livelihood development should be considered for people with disabilities as part of comprehensive programmes.**

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